

Honest Broker Service Annual Report 2019/20





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

All queries can be forwarded to:

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Further background information can be found <u>here</u>.

Previous year's Annual Reports can be found here.

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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 research, planning, commissioning of services and public health monitoring.

This year has been another successful year of growth for the Honest Broker Service with a further 16 projects approved by the Honest Broker Regional Governance Board, a marked increase on the 10 projects approved in 2018/19.

There have been a number of successes, including the Honest Broker Service support to the Data Analytics Dementia Pathfinder Programme which is now approaching an end and the publication of the Pathways to a Cancer Diagnosis report in January 2020. The cancer report was the culmination of an 18 month joint project between BSO and QUB and would not have been possible without the support of the Honest Broker Service.

This year also saw the commencement of a pilot collaboration with Health Data Research UK (HDR UK). The project is exploring the potential use of UK Secure eResearch Platform (UKSeRP) technology and may ultimately allow for secure remote access for researchers.

Further details of these projects are available later in this report.

Bids have been made for proposed investment in the service, and if successful, the HBS will continue to build on this success with further resource and infrastructure necessary to support the growing needs of the HSC in this area; 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.

At time of writing, the COVID-19 outbreak has posed a significant challenge for the service and, from mid-March, forced the closure of the safe haven facility in the BSO at Franklin Street, Belfast, with the team continuing to support our researchers remotely – helping with applications, clearing outputs, and, where possible, running analysis. The safe havens were able to re-open in a limited capacity in August, and we are closely following guidance from the NI Executive and PHA with regards to our opening procedures in order to keep both staff and researchers safe.

Karen Bailey, Interim Chief Executive, Business Services Organisation, and Dr Michael Quinn, Chair of Honest Broker Governance Board

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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 (NI) 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.

The 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) 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 <u>Appendix 2</u>. Minutes of Board meetings can be found here.

The HBGB provide robust governance reviews of research projects before access to HBS data is given. This is an important method of assurance that the research project feasibility has been assessed, and so before data access is approved, the HBGB must be satisfied that the following criteria are met:

- The project relates to Health and Social Care and will support the development and delivery of public policy.
- The requested data can be provided to the researchers by the HBS in a form which will maintain anonymity of the service user but will also satisfactorily address the research questions.
- The research team has identified the relevant stakeholders and a relevant means of dissemination of the project's results.
- The research summary and objectives are clearly set out in lay terms by the research team. (In the interests of research transparency, the research summary of the project will be published on the <u>HBS Website</u>).
- The project timeframe is feasible.
- The research team has considered potential information disclosure risks and described adequate safeguards by use of totally anonymised data.
- The study has a sound scientific basis and research methodology, and will be managed by a research team with the relevant experience.

The Board checks if a research sponsor has taken overall responsibility for the research project in accordance with the UK Research Governance Framework and whether or not a Health and Social Trust is involved in the project.

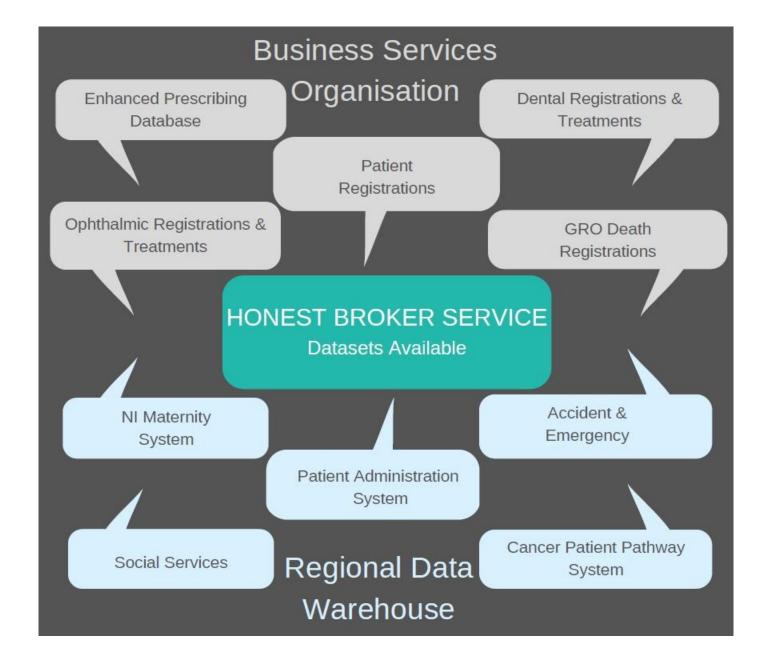
Memorandum of Understanding

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.

Available Datasets



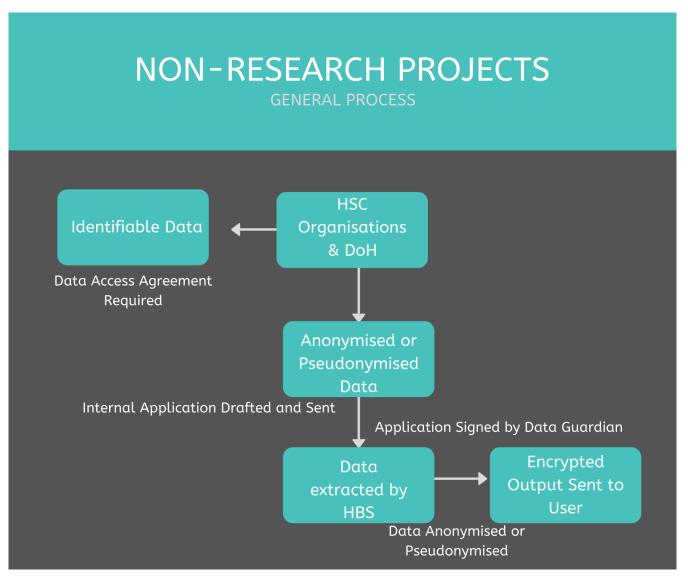
The HBS can facilitate access to both primary and secondary care datasets within the HSC (Shown in grey and green respectively, above). The HSC Regional Data Warehouse (RDW) is a large, secure data store which receives regular data extracts from a range of key HSC Information Systems. It is managed by BSO and hosted within the HSC Regional datacentres. The HBS can also facilitate access to death registrations data held by the NI General Register Office (GRO) outside of the HSC Information Systems.

Routes of Application

The 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.

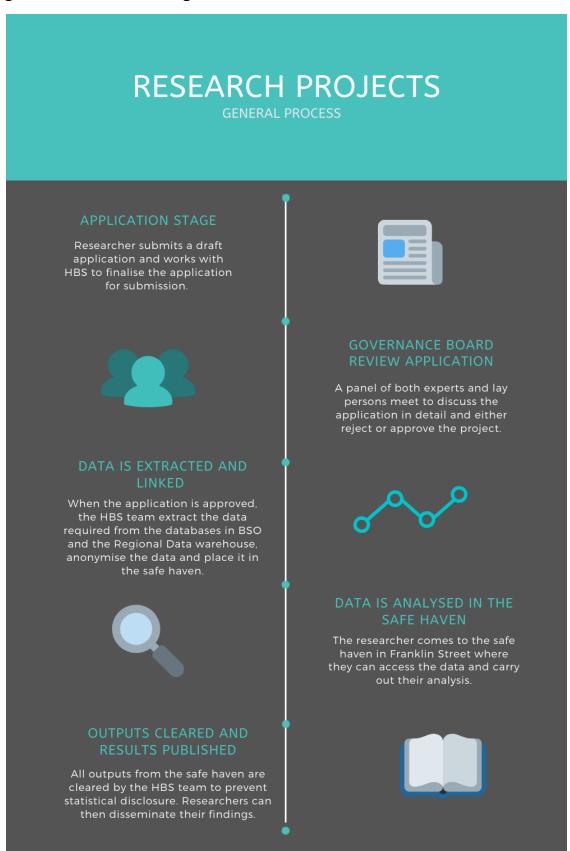
The HBS is now the preferred method of granting organisations access to data. It provides a more streamlined, secure process for data sharing for the HSC and also for the wider research community. This creates efficiencies and ensures the full benefits of data sharing for public health and well-being, 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. The diagram below shows the general process followed by non-research projects applying to use the service.



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.

The diagram below shows a summary of the process completed by Research Projects applying to use HSC data through the Honest Broker service.



Safe Research Environment

At present researchers are required to 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, Belfast. Researchers are supervised at all times to ensure compliance with security requirements. Up to seven research teams can be accommodated at one time, across two secure rooms. All research stations are equipped with software packages such as SPSS, STATA and R.

Remote Data Access—The Future of Honest Broker Service?

At the request of DoH, the HBS is taking forward a pilot collaboration project with Health Data Research UK (HDR UK). The project is exploring the potential use of UK Secure eResearch Platform (UKSeRP) technology; a software service that allows researchers remote access to large scale and complex linked datasets. UKSeRP has been developed by Swansea University based on experience gained in the use and development of the SAIL Gateway. It provides a secure environment with standard and bespoke analytical tools which conforms to best practices of data management, security and information governance. Importantly, the HBS retains ownership of all data, and is responsible for account and access controls.

An instance of UKSeRP has been installed in the HSC datacentres. HBS Staff received a training session from the Swansea team in February 2020, and are currently testing the system using Open Data (freely available and published on the BSO Website, which poses no security risks) prior to the next stage of the pilot commencing. We plan to further test the platform security and functionality over the coming months. If all is satisfactory we will propose amendments to the MOU, which would allow us to offer researchers the chance to securely access their data online, 24/7, without the need to come into the Safe Haven. This would open up more opportunities for the HBS to be utilised by UK wide research teams, who currently have difficulties arranging travel to visit the Safe Haven.

With the UK wide lockdown due to coronavirus imposed on 23rd March 2020, it became even more apparent that remote data access is an important step for the HBS future in the health research community.

Pathways to Cancer Diagnosis:

A major new project facilitated by the Honest Broker Service

The Pathways to Cancer Diagnosis project was a joint project undertaken by BSO Information Unit and the Centre for Public Health in Queen's University Belfast (QUB), with funding from the Health Foundation charity. The project aimed to assess, for the first time, the different routes to diagnosis that cancer patients experience in Northern Ireland (NI). The report looked at eight different pathways to diagnosis (including, for example, screening, GP referral and emergency admission) and showed that these can have a significant impact on patient outcomes.

To carry out the project, data from the NI Cancer registry was linked with screening information, hospital information (for both inpatients and outpatients) and data from the cancer patient pathway system. The linkage and analysis was facilitated by the HBS.

Some of the main findings from the project included:

- Around 46,000 patients were diagnosed with cancer in NI from 2012-2016. One fifth of these were diagnosed through an emergency route-to-diagnosis.
- Three year survival for patients from the screening route is 97%, across all cancers.
 This reduces to 21% for the emergency admission route.
- Six in every ten patients diagnosed via screening had Stage I cancer. In contrast, around seven in ten patients diagnosed through emergency presentation had either Stage IV or unknown stage.
- The proportion of emergency presentations was higher in deprived areas and among older patients.

This HBS project was unique in scope and ambition and has been the first project carried out jointly by Family Practitioner Service Information Unit statisticians and researchers from QUB. It will help to inform the Cancer Strategy being developed by the Department of Health and it is hoped that it can be used to assess the effectiveness of changes to cancer policy and services in future years.

The report was released in January this year and can be found <u>here</u>. The project attracted some attention in the local media, and was featured in articles on <u>BBC NI News</u> and the <u>Belfast Telegraph</u>.

Dementia Analytics Research User Group (DARUG)

Better standards of health care mean that people are living longer. This also means that the number of people living with dementia is increasing. To offer effective support to people with dementia and their carers we need to know the number of people who are assessed for dementia, how they access a diagnosis, what services are offered before and after assessment and how accessible and helpful these services are. To answer these and the many other important questions associated with a person's journey with dementia we need to collect the appropriate data.

The Dementia Analytics Research User Group (DARUG) was set up in March 2018 to bring together key stakeholders such as commissioners, health professionals, researchers, academics, voluntary and community representatives, people living with dementia and carers, to come together once a month to discuss and share information about dementia.

A number of data analytics projects, aimed at improving our understanding of dementia in Northern Ireland have received funding under the Dementia eHealth and Data Analytics Pathfinder Programme. This programme is part funded by the Northern Ireland Executive Office, Atlantic Philanthropies and the Department of Health. The programme focuses on using data to enable better understanding of the needs of people with dementia and their carers to inform better services and support and help with planning to meet predicted future needs. The call for funding solicited proposals consistent with the aims of the Northern Ireland Regional Dementia Care Pathway (Health and Social Care Northern Ireland, 2018)

11 projects that were successfully awarded funding through the eHealth and Data Analytics Dementia Pathfinder Programme are summarised here.

The outcomes of the projects are now emerging and the results are being presented at local, national and international conferences, together with papers accepted and submitted for publication in peer reviewed journals. There are also plans to use the results to make changes and bring about impactful changes to clinical practice as well as influence policymakers in the various areas.

Some quotes from attendees about their experience with DARUG:

"DARUG is very informative and I can see the benefit of the outcome of the research and how this will greatly improve the dementia journey for people in the future."

"DARUG is unique. There is no other forum that has the range of disciplines and services coming together to discuss data in dementia. This range of ideas improves our knowledge and understanding of dementia data and what we can do with this data."

"DARUG helps us to understand clinical best practice in dementia."

"The sharing of experiences is invaluable."

"PPI and the voice of people with dementia and carers shape DARUGS' priorities and work."

"With DARUG there is clear progress being made and it is great to be kept informed and provided with opportunities to engage."

"I am new to the area of dementia health / research and have found the group inspirational. So many experts working in different areas you can see such value on all their information coming together. From a research team perspective we have had such useful input to our project from the wider DARUG group. I am thoroughly enjoying being part of this dynamic group and learning so much along the way."

For further information about DARUG or specific projects please contact Soo Hun: Soo.Hun@hscni.net



Successful applicants and teams who secured funding through DARUG pictured with (far left) Soo Hun from the Health and Social Care Board and Angela Hodkinson from The Atlantic Philanthropies.

Projects Approved in 2019/20

In 2019/20, 16 applications were considered and approved by the Honest Broker Governance Board. In comparison, 10 projects were approved in 2018/19—see Appendix 6 for more details:

Project	Title	Organisation	Chief Investigator	Panel Approval
34	Mental health, firearm ownership, and risk of death by suicide: a population-wide data linkage study	QUB	A. Maguire	14/01/20
37	Acute myocardial infarction rates and management in dementia	QUB	B. McGuinness	09/04/19
40	Co-medication burden with polypharmacy and hyper polypharmacy in people with dementia	QUB	B. McGuinness	13/06/19
41	Investigating the relationship between dementia and cancer in NI	QUB	B. McGuinness	13/06/19
42	Living alone with dementia: related use of drugs	QUB	B. McGuinness	07/05/19
43	Using NICOLA linked to administrative data to understand how older adults in NI transition from MCI to dementia, and to examine equity in dementia-related health care access	QUB	S. Cruise	07/05/19
44	Assessing the rates and reasons behind falls and fractures of people with dementia in NI	QUB	B. McGuinness	03/07/19
45	Mothers first unlocking potential of NIMATS	UU	J. Murphy	17/07/19
46	Understanding real world healthcare costs for living donor kidney transplantation	BHSCT	M. Quinn	04/10/19
47	Dental and Ophthalmic Health in NI: an examination of disparities in rates between those with severe mental Illness (SMI) and the general hospital population	UU	M. Rosato	27/08/19
48	Physical Healthcare Outcomes in those with Severe Mental Illness (SMI's) in NI	UU	G. Leavy	27/08/19
49	Health service use and outcomes in later life: an examination of urban and rural health inequalities in NI	UU	M. Rosato	27/08/19
50	Linking Psychological Therapies Service outcomes data with hospital admissions and prescriptions data	NHSCT	K. Dyer	04/10/19
51	Antipsychotic and antidepressant use among people with dementia in NI: A retrospective analysis	QUB	B. McGuinness	04/10/19
52	Maternal Exposure to Air Pollution during Pregnancy and Infant Health	QUB	N. Rowland	04/10/19
54	Using linked healthcare records to identify the prevalence, characteristics and clinical outcomes of patients with Severe Eosinophilic Asthma in NI	QUB	Dr. J. Stewart	20/12/19

Research Activity in 2019-20:

Safe Haven Usage

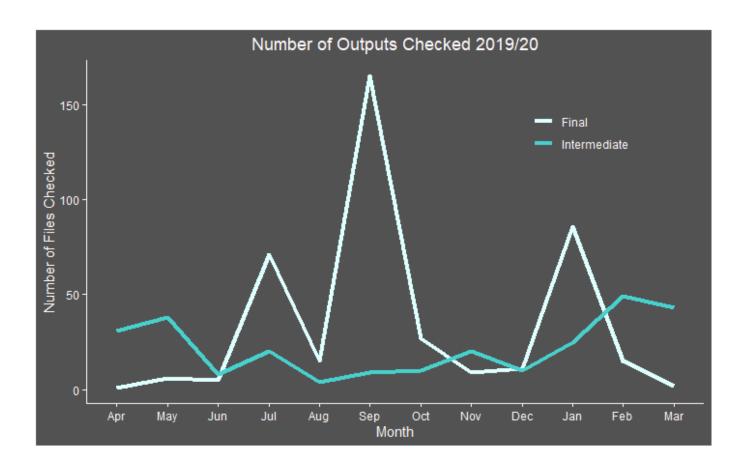
2019-20 was the busiest year to date for the Safe Haven, with 76% of the 231 available days being utilised by researchers (compared to 2018/19 where 56% of the 248 days were utilised.) August 2019 was the busiest month with 95% of the 21 working days utilised. October was one of the quieter months, with 61% of the 23 working days utilised. Only 10.5 working days were lost in the Safe Haven between April 2019—February 2020 due to staff training and leave.

Unfortunately, the Safe Haven was closed on March 18th 2020 due to the coronavirus pandemic. Researchers were notified via email, and 10 working days were lost as a result of this. The HBS Staff continued to provide support to teams writing new applications, and to clear Final Outputs for ongoing research. At the time of writing (Sept 2020) the Safe Haven has re-opened in a limited capacity, and the HBS staff are continuing to follow the advice provided by the NI Executive and PHA with regards to the facility remaining operational.



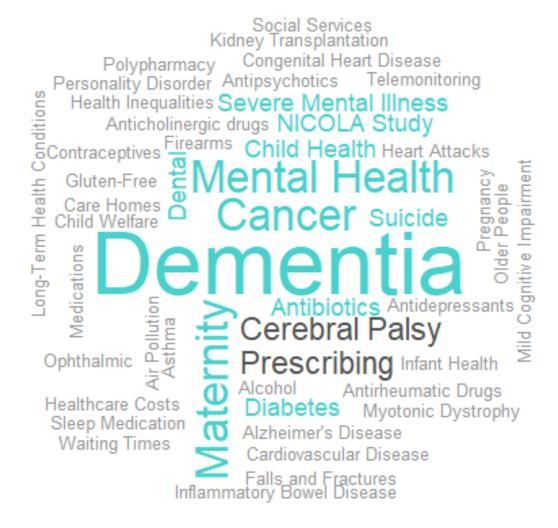
The average booking length in 2019/20 was just under 5 hours (4 hours and 43 minutes). In 2018/19, the average booking time was 5 hrs 20 mins. This decrease is likely due to the increased capacity of the Safe Haven, meaning researchers are able to make more frequent but shorter and more convenient bookings to fit in around their work schedules (as they know there are more workstations available and we are able to offer more flexibility with bookings than ever before). The total number of research hours booked into the safe haven in 2019/20 was 1,344, an increase of 28% on the previous year's figure of 1,054 researcher hours.

680 files were checked by the HBS staff throughout the year; 253 intermediate outputs and 413 final outputs. 61% of the files were checked and returned to the researchers the same day they were submitted. 34% of the files were returned within 1 day of submission and just 5% took 2 or more days. This is an improvement on last year, and likely down to improved staffing in the HBS. Current guidelines state that intermediate outputs should be cleared within 5 days, and final outputs within 20 days. This target was met in all cases.



Research Activity in 2019-20:

Themes



Research projects in this year cover a wide range of topics (see word cloud, above). The DARUG funding has continued to influence the number of dementia related projects taking place in the HBS Safe Haven; they involve dementia drug use when living alone, falls and fractures in dementia patients, acute myocardial infarctions, antipsychotic and antidepressant use, and hospitalisation rates in dementia patients. Another dementia project of interest is using the NICOLA study (NI Cohort for the Longitudinal Study of Ageing) to understand how older adults transition for Mild Cognitive Impairment to dementia, and an examination of equity in dementia-related healthcare access.

Other projects cover areas such as healthcare costs for kidney transplant patients, physical healthcare outcomes and dental and ophthalmic health in those with severe mental illness, and health service use and outcomes in later life which looks at urban and rural inequalities in NI.

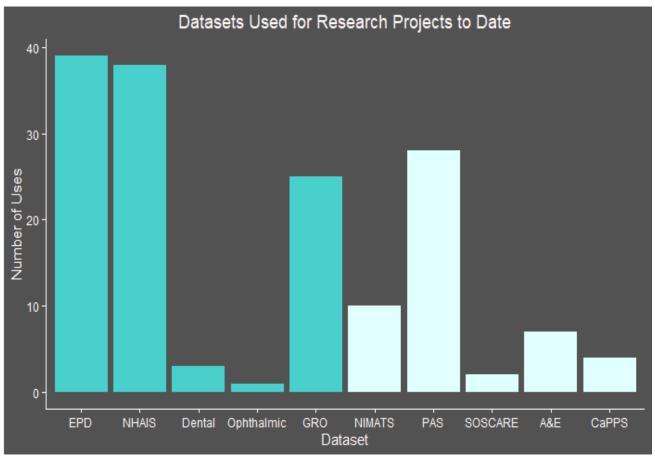
Research Activity in 2019-20:

Datasets used

In 2018/19, there were 27 active projects being worked on in the HBS safe haven. In 2019/20, this increased to 31 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, being used by 39 and 38 projects since the inception of HBS respectively. In 2019/20, 14 of the 16 approved projects requested access NHAIS data and 13 requested EPD data.

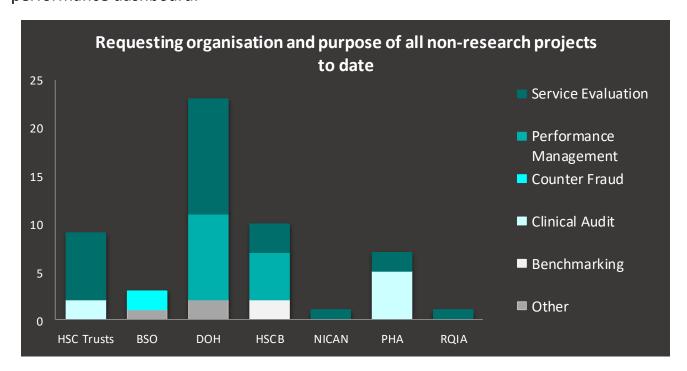
The Regional Data Warehouse hold the Secondary Care Datasets (shown in white). The Patient Administration System (PAS) is the most commonly requested of these datasets, and has been used by 28 projects to date (12 projects requested this dataset in 2019/20). The Northern Ireland Maternity Service (NIMATS) dataset is the second most commonly requested dataset, being utilised by 10 projects. SOSCARE (Social Services Client Administration & Retrieval Environment), CaPPS (Cancer Patient Pathway System), and Accident & Emergency department datasets are less commonly requested.



Non-Research Projects in 2019-20:

Requesting Organisations, Purpose & Themes

There were 9 non-research projects active in 19/20, (compared to 11 in 2018/19). They supported the Department of Health (5 projects), Health & Social Care Board (1 project), Public Health Agency (1 project), and HSC Trusts (2 projects). 7 projects this year were for service evaluation. Areas covered included Antimicrobial use and resistance, analysis of long-term conditions, and the development of a regional stroke performance dashboard.



This brings the total number of non-research projects completed through the HBS to 54. 23 of these projects supported the DoH, 9 were for Health Trusts, and 10 for the Health and Social Care Board. Almost half of projects (26) were for service evaluation, and 14 for performance management. The topics covered (shown in this word cloud, right,) have focussed most on areas including prescribing patterns, hospital admissions, and mortality rates.

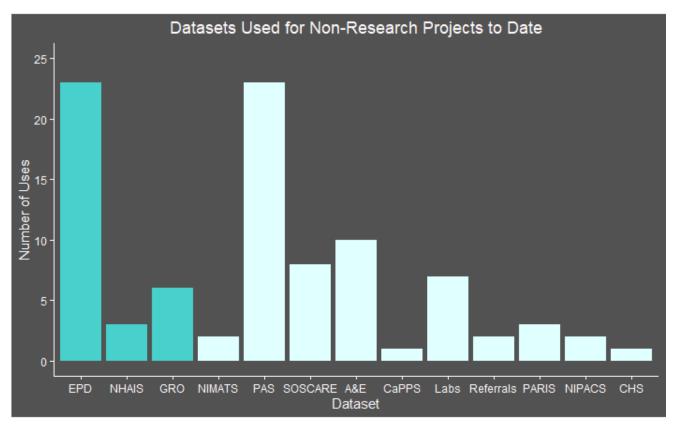


Non-Research Projects in 2019-20:

Datasets used

The dataset most commonly used by non-research projects in 2019/20 was the Enhanced Prescribing Database (EPD— this was also the most commonly requested in 2018/19). Considering that we get such a high proportion of projects looking at prescribing trends, this is to be expected.

Since the Honest Broker Service began in 2014, EPD and the Patient Administration System (PAS) have been used for 23 non-research projects each. The A&E datasets (NIRAES / eEMS from the South & South Eastern Trusts, and Symphony from the Belfast, Northern & Western Trusts) would be the third most commonly requested after these, being utilised by 10 projects in total.



Primary Care Datasets (shown in blue):

EPD (Enhanced Prescribing Database), NHAIS (GP Registrations), GRO (General Register Office).

Secondary Care Datasets (shown in white):

NIMATS (Northern Ireland Maternity Service), PAS (Patient Administration System), SOSCARE (Social Services Client Administration & Retrieval Environment), A&E (Accident & Emergency Datasets), CaPPS (Cancer Patient Pathway System) Labs (Laboratory Systems), Patient Referrals, PARIS (Mental Health Dataset), NIPACS (NI Picture Archiving and Communications System) and CHS (Child Health System).

Honest Broker Service User Interview

What is your Project?

Understanding how mild cognitive impairment transitions to dementia in older adults and their access to health care.

How will your research benefit the health service?

Our research aims to determine the uptake of anti-dementia medication among the NICOLA cohort, and to determine what factors are associated with variation in uptake of anti-dementia treatment. This research aims to benefit the health service by assessing equity in access to dementia treatment to ensure that those who are in need are getting the services they require.

How was your experience using the Honest Broker Service?

I have had a very positive experience with HBS, the staff are extremely helpful and provide an excellent service to researchers.

If you could improve one thing about the HBS, what would it be?

I think that having remote access would be an improvement especially given the lockdown restrictions with Covid-19, however, I am aware that this is not a straightforward process and HBS are trying to accommodate researchers as best they can.

Siobhán Murphy,

Centre for Public Health, Queen's University Belfast

Appendix 1—List of Journal Articles Facilitated by HBS, 2019/20

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

Given, J,E., Gray, A, M., Dolk, H. (2020). **Use of prescribed contraception in Northern Ireland 2010–2016.** The European Journal of Contraception & Reproductive Health Care, Vol 25 2020.

https://www.tandfonline.com/doi/full/10.1080/13625187.2020.1723539

Bannon, F., McKenna, H., Donnelly, C., Mathieson, S., Price, J. (2020). **Pathways to a**Cancer Diagnosis: Monitoring variation in the patient journey across Northern Ireland
2012 to 2016.

http://www.hscbusiness.hscni.net/pdf/Routes%20to%20Diagnosis%20Report%20-%20Main%20Report%20Jan%202020.pdf

Please note that the articles listed above were those that Honest Broker Service were notified of prior to or subsequent to, their publication. The HBS staff regularly search the known journals for publications coming from research teams that have used HBS data, but there may be other publications that the HBS Staff were not notified about and have been unable to find.

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

Appendix 2:

Membership of the Honest Broker Governance Board 2019/20

Voting Members			
Dr Brendan O'Brien (Chair Apr 2019—Dec 2019)	HSCB		
Lisa Whyte (Acting Chair, Jan—Feb 2020)	HSCB		
Dr Michael Quinn (Chair Feb—Mar 2020)	HSCB		
Paul Carlin (Vice-Chair Apr 2019—Dec 2020)	SEHSC Trust		
Dr Nicola Armstrong	РНА		
Dr Peter Sharpe	SHSCT		
Dr Hilary Russell	Lay Member		
Alison Murphy	BHSCT		
Dr Seamus O'Reilly	NHSCT		
Dr Suzanne Martin	Patient Client Council		
Karen Bailey	BSO		
Christine Kennedy	DoH		
Dr Aaron Peace	WHSCT		
Non-Voting Members			
Susan Campbell	BSO		
Rita McAuley	BSO		
Alan Harbinson	BSO		
Charlene McQuillan	DoH		
Dr Siobhan McGrath	BSO		
Martin Mayock	BSO		

Appendix 3:

Membership of the Honest Broker Working Group 2019/20

Susan Campbell	BSO
Dr Nicola Armstrong	РНА
Alan Harbinson	BSO
Martin Mayock	BSO
Charlene McQuillan	DoH
Karen Bailey	BSO
Siobhan McGrath	BSO
Eddie Ritson	BSO
Rita McAuley	BSO
Alison Afrifa	BSO

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 foetal 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

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

Appendix 6:

Projects Approved in 2018/19

Project	Title	Organisation	Panel Approval
28	Early and late onset of dementia in NI	QUB	2018/19
29	Assessing the rate of anticholinergic drug prescriptions for dementia patients in Northern Ireland	QUB	2018/19
30	Childhood interactions with social services and risk of poor health and social outcomes in adulthood: A population wide data linkage study	QUB	2018/19
31	Myotonic dystrophy in NI	QUB / BHSCT	2018/19
32	Investigation of the link between maternal body mass index in early pregnancy and incidence of cerebral palsy in NI.	QUB	2018/19
33	Evaluation of outcomes for patients with elevated tTG antibodies and Gluten-free food prescription utilisation in NI	QUB / BHSCT	2018/19
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	2018/19
36	Hospitalisation rates in dementia	QUB	2018/19
38	Health and social selection bias on consent to participation in the NI Cohort for the Longitudinal Study of Ageing	QUB	2018/19
39	Sleep medication use in Cerebral Palsy: a comparison between those with Cerebral Palsy and the typically developing population in Northern Ireland.	QUB	2018/19



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