

Annual Report June 2014 – May 2015

Our Mission

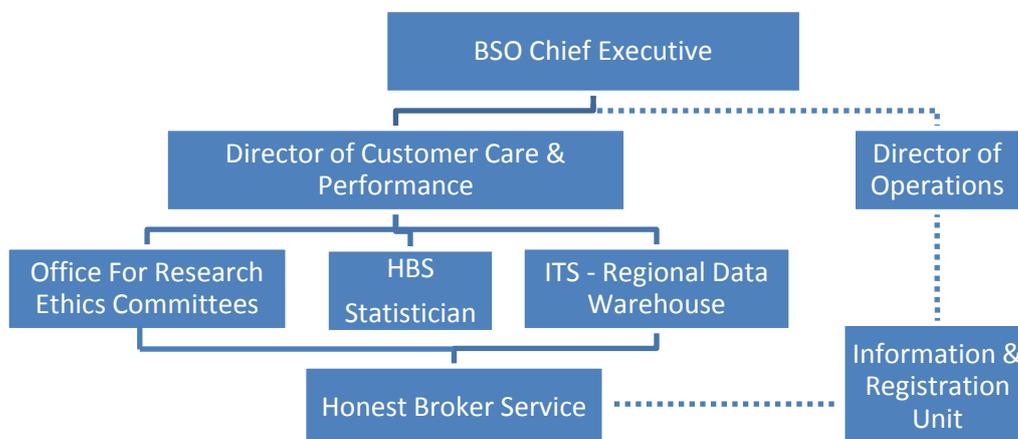
To facilitate access for ethically approved researchers, health planners and policy makers to anonymised and pseudonymised Northern Ireland Health and Social Care (HSC) data and to assist in the analysis of such data as required.

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.

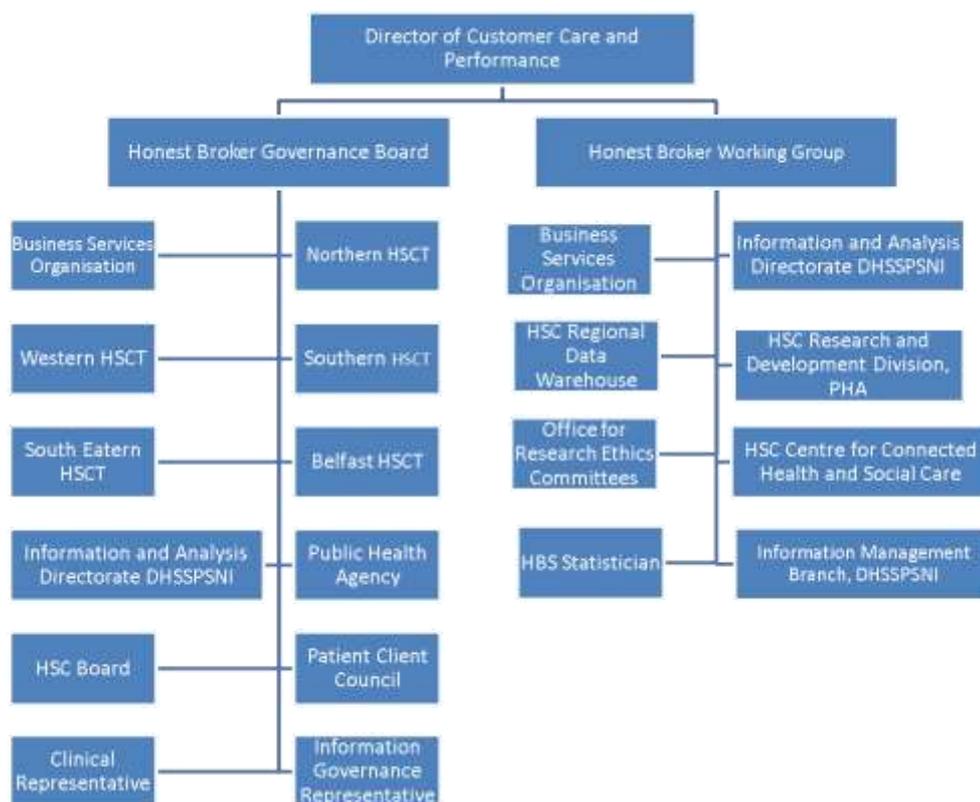
Background

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 Research Unit, Operations Directorate (see internal organisation chart below).



Two staff members work solely within HBS, one of whom is funded by the Department of Health, Social Services and Public Safety (DHSSPS) 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 applications. 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 Data Warehouse, as well as representation from the main users of the data from within the HSC family (see chart below).



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 DHSSPS) 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 the needs of secondary users can be satisfied. 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 year 1.

Priority 1: Infrastructure

1.1 Recruit appropriately skilled staff:

The HBS is managed jointly by the heads of the Regional Data Warehouse and the Information and Registration Unit within BSO who report on its performance to the Director of Customer Care and Performance. There are two members of staff who work full time within HBS: a statistician on secondment from the Northern Ireland Statistics and Research Agency and an ICT specialist.

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:

The Regional Data Warehouse is continually growing, expanding the types of dataset held and increasing the number of functions and HSC organisations covered. A programme of work is ongoing to expand the scope of data captured to additional service areas and IT systems. It currently holds demographic information about patients or clients, administrative information (such as appointment details) and clinical information (such as operations performed or drugs dispensed). There are 45 datasets now available from HSC (including BSO) systems. This is expected to increase further in the coming year.

1.3 Develop the HBS Website and Metadata:

Development work on the HBS web page began in July 2013. 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 is continuously reviewed and updated to reflect the development and growth of the service.

1.4 Establish an operational Honest Broker Working Group:

An HBS Working Group was set up to establish the Honest Broker Service. It met when required up to the point that the HBS was implemented. It 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, Public Health Agency (PHA), DHSSPSNI and the Office for Research

Ethics Committees for Northern Ireland (ORECNI). Eight Working Group meetings took place between June 2014 and May 2015.

1.5 Establish a secure research 'safe haven':

A research safe haven is defined by the Data Sharing Review Report (<http://systems.hscic.gov.uk/infogov/links/datasharingreview.pdf/view>) 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 physical or virtually, but a key characteristic is that researchers can only keep their results and even the results are screened to ensure that no disclosive data are released.

HBS staff undertook a review of the policies and practices of UK research safe havens. This involved investigating relevant guidance and protocols and consulting with similar bodies. They then developed a suite of operational protocols to be reviewed and agreed by the Working Group and HBGB. The secure safe haven was then set up 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 HBS staff, is required before any access to data is granted.

1.6 Produce a research report on a pilot HBS study to demonstrate the capabilities of the Service:

Two HBS pilot projects were undertaken. The first project involved the creation of a linked dataset which joined all patients who had had a hospital episode in 2012 to their antibiotic prescription data to be analysed and reported upon by the HBS statistician. This exercise tested the dataset creation process and also explored the amount of resource required to further manipulate and transform the data accessed to enable the appropriate statistical techniques to be carried out. A report on Post-operative Variation in Patient Health was completed in June 2015. It has been peer-reviewed and feedback obtained. It will be published in December 2015.

A second pilot study involved a research team from the Centre for Public Health, QUB making a research application for a project accessing a linked dataset. This project was conducted within the rules and constraints imposed by the HBS structures in order to test and improve the actual HBS process, as well as investigating the hypotheses put forward. The study is on-going and a progress report will be produced in 2015/16.

Priority 2: Security and Governance

2.1 Establish an Honest Broker Governance Board, with operating rules and procedures, to approve all research applications and oversee the running of the Service:

The HBGB is established and in operation with an agreed Terms of Reference. It aims to meet twice a year and held 2 full meetings during the period covered by this report. Sub-panels of members considered and approved eight research applications (see Table 1).

2.2 Ensure that the Service complies with all statutory requirements and best practice elsewhere in Northern Ireland and the UK:

In establishing the service, full consideration was given to Data Protection and common law duty of confidentiality requirements. The ICO was consulted about the establishment of the service and the Memorandum of Understanding (MOU) for the service, which all HSC organisations and DHSSPS have signed. Considerable research was undertaken, including establishing how similar functions (e.g. Northern Ireland Longitudinal Study (NILS)) meet security requirements and all best practice policies and standards have been adopted within HBS. Research was also undertaken regarding Research Ethics Committee (REC) standards and some of their processes were also adopted.

Priority 3: Communication

3.1 Launch the HSC Honest Broker Service:

The Service was launched on 20 June 2014 by the then Health Minister, Edwin Poots. The Minister said the new service would ultimately improve the overall health of the people of Northern Ireland and presents a real opportunity for researchers to make a valuable contribution to the future development of health and social care related policy in Northern Ireland.

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

HBS staff and senior BSO officials have undertaken a challenging programme of outreach to promote and raise awareness of the Service. A number of formal presentations to academic and health related audiences were given throughout the year. 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.

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

The Collaborative Network International Health Analytics Capability (IHAC) Scoping Study Final Report (Issue 1) commented that HSCNI is making strides in how it makes better use of cross domain data through the creation of the data warehouse and HBS infrastructure. The report assumed that this work will continue to evolve to form a Connected Health Integrated Platform (CHIP) and embrace the use of Analytics via an IHAC. It stressed that access to open data via the HBS was critical if IHAC is to become a reality. Senior staff within BSO have therefore been working closely with the IHAC to continue to develop this potential. HBS staff have also attended NI Connected Health Ecosystem events to both promote the Service and stay informed of developments in that arena. In preparation of the official launch of the service a workshop to explore the value of the appropriate application of tools/techniques was held with specialists from the two local universities and commercial companies. 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.

3.4 Develop and maintain networks with similar bodies:

HBS staff have worked with the NILS 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 NILS groups to maintain the alignment of the services. BSO has also had early stage discussions regarding the inclusion of HSC data in the Administrative Data Research Network (ADRN). HBS staff will lead in the development of the protocols and practice guiding the relationship with ADRN.

Priority 4: Operating Procedures

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

The HBS Working Group initially consulted with the NILS on their processes before working closely with the head of the ORECNI to develop a detailed process map for the HBS research application process. This includes an in-depth application form and a requirement for the application to be endorsed by the applicant's organisation and signed off by the Chief Investigator. The process is continuously reviewed and is overseen by the HBGB. The Honest Broker Advice Service (HBAS) works closely with research applicants to develop their applications. Providing support and guidance at this stage of the application process helps to ensure that the form that is submitted to HBGB for approval contains all of the information that the approvals panel will require, in the correct format. It will also ensure that the datasets requested are available in the format required by the applicant. The application process operated successfully during the year. 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.

4.2 Develop a set of guidelines and rules for researchers applying to and using the HBS:

HBS staff developed a detailed Guidance document to assist researchers with the application process. The Guidelines have been accepted by the Working Group and HBGB. 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.

4.3 Agree and document all processes and standards for HSC bodies accessing HSC data:

The internal HSC application process for access to data for the purpose of audit or evaluation is not the same as the research application process. (The research application process is the same for both internal HSC and external applications.) The initial consultation and advice provided by HBAS operates in a similar way. However, the application for access to the data does not require HBGB or ethical approval. Once the application is finalised and accepted by HBAS, access to the data will be facilitated either through a BOXI account or a data download enabled via an HSC device to a secure network drive or via a disk.

Table 1: Research Projects Approved and Underway in Year 1

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

| Project Number | Applicant | Study |
|-----------------------|---|--|
| E-001 | Centre for Public Health, QUB | Early Life Factors and Mental Health - To determine if early life factors such as low birth weight and gestational age influence the likelihood of poor mental health in later life and if risk of poor mental health is influenced by socio-economic position throughout the life-course. (HBS Beta Project). |
| E-002 | QUB/HSC Northern Trust | The impact of antibiotic prescription in surrounding community on the incidence rates of nosocomial extended-spectrum β -lactamase (ESBL)-producing strains in hospitalised patients. |
| E-003 | HSC Southern Trust/Centre for Public Health QUB | A pilot study to assess the influence of early life events on future risk of development of inflammatory bowel disease. |
| E-004 | QUB/Public Health Agency | An evaluation of past and present implementation of Telemonitoring NI. |

The following projects have received HBGB approval and preparation of the datasets was underway at end June 2015*

| | | |
|-------|----------------|---|
| E-005 | UU Magee | A study to explore care provision to older people with mental health needs who access pre-hospital and in-hospital emergency care service (EMS). |
| E-006 | UU Jordanstown | To determine the profile of women in Northern Ireland from 2014-2015 who have accessed maternity services and who have complex healthcare needs and/or disabilities |
| E-008 | UU Jordanstown | Investigating maternal and foetal outcomes for women with Gestational Diabetes Mellitus (GDM). |

*Project E-007 has not yet been submitted for HBGB approval.

Table 2: HSC Requests for Which Data Was Provided

| | Applicant | Type of Request | Details |
|-------|------------------|------------------------|---|
| H-001 | DHSSPS | Clinical Evaluation | HBS Pilot request - Activity Based Funding model. |
| H-002 | DHSSPS | Performance Management | Requesting SOS CARE data from 1/4/12 to 31/3/13 for regional validation of data recording |

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|--------------|----------------------|------------------------|--|
| H-003 | DHSSPS | Performance Management | Details of all Hospital Admissions for the last 5 years to establish a Northern Ireland version of the Summary Hospital level Mortality Indicator (SHMI). |
| H-004 | DHSSPS | Performance Management | Requesting new HIS Extraction Variable objects to be added to previous Admissions and Discharges Universe (Request 3) |
| H-005 | DHSSPS | Performance Management | Requesting access to the Admissions and Discharges Universe along with two tables from the Enhanced Prescribing Database - analysis of costs regarding treatment of diabetes and value for money. |
| H-008 | Public Health Agency | Clinical Audit | Labs - A validation of existing communicable disease surveillance systems The PHA hope the information gathered will help lead to more accurate surveillance data and help make it more timely, provide denominator data (positivity rates) and also provide time savings for individual trusts as they will no longer have to support the existing system. |
| H-009 | Public Health Agency | Clinical Audit | Labs Data related to 'Campylobacter' between 01/01/2030-31/12/2013 - to determine the incidence and public health significance of this condition . |
| H-010 | Public Health Agency | Clinical Audit | Admissions and Discharges request looking at 30 day mortality. The aim of the project is to estimate 30-day mortality following primary Percutaneous coronary intervention for STEMI. |
| H-011 | South Eastern Trust | Service Evaluation | Developing a business case for an Insulin Management Guidance Survey. In order to analyse cost savings, SET requires a summary of the total drug costs being used by all 267 dNAV patients from 22 October to Dec 31 2014 and a subset of the insulin drugs and costs also being used by the same group over the same period. |
| H-012 | DHSSPS | Service Evaluation | Telemonitoring Analysis - carry out linkage to a telemonitoring service-user dataset in order to facilitate a range of outcome analysis in support of Departmental information priorities such as TYC reform, assessment of integrated Care Partnerships etc. |
| H-013 | Public Health Agency | Service Evaluation | To determine if men are prescribed the appropriate medications to reduce their cardiovascular risk following a diagnosis of a small or medium AAA (Abdominal Aortic Aneurysm) by the screening programme. |