Honest Broker Service Annual Report
2018/19

17th Dec 2019

This Report has been produced by the Honest Broker Service, part of the HSC Business Services Organisation.

All queries can be forwarded to:

HonestBrokerService@hscni.net

Further background information can be found at:

http://www.hscbusiness.hscni.net/services/2454.htm

Previous year's Annual Reports can be found at:

http://www.hscbusiness.hscni.net/services/2740.htm

Foreword

The Honest Broker Service has been operating since 2014. Since it's inception, it has allowed more than 100 projects (both research & internal / non-research) to access data held securely within the Business Services Organisation's Regional Data Warehouse. These projects have covered a wide range of topics including mental health, maternity services, cancer and dementia. By facilitating the safe sharing of non-identifiable data, we aim to maximise the uses and health service benefits which can be gained from it, including planning, commissioning of services and public health monitoring.

There has been a marked increase in the number of dementia-related projects approved and in progress during the year; this is due to the Data Analytics Dementia Pathfinder Programme, which is part funded by the NI Executive Office, Atlantic Philanthropies and the Department of Health. This has been a great boost to dementia research in Northern Ireland, and further details of the projects are available later in this report.

The 2018/19 financial year has been an extremely busy and challenging one for the service; with staff changes, higher demand than ever before, and the expansion of the Research Safe Haven in the Franklin Street office.

We hope to build on this success and forecast continued growth for the service in the years to come, unlocking the potential of health service data to ultimately improve services and care outcomes for the Northern Ireland population.

Thanks are also due to the Honest Broker Regional Governance Board, who give of their time unselfishly to facilitate the approval mechanisms which allow research to progress in a safe and supported fashion.

Karen Bailey

Director of Customer Care & Performance,

Customer Care Directorate

Contents

Providing Support to Health and Social Care

Introduction

Background

The Honest Broker Service (HBS) is a function within the Health and Social Care (HSC) Business Services Organisation (BSO) aimed to enable non-identifiable Northern Ireland HSC data to be safely shared to maximise the uses and health service benefits which can be gained from it, including planning and commissioning of services and public health monitoring. HBS provides two key services:

- the provision of anonymised patient level data for the purposes of research, with access only being permitted through the safe research environment, and

- the provision of anonymised, or in some cases pseudonymised, patient level data to Department of Health (DoH) and HSC organisations for the purposes of clinical audit and service evaluation.

Data access is arranged following a formal application process. The Heads of the Regional Data Warehouse and the Information Unit manage the Service and are accountable for its efficient running.

Governance

The Honest Broker Governance Board (HBGB) 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. Current membership of the HBGB is detailed in Appendix 2. Minutes of Board meetings can be found at: *http://www.hscbusiness.hscni.net/services/2843.htm.*

Memorandum of Understanding

The Memorandum of Understanding (MOU) is established for the purposes of informing the development of an HBS for Health and Social Care. It has been agreed by:

- Health and Social Care Board (HSCB)
- Business Services Organisation (BSO)
- Belfast Health and Social Care Trust (BHSCT)
- Northern Health and Social Care Trust (NHSCT)
- Southern Health and Social Care Trust (SHSCT)
- South Eastern Health and Social Care Trust (SEHSCT)
- Western Health and Social Care Trust (WHSCT)
- 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)

A copy of the Memorandum is available here: *http://www.hscbusiness.hscni.net/pdf/Memorandum%20of%*

Providing Support to Health and Social Care

Available Datasets

The HBS can facilitate access to both primary and secondary care datasets within the HSC. 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.
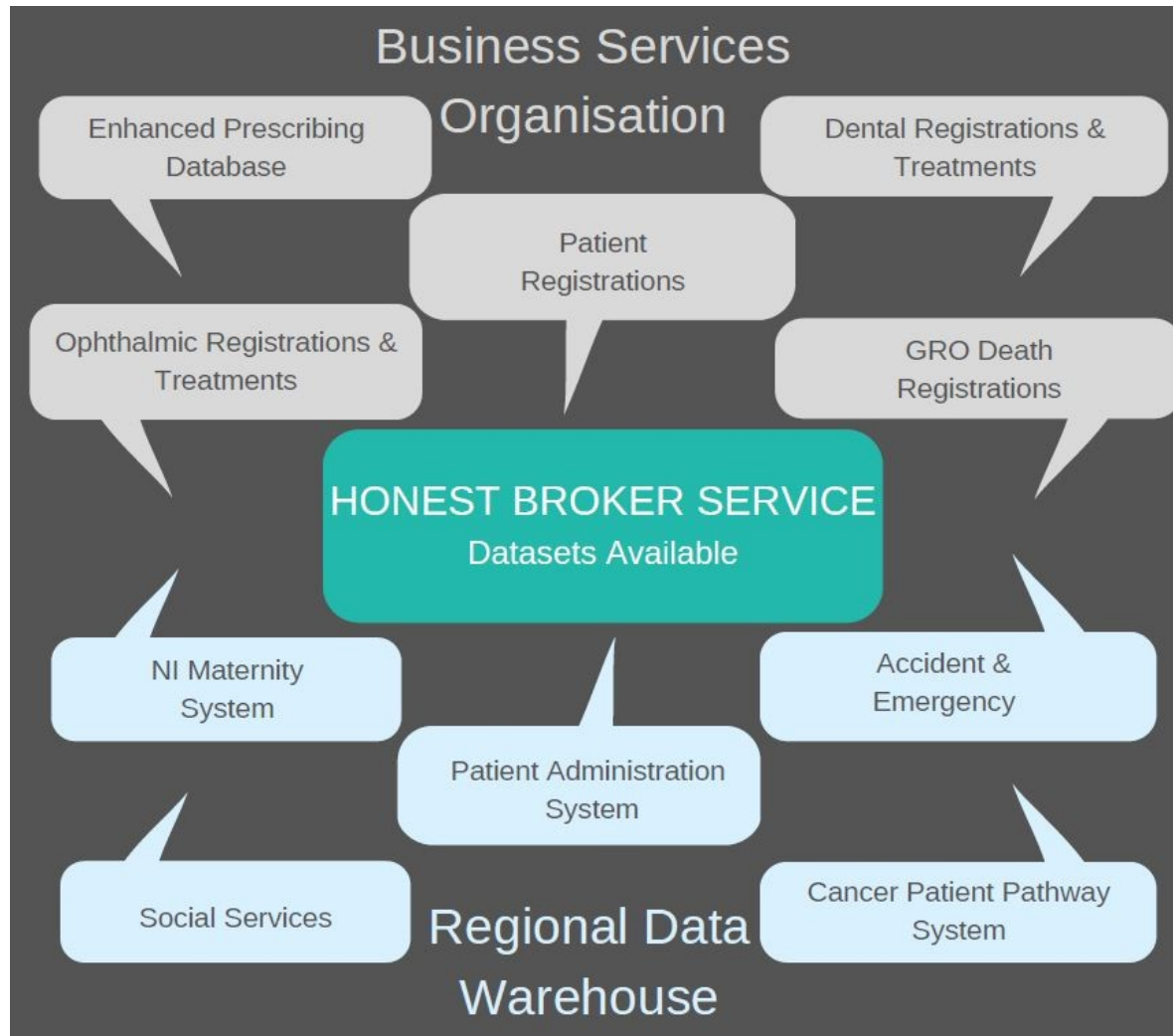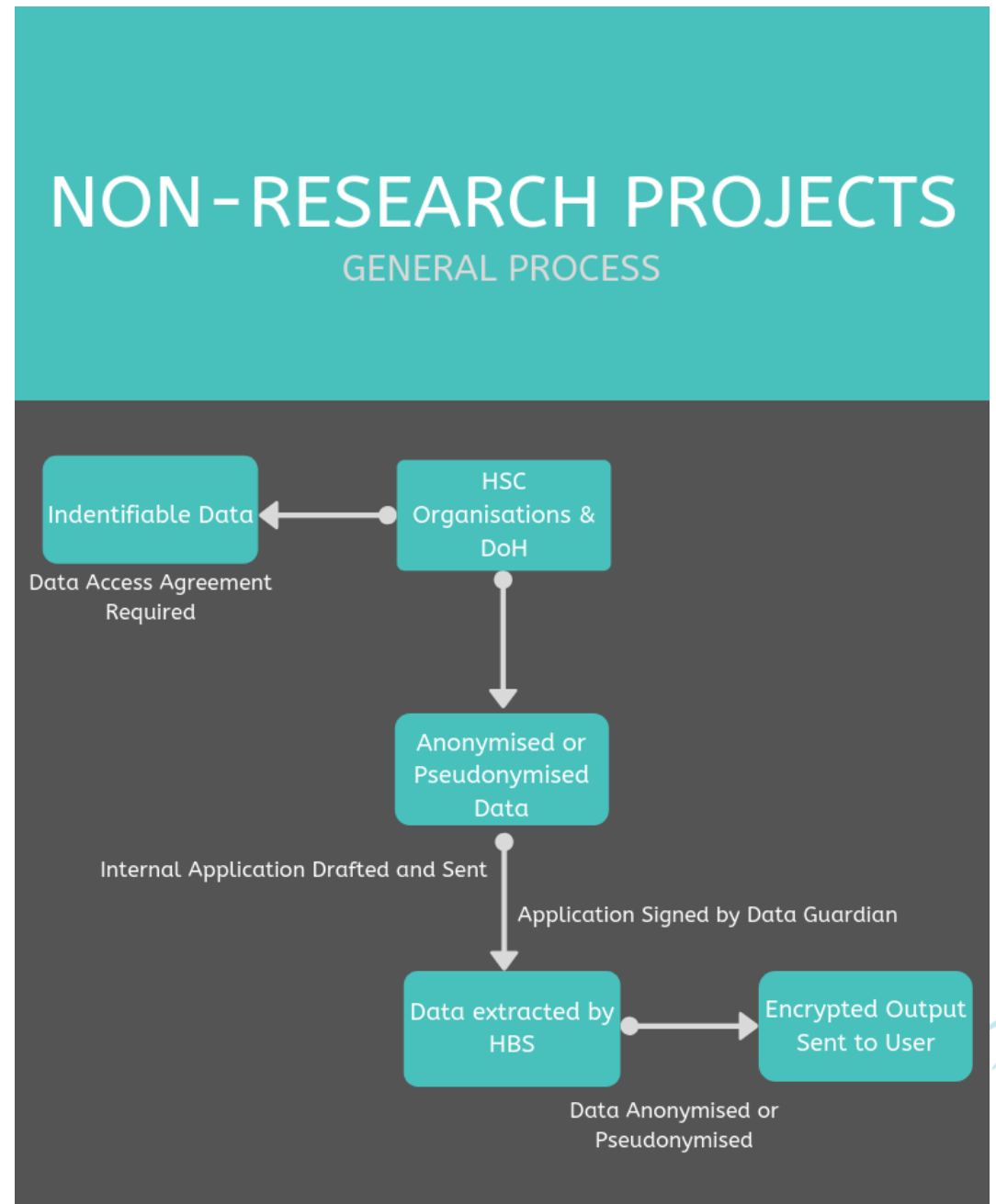
Routes of Application

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.

Non-Research projects, carried out within HSC organisations, are routed via a streamlined application process and the analysis is conducted outside of the HBS Safe Haven environment. Research projects, on the other hand, must be approved by an independent panel of the Honest Broker Governance Board, analysis undertaken within the Safe Haven and all outputs are subjected to disclosure control .

NON-RESEARCH PROJECTS
GENERAL PROCESS

Indentifiable Data

Data Access Agreement Required

HSC Organisations & DoH

Anonymised or Pseudonymised Data

Internal Application Drafted and Sent

Application Signed by Data Guardian

Data extracted by HBS

Encrypted Output Sent to User

Data Anonymised or Pseudonymised

RESEARCH PROJECTS
GENERAL PROCESS

APPLICATION STAGE

Researcher submits a draft application and works with HBS to finalise the application for submission.

DATA IS EXTRACTED AND LINKED

When the application is approved, the HBS team extract the data required from the databases in BSO and the Regional Data warehouse, anonymise the data and place it in the safe haven.

OUTPUTS CLEARED AND RESULTS PUBLISHED

All outputs from the safe haven are cleared by the HBS team to prevent statistical disclosure. Researchers can then disseminate their findings.

GOVERNANCE BOARD REVIEW APPLICATION

A panel of both experts and lay persons meet to discuss the application in detail and either reject or approve the project.

DATA IS ANALYSED IN THE SAFE HAVEN

The researcher comes to the safe haven in Franklin Street where they can access the data and carry out their analysis.

Providing Support to Health and Social Care

Safe Research Environment

At present researchers are required to physically attend the HBS 'Safe Haven' to gain access to the requested datasets. All researchers named on an HBS research application, who wish to access data within the Safe Haven, must have completed Safe Users of Research data Environment (SURE) training. The Research Support Unit (RSU) within the Northern Ireland Statistics and Research Agency (NISRA) deliver this training every two months in their headquarters in Colby House.

The secure Safe Haven is located in BSO Franklin Street. Researchers are supervised and monitored at all times to ensure compliance with security requirements. When the 'Safe Haven' was first launched it could facilitate two research teams at any one time, however a recent extension now means that up to seven research teams can be accommodated. All research stations are equipped with software packages such as SPSS, STATA and R.

Above: Official Opening of the new Safe Haven by Professor Ian Young, Director of HSC Research and Development Division, on 9th May 2019.

The Honest Broker Team in BSO: Scott Mathieson, Neil Marsden, Naomi Mill, Rachel Coey

Providing Support to Health and Social Care
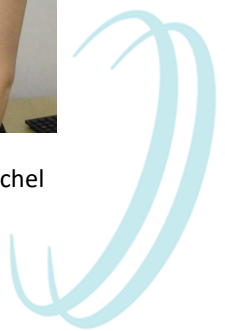
Projects Approved in 2018/19

In 2018/19, 14 applications were considered by the Honest Broker Governance Board. The following 10 projects were approved during the year (in comparison, 6 projects were approved in 2017/18—see Appendix 5 for more details) :

Project	Title	Organisation	Chief Investigator	Panel Approval
28	Early and late onset of dementia in NI	QUB	Dr B McGuiness	25/05/2018
29	Assessing the rate of anticholinergic drug prescriptions for dementia patients in Northern Ireland	QUB	Dr B McGuiness	25/05/2018
30	Childhood interactions with social services and risk of poor health and social outcomes in adulthood: a population wide data linkage study	QUB	Dr A Maguire	25/05/2018
31	Myotonic dystrophy in NI	QUB / BHSCT	Dr L Anderson	24/08/2018
32	Investigation of the link between maternal body mass index in early pregnancy and incidence of cerebral palsy in NI.	QUB	Dr K A Eastwood	24/08/2018
33	Evaluation of outcomes for patients with elevated tTG antibodies and Gluten-free food prescription utilisation in NI	QUB / BHSCT	Dr L Anderson	28/09/2018
35	Short, medium and long term outcomes of root-filled molar teeth treated within Northern Ireland General Dental Practices and factors that may affect this outcome	QUB	Dr I E Karim	28/09/2018
36	Hospitalisation rates in dementia	QUB	Dr B McGuiness	04/12/2018
38	Health and social selection bias on consent to participation in the NI Cohort for the Longitudinal Study of Ageing	QUB	Dr D O'Reilly	04/12/2018
39	Sleep medication use in Cerebral Palsy: a comparison between those with Cerebral Palsy and the typically developing population in Northern Ireland.	QUB	Miss M E McCavert	04/12/2018

Research Activity in 2018-19

2018-19 was the busiest year to date for the service, with 56% of the 248 available days being utilised. March 2019 was the busiest month with almost 80% of days utilised. April 2018 was one of the quieter months, with just 38% of days utilised.

Only 7 working days were lost in the Safe Haven throughout the year; these were due to maintenance work and conference / team events.

Safe Haven Usage 2018/19

Number of Outputs Checked 2018/19
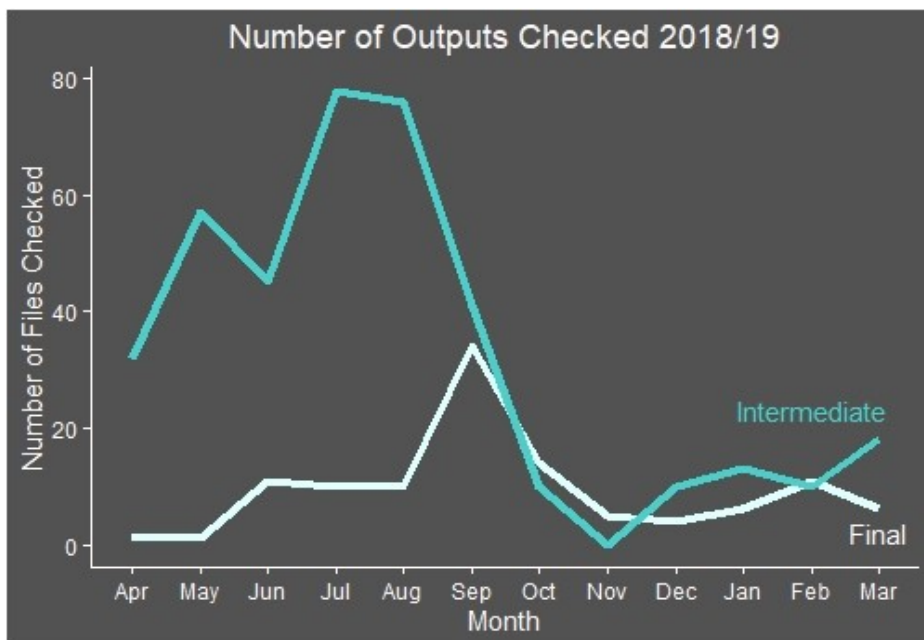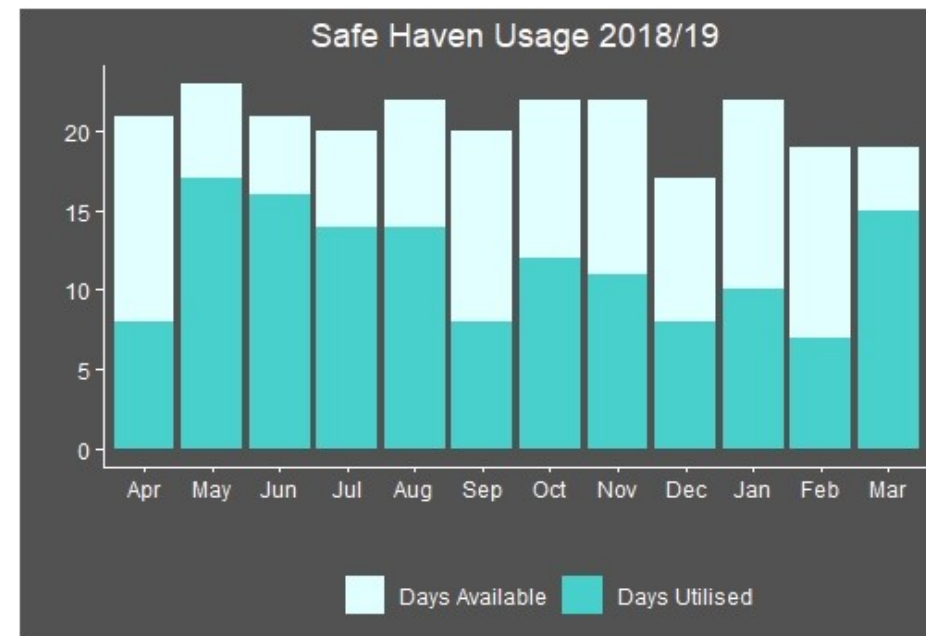
More than 500 files were checked by BSO Staff; 390 intermediate outputs and 113 final outputs. More than a third of these files (174) were checked in July and August alone.

Almost half of the files (246) were checked and returned to the researchers the same day they were submitted. 153 were returned within 1 day of submission and 85 within 2 days. A small number took longer than 2 days to clear.

Current guidelines state that intermediate outputs should be cleared within 5 days, and final within 20 days. This target was met in all cases.

Providing Support to Health and Social Care

Research Facilitated in 2018-19 by Theme

Research projects in this year cover a wide range of topics. A number of Dementia related projects have been facilitated through the DARUG funding, these involve drug use when living alone, polypharmacy, falls and fractures and hospitalisation rates in patients with Dementia.

Other projects cover areas such as childhood diabetes, the NICOLA study and mental disorders during pregnancy.

Of particular note is a joint project entitled 'Pathways to a Cancer Diagnosis' that has been undertaken by BSO and QUB. This is the first time BSO have collaborated on an Honest Broker Service research project.
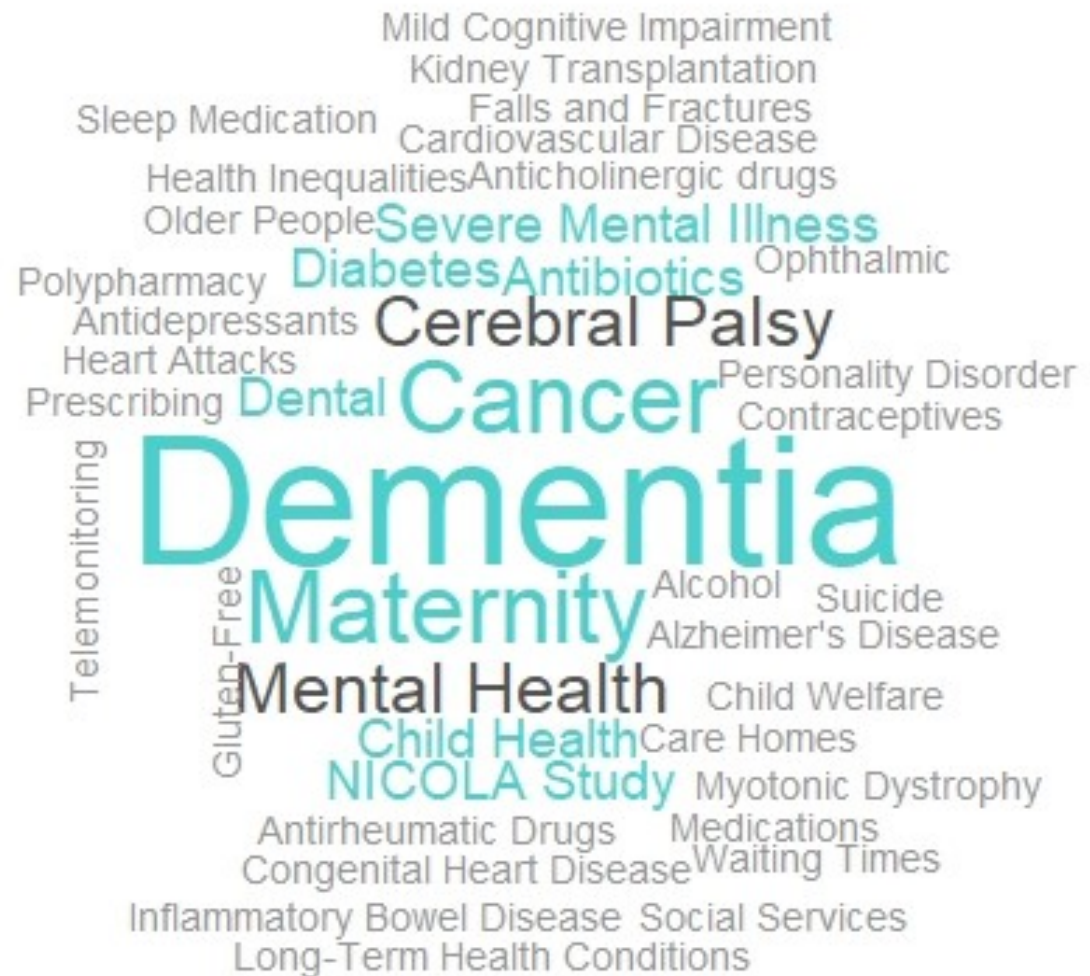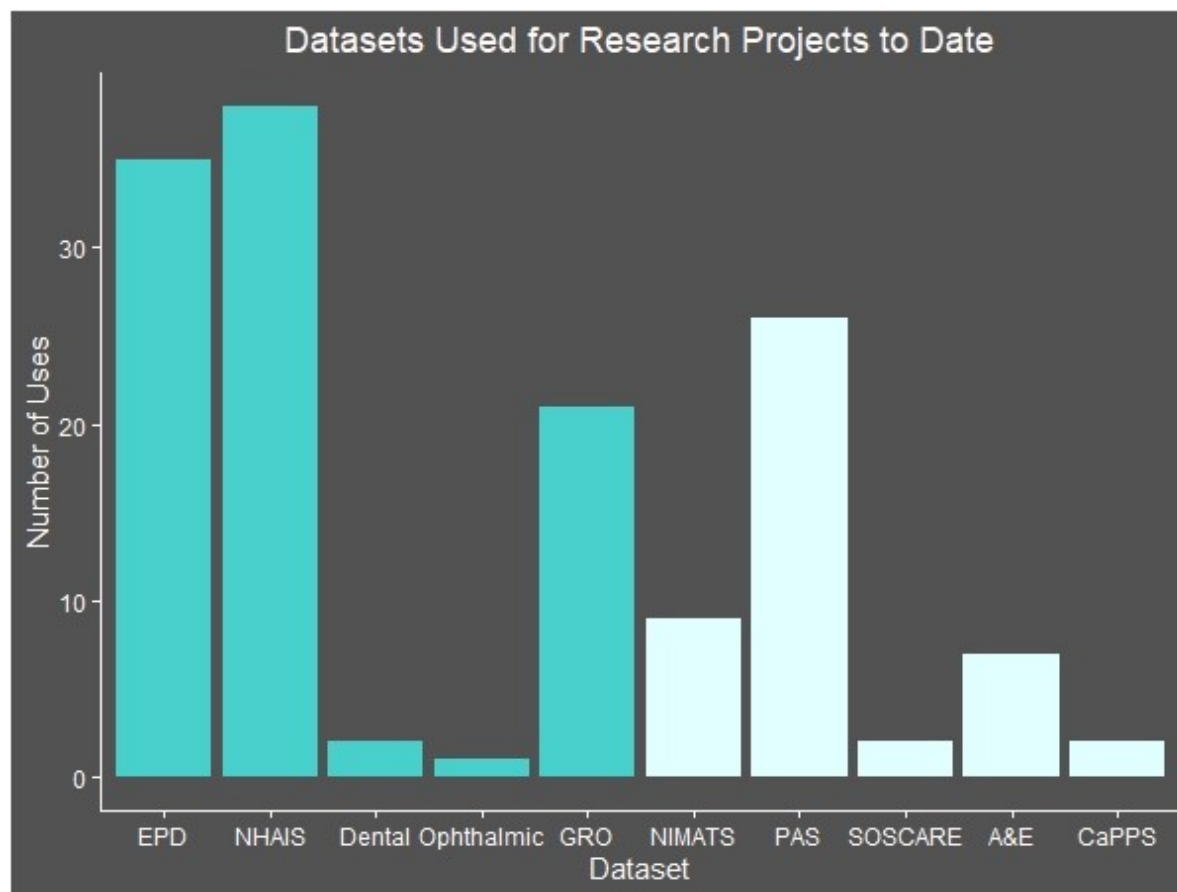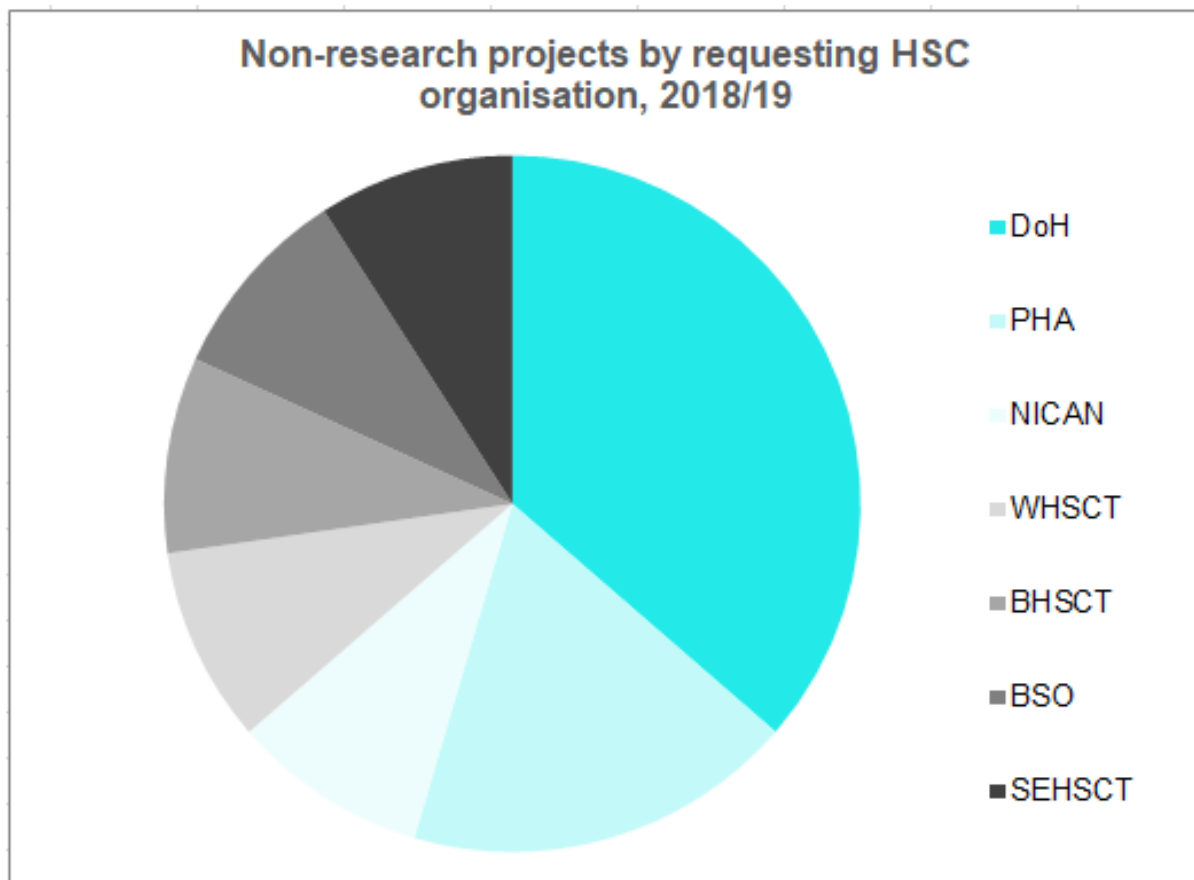
Research Facilitated in 2018-19 by Theme

In 2017/18, there were 17 active projects being worked on in the HBS safe haven. In 2018/19, this increased to 27 active projects. These projects accessed a range of datasets held by BSO and the Regional Data Warehouse.

The Primary care datasets held by the BSO Information Unit are shown in blue. The Enhanced Prescribing Database (EPD) and Patient Registrations (NHAIS) are the most commonly used datasets.

The Regional Data Warehouse hold the Secondary Care Datasets (shown in white). The Patient Administration System (PAS) and Northern Ireland Maternity Service (NIMATS) datasets are the two most commonly used.

Datasets Used for Research Projects to Date

Non-Research Projects in 2018-19

Non-research projects by requesting HSC organisation, 2018/19

Legend:
- DoH
- PHA
- NICAN
- WHSCT
- BHSCT
- BSO
- SEHSCT

There were 11 non-research projects active in 18/19, (compared to 17 in 2017/18). They supported the Department of Health (4 projects), Public Health Agency (2 projects), HSC Trusts (3 projects), BSO (1 project) and the Northern Ireland Cancer Network (1 project) in clinical audits and service evaluation in areas as diverse as Antimicrobial use in NI, Analysis of long-term conditions and Patient Experience. This brings the total number of non-research projects completed through the HBS to 52.

Providing Support to Health and Social Care

Non-Research Projects in 2018-19

The datasets most commonly used by Non-Research Projects in 2018/19 were the EPD (8 projects) and PAS datasets (4 projects). Projects also utilised NHAIS, Mortality, SOSCARE, Emergency Dept. and HSC Trust Laboratories Data, amongst others.

Datasets Used for Non-Research Projects 2018/19

Datasets Used for Non-Research Projects to Date
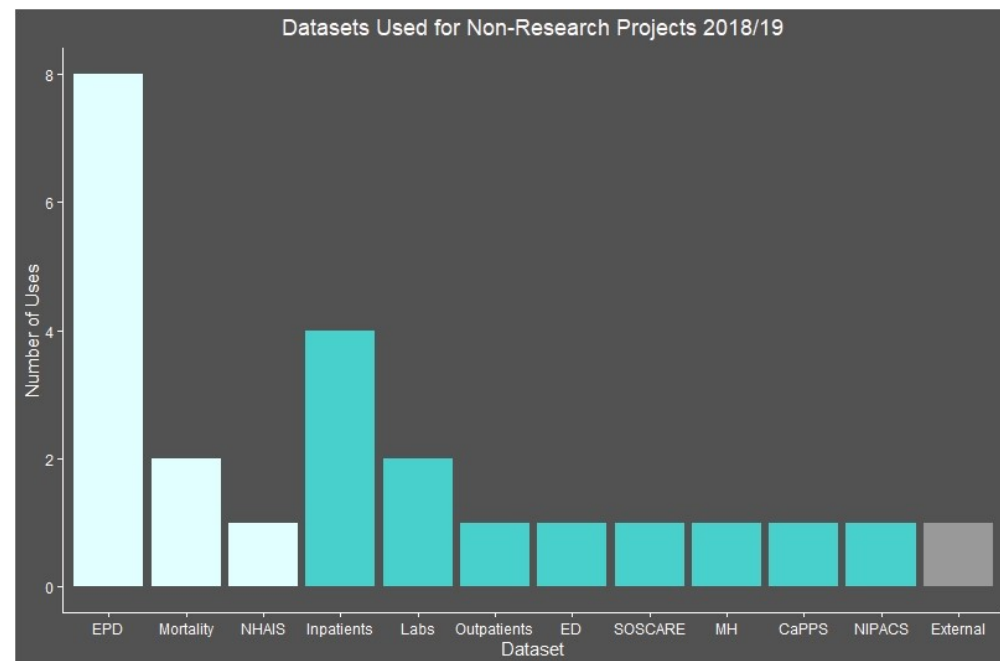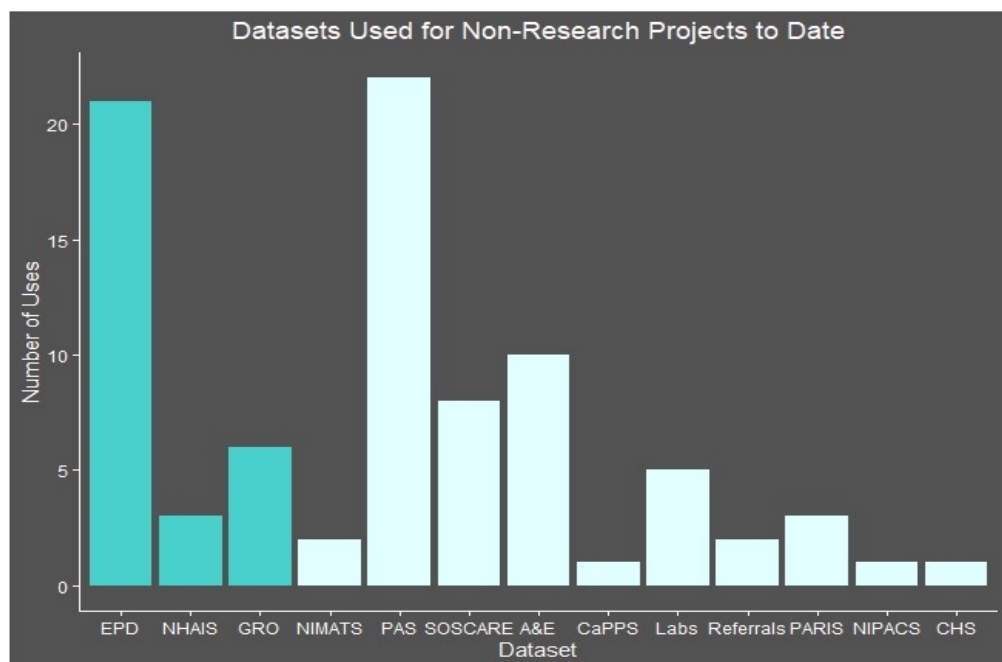
Since the Honest Broker Service began in 2014, EPD and PAS have been used for more than 20 Non-Research Projects each. The A & E dataset would be the third most commonly requested after these.

Providing Support to Health and Social Care

16

Honest Broker Service User Interviews

What is your Project?

I have been working on several dementia projects within the Honest Broker Service.

My Project was a study on prevalence and risk factors of congenital heart disease (CHD) in NI.

How was your experience using the Honest Broker Service?

My experience has been very good, especially now that more computers are available for analysis in the safe haven.

I have had a very good experience with HBS regarding giving me help about availability of the data set, application process, data access in the safe haven, and release of final outputs.

How will your research benefit the health service?

My research provides findings for the dynamics of dementia in NI, and can benefit numerous policies and services locally.

It will help improve the estimation of prevalence of CHD in NI, and to identify risk factors related to CHD, which will help guide public health action to prevent the disease.

Any other comments on your HBS experience?

The Honest Broker Staff are always helpful.

The staff were really helpful, and the booking process is easy and straightforward.

Evi Zafeiridi

Research Fellow at Queens University

Hafi Saad

PhD Researcher at Ulster University

Providing Support to Health and Social Care

Appendix 1—List of Journal Articles Facilitated by HBS, 2018/19

Maguire, A., Tseliou, F. & O'Reilly, D. (2018). **Consanguineous Marriage and the Psychopathology of Progeny: A Population-wide Data Linkage Study.** *JAMA Psychiatry*, 75(5), pp. 438-446. DOI: https://doi.org/10.1001/jamapsychiatry.2018.0133

O'Reilly, D. & Maguire, A. (2018).**Parental mental health and risk of poor mental health and death by suicide in offspring: a population-wide data-linkage study**. International Journal of Population Data Science, 3(4), pp. 151. DOI: https://doi.org/10.23889/ijpds.v3i4.743

O'Neill, S., Graham, B. & Ennis, E. (2019). **Prescribed pain and mental health medication prior to suicide: A population based case control study.** Journal of Affective Disorders, 246, pp. 195-200. DOI: https://doi.org/10.1016/j.jad.2018.12.018

Al-Obaidi, H., Al-Azzam, S., Faith, V., Gardner, E. and McElnay, JC. (2018). **Telecare provision in Northern Ireland.** Abstract set 47th ESCP symposium on clinical pharmacy. Int *J Clin Pharm*. 412 p. 312. DOI: https://doi.org/10.1007/s11096-018-0759-9

Jordan, J., McCann, M., Katikireddi, S. & Higgins, K. (2018). **Harmonising alcohol consumption, sales and related outcomes data across the UK and Ireland: an insurmountable barrier to policy evaluation?** *Drugs: Education, Prevention and Policy* DOI: 10.1080/09687637.2018.1488948

Given, J., Casson, K., Dolk, H. & Loane, M. (2018). **Evaluation of maternal medications and diseases recorded in Northern Ireland Maternity System (NIMATS) database compared to NI Enhanced Prescribing Database (EPD): a data linkage validation study.** *International Journal of Population Data Science* 2018, 3(2). DOI: https://doi.org/10.23889/ijpds.v3i2.497

Gillespie, M., Bunting, B., Sinclair, M. & Condell, J. (2018). **Using the Northern Ireland Maternity System (NIMATS) to determine the relationship of Body Mass Index (BMI) in the pregnant population with other chronic conditions and with pregnancy and birth outcomes.** *International Journal of Population Data Science*, 3(2). DOI: https://doi.org/10.23889/ijpds.v3i2.554

A full list of all Published Research Papers facilitated by HBS since 2014 is available here.

Providing Support to Health and Social Care
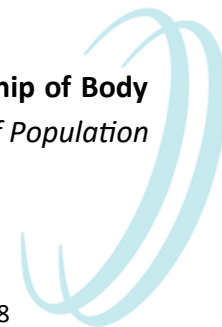
Appendix 2

Membership of Honest Broker Governance Board 2018/19:

Voting Members		Non-Voting Members	
Dr Brendan O'Brien *(Chair)*	HSCB member	Mrs Susan Campbell	BSO
Mr Paul Carlin *(Vice-Chair)*	SEHSC Trust	Mr Neil Marsden	BSO
Dr Nicola Armstrong	PHA	Mr Alan Harbinson	BSO
Dr Peter Sharpe	SHSCT	Dr Siobhan McGrath	BSO
Dr Hilary Russell	Lay Member	Mr Martin Mayock	BSO
Ms Alison Murphy	BHSCT		
Dr Seamus O'Reilly	NHSCT		
Dr Suzanne Martin	Patient Client Council		
Mrs Karen O'Loan	BSO		
Mrs Christine Kennedy	DoH		
Dr Aaron Peace	WHSCT		

Providing Support to Health and Social Care

Appendix 3

Membership of Honest Broker Working Group 2018/19:

Mrs Susan Campbell	BSO
Dr Nicola Armstrong	PHA
Mr Alan Harbinson	BSO
Mr Martin Mayock	BSO
Charlene McQuillan	DoH
Karen Bailey	BSO
Siobhan McGrath	BSO
Eddie Ritson	BSO
Neil Marsden	BSO
Naomi Mill	BSO

Providing Support to Health and Social Care

Appendix 4—Projects Approved 2014/15—2015/16

Project	Title	Organisation	Panel Approval
001	Early life factors and mental health	QUB	2014/15
002	The impact of antibiotic prescription in surrounding community on the incidence rates of nosocomial extended-spectrum β-lactamase (ESBL)-producing strains in hospitalised patients	QUB	2014/15
003	A pilot study to assess the influence of early life events on future risk of development of inflammatory bowel disease	SHSCT	2014/15
004	Evaluation of Past and Present Implementation of Telemonitoring NI	QUB	2015/16
005	A study to explore care provision to older people with mental health needs who access pre-hospital and in-hospital emergency care service (EMS).	UU	2015/16
006	To determine the profile of women in Northern Ireland from 2013-2015 who have accessed maternity services and who have complex healthcare needs and/or disabilities	UU	2015/16
007	Investigating morbidity and mortality outcomes in patients with Tetralogy of Fallot (TOF)	WHSCT / UU	2015/16
008	Investigating maternal and fetal outcomes for women with Gestational Diabetes Mellitus (GDM).	UU	2015/16
009	The relationship between people with borderline personality disorder and general practitioners: Analysis of Northern Ireland patient Health and Social Care data	UU	2015/16
010	Exploring the problem of pain in the CP population: Piloting a big data approach.	QUB	2015/16
011	Identifying and understanding inequalities in child welfare intervention rates: comparative studies in four UK countries	QUB	2015/16
012	Commonly prescribed drugs and association with cancer progression	QUB	2015/16
013	Antibiotic prescribing in older people and trends on movement into institutional care: a record linkage study.	PHA	2015/16
014	Analysis of antidepressant prescribing patterns in Northern Ireland	UU	2015/16
015	Evaluating the implementation of Minimum Unit Pricing of Alcohol – Harmonising alcohol-related outcomes data across the UK & Ireland	UG	2015/16

QUB—Queen's University of Belfast,   UU—Ulster University,   UG—University of Glasgow,   PHA—Public Health Authority

Providing Support to Health and Social Care

Appendix 5—Projects Approved 2016/17—2017/18

Project	Title	Organisation	Panel Approval
016	The relationship between waiting times and treatment outcomes for cancer patients	NI Assembly	2016/17
017	Beta-adrenergic receptor expression and beta-blocker drug use: association with breast cancer survival	QUB	2016/17
018	Suicide deaths in Northern Ireland: Medication and Health Service use	UU	2016/17
019	Are newer disease-modifying anti-rheumatic drugs associated with a lower risk of Alzheimer's disease?	QUB	2016/17
020	Prevalence and Risk Factors of Congenital Heart Disease in Northern Ireland	UU	2016/17
021	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 validation study	UU	2017/18
022	Self-reported mental disorders in pregnancy: analysis of data from the Northern Ireland Maternity System (NIMATS)	QUB	2016/17
023	Type 1 diabetes diagnosed in Northern Ireland children - risk factors, complications and mortality	QUB	2017/18
024	Pathways to a Cancer Diagnosis: Monitoring variation in the patient journey across Northern Ireland	QUB	2017/18
025	Use of prescribed contraception in Northern Ireland 2010-2016	UU	2017/18
026	Transition from home to care home for people with dementia in Northern Ireland	QUB	2017/18
027	Mortality rates of dementia and associated factors in Northern Ireland	QUB	2017/18

Providing Support to Health and Social Care

OGL

Providing Support to Health and Social Care