



Health and Social Care
in Northern Ireland

Honest Broker Service

Biennial Report June 2015 – May 2017

Our Mission

To facilitate access for ethically¹ approved researchers, health planners and policy makers to anonymised and pseudonymised Northern Ireland Health and Social Care (HSC) data and to assist in the analysis of such data as required.

Our Aims are to:

- facilitate ethically approved research that may contribute to the promotion, protection and maintenance of the health of the public;
- facilitate the planning, evaluation and delivery of health services;
- support activities related to the above aims across the full spectrum of health;
- contribute to knowledge regarding research methods relating to health data collection, linkage of health-related data and compilation and use of health related statistics generally; and
- following appropriate governance, to permit the outcomes of activities related to the above aims to be available for the benefit of the public and to contribute to knowledge on an open and equitable basis.

Background

The Honest Broker Service (HBS) is a function within HSC Business Services Organisation (BSO) Directorate of Customer Care and Performance, with support and input from the Information and Registration Unit, Operations Directorate.

Two staff members work solely within HBS, one of whom is funded by the Department of Health (DoH) and one of whom is funded by BSO. The Heads of the Regional Data Warehouse and the Information and Registration Unit manage the Service and are accountable to the Director of Customer Care and Performance for its efficient running.

The Honest Broker Governance Board oversees and endorses all HBS operating rules and procedures and approves all research applications². It oversees and assures the efficient and proper running of the Service. It comprises representatives of the Data Controllers of the data held within the Regional

¹ Ethical approval was a requirement for research projects during the period that this report covers. The requirement has since been rescinded.

² Minutes of HBGB meetings can be found at <http://www.hscbusiness.hscni.net/services/2843.htm>

Data Warehouse, as well as representation from the main users of the data from within the HSC family. Current membership is detailed in Appendix 1.

The HSC Regional Data Warehouse (RDW) is a large, secure data store which receives regular data extracts from a range of key HSC Information Systems. It is managed by BSO and hosted within the HSC Regional datacentres. It ensures that authorised users have secure access to timely, robust and accurate management information, while complying with the requirements of the Data Protection Act (DPA). It enables sophisticated analysis of stored de-identified data using a Business Intelligence toolset and a Management Information Portal. HSC organisations have access to their own data collected for direct patient care, with any other organisation (for example the Health and Social Care Board or DoH) only granted access through Data Access Agreements or through HBS.

HBS enables secure access to linked de-identified Warehouse data for HSC purposes, including Business Intelligence and management reporting facilities, and for approved HSC related research. HBS is now the preferred method of granting organisations access to data. It provides a more streamlined, secure process for data sharing for the HSC and also for the wider research community. This creates efficiencies and ensures the full benefits of data sharing for public health and well-being, while ensuring Data Protection and Confidentiality requirements are met. Data access is arranged following a formal application process.

The HBS provides greater protection of service user information whilst satisfying the needs of secondary users. Under current legislation, it does not share patient identifiable information with anyone, 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 data safely. All HBS processes are in line with Data Protection and confidentiality requirements, and with the Information Commissioner's Office (ICO) Codes of Practice.

Performance

The HBS had four main priority areas for years 2 (June 2015-May 2016) and 3 (June 2016-May 2017):

Priority 1: Infrastructure

1.1 Maintain appropriately skilled staffing levels:

The HBS is managed jointly by the heads of the Regional Data Warehouse and the Information and Registration Unit (IRU) within BSO who report on its performance to the Director of Customer Care and Performance. There are three members of staff in IRU working on the HBS: a Deputy Principal Statistician who is the operational manager for the service; an Assistant Statistician who assists with Public Health Agency (PHA) projects as well as HBS; and a further Assistant Statistician who works primarily on Administrative Data Research Centre projects that have a health data element but also provides valuable input towards HBS work. All three staff are on secondment from the Northern Ireland Statistics and Research Agency (NISRA). There is also an ICT specialist based in the Regional Data Warehouse who provides expert assistance on the extraction of secondary care data, data linkage, and the anonymisation of datasets.

There has been recent turnover of staff, with the DP statistician on secondment from NISRA moving on promotion and the Assistant Statistician funded through PHA taking a career move to another post. These vacancies were filled very quickly (December 2016 for the Assistant Statistician post, and January 2017 for the DP Statistician post) and both staff have been familiarising themselves with the various functions of the HBS over the past 6 to 7 months (December 2016 to May 2017). They have been supported by staff within IRU and the Regional Data Warehouse. In the past 2 years guidance documentation has been produced to assist any new staff members and the service has moved towards producing detailed project guidance and Standard Operating Procedures for internal use³.

1.2 Enable access via the Honest Broker Service to new datasets in line with the existing programme of work to extend the scope and coverage of the Regional Data Warehouse:

Two new datasets were added to the Regional Data Warehouse and made available through Honest Broker arrangements. These were:

Clinical Communications Gateway (CCG) – this system is used in the majority of GP practices and provides rapid, secure and auditable transfer of referrals, electronically, from primary to secondary care. The system is integrated with the GP practice clinical information system from which it extracts relevant data for inclusion in the referral.

Patient Record Information System (PARIS) – this is the Community Information System used by Belfast, Southern and Western HSC Trusts. Initial test snapshots from Southern & Belfast Trusts were loaded into the Regional Data Warehouse and access granted to HSCB for testing purposes.

³ <http://www.hscbusiness.hscni.net/services/2454.htm>

1.3 Develop the HBS Website and Metadata:

The Honest Broker Service has its own dedicated web page on the BSO website. It contains links to all of the guidance and information required by researchers and HSC applicants to enable applications to be made to HBS, as well as links to other useful information sources. It also includes information on all research projects that have been approved by the Honest Broker Governance Board. The page is continuously reviewed and updated to reflect the development and growth of the service. Over the past 2 years details of all approved research projects have been made available on the site and relevant information has been updated and improved upon on a continuous basis. There has also been ongoing work to develop metadata for the Northern Ireland Maternity System (NIMATS), work carried out by PHA staff and funded by Health and Social Care Research and Development Division. This will be made available on the HBS website as soon as possible.

1.4 Maintain the Honest Broker Working Group:

The Honest Broker Working Group continues to meet to discuss operational and other issues, which are then fed through to the Honest Broker Governance Board (HBGB). The group's Terms of Reference enabled it to directly influence the policies and practices of HBS. It consists of representatives of BSO, HBS, PHA, DoH and the Office for Research Ethics Committees for Northern Ireland (ORECNI). Eight Working Group meetings took place between June 2015 and May 2017.

1.5 Maintain the secure research 'safe haven':

A research safe haven is defined by the Data Sharing Review Report⁴ as an environment for population based research and statistical analysis in which the risk of identifying individuals is minimised, i.e. a place where research can be done on sensitive data such that the risk of disclosure is reduced by controlling who can have access, what data they can analyse and what outputs can be taken away. A safe haven may be accessed physically or virtually, but a key characteristic is that researchers' results are screened to ensure that no disclosive data are released.

The secure safe haven is in BSO Franklin Street. At present the HBS Safe Haven must be accessed physically. Research users are supervised and monitored at all times to ensure compliance with security requirements. 'Safe Researcher' training, delivered by staff in HBS and the Administrative Data Research Centre Northern Ireland (ADRC-NI), is required before any access to data is granted. The safe haven is used several times each week. It facilitates up to two research teams at any one time, and recent improvements have included the provision of additional software packages. If the HBS continues to grow there may be the need to seek extra desk space to allow accommodation of more than two teams at any one time.

⁴ <http://webarchive.nationalarchives.gov.uk/+http://www.justice.gov.uk/docs/data-sharing-review.pdf>

Priority 2: Security and Governance

2.1 Organise meetings of the Honest Broker Governance Board and approval subgroup, approve all research applications and oversee the running of the Service:

The HBGB is established and in operation with an agreed Terms of Reference⁵. It aims to meet four times a year and held 4 full meetings between June 2015 and May 2016 and 3 full meetings between June 2016 and May 2017. Sub-panels of members considered and approved fourteen research applications, eight in year two and six in year three (see Table 1).

2.2 Carry out a review of the Honest Broker Service

A review of the Honest Broker Service was instigated in May 2017. The aim of the review is to assess the effectiveness of the current Honest Broker Service and to explore options for future service delivery. The review was carried out by a consultant from the Health and Social Care Leadership Centre. It will be considered by the Honest Broker Governance Board in the winter of 2017/18. It is anticipated that further detail on this will be made available in the next annual report.

Priority 3: Communication

3.1 Engage, collaborate and communicate to promote awareness and support for the Service:

HBS staff and senior BSO officials have delivered a number of formal presentations to academic and health related audiences throughout the two year period. These were supported and enhanced by less formal meetings and conversations with potentially interested parties and groups. The BSO website has a dedicated HBS page, which facilitates access to a wide range of information about the Service, including metadata and application packs.

3.2 Establish partnerships and relationships within HSC, Industry and Higher Education to ensure the most effective use of the service:

The HBS statistician is in regular contact with Research Governance officers in Ulster and Queens Universities to exploit opportunities to develop relationships with the academic community. He also meets and discusses the feasibility of the Honest Broker Service to assist colleagues in HSC and DoH with service evaluations, clinical audits, and potential research projects, and has met with representatives from the third sector.

3.3 Develop and maintain networks with similar bodies:

HBS staff continue to work with the Northern Ireland Longitudinal Study team to align services and ensure that standard practices exist as far as possible. This ensures that HBS is up to date with current best practice and that the experiences and expectations of the research community are similar across the two services. HBS is represented on the strategic and operational Northern Ireland Longitudinal Study (NILS) groups to maintain the alignment of the services. BSO also provide HSC data for ADRC-NI projects.

⁵ The Terms of Reference are available under appendix 5 in the Memorandum of Understanding (MOU). The MOU is available at:
[http://www.hscbusiness.hscni.net/pdf/Memorandum%20of%20Understanding%20\(MOU\)%20Revised%20Dec%202017.pdf](http://www.hscbusiness.hscni.net/pdf/Memorandum%20of%20Understanding%20(MOU)%20Revised%20Dec%202017.pdf)

Priority 4: Operating Procedures

4.1 Maintain a robust research application process, including a Charging Policy:

The application process has continued to operate successfully over the last two years. A charging policy for the service, including management and administrative overheads, was agreed and introduced in April 2015. As well as setting out the required costs of £475 per day, it also lists the services that HBS will deliver, demonstrating the value for money provided. The application form has been updated, as has the application guidance document, to clarify and streamline what is required. The HBS also monitors time spent on data preparation for each project in order to produce accurate invoicing and to provide evidence of value for money to customers.

4.2 Review and monitor guidelines and rules for researchers applying to and using the HBS:

The HBS has in place detailed Guidance documents to assist researchers with the application process⁶. The rules for the use of the safe haven and the description of the service and assistance to be expected from the HBS staff by researchers using the safe haven were closely based on best practice from other such facilities within the UK. Care was also taken to ensure that the rules and guidance reflected all of the relevant legislative and statutory requirements. This is to ensure that researchers using the service are aware of their personal obligation to uphold them. All researchers who do not have a current status of 'safe researcher' are required to undergo safe researcher training before being given access to any data within the safe haven. It is anticipated that further improvements will be made with the withdrawal of the requirement for ethical approval for research projects. The reasons for making this are twofold. Firstly, there is no requirement for ethical approval when dealing with anonymised datasets. Secondly, it will bring HBS into line with its counterparts in Scotland and Wales.

⁶ <http://www.hscbusiness.hscni.net/services/2454.htm>

Table 1: Research Projects Approved and Underway in Years 2 and 3

The following projects were approved by HBGB and the datasets have been prepared and made available⁷:

Project Number	Lead employing organisation	Title
007	Western Health & Social Care Trust and Ulster University at Jordanstown	Investigating morbidity and mortality outcomes in patients with Tetralogy of Fallot (TOF).
009	Ulster University at Magee	The relationship between people with Borderline Personality Disorder and General Practitioners: Analysis of Northern Ireland Patient Health and Social Care Data.
010	Queen's University Belfast	Exploring the problem of pain in the cerebral palsy population: Piloting a big data approach.
011	Queen's University Belfast	Identifying and understanding inequalities in child welfare intervention rates: comparative studies in four UK countries.
012	Queen's University Belfast	Commonly prescribed drugs and association with cancer progression.
013	Queen's University Belfast	Antibiotic prescribing in older people and trends on movement into institutional care: a record linkage study.
014	Queen's University Belfast	Stratified Medicine in Mental Health: Antidepressant prescribing patterns in Northern Ireland.
015	Queen's University Belfast	Evaluating the implementation of Minimum Unit Pricing of Alcohol – Harmonising alcohol-related outcomes data across the UK & Ireland.
017	Queen's University Belfast	Beta-adrenergic receptor expression and beta-blocker drug use: association with breast cancer survival.
018	Ulster University at Jordanstown	Suicide deaths in Northern Ireland: Medication and Health Service use.
019	Centre for Public Health, Queen's University Belfast	Are newer disease-modifying anti-rheumatic drugs associated with a lower risk of Alzheimer's disease?
020	Ulster University at Jordanstown	Study linking heartsuite data to Child Health System data and NIMATS (maternity system).
021	Ulster University at Jordanstown	Evaluation of maternal diseases and medications recorded in the Northern Ireland Maternity System (NIMATS) database compared to the NI Enhanced Prescribing Database (EPD): a data linkage study.
022	Queen's University Belfast	Self-reported mental disorders in pregnancy (NIMATS).

*Project 016 has not commenced due to funding issues.

⁷ Further information on these projects is available at: <http://www.hscbusiness.hscni.net/services/2555.htm>

Table 2: Health and Social Care Requests for Which Data Was Provided in Years 2 and 3

	Applicant	Type of Request	Details
H-013	Public Health Agency	Service Evaluation	An evaluation to look at men with an AAA (Abdominal Aortic Aneurysm) and the medication they are being prescribed.
H-014	Health and Social Care Board	Performance Management	Access via test CCG BOXI universe.
H-015	Belfast Health and Social Care Trust	Clinical Audit	To examine patients with two types of heart attack (NSTEMI and STEMI) to see if there is any difference in mortality at weekdays versus weekend.
H-016	Health and Social Care Board	Benchmarking	Enhanced National Keele benchmarking scheme for laboratories.
H-017	South Eastern Health and Social Care Trust	Service Evaluation	A service evaluation to see the effectiveness of a Diabetes Insulin Guidance System in reducing insulin and other oral diabetic drugs consumed.
H-018	Health and Social Care Board	Performance Management	User acceptance testing of the PARIS system.
H-019	Department of Health	Service Evaluation	Linkage of telemonitoring clients to EPD.
H-021	Public Health Agency	Service Evaluation	Child Health outcome review.
H-022	Regulation and Quality Improvement Authority	Service Evaluation	Analysis of Accident and Emergency attendances by nursing home location.
H-023	Health and Social Care Board	Benchmarking	Enhanced National Keele benchmarking scheme for laboratories 2015/16.
H-025	Department of Health	Service Evaluation	Prescription data (processed between 1 st January 2015 and 31 st December 2015) for mood and anxiety, statin and antihypertensive drugs dispensed to individuals.
H-026	Health and Social Care Board	Performance Management	Estimate hospital admissions from nursing/residential homes.

H-027	Department of Health	Performance Management	NIMATS data for Northern Ireland version of the Summary Hospital level Mortality Indicator (SHMI) casemix model.
H-028	Department of Health	Performance Management	DoH Admissions and Discharges with EPD.
H-029	South Eastern Health and Social Care Trust	Service Evaluation	EPD – drugs prescribed between 2012 and 2016 and DNAV user.
H-030	Northern Health and Social Care Trust	Clinical Audit	Water quality in adult augmented care units
H-031	Health and Social Care Board	Performance Management	Access to acute datasets
H-033	Health and Social Care Board	Counter Fraud	Access to Healthcare pilot
H-034	Health and Social Care Board	Performance Management	Access to SOS CARE data

Appendix 1

Membership of Honest Broker Governance Board at May 2017

Chair – Brendan O’Brien (HSCB)
Vice-Chair – Paul Carlin (SEHSCT)
Alison Murphy (BHSCT)
Peter Sharpe (SHSCT)
David Hill (SEHSCT)
Aaron Peace (WHSCT)
Karen Bailey (BSO)
Nicola Armstrong (PHA)
Suzanne Martin (Patient and Client Council)
Eugene Mooney (DoH)
Seamus O’Reilly (NHSCT)
Hilary Russell (Lay Member)

Membership of Honest Broker Working Group at May 2017

Chair – Karen Bailey (BSO)
Nicola Armstrong (PHA)
Eddie Ritson (BSO)
Charlene McQuillan (DoH)
Sandy Fitzpatrick (BSO)
Siobhan McGrath (ORECNI)
Susan Campbell (BSO)
Neil Marsden (BSO)