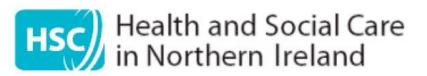


Honest Broker Service

Honest Broker Service Annual Report 2022/23





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 <u>here</u>.

Previous year's Annual Reports can be found here.

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Foreword

This year marks the end of the Data and Connectivity Programme of work with Health Data Research UK to support the National Core Studies during the COVID-19 pandemic. This collaborative working across the UK has brought data to the forefront of policy delivery. The legacy of the work has lead to major reviews such as <u>Data Saves Lives</u> and <u>the Goldacre Review</u>.

The investment in Trusted Research Environment / Secure Data Environment infrastructure across the UK allowed the Honest Broker Service to expand and offer new services such as the remote access via the Secure electronic Research Platform (SeRP) and has helped the Honest Broker Service to mature and develop through shared learning with equivalent providers across the UK.

Focus now shifts to maintaining the service and continuing to develop as HSC looks to the implementation of its own <u>HSC Data Strategy</u> and major programmes of work such as the <u>encompass programme</u>.

The Northern Ireland Trusted Research Environment (NITRE) Strategic Programme Board, which was initially established to co-ordinate efforts on use of data for research across HSC, has been integral in securing funding for continued provision of the Honest Broker Service during 2023/24, including extension of the collaboration with Swansea University who provide the Secure e-Research Platform.

This annual report covers new developments in governance and access as well as a summary of research and non-research activity in 2022/23.

Dr Aaron Peace, Chair of HBGB, Consultant Cardiologist WHSCT Chief Executive of the Clinical Translational Research and Innovation Centre (C-TRIC)



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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 via a secure 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.

Further details about the Honest Broker Service routes of application are detailed in <u>Appendix 1</u>.

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 <u>here</u>.

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 Care Trust is involved in the project.

An Honest Broker Working Group (HBWG) has also been established to support the work of the HBGB. Current membership of the HBWG is detailed in <u>Appendix 3</u>.

A Memorandum of Understanding (MOU) has been developed to inform the development of the Honest Broker Service—more details can be found in <u>Appendix 4.</u> The MOU is currently under review to take into account the future roll out of the Encompass programme across the HSCNI. This should also reduce the need for additional Data Access Agreements in cases where hospital data is stored outside of the Regional Data Warehouse, and access is required for a project.

NITRE

Health and Social Care Northern Ireland Trusted Research Environment (NITRE) is a component of the collective strategic response of the Department of Health, the Northern Ireland Public Health Agency and the Health and Social Care Honest Broker Service to provide data for research for public good.

NITRE was initially constituted to provide a governance structure, data assets, research platform and programme management to ensure the contribution of relevant HSC data to answer priority research questions of regional importance to the COVID response and as part of UK HDRUK National Core Studies in the first instance; however the Strategic Programme board has been reconstituted now that the HDR-UK Core Studies programme of work has been completed.

The NITRE Strategic Programme Board reports to the HSC Data Coordination Board.

Objectives

NITRE provides strategic direction, support and investment, developing HSC infrastructure to enable utility of HSC data assets for evaluation and research, within safe guards of best practice.

- NITRE Strategic Board objective is to coordinate within HSC, and in conjunction with key external stakeholders, developments and delivery in the provisioning of data and infrastructure for research and evaluation.
- DoH have determined NITRE should become a function of the Data Institute when established; setting priorities to improve architecture for access to, and utility of HSC data for research and evaluation.
- NITRE Strategic Board delivery objectives will be an implementation mechanism of the HSC DoH data strategy¹, PHA HSCR&D Strategy², PH framework 'Making Life Better'³, and the recommendations of 'Better, broader, safer using health data for research and analysis'⁴.

References:

- 1 HSC Data Strategy | Department of Health (health-ni.gov.uk)
- 2 Strategy for HSC R&D | Public Health Agency Research & Development in Northern Ireland (hscni.net)
- 3 Making Life Better | HSC Public Health Agency (hscni.net)
- 4 Better, broader, safer: using health data for research and analysis GOV.UK (www.gov.uk)

NITRE Achievements 2022/23

A key achievement of the NITRE Strategic Programme Board in 2022/23 was securing bridge funding for the Honest Broker Service to enable it to continue operating following the completion of the Health Data Research UK Data & Connectivity Programme of work.

In addition to this, the NITRE Strategic Programme Board was instrumental in supporting the PANORAMIC Trial request for follow up data, this was the first time a UK wide clinical trial had been able to access data of this type from HSCNI.

The NITRE Strategic Programme Board was also integral in supporting a pilot initiative which has recommended establishing a public panel to consider how data is used in research, innovation and decision-making in Northern Ireland. (For press briefing please see <u>Report recommends establishing Northern Ireland's first public</u> panel on data use - ADR UK)

HDR UK: Health Data Research Innovation Gateway

Health Data Research Innovation Gateway As part of the Data and Connectivity Study, Health Data Research UK have established the <u>Health Data Research</u> <u>Innovation Gateway</u> which is the UK's portal for data discovery and tools for health research and innovation. The Gateway allows researchers to discover research datasets

and metadata, and to request access to data via the Trusted Research Environments. It also allows data custodians to have an end to end Data Access Request system with technology for integrating into their governance processes, and provides resources for patients and the public to find out more about how data is being used.

Metadata for the Honest Broker Service is now discoverable under the <u>Health and Social Care Northern</u> <u>Ireland "Collection"</u> on the Gateway. The Honest Broker Service have received a number of enquiries and applications via the Gateway including the applications for the National Core Studies.

Data Use Register

HDR UK published a <u>Green Paper</u> in Autumn 2021 around standards for Data Use Registers and have subsequently launched the <u>Data Use Register</u> on the HDR UK Innovation Gateway.

Through the recommendations in the Green Paper and the establishment of the Register HDR UK aim to:

- Improve transparency in the use of health data for research and innovation
- Demonstrate the value and benefit of using health data
- Develop a culture of openness amongst data custodians and researchers
- Generate better insight into health data usage
- Build public trust and advocacy for data use.

The Honest Broker Service COVID-19 related projects were published on the Data Use Register in 2021/22, and in 2022/23 the HBS added the back series of projects that we have been supporting since the introduction of the Service in 2014.

Secure Data Environment

Since the establishment of the HBS, researchers have been 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, must become an accredited researcher under the Digital Economy Act 2017. This is facilitated through the Office for National Statistics (ONS) Safe Researcher Training programme. This training (formerly known as SURE) was previously provided by The Research Support Unit (RSU) within the Northern Ireland Statistics and Research Agency (NISRA).

The HBS Safe Haven is located in BSO, Franklin Street, Belfast. 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.

SeRP—Remote Data Access

The UK Secure electronic Research Platform (SeRP) has been developed by Swansea University based on experience gained in the use and development of the <u>SAIL Gateway</u>. It provides a secure environment with standard and bespoke analytical tools which conforms to best practices of data management, security and information governance.

SeRP provides secure remote access to de-identified data for research purposes, via a Virtual Desktop Infrastructure.

The HBS tenancy of SeRP is now in it's third year of full implementation, all projects suitable for remote access have been migrated and the majority of new projects are facilitated via remote access.

Importantly, the HBS retains ownership of all processes, and is responsible for account and access controls as well as output checking.



Under the renewed agreement HBS has 20 concurrent licenses as well as 10 Stata Licenses and 10 "large" desktop licenses which provide additional processing power for large databases.

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SafePod Network

Health and Social Care Northern Ireland (HSCNI) has joined the SafePod Network to provide approved Honest Broker Service researchers access to their project data from SafePods.

A SafePod is a standardised safe setting that provides the security and controls for data that requires secure access for research. A SafePod includes a door control access system, CCTV, a researcher area for dataset analysis, and secure IT cupboard. More info is available <u>here</u>

The <u>SafePod at Ulster University</u> opened for bookings in December 2022, and is the first organisation in NI to host a SafePod for researchers to access their project datasets from the SAILdatabank, UK Data Service Secure Lab, Office for National Statistics Secure Research Service and of course, the HBS!

This is a great new service for those researchers who currently have a live HBS Project which is accessible via the HBS Secure e-Research Platform (SeRP), as it guarantees a quiet, secure area to work in whilst on the UU Coleraine campus, without risk of computer screens being overlooked. The SafePod is a comfortable space to work in, with a height adjustable desk, chair and 2 monitors.

The standard SeRP terms and conditions apply while accessing data in the SafePod, while the SafePod has optional CCTV functionality this will not be switched on when accessing HBS data.

To make a SafePod booking in the UU Coleraine Campus, please click here.



New Projects Approved in 2022/23

In 2022/23, 3 application panels were convened and 8 applications approved by the Honest Broker Governance Board with a further 3 approvals just falling into the following year due to panel timings. Taken together, this is on a par with the 12 projects approved in 2021/22.

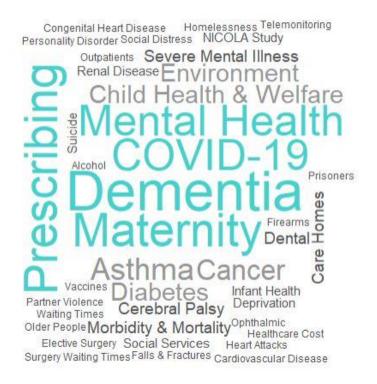
At the time of writing 5 new projects , including the 3 referenced above, which HBS assisted in drafting in 2022/23 have subsequently been approved in 2023/24.

Project	Title	Organisation	Chief Investigator	Panel Approval
E077	Gestational diabetes in Northern Ireland during the COVID-19 pandemic: a data linkage study of multidisciplinary healthcare records	QUB	Hannah O'Hara	16/09/22
E078	Antidepressant and anxiolytic prescribing and risk of mortality for people with dementia in Northern Ireland: a nested case-control study.	QUB	Heather Barry	13/09/22
E079	INHALER Study: INvestigating How Asthma Links to Early-life Respiratory tract infections	QUB	Helen Groves	31/08/22
E080	Greenhouse gas emissions associated with severe asthma care in the United Kingdom	QUB	John Busby	24/11/22
E081	Can cost-effective strategies identify and stabilise higher risk patients with Immunoglobulin A (IgA) Nephropathy and prevent end-stage renal disease?	BHSCT	Christopher Hill	24/11/22
E082	Effects of COVID-19 Mitigation Policies on Diagnostic Conversion to Colorectal Cancer	QUB	Ethna McFerran	01/03/23
E083	Exploring the relationship between natural environments, COVID-19 and mental health: Evidence from Northern Ireland	QUB	Ruoyu Wang	01/03/23
E084	Creating the first linked research dataset including general practice records within Northern Ireland	QUB	John Busby	01/03/23

Research Activity in 2022-23

As in previous years, research projects approved this year cover a wide range of topics. This word cloud provides a brief summary of the areas covered by all research projects to date. Dementia, Maternity and Prescribing are the 3 most popular areas of research.

The COVID-19 pandemic has resulted in an influx of projects on this topic since 2020/21, and it is now the 4th most common area of research in the HBS. A further three COVID-19 related projects were approved in



2022/23. These projects aim to investigate the effects of changing Gestational diabetes diagnostic techniques during the pandemic on rates of diagnosis, the effect of infection mitigation polices on diagnostic conversion to colorectal cancer, and the relationship between access to natural environments and mental health during the pandemic.

Three distinct linkage projects were approved in 2022/23. These require datasets external to the HSC to be linked to datasets within the Regional Data Warehouse, and as such require additional data access agreements to be written and signed by the relevant parties before data transfer can proceed.

A pilot project involving General Practice Intelligence Platform (GPIP) data was approved in March 2023, and work is underway to establish a set of standard operating procedures to allow GPIP data to be linked to other data sources in a privacy preserving fashion, to apply to all future HBS projects involving GPIP data.

The other projects approved cover areas such as antidepressant and anxiolytic prescribing for people with dementia, Asthma and early-life respiratory tract infections, and the greenhouse gas emissions associated with severe asthma care.

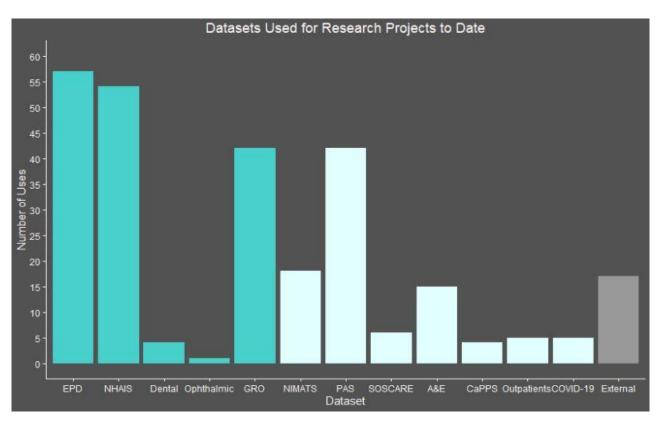
A list of journal articles published in 2022/23 relating to Honest Broker Service research projects can be found in <u>Appendix 6</u>.

Datasets used

The vast majority of projects analyse a range of linked datasets held by BSO and the Regional Data Warehouse.

The Primary care datasets held by the BSO Family Practitioner Services Information Unit are shown in green. The Enhanced Prescribing Database (EPD) and Patient Registrations (NHAIS) are the most commonly used datasets, being used by 58 and 51 projects since the inception of HBS respectively. In 2022/23, 6 of the 8 approved projects requested access to EPD data, and 4 requested NHAIS data.

The Regional Data Warehouse hold the Secondary Care Datasets (shown in grey). The Patient Administration System (PAS) is the most commonly requested of these datasets, and has been used by 43 projects to date (5 projects requested this dataset in 2022/23). The Northern Ireland Maternity Service (NIMATS) dataset is the second most commonly requested dataset from the Regional Data Warehouse, being utilised by 18 projects (2 projects requested this dataset in 2022/23). Demand for Accident and Emergency data has continued to increase from 2021/12, with a further 3 projects in 2022/23 requesting this data (15 projects to date). SOSCARE (Social Services Client Administration & Retrieval Environment), CaPPS (Cancer Patient Pathway System), and Outpatient datasets are less commonly requested. COVID-19 related datasets introduced in 2020/21, including Pillar 1 and Pillar 2 COVID-19 testing and Vaccine Management System data continue to be requested regularly.

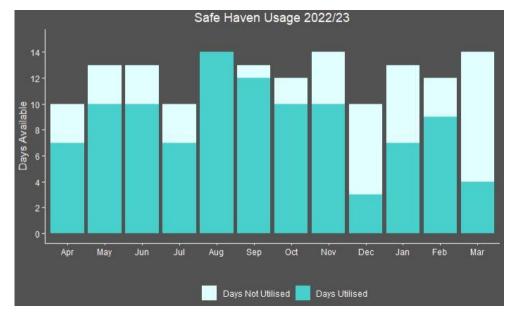


Safe Haven Usage (Safe Room Belfast)

Since re-opening after the COVID-19 pandemic, the HBS continued to offer access to the Safe Haven on a limited basis during the last year. In line with government guidance, only two researchers could access data in each session (1 per room, due to social distancing) allowing a maximum of four researchers in the safe setting per day (2 x 3hour sessions are offered each day). To allow additional cleaning to take place and rotation of work stations, the Safe Haven could also only be made available for a reduced number of days each week. Researchers are contacted fortnightly to make their booking requests.

Safe Haven usage has decreased in 2022/23 compared to the marked increase we saw in 2021/22 when we offered limited re-opening for the first time since the pandemic began in 2020. The Safe Haven was open for morning and afternoon sessions for 148 days in 2022/23, this is compared to 135 days in 2021/22. Researchers did not avail of all sessions in either of the last 2 years, indicating that availability outweighed demand with the majority of researchers now having remote access to their data via SeRP.

In 2021/22, there was 94% utilisation available of sessions; this has decreased 70% utilisation in to 2022/23. But the Safe Haven remains an essential part of HBS because some projects utilise data which is not permitted to be uploaded to the remote platform (for example,



some of the more sensitive projects containing GRO Mortality Data are only permitted for access via the Safe Haven)

Total number of Active HBS Projects at year end: 36 - 32 on SeRP - 4 Safe Haven

SeRP

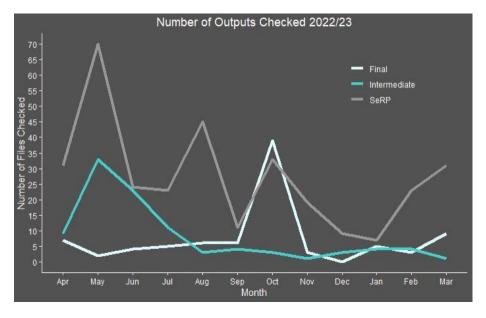
35 Projects were active on SeRP during the course of the year, with 40 researchers named as active users. The majority of users (73%) were working on a single project, 15% working on 2 projects, and the remaining 13% working on between 3 and 6 projects.

Output Requests

514 files were checked by HBS in 2022/23;

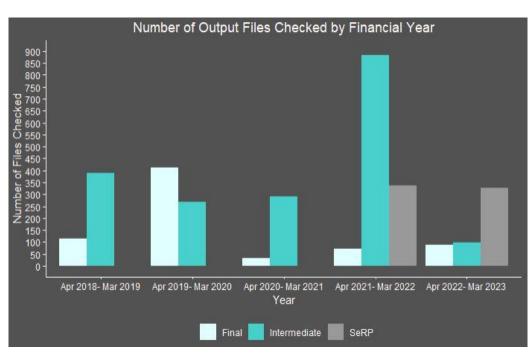
- 99 intermediate files
- 89 final files
- 326 SeRP files

This is a decrease from 2021/22, but is to be expected



because of the massive increase seen last year due to researchers resuming their work after the pandemic closure and effectively making up for lost time. Over half of the files checked in 2021/22 (704 of 1,291) related to the COVID-19 projects which had been developed in response to the pandemic. In 2022/23, this has decreased to less than a quarter (120 of 514 files, made up of over 1,300 individual tables and charts). Since the initial rush on the service when it re-opened, HBS has now returned to business as usual with regards to the number of outputs we are screening for researchers, with overall figures comparable to the pre-pandemic years (albeit with the majority now coming through SeRP rather than the Safe Haven). May and October were the busiest months for the service with regards to output checking, with over a third of files received in these two months alone (179 across the 2 months).

56% of the files were checked and returned to the researchers the same day they were submitted. 32% of the files were returned within one day of submission and the remainder took two or more days.



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

Project Modifications

Project modifications form a significant part of the HBS workload every year. They can include:

- Research team personnel changes
- Addition of new datasets to the existing project data
- Addition of new variables from datasets already approved for use by the project team.
- Other changes to the originally approved project application.

All of these changes require a significant amount of work from the HBS team to implement , and can be vital to ensure a project can meet it's desired objectives.

During this year, the HBS team received 43 project modification requests. These included 27 requests to extend the project end date to allow analysis to continue beyond the planned end date, 6 requests to add additional team members, and 8 requests to change project data—for additional datasets or variables to be added, or to extend the date range covered by the existing data provided to the team.

Registry Updates

The Honest Broker Service provide vital patient healthcare updates, including prescription data and General Registry Office Mortality Data to a number of organisations (including Queen's University Belfast, QUB) who maintain important disease registries both in NI, and across the UK as a whole. These include the NI Cancer Registry (NICR), the NI Cerebral Palsy Register (NICPR), the NI Cohort for the longitudinal study of ageing (NICOLA), and the National Joint Registry (NJR).

More information is available here:

NICR—The Registry | N. Ireland Cancer Registry (qub.ac.uk)

NICPR—Northern Ireland Cerebral Palsy Register | Queen's University Belfast (qub.ac.uk)

NICOLA – About NICOLA | NICOLA | Queen's University Belfast (qub.ac.uk)

NJR—Home - The National Joint Registry (njrcentre.org.uk)

NILS

The Honest Broker Service has a dedicated statistician who works with the <u>Northern Ireland Longitudinal Study (NILS)</u> in the NI Statistics and Research Agency (NISRA), acting as both an advisor and data processor for distinct data linkage projects involving healthcare data.



Northern Ireland Longitudinal Study Research Support Unit

The NILS is proportionally the largest longitudinal study in the UK covering 28% of the Northern Ireland population and accounting for approximately 50% of Northern Ireland households. The NILS 'core' data are drawn from the Health Card Registration data and then linked to data from Census returns (1981, 1991, 2001 & 2011), Vital Events (births, deaths and marriages), Migration and Property data. The result is over 30 years of longitudinal data which is regularly being updated. In addition to this rich resource the HBS supply further Health and Social Care data via Distinct Linkage Projects which undergo an approvals process involving input not only from both NILS and HBS statisticians, but other industry experts and academics. Due to the nature of these projects, they are extremely complex and follow strict procedures ensuring patient confidentiality is protected at all times, and data is pseudonymised prior to being transferred to NILS.

In 2021/22, HBS provided data for 2 NILS projects. This increased to 5 in 2022/23, but it should be noted that part of this increase is due to projects in previous years being delayed due to COVID-19 restrictions. The 5 projects were:

- Jobs, mental health and family responsibilities: an extended administrative data study of occupations, mental health and mortality among the NI population and examination of the role of the COVID-19 pandemic.
- The impact of the COVID-19 pandemic and quarantine on people with Severe Mental Illness (SMI) in NI: an examination of prescribed psychotropic medication and mortality between Census 2011 and 2021.
- Analysis of multimorbidity, prescribed medication use and mortality over the Covid-19 pandemic period, with a specific focus on those with dementia – a longitudinal study of persons aged forty or more in 2011 in NI.
- A comparative analysis of the impact on disparities in oral healthcare use of the introduction of an objective measure of treatment need in orthodontics.
- Residual disadvantage among neighbourhoods in NI.

Research in Focus

The PANORAMIC Trial in 2022-23



PANORAMIC Platform Adaptive trial of NOvel

antiviRals for eArly treatMent of COVID-19 In the Community

PANORAMIC (<u>Platform Adaptive trial of NOvel antiviRals for eArly treatMent of COVID-19 in the Community</u>), is a clinical research study. The purpose of this clinical study is to find new antiviral medicines that help those suffering with COVID-19 at home and in the community get better quicker and without needing to be treated in hospital. Most people with COVID-19 are treated in the community and treatments need to be found that are suitable and effective for use early on in the illness. It is a UK wide study with recruitment from all four nations; administered by The University of Oxford and approved by the Health Research Authority. It is the UK's fastest ever recruiting trial of its kind.

Recruitment in NI was a significant success, with co-ordination from the Northern Ireland Clinical Research Network and support from across HSC and GP Practices, the Trial teams were able to recruit in excess of 1,000 participants; significantly exceeding what would be expected based on the relative population size. Trial participants agreed to a 6 month follow up period which included submitting diary returns as well as being contacted directly by the study team at set intervals depending on the trial medication administered.

HBS staff have been providing linked "follow up" data to the Oxford team on a monthly basis and will continue to do so until September 2023. The data sent includes relevant records on hospitalisations including admitted patient care, outpatient care, accident and emergency attendance and critical care, as well as mortality records.

This was particularly challenging to establish for HSC as there is not a single route of application for consented data linkage and the project involved setting up a data sharing framework with all the respective organisations involved.

One of the key findings so far has been that molnupiravir does not reduce hospitalisation / deaths in vaccinated people at high risk (<u>published 22nd December 2022</u>). Other treatments are also being investigated.

The latest news from the trial is available here: <u>News — PANORAMIC (panoramictrial.org)</u>

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Research in Focus

MuM-PreDiCT wins HDR-UK Team of the Year

The HBS would like to offer our congratulations to the MuM-PreDiCT project team (and in particular the researchers from NI on the team), who won the Team of the Year Award at HDR-UK's annual awards ceremony in December 2022.

Team working is core to HDR UK's mission. This award celebrates collaborative endeavours by groups of researchers, innovators, technologists, triallists and more working together within HDR UK and beyond. As well as being diverse and inclusive in membership, the winning team will exemplify HDR UK's values of transparency, optimism, courage, respect and humility.

"A consortium of eight universities from all four UK nations with a multidisciplinary team, comprising of health data scientists, clinicians and patient and public representatives, was established for MuM-PreDiCT. Their vision was to use data-driven research to characterize and understand the determinants and consequences of multimorbidity in pregnant women; and to predict and prevent multimorbidity and its adverse consequences in women and their offspring."

"The team is recognised for their leadership, inclusivity – particularly their involvement and support of early career researchers. The panel applaud the team's public and patient involvement and engagement which shows real evidence of co-production in an underserved area."

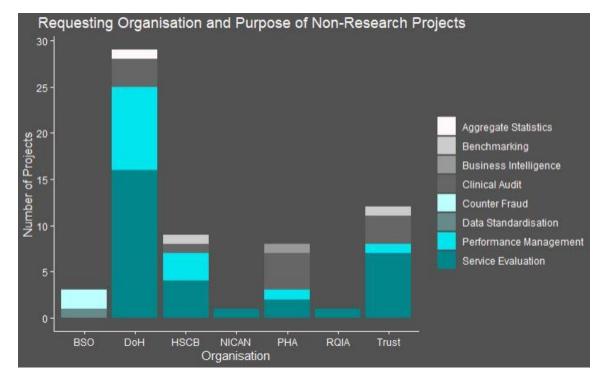
- The Team of the Year Award Panel



Non-Research Projects in 2022-23

Requesting Organisations, Purpose & Themes

There were three new non-research projects approved in 2022/23, (compared to just one in 2021/22). These projects all supported the Department of Health, and were composed of two clinical audits and one service evaluation project. One project focused on Antibiotic prescribing, another on the waiting lists for neurology outpatients appointments, and the final one was to update the NI Health and Social Care Inequalities Monitoring system with up to date prescriptions data (relating to Anxiety, Antihypertensive drugs and Statins).



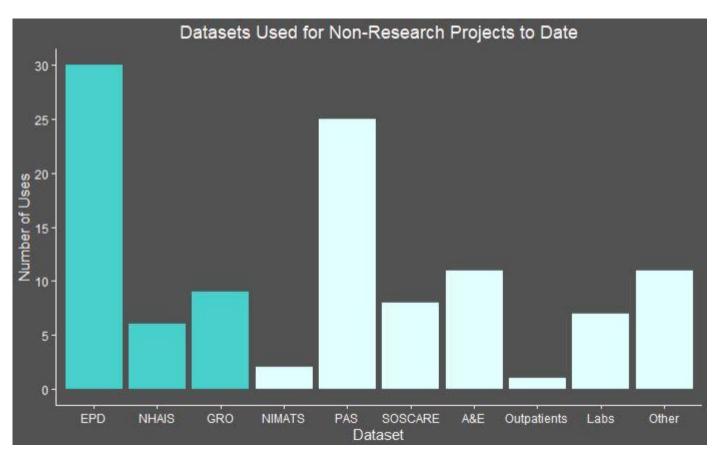
This brings the total number of non-research projects completed through the HBS to 63. 29 of these projects supported the DoH, 12 were for Health Trusts, and nine for the Health and Social Care Board. Half of projects (31) were for service evaluation, 14 for performance management., and 11 for Clinical Audit. Topics covered (shown in this word cloud, right, have focussed mostly on areas including prescribing patterns, hospital admissions and mortality rates.



Datasets used

The dataset most commonly used by non-research projects in 2022/23 was the Enhanced Prescribing Database (EPD) - this was also the most commonly requested in the previous two years). Considering the Honest Broker Service receive a high proportion of research projects looking at prescribing trends, this is to be expected.

Since the Honest Broker Service began in 2014, EPD has been used for 30 non-research projects and the Patient Administration System (PAS) has been used for 25 non-research projects. 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 11 projects in total.



Primary Care Datasets (shown in green):

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

Secondary Care Datasets (shown in grey):

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).

Non-Research Projects In Focus

Neurology Review: Using data to support care co-ordination

On 31 July 2018 the Department of Health announced a comprehensive regional review of Neurology services covering all neurology specialties. The review is tasked with identifying an optimal service configuration of neurology services through to 2035. It was acknowledged that improving care co-ordination is important to stakeholders at multiple levels within the health and social care systems. Therefore; a Regional Neurology Care co-ordination and community neurology workstream was established as part of the review

The care co-ordination workstream carried out a project to understand how data associated with those on a neurology waiting list could be used to understand how patients interact with the system and therefore determine how patients can receive the right level of care depending on their health and social care needs. In order to understand how patient's move through the system we needed to be able to connect the data within the system.

Within HSC we collect data each time a patient interacts with the system, therefore by extracting that information and carrying out analysis at a patient level we can better understand how patients use the system and how we can co-ordinate the care patients receive to meet their needs more effectively.

Dataset	Information	Variables	
Symphony	Emergency data — Belfast, Northern & Western Trusts	Arrival, departure, incident type	
NIRAES	Emergency data — Southern & South Western Trusts		
Electronic Prescribing Data (EPD)	Prescription data	Issue / scan date, BNF Information, prescribed drug DMAD code	
Patient Administration System (PAS)	Inpatient data	Arrival, departure, hospital, length of stay, diagnosis (up to 15), method admission, discharge destination, internal management (day case, planned sequence overnight etc.)	

Table 1: Datasets used in neurology care co-ordination work.

Data on neurology waiting lists for 4 years was linked to the datasets outlined in table 1 below within the Honest Broker Service and pseudonymised data was provided back to the HSC. The HBS played a pivotal role in identifying and matching datasets and providing that data in a format that ensured confidentiality was not compromised. In total this project tested the concept of matching 5 datasets in order to create a longitudinal neurology dataset.

As we start to understand the profile and service usage of neurology patients we can target services to better meet their needs. One of the proposed outputs of this work is a neurology dashboard and this idea can be developed further to provide 'real time' information so that services can be proactive rather than re-active. In the initial phase of this work we demonstrated how we could join 5 Health and Social Care datasets together, through the HBS to provide health intelligence into the patient journey. This work could be enriched further by adding in further datasets such as Primary care data, community data and imaging data.

Data mining

The datasets were also used to investigate the feasibility of carrying out a data mining exercise to map the journey of patient through the system. This approach could be used to work out statistical patterns and create a simulation of the patient journey. We know each person is moving between various states. This approach would allow us to work out the probability of moving from one state to another. This tool gives us a synthetic population that simulates into the future how the population will behave.

This could be a valuable tool to assist in commissioning services that meets patients need; for example; in relation to workforce there is the potential to use this approach to work out how many consultant neurologist hours are needed to make the system behave in the way we want e.g. see patients within a defined timeframe. It can help us determine level of need within the system and provide a segmented approach in order to ensure services are targeted at the right level.

Laura Gillespie

Deputy Commissioning Lead BLCG

Honest Broker Service User Feedback

Two surveys were developed to ask researchers about their experience of the Honest Broker Service. The post application survey is issued when the research application has been approved and the active user survey is issued on an annual basis to all active users of the Honest Broker Service. In 2022/23, three responses were received to the post application survey (compared to 2 last year). Two respondents were very satisfied with the customer service provided during the application process and the other was satisfied.

Six responses to the active user survey were received (compared to 9 last year). All six customers were very satisfied with the customer service provided during the financial year, which is testament to the hard work and dedication of the HBS team. Feedback from some of the current HBS Users are provided below.

Overall Satisfaction with HBS Services 2022/23

100% Very Satisfied

"The HBS provided good availability across a time with exceptional barriers to physical availability... the service was very satisfactory."

"Staff are helpful, professional and the service is essential..."

"Safe Haven Booking system works well and HBS staff are very helpful in case of last minute changes to requirements." "Fast and efficient"

"The staff at the HBS are among some of the most helpful I have encountered – they are always happy to read the application and provide informal guidance on areas that need additional detail etc."

"Excellent service and support throughout application process. Thanks very much!"

"... The staff have been very helpful in discussing research proposals that I hope to advance. Their input has extended beyond "can something be done" to how it might be done better with the data HBS work with. This is to be commended..."

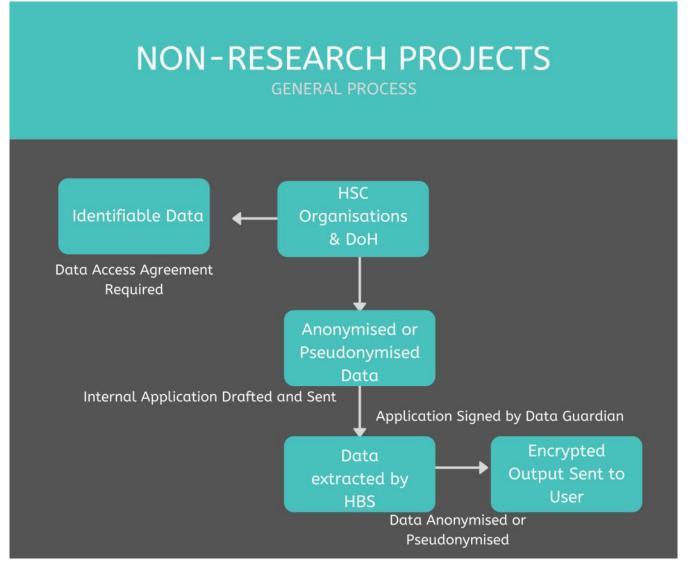
Appendix 1:

HBS 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 one of the secure research environments 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.



Appendix 2:

Membership of the Honest Broker Governance Board 2022/23

Voting Members			
Chair	Dr Aaron Peace Consultant Cardiologist/Chief Executive of the Clinical Translational Research and Innovation Centre (C-TRIC) and Clinician		
Vice-Chair	Vacant		
Belfast Trust	Alison Murphy R&D Manager, Belfast HSC Trust		
Southern Trust	Dr Peter Sharpe Associate Medical Director for Research, and Clinician Nominee: Miss Irene Knox (Now retired) R&D Manager, Southern HSC Trust		
South Eastern Trust	Laura Moore Interim R&D Manager, South Eastern HSC Trust		
Northern Trust	Dr Seamus O'Reilly Acting Medical Director and Clinician Nominee: Mr Neil Martin Acting Director of Planning and Performance Management		
BSO	Mark Bradley (Now retired) Interim Director Customer Care and Performance		

Voting Members			
HSCB	Lisa Whyte (Stood down January 2023) Senior Programme Manager HSCB		
РНА	Dr Nicola Armstrong Programme Manager, PHA R&D Division		
PCC	Kate Laverty (Stood down) Patient and Client Council		
DoH	Siobhan Morgan Principal Statistician. Head of Hospital Infor- mation Branch		
Non-HSC Lay member	Dr Hilary Russell Retired medical geneticist and Health and Social Care Research Ethics Committee Chair		

Non-Voting Members			
BSO	Alan Harbinson		
BSO	Martin Mayock		
BSO	Stephen Gibbons		
BSO	Fiona McNally <i>(until Dec 2022)</i>		
BSO	David Bryce (Now retired)		
BSO	Cormac O'Brien		
DOH	Charlene McQuillan		
NITRE	Frances Burns (Guest)		

Appendix 3:

Membership of the Honest Broker Working Group 2022/23

HBWG Membership			
BSO	Mark Bradley (Chair, now retired)		
BSO	Alison Afrifa		
РНА	Dr Nicola Armstrong		
BSO	Karen Beattie		
BSO	Alan Harbinson		
DoH	Charlene McQuillan		
BSO	Martin Mayock		
BSO	Naomi Mill		
BSO	Cormac O'Brien		
РНА	Eddie Ritson		

Appendix 4:

HBS 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 <u>here</u>.

Appendix 5:

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).		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.	РНА	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, SHSCT—Southern Health & Social Care Trust UG—University of Glasgow, PHA—Public Health Authority, WHSCT—Western Health & Social Care Trust

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

QUB—Queen's University of Belfast

UU—Ulster University

Projects Approved in 2018/19

Project	Title	Organisation	Panel Approval
028	Early and late onset of dementia in NI	QUB	2018/19
029	Assessing the rate of anticholinergic drug prescriptions for dementia patients in Northern Ireland	QUB	2018/19
030	Childhood interactions with social services and risk of poor health and social outcomes in adulthood: A population wide data linkage study	QUB	2018/19
031	Myotonic dystrophy in NI	QUB / BHSCT	2018/19
032	Investigation of the link between maternal body mass index in early pregnancy and incidence of cerebral palsy in NI.	QUB	2018/19
033	Evaluation of outcomes for patients with elevated tTG antibodies and Gluten-free food prescription utilisation in NI	QUB / BHSCT	2018/19
035	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
036	Hospitalisation rates in dementia	QUB	2018/19
038	Health and social selection bias on consent to participation in the NI Cohort for the Longitudinal Study of Ageing	QUB	2018/19
039	Sleep medication use in Cerebral Palsy: a comparison between those with Cerebral Palsy and the typically developing population in Northern Ireland.	QUB	2018/19

QUB—Queen's University of Belfast BHSCT—Belfast Health and Social Care Trust

Projects Approved in 2019/20

Project	Title	Organisation	Chief Investigator	Panel Approval
034	Mental health, firearm ownership, and risk of death by suicide: a population-wide data linkage study	QUB	A. Maguire	14/01/20
037	Acute myocardial infarction rates and management in dementia	QUB	B. McGuinness	09/04/19
040	Co-medication burden with polypharmacy and hyper polypharmacy in people with dementia	QUB	B. McGuinness	13/06/19
041	Investigating the relationship between dementia and cancer in NI	QUB	B. McGuinness	13/06/19
042	Living alone with dementia: related use of drugs	QUB	B. McGuinness	07/05/19
043	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
044	Assessing the rates and reasons behind falls and fractures of people with dementia in NI	QUB	B. McGuinness	03/07/19
045	Mothers first unlocking potential of NIMATS	UU	J. Murphy	17/07/19
046	Understanding real world healthcare costs for living donor kidney transplantation	BHSCT	M. Quinn	04/10/19
047	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
048	Physical Healthcare Outcomes in those with Severe Mental Illness (SMI's) in NI	UU	G. Leavey	27/08/19
049	Health service use and outcomes in later life: an examination of urban and rural health inequalities in NI	UU	M. Rosato	27/08/19
050	Linking Psychological Therapies Service outcomes data with hospital admissions and prescriptions data	NHSCT	K. Dyer	04/10/19
051	Antipsychotic and antidepressant use among people with dementia in NI: A retrospective analysis	QUB	B. McGuinness	04/10/19
052	Maternal Exposure to Air Pollution during Pregnancy and Infant Health	QUB	N. Rowland	04/10/19
054	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

QUB—Queen's University of Belfast, UU—Ulster University,

BHSCT – Belfast Health and Social Care Trust, NHSCT – Northern Health and Social Care Trust

Projects Approved in 2020/21

Project	Title	Organisation	Chief Investigator	Panel Approval
053	Elective surgery rates in people with dementia	QUB	B. McGuinness	23/07/20
056	An examination of the role of socio-economic factors and maternal health on child oral health.	QUB	C. O'Neill	24/08/20
058	Challenges and Possible Solutions for Long Waiting Times for Elective Surgeries in Northern Ireland	QUB	D. Rathnayake	23/07/20
059	SARS-CoV-2 related deaths: an in-depth examination	QUB	A. Maguire	12/08/20
060	Impact of COVID-19 on mental health in Northern Ireland	QUB	A. Maguire	12/08/20
061	Northern Ireland Multi-morbidity Cohort (NIMC): Measures of multi- morbidity and its impact on mortality.	QUB	D. O'Reilly	19/01/21
062	Multimorbidity and pregnancy: epidemiology, clusters, prescriptions and preterm birth	QUB	K. Eastwood	19/01/21
063	Prescribing trends for Depression, Anxiety and Alzheimer's Disease in the Northern Ireland Type 2 Diabetes Population- are GLP-1 agonists protective	UU	P. McClean	19/01/21
064	National Core Study – Data and Connectivity: COVID-19 Vaccines Pharmacovigilance (DaC-VaP)	QUB	D. Bradley	18/03/21
065	National Core Study—CovPall-Connect. Evaluation of the COVID-19 pandemic response in palliative and end of life care: Connecting to boost impact and data assets.	KCL	I. Higginson	26/03/21

QUB—Queen's University of Belfast

UU—Ulster University

KCL—Kings College London

Projects Approved in 2021/22

Project	Title	Organisation	Chief Investigator	Panel Approval
055	The relationship between neighbourhood deprivation levels and indicators of social distress	UU	M Rosato	07/07/21
066	COVID-19 impact in those with Severe Mental Illness (SMI), and neurodevelopmental disorders (NDD) in Northern Ireland: exploring the relationship between COVID-19 and patterns of hospitalisation and medication use; rates of suicide/suicidal behaviour; treatment out- comes (including relationship with GP); and mortality	UU	G Leavey	07/07/21
067	The changing relationship between disadvantage and child welfare interventions	QUB	L Bunting	07/07/21
068	Using data science and systems engineering to plan pa- tient-centred outpatient healthcare services	QUB	D Bradley	21/07/21
069	Estimation of Vulnerable Newborn phenotypes: individu- al-level analyses of national and sub-national data	QUB	E Lowry	27/07/21
070	Investigating the association between biologic use, medi- cation adherence and comorbidities in severe asthma: an analysis of linked data	QUB	J Busby	21/07/21
071	Adult Safeguarding in Northern Ireland: a study of the relationship between social deprivation and adult pro-tection referrals in Northern Ireland	QUB	L Bunting	08/12/21
072	An examination of the health, mental health and post- release mortality risk of prisoners in Northern Ireland	QUB	M Donnelly	08/12/21
073	Identifying predictors and consequences of homeless- ness in Northern Ireland using linked homelessness, so- cial services and health administrative data	QUB	D Bradley	08/12/21
074	Improving Health in the Preconception Period: Using ex- isting data to characterise health in the preconception period and during pregnancy in NI.	QUB	L McGowan	31/03/22
075	Did periods of 'lock down' demonstrate higher incidenc- es of reported intimate partner violence, mental disor- der, or drug and alcohol use during pregnancy?	QUB	D Hanna	31/03/22
076	COVID-19 and Deprivation in Northern Ireland	ESRI	A Devlin	31/03/22

QUB—Queen's University Belfast; UU—Ulster University; ESRI— Economic and Social Research Institute

Appendix 6:

List of Journal Articles Facilitated by HBS, 2022/23

Ross , E., O'Reilly, D. and Maguire, A. (2022) Mental health, firearm ownership, and risk of death by suicide: a population-wide data linkage study. International Journal of Population Data Science, 7(3). doi: <u>10.23889/</u><u>ijpds.v7i3.1935.</u>

McKenna, S., Maguire, A. and O'Reilly, D. (2022) **Uptake of psychotropic medication amongst young adults known to social services in childhood: a longitudinal population-wide cohort study in Northern Ireland.** *International Journal of Population Data Science*, 7(3). doi: <u>10.23889/ijpds.v7i3.1868.</u>

McKenna, S., O'Reilly, D., & Maguire, A. (2023). The mental health of all children in contact with social services: A population-wide record-linkage study in Northern Ireland. Epidemiology and Psychiatric Sciences, 32, E35. doi:10.1017/S2045796023000276

Kent, L., O'Reilly, D. and Maguire, A. (2022) Impact of the COVID-19 pandemic on commencement of psychotropic medications in Northern Ireland: a population-wide, administrative data linkage study. *International Journal of Population Data Science*, 7(3). doi: 10.23889/ijpds.v7i3.1915.

Maguire, A., Kent, L., O'Neill, S., O'Hagan, D., & O'Reilly, D. (2022). Impact of the COVID-19 pandemic on psychotropic medication uptake: Time-series analysis of a population-wide cohort. *The British Journal of Psychiatry*, 221(6), 748-757. <u>https://doi.org/10.1192/bjp.2022.112</u>

Maguire, A., Kent, L., O'Hagan, D., Paterson, E. and O'Reilly, D. (2022) Impact of the COVID-19 pandemic on Self-Harm and self-harm/suicide Ideation and subsequent mortality in Northern Ireland: a longitudinal, population-wide data linkage study, *International Journal of Population Data Science*, 7(3). doi: <u>10.23889/ijpds.v7i3.1899.</u>

C C Butler, F D R Hobbs, O A Gbinigie, N M Rahman, G Hayward, D B Richards, et al. **Molnupiravir plus usual care** versus usual care alone as early treatment for adults with COVID-19 at increased risk of adverse outcomes (PANORAMIC): an open-label, platform-adaptive randomised controlled trial. *The Lancet*, 22 Dec 2022. DOI: <u>https://doi.org/10.1016/S0140-6736(22)02597-1</u>

J Leniz, JM Davies, A E Bone, M Hocaoglu, J Verne, S Barclay, FEM Murtagh, LK Fraser, IJ Higginson, and KE Sleeman (2023) **Deaths at home, area-based deprivation and the effect of the Covid-19 pandemic: An analysis of mortality data across four nations.** *Palliative Medicine* 1–6. DOI: 10.1177/02692163231167212journals.sagepub.com/home/pmj

Ferry F, Rosato M, Leavey G. Mind the gap: an administrative data analysis of dental treatment outcomes and severe mental illness. *Journal of Mental Health*. 2022. DOI: <u>https://doi.org/10.1080/09638237.2022.2069722</u>

C O'Neill, J Woodside, F Kee, M Clarke, L Barry, J Cawley, E Doherty, G Crealey, J Duggan. Fiscal and pricing policies related to food and non-alcoholic drinks: A review of the evidence. SafeFood Ireland

Pask S, Davies JM, Mohamed A, Leniz J, Chambers RL, McFarlane P, Bone AE, Barclay S, Higginson IJ, Sleeman KE & Murtagh FEM. Better End of Life 2022. Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. *Research report. London (UK): Marie Curie. (Nov2022)* <u>https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2022/j409-beol-report-2022.pdf</u>

Please note that the articles listed above were those that the 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.



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