

Annual Outcome & Impact Assessment
Completed Case Studies

An abstract graphic in the bottom right corner of the page, consisting of a network of thin white lines connecting various nodes. Some nodes are represented by small white dots, while others are larger, glowing blue circles. The overall effect is that of a complex, interconnected data network or a stylized molecular structure.

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Timeline

DATE	ACTIVITY
19 JULY	Case studies and supporting guidance provided to all panellists for review
JULY-SEPTEMBER	Panellists to review and rate all case studies
24 SEPTEMBER	Deadline for panellists review and ratings to be returned to HDR UK
LATE SEPTEMBER	Collated rating circulated to all panellists
15 OCTOBER	Panel meeting

Further Information and Support

Should you have any questions, please contact impact@hdruk.ac.uk.

1. Improving transparency in the use of health data for research by developing and driving adoption of recommendations for a data use register standard

1	Researcher(s) Name: Nada Karrar , Paola Quattroni
2	HDR UK Programme: UK Health Data Research Alliance
3	Affiliation(s): n/a
4	<p>Title of Case Study (150 characters):</p> <p>Improving transparency in the use of health data for research by developing and driving adoption of recommendations for a data use register standard</p>
5	<p>Summary of the Impact (150 words):</p> <p>In Feb 2022, the UK Health Data Research Alliance (the Alliance) published its recommendations for a data use register (DUR) standard, to improve transparency on health data usage. The standard has been downloaded over 2,000 times.</p> <p>Following the publication of the White Paper, activities aimed at improving transparency of data use among Alliance members have increased. This includes amending the Letter of Intent to emphasise transparency as a vital principle that new members of the Alliance are expected to abide by upon joining. To further facilitate the implementation of this standard, the Gateway Data Use Register was developed and launched in April 2022. To date, more than 1,000 data uses have been published on the Gateway.</p> <p>A current state analysis of the levels of transparency among Alliance members was conducted in January 2024, nearly two years after the publication of the standard. This showed that 51 out of 88 data custodians within the Alliance (58%) publish a Data Use Register. This is an improvement on a baseline analysis carried out in May 2021, which showed that 22 out of the 46 data custodians in the Alliance had data use registers that were discoverable via public websites.</p>
6	<p>Underpinning Research (250 words):</p> <p>A data use register (also known as a data release register or list of approved projects) offers the public a clear record of how their data is being used, by whom and for what purpose.</p> <p>In March 2021, the Alliance established a working group to help ensure that clear, consistent, and standardised public records are regularly published on data use to demonstrate the value and benefit of using health data. The Alliance engaged multiple stakeholders through a series of workshops with data custodians, researchers, funders, regulatory bodies, and members of the public.</p> <p>Additionally, to better understand the landscape and levels of transparency among health data custodians, an analysis was carried out on data use registers published by health data custodians in the UK, which was published as a preprint in May 2021. This revealed that less than 50% of data custodians were publishing information on who, how, and why health data was being used.</p> <p>To ensure widespread community input, a public consultation was held in the summer of 2021 on a Green Paper for the emerging recommendation for a data use standard. This included responses from more than 50 public contributors, which underlined the importance of Patient and Public Involvement and Engagement (PIE) to the public. A summary of the responses to the Green Paper was published in a blog on the Alliance website, highlighting the interest in and level of support for this work.</p> <p>The feedback was incorporated into a White Paper that was presented to the Alliance Council, and in January 2022, the Alliance recommendations for a Data Use Register standard were published.</p>

7	<p>Description of the Impact (500 words):</p> <ul style="list-style-type: none"> <p>Advancing methods and technology: In May 2021, a baseline analysis of the current state of health data transparency revealed that less than 50% (22 out of 46) of data custodians were publishing a Data Use Register in the UK. An analysis carried out earlier this year has shown that the levels of transparency have improved, with 51 out of 88 data custodians in the Alliance now publishing a Data Use Register. Examples of a few early adopters include:</p> <ul style="list-style-type: none"> UK Longitudinal Linkage Collaborative Health Data Research Hub Discover-Now NHS England <p>To better support Alliance member organisations in meeting the principles of transparency and aligning with the proposed standard, Health Data Research UK developed a Data Use Register for the Health Data Research Innovation Gateway (the 'Gateway'). The register improves accessibility for members of the public through its user-friendly interface and design. Additionally, the aggregation of data uses across different custodians allows for better insights into data usage. To date, 17 members have uploaded over 1,000 data uses to the Gateway Data Use Register, the most recent of which is Our Future Health.</p> <p>Forming public trust: Patients and members of the public, along with key public involvement and advocacy groups, were engaged and consulted throughout the development of the standard. In total, more than 50 members of the public participated and contributed to the standard. One public contributor said:</p> <p style="padding-left: 40px;">“The public and patients need to know that data use registers are there. We may not want to find or use them, but we need to know they are there.”</p> <p>Informing decision making: The Alliance is a network of leading healthcare and research organisations from across the UK. It is made up of senior leaders and decision-makers who come together to establish best practices in the ethical and responsible use of health data. The White Paper on recommendations for a Data Use Register (DUR) standard is an example of how the Alliance uses its network to shape standards that drive best practice. By endorsing the White Paper through the forum of the Alliance Council, its member organisations commit to upholding and adopting the principles outlined in the standard within their individual organisations. An example of this is NHS England, which relaunched what was previously a 'Data Release Register' into what is now the NHSE data uses register, adopting recommendations from the standard regarding content and consistent language.</p> <p>Improving research culture and capacity: This project has led to the publication of several papers and multiple blogs, including:</p> <ul style="list-style-type: none"> Pre-print: Analysis of data use registers published by health data custodians in the UK Green Paper: Draft recommendations for a data use register standard (2,022 views and 1,393, downloads) White paper: Recommendations for a data use register standard (3,179 views and over 2,178 downloads) Blog post: Community response to the Green Paper Blog post: Supporting adoption of the data use register standard <p>Spotlight blog: Our Future Health a model of transparency in health data access and use</p>
8	<p>Role of HDR UK (250 words):</p> <p>The Alliance has been responsible for convening the community around the principle of transparency and developing the recommendations for a standard. The Alliance has also been pivotal in driving adoption among its membership. This includes facilitating the development of a Data Use Register functionality on the Gateway, which serves as a reference implementation of the standard.</p> <p>Describe the role of HDR UK and/or HDR UK's contribution to the impact.</p>

9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>See 'Description of Impact' section</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>See 'Description of Impact' section</p>
11	<p>Research Team and Collaborators:</p> <p>Nada Karrar (Alliance Delivery Manager),</p> <p>Paola Quattroni (Head of Alliance Strategy and Engagement),</p> <p>David Seymour (Director of Infrastructure and Services, HDR UK),</p> <p>Susheel Varma (previously Technical Director, HDR UK)</p> <p>Sinduja Manohar (Public and Patient Involvement Manager),</p> <p>Shahrihar Kabir Khan (Data Analyst).</p>
12	<p>Funding:</p> <p>This work was funded through core Alliance funds. To drive adoption forward, in September 2023, 19 projects from across the UK were funded with grants averaging £12,904 to implement the Alliance Transparency Standards over a period of 53 months. These “quick fire” projects covered a range of practical approaches to adopting the standards and increase transparency in both data access and use. 11 out of the 19 projects addressed transparency of data use.</p>

2. Enhancing diversity and quality in Health Data

1	<p>Researcher(s) Name:</p> <p>Paola Quattroni¹, Kamlesh Khunti², Ashley Akbari³, Claire Argent¹, Uwaye Ideh¹</p>
2	<p>HDR UK Programme:</p> <p>UK Health Data Research Alliance</p>
3	<p>Affiliation(s):</p> <p>1 Health Data Research UK, 2 University of Leicester, 3 Swansea University</p>
4	<p>Title of Case Study (150 characters):</p> <p>Enhancing diversity and quality in health data</p>
5	<p>Summary of the Impact (150 words):</p> <p>The Alliance Ethnicity coding standards working group calls for action to improve quality of data to inform decision making and ensure reliability of research. This set of recommendations (summarised below) approved by the Alliance can be used by researchers, clinicians, and decision makers to improve representativeness in data:</p> <ol style="list-style-type: none"> 1. Improve consistency and completeness in data collection. 2. Align approaches to standardisation and categorisation across the UK. 3. Improve transparency and communication about the reason for collecting ethnicity data. 4. Develop national guidance and training for data collectors in NHS and social care settings. 5. Facilitate data linkage to enrich the information available on ethnicity. <p>This work has the potential to improve public trust by empowering ethnic minorities in making decisions around sharing of sensitive information; health and wellbeing, by ensuring members of the public feel included and have a choice and their voice is represented in the data; decision making, by informing processes and operations in data collection in NHS, local authorities, GP and clinical settings; training and skills by providing guidance to be embedded in training material for NHS professionals and facilitate standardized data collection.</p>
6	<p>Underpinning Research (250 words):</p> <p>Covid-19 has affected ethnic minority populations disproportionately and exposed the need for improved collection and coding of ethnicity data. Early publications during the pandemic reported that only 7% of Covid-19 research papers presented ethnicity-disaggregated data. The Ethnicity Coding Standards working group is a sub-group of the Alliance Special Interest Group on Diversity in Data, which aims to tackle issues around representativeness in research. Over the past 2 years, we have held several working group meetings that led to a set of recommendations to improve recording on ethnicity data. Main discussion topics included:</p> <ul style="list-style-type: none"> • Needs for improvements in the way ethnicity data is collected; • Demands for training and guidance for primary data collection and healthcare professionals; • Prioritisation of activities within healthcare systems that can improve the use of diverse and high quality data; • What codes, standards and approaches need to be taken to ensure the whole population is represented in data-driven research. <p>A set of five recommendations have been consolidated in a white paper that will be published in Zenodo. These are addressed to policy makers, researchers and the NHS and will inform policy and practice. The paper includes the methodology and research work that underpinned this work.</p>

	<p>This working group leveraged impressive expertise from multiple sectors (academia, healthcare profession, NHS and the public). Key research, standards and reports produced by members of this group directly informed the policy recommendations currently being summarised by working group co-authors.</p> <p>Relevant outputs:</p> <p>https://www.nature.com/articles/s41591-022-01842-y https://link.springer.com/article/10.1186/s12911-022-02093-0 https://blog.ons.gov.uk/2023/01/16/how-ethnicity-recording-differs-across-health-data-sources-and-the-impact-on-analysis/ https://www.ons.gov.uk/releases/understandingconsistencyofethnicitydaterecordedinhealthrelatedadministrativedatasetsinengland2011to2021 https://understandingpatientdata.org.uk/insights-black-south-asian-people-patient-data</p>
7	<p>Description of the Impact (500 words):</p> <p>The Alliance Ethnicity Coding Standards working group (Chaired by Ashley Akbari and Kamlesh Khunti) was established in response to growing concerns about poor data quality and missing information in health and social care data research and specifically addresses the challenges and opportunities in the collection and use of ethnicity data.</p> <p>The group calls for action to improve quality of data to inform decision making and ensure reliability of research. The following set of recommendations to be used by researchers, clinicians, decision makers and public groups have been approved by the Alliance:</p> <ul style="list-style-type: none"> • Improve consistency and completeness in data collection. • Align approaches to standardisation and categorisation across the UK. • Improve transparency and communication about the reason for collecting ethnicity data. • Develop national guidance and training for data collectors in NHS and social care settings. • Facilitate data linkage to enrich the information available on ethnicity. <p><u>The recommendations</u> on recording of ethnicity data were approved by the Alliance Council on 22 May 2024, and will serve as a guidance for decision makers, researchers and the NHS to improve data collection and use. In addition, these recommendations can be applied in both health and social care settings. These will complement ongoing work by key ecosystem players such as the Office for National Statistics (ONS), the Centre for Ethnic Health Research, the NHS Race and Health Observatory, and Understanding Patient Data among others. Professor Andrew Morris has invited Chief Medical Officer Chris Whitty to contribute a <i>Foreword</i> to the paper (pending agreement), which would increase influence and reach.</p> <p>The convening of this working group has first of all contributed to raising awareness of the topic across NHS settings, hospitals and clinical settings. Members of the core team driving the projects have been invited to speak at multiple conferences including:</p> <ul style="list-style-type: none"> • HDR UK Strategy and Integration Group (Kamlesh Khunti) 30.05.23 • Black internship programme event (Kamlesh Khunti; Ashley Akbari) 11.08.23 • Tackling Health and Social Inequalities in data-driven systems, Ada Lovelace (Paola Quattroni) 19.09.23 • Health Inequalities and Diversity in Health Data Science, HDR Midlands (Paola Quattroni) 18.10.23 • HDR UK data access webinar (Ashley Akbari) 19.10.23 • EMRI Webinar on Data in Health and Care Research (Paola Quattroni) 01.11.23 <p>Collaborators and contributors of the working groups have been instrumental in amplifying messages around the need for improving representativeness.</p> <p>This work has the potential to improve public trust by embedding empowering minority groups in making decisions about how they want to share sensitive information with clinicians; health and wellbeing, by ensuring members of the public feel included and have a choice and their voice is represented in the data; decision making, by informing processes and operations in data collection in NHS, local authorities, GP and clinical settings; training and skills by providing guidance that can be embedded in training material for NHS professionals and enable standardized data collection.</p>

	<p>This work can inform similar research exploring representativeness across diverse communities and other protected characteristics, such as work by Hayley Lowther-Payne (University of Lancaster) on LGBT+ communities.</p> <p>Minutes from the working sessions have been published in Zenodo: Workshop #1 Workshop #2 Workshop #3 Final event A blog highlighting this work was published in June 2023.</p>
8	<p>Role of HDR UK (250 words):</p> <p>The working group has been set up as an Alliance working group. It benefitted from core funding, and this has enabled organization of the meetings, coordination, secretariat and project management. HDR UK has played a key role in convening communities from across various sectors; in particular, membership of the Alliance has been leveraged to ensure wide reach across the health sectors. Using the Alliance forum and ways of working has provided an opportunity for sharing knowledge on the current landscape, created connections and increased visibility and impact of this work.</p> <p>The Alliance reach to NHS organizations has enabled key discussions with NHS professionals who play a key role in collecting and recording sensitive information at point of care.</p> <p>This activity has also informed the HDR UK institute priorities and insights from this group have directly informed plans for renewal and implementation of HDR UK’s EDI policy and strategy.</p> <p>Integration with other key HDR UK programmes will be key to bring this work forward in future: (e.g.) HDR UK Midlands; Gateway potential for improving metadata catalogue; Black internship programme; data quality and standards and applications of the Observational Medical Outcome Partnership common data model (where ethnicity coding is key for data transformation).</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>The output produced is an example of co-creation. Authorship has been offered to all contributors to the white paper. A Section Lead has been assigned to each recommendation described in the paper. The Leads chosen were from different background, sectors and career levels (as described below).</p> <p>We leveraged expertise from the wider Alliance and HDR UK community, demonstrating the multidisciplinary, multi-organisational nature of the team. Each team member acts as a lead responsible for each recommendation proposed.</p> <ul style="list-style-type: none"> • Alastair Denniston: Consultant Ophthalmologist and Honorary Professor, University Hospitals Birmingham; • Vahe Nafilyan: Head of Health Modelling Hub and Principal Statistician, Office for National Statistics; • Rose Drummond: Lead on Ethnicity for Health Analysis, Office for National Statistics; • Jonathan Valabhji: National Clinical Lead for Multiple Long-Term Conditions (NHS England) and Clinical Chair in Medicine at Imperial College London • Angela Wood: Professor of Health Data Science and Associate Director of the BHF DSC • Sara Khalid: Associate Professor of Health Informatics and Biomedical Data Science • Marta Pineda Moncusi, postdoctoral research assistant, University of Oxford <ul style="list-style-type: none"> • In addition, the core project team brought together individuals from different geographies and different career stages (see team details below).
10	<p>Contribution to Research Culture (250 words):</p> <p>This is a clear example of a truly multidisciplinary, community-driven approach where we had wide engagement and a collegiate opportunity for all those involved to input in the development of the group and associated outputs. Transparency was embedded in all our communications, in the way people expressed opinions, shared knowledge in an honest way and being as clear as possible and made discussions accessible to everyone participating.</p> <p>We have always operated an open and welcoming group, open to all in terms of attending and contributing to the direction of the group. We used accessible tools to ensure everyone would feel welcome to share opinions and perspectives, for example, offering the option to use online whiteboards for people to express views in writing and capturing a wide range of topics for discussions and participant input. We identified speakers from across different backgrounds, expertise, and career roles and stages, who could talk to specific points and lead on working sessions, taking ownership for their area of expertise.</p> <p>We also had significant participation and engagement from organisations across sectors, including the Office for National Statistics, NHS England, Public Health Wales, the research community, the Centre for Ethnic Health, patient and public contributors, and a mixture of genders, sexes, ethnicities and career developments.</p>

11	<p>Research Team and Collaborators:</p> <p><u>Core Alliance Team</u></p> <ul style="list-style-type: none"> • Professor Kamlesh Khunti and Associate Professor Ashley Akbari provided leadership to the working group, overseeing the project and providing expert advice on scientific content. • Dr Paola Quattroni (Head of Alliance Strategy & Engagement) provided programme direction in alignment with HDR UK’s core values, expertise and knowledge on Alliance membership, involvement, and engagement. • Ms Claire Argent and Ms Uwaye Ideh provided leadership on project management, coordination and event planning, as well as tracking progress. <p><u>Key collaborations</u></p> <p>We leveraged expertise from the wider Alliance and HDR UK community, demonstrating the multidisciplinary, multi-organisational nature of the team. Each team member acts as a lead responsible for each recommendation proposed.</p> <ul style="list-style-type: none"> • Alastair Denniston: Consultant Ophthalmologist and Honorary Professor, AI and Digital Health at University Hospitals Birmingham; improving diversity and representation within data used in AI, through STANDING Together. • Vahe Nafilyan: Head of Health Modelling Hub and Principal Statistician, Office for National Statistics; provided expertise on using ethnicity data to measure risk factors to COVID-19 in minority groups. • Rose Drummond: Lead on Ethnicity for Health Analysis, Office for National Statistics; provided expertise on work with Wellcome and the Race Equality Foundation to improve estimate of ethnic health disparities in England using Census data. • Jonathan Valabhji: National Clinical Lead for Multiple Long-Term Conditions (NHS England) and Clinical Chair in Medicine at Imperial College London; provided insights from work on the National Health Service Diabetes Prevention Programme as well as clinical practices used across the NHS. • Angela Wood: Professor of Health Data Science and Associate Director of the BHF DSC; expert on developing methods for reproducible analysis of electronic health records and large, complex datasets and working within the NHSE trusted research environment. • Sara Khalid: Associate Professor of Health Informatics and Biomedical Data Science and PI for the Ethnicity, Health Equity and AI study; expert in improving methods in health technologies to reduce inequalities. • Marta Pineda Moncusi, postdoctoral research assistant in health data. Marta; expertise in addressing health inequity via machine learning technologies. <p>Finally, we thank over 100 participants of the working group, including clinicians, researchers, members of the public, data custodians.</p>
12	<p>Funding:</p> <p>This work has been founded through core Alliance funds. While further research studies might be supported through work of individuals within the academic teams mentioned above, this policy work cannot continue without dedicated funding.</p>

3. Using health data to influence COVID-19 policy decisions – A study to assess the impact of COVID-19 vaccination uptake on stroke, heart attack and blood clots

1	<p>Researcher(s) Name:</p> <p>Alan Keys, Alexia Sampri, Amitava Banerjee, Angela Wood, Ashley Akbari, Aziz Sheikh, Cathie Sudlow, Christopher Robertson, Christopher Sullivan, David W, Declan Bradley, Efosa Omigie, Elsie Horne, Emanuele Di Angelantonio, Fatemeh Torabi, Frank Kee, Genevieve Cezard, Hoda Abbasizanjani, Jan D, Jennifer Cooper, Jim McMEnamin, Jonathan Sterne, Kamlesh Khunti, Karen Mooney, Kirsty Morrison, Lewis Ritchie, Lynsey Patterson, Rachel Denholm, Ronan Lyons, Sam Hollings, Samaira Khan, Samantha Ip, Siobhan Murphy, Spencer Keene, Spiros Denaxas, Steven Kerr, Stuart Bedston, Teri-Louise North, Thomas Bolton, Venexia Walker, William Whiteley and Yangfan Li.</p>
2	<p>HDR UK Programme: BHF Data Science Centre – CVD-COVID-UK</p>
3	<p>Affiliation(s):</p> <p>BHF Data Science Centre, NHS England, Public Health Scotland, Queen's University Belfast, Swansea University, University College London, University of Aberdeen, University of Bristol, University of Cambridge, University of Edinburgh, University of Leicester and University of Strathclyde.</p>
4	<p>Title of Case Study (150 characters):</p> <p>Using health data to influence COVID-19 policy decisions – A study to assess the impact of COVID-19 vaccination uptake on stroke, heart attack and blood clots.</p>
5	<p>Summary of the Impact (150 words):</p> <p>Using whole-population electronic health record (EHR) data for up to 67 million people living in England, Northern Ireland, Scotland and Wales, accessible via Trusted Research Environments/Secure Data Environments (TRE/SDE), a series of research studies were conducted to further our understanding of the impact of COVID-19 vaccination on risk of stroke, heart attacks and blood clots (such as deep vein thrombosis and pulmonary embolism). This collective research provided vital data-driven insights which informed policy around COVID-19 vaccinations.</p>
6	<p>Underpinning Research (250 words):</p> <p>Researchers analysed EHRs for 46 million adults in England, comparing the incidence of venous and arterial events before and after the first COVID-19 vaccination with AstraZeneca and Pfizer/Biotech vaccines.</p> <p>Key outputs:</p> <ul style="list-style-type: none"> • Rates of major arterial and venous events were lower after vaccination with both vaccines. • For rare events of intracranial venous thrombosis (ICVT) or thrombocytopenia, rates of hospitalisation for people <70 years were higher after AstraZeneca but not Pfizer/Biotech. • The increased risk of these events was small and outweighed by the vaccines' effect in reducing severe COVID-19 outcomes and death. <p>This analysis was extended to compare the cardiovascular safety of different COVID-19 vaccination doses (beyond just the first vaccination).</p>

	<p>Key outputs:</p> <ul style="list-style-type: none"> • Diseases caused by arterial thromboses were less common after each dose, brand and combination of COVID-19 vaccine. • Incidence of Arterial thromboses were up to 10% lower in the 13-24 weeks after the first dose of a COVID-19 vaccine. Following a second dose, the incidence was 27% lower after receiving the AstraZeneca vaccine and 20% lower after the Pfizer/Biotech vaccine. • Incidence of common venous thrombotic events were also lowered by each vaccine dose. <p>Researchers, as part of the COALESCE study, from across the UK studied EHRs from individuals over 5 years old (June-September 2022) to investigate factors associated with under-vaccination, and investigate the risk of severe COVID-19 outcomes in under-vaccinated people across the UK.</p> <p>Key outputs:</p> <ul style="list-style-type: none"> • Under-vaccination rates were highest amongst people who were younger, from deprived backgrounds, of non-White ethnicity or with fewer comorbidities. • Over 7,000 hospitalisations and deaths might have been averted in summer 2022 with better vaccine coverage across the UK. • Under-vaccination was related to significantly more hospitalisations and deaths across all age groups, with under-vaccinated people over 75 more than twice as likely to have a severe COVID-19 outcome than those who were fully protected. <p>Multi-disciplinary and multi-institutional research teams worked together for the first time to clean, curate and analyse whole-population EHRs from people living in England, Wales, Northern Ireland and Scotland. They conducted a series of analyses including logistic and Cox regression in each nation separately and combined results in meta-analyses as necessary.</p> <p>As part of the CVD-COVID-UK consortium, researchers engaged with public contributors, as part of the approvals process, holding meetings to discuss project proposals allowing for discussions to address challenges and adapt proposals. COALESCE's team includes public members from all four UK nations who provided input throughout the whole project.</p>
7	<p>Description of the Impact (500 words):</p> <p>Together these studies were able to provide evidence of the risks associated with COVID-19 vaccinations and vascular events, and the risks associated with under-vaccination. This research provides evidence to address public concerns and support continued participation in vaccine programmes. Researchers were able to make the following recommendations based on this research:</p> <ul style="list-style-type: none"> • Healthcare systems planning to use AstraZeneca should balance the very small harms against the known benefits of the vaccine. For older populations, who are most vulnerable to COVID-19, researchers found no evidence of increased risk of any event with AstraZeneca. In younger populations, who have a lower morbidity and mortality due to COVID-19, other available vaccines might be prioritised, especially when the risk of COVID-19 is otherwise low. • This extensive England-wide study offers reassurance regarding the cardiovascular safety of COVID-19 vaccines, with lower incidence of common cardiovascular events outweighing the higher incidence of their known rare cardiovascular complications. Researchers found no novel cardiovascular complications or new associations with subsequent doses. Their findings support the wide uptake of future COVID-19 vaccination programmes. <p>Researchers provided several short update reports on this work to Medicines and Healthcare products Regulatory Agency (MHRA), the Joint Committee on Vaccination and Immunisation (JCVI), the UK Government's Chief Medical Officer (CMO) and the UK Government Chief Scientific Adviser (CSA), which have informed Department of Health and Social Care secondary prevention policies.</p>

	<p>COALESCE findings supported government messaging and national public health agencies to maximise vaccine-based protection to as many people in the UK as possible. The COALESCE team’s research, by extension, helped save lives, reduced the incidence of COVID-19 related hospital admissions and deaths, particularly for the most vulnerable members of society. This is especially relevant due to future epidemic waves that are anticipated due to waning immunity against COVID-19, increases in social contact and the emergence of new viral variants. Furthermore, COALESCE helped pave the way for future UK-level analyses that include data from all four nations, by further developing the necessary data intelligence, frameworks and partnerships for the rapid and efficient delivery of UK-wide population studies. In the future it’s hoped these could extend to beyond COVID-19 research and facilitate studies addressing other pressing health challenges such as cancer, heart disease and respiratory disorders.</p> <p>In addition, the results of the COALESCE study and their policy implications were presented to key stakeholders, including CMOs and relevant CSAs from each of the four UK nations, at a joint HDR UK / Government Office for Science webinar, chaired by the UK Government’s CSA, Prof Dame Angela McLean.</p>
8	<p>Role of HDR UK (250 words):</p> <p>Key infrastructure from the BHF Data Science Centre supported all projects within this case study and accelerated the researcher journeys through the following actions.</p> <p>To support researchers in assessing feasibility of studies and preparing and publishing pre-specified analysis plans, they accessed:</p> <ul style="list-style-type: none"> • “Live” data dictionaries in a consistent format for >70 datasets, frequently updated; • A user-friendly interactive dashboard of available datasets providing key information such as counts, data coverage, completeness descriptive statistics and plots; • Written tutorials, data summaries and insights driven by specific projects; • The above support is also accessible via the Innovation Gateway. <p>To support data cleaning and curation researchers used the following resources:</p> <ul style="list-style-type: none"> • Boiler-plate ready-to-use PySpark notebooks for common data management processes, available in the BHF DSC GitHub open-access repository. <p>Related work, conducted as part of the CVD-COVID-UK consortium, from the below papers was used to support this project. https://www.nature.com/articles/s41597-024-02958-1 https://doi.org/10.1016/S2589-7500(22)00091-7</p> <p>HDR UK coordinated the meetings to present this work to the CMOs and CSAs – thereby influencing policy makers and funders.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>As part of the CVD-COVID-UK ways of working, all research outputs are made freely and openly available, including publications, analysis code and phenotyping algorithms. All analysis code is made available via the BHF DSC GitHub repository and all phenotyping code is made available via HDR UK’s Phenotype Library.</p> <p>The COALESCE study made all analysis code available via their GitHub repository and all Phenotyping and analysis code in England was made available on the BHF DSC GitHub repository.</p> <p>All the studies were presented through our monthly BHF Data Science Centre Webinar Series, which includes clinicians, researchers and members of the public and patients. The webinars are attended by approximately 60 participants</p>

10	<p>Contribution to Research Culture (250 words):</p> <p>A key part of this work being successful was the development of multi-institutional, cross-nation teams. Ensuring that people who really knew the data from each nation were part of the teams was paramount to this work being successful. The teams had regular online meetings during which time they shared knowledge, learnings and interpreted results. Building the culture of equality, diversity, inclusivity and openness within these teams, where in particular all members felt valued for their different contributions, has led the team to apply for further funding to extend this work.</p> <p>The team also embedded active PPIE to support the research and strengthen trust in using whole-population EHRs through accredited TRE/SDEs. PPIE members from the four nations contributed towards:</p> <ul style="list-style-type: none"> • co-developing outward facing communication material about the data and the descriptions of the different research studies; • the co-design and conduct of the studies through input at regular online meetings • the interpretation of the research findings through online meetings and input into written reports and outward-facing material <p>PPIE contributors from our UK-wide COALESCE study urged us to continue using UK-wide EHRs for research and have emphasised the importance of our work, calling it “<i>crucial footwork for UK-wide research</i>” and likening it to “<i>seeds from which mighty oaks grow</i>”.</p> <p>Our researchers also worked closely with the communication teams, within HDR UK, BHF DSC and Universities to optimise dissemination of research findings through co-development of press releases, infographics and web material.</p>
11	<p>Research Team and Collaborators:</p> <p><u>Undervaccination and sever COVID-19 outcomes: meta-analysis of national cohort studies in England, Northern Ireland, Scotland and Wales</u></p> <p>Alan Keys (Public Contributor), Alexia Sampri (PhD), Angela Wood (Professor of Health Data Science, BHF Data Science Centre Associate Director), Ashley Akbari (Senior Research Manager & Data Scientist), Aziz Sheikh (Professor of Primary Care Research and Development), Cathie Sudlow (Chief Scientist, Deputy Director of HDR UK and Director of the BHF Data Science Centre), Christopher Robertson (Professor of Public Health Epidemiology), Christopher Sullivan (Public Health Scotland), David W (Public Contributor), Declan Bradley (Clinical lecturer in public health), Frank Kee (Clinical Professor), Genevieve Cezard (Research Associate in Statistical Epidemiology), Jan D (Public contributor), Jim McMenemy (Head of Infections Service, Public Health Scotland), Kamlesh Khunti (Professor of Primary Care Diabetes and Vascular Medicine), Karen Mooney (Public contributor), Kirsty Morrison (Principal Healthcare Scientist, Public Health Scotland), Lewis Ritchie (Mackenzie Chair of General Practice), Lynsey Patterson (Epidemiologist), Ronan Lyons (Clinical Professor of Public Health), Samaira Khan (PPIE Manager), Siobhan Murphy (Research Fellow), Spiros Denaxas (Professor of Biomedical Informatics, BHF Data Science Centre Associate Director), Steven Kerr (Chancellor’s Fellow), Stuart Bedston (Research Officer & Data Scientist), Thomas Bolton (Senior Health Data Scientist) and William Whiteley (Professor of Neurology and Epidemiology, BHF Data Science Centre Associate Director).</p> <p><u>Cohort study of cardiovascular safety of different COVID-19 vaccination doses among 46 million English adults</u></p> <p>Amitava Banerjee (Professor of Clinical Data Science), Angela Wood (Professor of Health Data Science, BHF Data Science Centre Associate Director), Ashley Akbari (Senior Research Manager & Data Scientist), Cathie Sudlow (Chief Scientist, Deputy Director of HDR UK and Director of the BHF Data Science Centre), Elsie Horne (Senior Research Associate), Fatemeh Torabi (Senior Research Officer and Data Scientist), Hoda Abbasizanjani (Research Officer and Data Scientist), Jonathan Sterne (Professor of Medical Statistics and Epidemiology), Kamlesh Khunti (Professor of Primary Care Diabetes and Vascular Medicine), Rachel Denholm (Lecturer in Applied Health Data Science), Samantha Ip (Research Associate), Spencer Keene (Research Associate), Spiros Denaxas (Professor of Biomedical Informatics, BHF Data Science Centre Associate Director), Teri-Louise North, Venexia Walker (Research Fellow), William Whiteley (Professor of Neurology and Epidemiology, BHF Data Science Centre Associate Director) and Yangfan Li (Health Data Scientist).</p>

	<p><u>Association of COVID-19 vaccines ChAdOx1 and BNT162b2 with major venous, arterial, or thrombocytopenic events: A population-based cohort study of 46 million adults in England</u></p> <p>Angela Wood (Professor of Health Data Science, BHF Data Science Centre Associate Director), Ashley Akbari (Senior Research Manager & Data Scientist), Cathie Sudlow (Chief Scientist, Deputy Director of HDR UK and Director of the BHF Data Science Centre), Efosa Omigie (NHS Strategic Workforce Planning Director), Emanuele Di Angelantonio (Professor of Clinical Epidemiology and Donor Health), Jennifer Cooper (Health Data Scientist), Jonathan Sterne (Professor of Medical Statistics and Epidemiology), Rachel Denholm (Lecturer in Applied Health Data Science), Sam Hollings (Principle Data Scientist), Samantha Ip (Research Associate), Spencer Keene (Research Associate), Spiros Denaxas (Professor of Biomedical Informatics, BHF Data Science Centre Associate Director), Thomas Bolton (Senior Health Data Scientist), Venexia Walker (Research Fellow) and William Whiteley (Professor of Neurology and Epidemiology, BHF Data Science Centre Associate Director).</p>
12	<p>Funding:</p> <p>These studies were funded by: the British Heart Foundation Data Science Centre (grant No SP/19/3/34678, awarded to Health Data Research (HDR) UK) funded co-development (with NHS England) of the Secure Data Environment service for England, provision of linked datasets, data access, user software licenses, computational usage, and data management and wrangling support; this work was supported by the Longitudinal Health and Wellbeing COVID-19 National Core Study (UKRI Medical Research Council MC_PC_20030 and MC_PC_20059); UK Research and Innovation National Core Studies: Data and Connectivity; Consortium partner organisations funded the time of contributing data analysts, biostatisticians, epidemiologists, and clinicians.</p>

4. Patients and the public at the heart of cardiovascular research. The British Heart Foundation (BHF) Data Science Centre's 1 model of involvement and engagement paves the way for patients and the public to play a central role across the research journey.

1	<p>Researcher(s) Name:</p> <p>The British Heart Foundation Data Science Centre team</p>
2	<p>HDR UK Programme:</p> <p>The British Heart Foundation Data Science Centre</p>
3	<p>Affiliation(s):</p> <p>The British Heart Foundation Data Science Centre, HDR UK</p>
4	<p>Title of Case Study (150 characters):</p> <p>Patients and the public at the heart of cardiovascular research.</p> <p>The British Heart Foundation (BHF) Data Science Centre's ¹ model of involvement and engagement paves the way for patients and the public to play a central role across the research journey.</p>
5	<p>Summary of the Impact (150 words):</p> <p>The BHF Data Science Centre works with partners including patients, researchers, clinicians, and the NHS to enable data-led research into the causes, prevention, and treatment of cardiovascular disease, diabetes, stroke, and dementia.</p> <p>To ensure our research is relevant and trustworthy to patients and the public the Centre has designed and embedded a model for patient and public involvement and engagement (PPIE). ² This integrates the public voice across all areas of our work, including governance, planning and priority setting, funding calls, communication, and evaluation, spanning all the areas in which our own staff work. This approach has wide-ranging impacts on research quality and capacity, public trust, organisational culture, and health and wellbeing.</p> <p>Here we present three examples to illustrate this model, and its impacts:</p> <ol style="list-style-type: none"> 1. Engaging and gathering public input to set research priorities 2. Helping shape research proposals 3. Coproducing our Smartphones and Wearables programme of work
6	<p>Underpinning Research (250 words):</p> <p>Engaging and gathering public input to set research priorities</p> <p>In 2022 we co-designed a priority-setting exercise with our PPIE group to understand which areas of cardiovascular research are important for patients and the public. Our findings ³ from 350 UK individuals, highlighted, diagnosis, treatment, and quality of life as most important. Public input was also gathered into how research should be prioritised; this was used to inform an exercise performed by researchers and healthcare professionals to identify research priorities in the area of imaging.</p> <p>Helping shape research proposals</p> <p>The CVD-COVID-UK/IMPACT ⁴ consortium was established in 2020 to understand the links between cardiovascular disease and COVID-19. The consortium supports research using de-identified, linked, nationally collated healthcare datasets via a Trusted Research Environment (TRE). The CVD-COVID- UK/IMPACT Approvals and Oversight Board ⁵ includes six public contributors who conduct face-to-face reviews of all projects seeking access approval and have reviewed 68 applications over the last four years.</p> <p>Coproducing our Smartphones and Wearables programme of work</p> <p>The Smartphones and Wearables PPIE group established in 2021, includes eight public contributors who attended a scoping workshop. They have co-developed all areas of this work stream, including the strategy development, study co-design and</p>

	<p>engagement with the wider public. This has included co-design of a smartphone app to enable participants to share personal monitoring data for research and identification ⁶ of smartphone and wearable data that is both important to research and acceptable for sharing by the public. Our public contributors have also been involved in shaping and delivering our communications to the wider public, including co-presenting a public webinar ⁷.</p>
7	<p>Description of the Impact (500 words):</p> <p>Our model of PPIE ensures that the work of the BHF Data Science Centre is relevant to and trusted by patients and the public. Our diverse range of public contributors work in small groups and individually across our areas of work. This model improves the quality of our work in two ways, by increasing diversity, and ensuring our members provide meaningful input on areas most relevant to their expertise or experience. This flexibility has increased our own capacity, as well as ensuring that the patient voice is incorporated at each stage of the research journey. Thereby increasing the impact and visibility of our PPIE, building trust, transparency, and relevance within health data research.</p> <p>Engaging and gathering public input to set research priorities.</p> <p>Co-development of our survey to identify areas of cardiovascular research that are most important to the public ensured:</p> <ul style="list-style-type: none"> • Survey design - understandable by public respondents and that the input gathered is meaningful • Analysis - results are valid and representative • Infographic design – accessible and understandable • Dissemination - results available across the community to build trust, transparency and to help shape future research <p>The results are a guide for future Centre work and will be of value for anyone planning, designing, performing, or funding research studies. The co-development of engagement with all audiences has increased trust and transparency with patients and the public, with input from the broader findings being openly reported ⁸ for research prioritisation.</p> <p>Helping shape research proposals</p> <p>The CVD-COVID-UK/IMPACT Approvals and Oversight Board has improved the quality of research, ensuring that it is relevant to patients and benefits the public, as evidenced by the researcher testimonials below:</p> <ul style="list-style-type: none"> • <i>“We got direct input from the public contributors, in terms of the diseases we focused on and which groupings of these they thought of, which helped us reformulate the question for our research protocol. We changed the way we grouped the illnesses explored which influenced the further analysis of the results.”</i> • <i>“The public contributors feedback helped me re-adjust my focus on what matters to the public.”</i> <p>Advice from our public contributors is available more broadly to researchers via our co-developed ‘ways of working guide’ ⁹. Public involvement in the approval process has had positive impacts on research culture and inclusivity, while our public contributors report feeling valued and listened to. ¹⁰</p> <p>Coproducing our Smartphones and Wearables programme of work</p> <p>Our work will help ensure that smartphone and wearable research studies are designed so that people want to and are able to take part. This will help in maximizing recruitment and retention, essential to building a large-scale dataset that can produce high quality and informative insights towards improving health and wellbeing. Input from our PPIE group has ensured equality, diversity, and inclusion are prioritised across all work.</p> <p>Developing public trust is essential in data-based research. Our PPIE group has helped us consider diverse audiences across the UK, both in the co-development of communications and dissemination plans, and material. For example, by working together to co-develop human interest stories that connect with the real world we have been able to reach wider audiences, further building on public trust, and attracting local ¹¹ and regional ¹² media coverage.</p>

8	<p>Role of HDR UK (250 words):</p> <p>The BHF Data Science Centre has played a crucial role in developing and delivering this model of PPIE. We co- designed our PPIE strategy ¹³ which underpins our vision and approach, how we work with stakeholders and the steps we take to improve and enable the delivery of our model across the Centre. We have dedicated staff and resources to support this, including a Senior PPIE Partnerships Manager, PPIE Manager and PPIE Officer. Our PPIE team works together with the Centre’s Operations Director and Project Mangers to deliver the Centre’s strategy and model for PPIE. Our model is aligned with the UK Standards for Public Involvement and PEDRI Draft Standards of Public Involvement.</p> <p>As integral members of our team, our public contributors are kept up to date on Centre progress, opportunities to get involved and key announcements via a monthly email newsletter, which we developed at their request. We host quarterly on-line public advisory group meetings, along with an annual face-to-face meeting attended by our senior leaders and members of our core team. This provides opportunities for us to build relationships and creates a collaborative environment.</p> <p>We increase accessibility and inclusivity by providing information, training, and support, enabling a more diverse range of patients and the public to contribute to work at that Centre and across HDR UK. Our public contributors have contributed to other work across the institute, for example one member was a co-author on the publication for the COALESCE study and another member is contributing to plans for HDR UK’s PPIE conference.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>We contribute to the impact of health data research by championing and demonstrating good practices for public involvement and engagement across all our areas of work. We provide advice and support to researchers through different workstreams and direct researchers to useful PPIE resources ¹⁴ where relevant. Individual research projects seeking access approval frequently benefit from the advice of the public contributors involved in the process to improve the dissemination of their results.</p> <p>We contribute to open science by being transparent and inviting our public contributors to provide ideas on how we can increase the visibility of our research. We co-produce communications such as, plain English summaries used in web stories, ¹⁵ blogs, ¹⁶ and papers ¹⁷ with our public contributors, ensuring they are accessible to the public and research community. We are inclusive, involving and acknowledging our public advisors for their research contributions, for example by including them as co-authors of publications or white papers.</p> <p>Our public contributors have gained skills that have led them to become involved in wider areas of health data research for example one of our public contributors was a speaker at HDR UK’s Scientific Conference in 2022. ¹⁸</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>As highlighted throughout this case study our PPIE model has been designed to contribute to a healthy culture across the Centre by placing the patients and public at the heart of the research journey. We’ve placed emphasis on ensuring that PPIE is not tokenistic and that our group are able to contribute at the appropriate points throughout the research journey. We think that we have demonstrated that a genuine and beneficial approach is possible and will continue to develop our model in the future.</p> <p>We invite researchers and health data scientists to present their findings to our public advisory group and encourage collaborative working relationships which has a positive impact on the public and health data professionals involved. Our approach displays the importance of PPIE and provides health data professionals who may not work with the public regularly with an opportunity to increase confidence and improve their approach when communicating with the patients and the public.</p> <p>We are a champion for patient and public involvement and encourage diversity of opinion wherever possible lead by example, in setting expectations of and providing a framework for mutually beneficial and respectful relationships. In doing so we have created a culture where our public advisory group are empowered and valued. This fosters an environment where they feel confident to share their differing ideas freely and respectfully. We encourage all researchers we work with to adopt a similar attitude to involving the public in their research.</p>

11	<p>Research Team and Collaborators:</p> <p>BHF Data Science Centre Team</p> <p>Jemma Austin (PPIE Officer), Dr Tom Bolton (Senior Health Data Scientist), Amy Coombe (Research Project Coordinator), Prof Tim Chico (Associate Director), Ross Forsyth (Research Project Manager), Amy Hodgkinson (PPIE Manager), Annette Jackson (Executive Assistant), Samaira Khan (Senior PPIE Partnerships Manager), Sarah Lessels (Research Project Manager), Dr Jackie MacArthur (Senior Scientific Programme Manager), Dr Kate McAllister (Communications and Events Manager), Holly Mckeena (Communications Manager), Dr Lynn Morrice (Operations Director), John Nolan (Senior Health Data Scientist), Prof Stefen Petersen (Deputy Director), Rouven Priedon (Research Project Manager), Debbie Ringham (Communications and Engagement Manager), Prof Cathie Sudlow (Director), Melissa Webb (Communications & Administrative Assistant), Prof Michelle Williams (Associate Director) Prof Angela Wood (Associate Director)</p> <p>BHF Data Science Centre Public Advisory Group</p> <p>Philip Blakelock, Joanna Burridge, Wendy Davis, Laurence Humphrey Davies, Anwar Gariban, Rachel Gerrard, Helen Grice, Rebecca Harmston, Alan Keys, Mustapha Koriba, Roger Lambert, Julian Meldrum, Nicola Monk, Poh-choo Pang, Suzie Power, Margaret Rogers, Peter Rogers, Matthew Tosh, John Walsh, Phyllis Windsor</p>
12	<p>Funding:</p> <p>Our patient and public involvement and engagement model and the examples illustrated throughout this case study are supported by the British Heart Foundation Data Science Centre (grant SP/19/3/34678); awarded to Health Data Research UK.</p>

¹ British Heart Foundation - Data Science Centre. (n.d.). Home. [online] Available at: <https://bhfdatasciencecentre.org> [Accessed 26 Jun. 2024].

² British Heart Foundation - Data Science Centre. (n.d.). Patients and Public. [online] Available at: <https://bhfdatasciencecentre.org/patients-and-public/> [Accessed 26 Jun. 2024].

³ Centre, B.D.S. (2023). Public survey to identify the most important areas for research into cardiovascular disease. [online] Zenodo. Available at: <https://zenodo.org/records/8215435> [Accessed 27 Jun. 2024].

⁴ British Heart Foundation - Data Science Centre. (n.d.). CVD-COVID-UK / COVID-IMPACT. [online] Available at: <https://bhfdatasciencecentre.org/areas/cvd-covid-uk-covid-impact/>.

⁵ Anon. (n.d.). Available at: <https://bhfdatasciencecentre.org/wp-content/uploads/2024/02/Case-Study-Portrait.pdf>.

⁶ Centre, B.H.F.D.S. (2024). Smartphone and wearable data in cardiovascular research: understanding the views of the public and professionals. [online] Zenodo. Available at: <https://zenodo.org/records/10894877> [Accessed 26 Jun. 2024].

⁷ HDR UK (2022). Could your smartphone help to diagnose heart disease? [online] YouTube. Available at: <https://youtu.be/x6NpiPZZmJY?list=PLBI5k9SgYrItGXrjo3wO2LtsxwfyvimZ5> [Accessed 27 Jun. 2024].

⁸ MacArthur, J.A.L., Yong, G.L., Dweck, M.R., Fairbairn, T.A., Weir-McCall, J., Puyol-Antón, E., Meldrum, J., Blakelock, P., Khan, S., Morrice, L., Sudlow, C.L.M. and Williams, M.C. (2023). Cardiovascular imaging research priorities. *Open Heart*, [online] 10(2), p.e002378. doi: <https://doi.org/10.1136/openhrt-2023-002378>.

⁹ CVD-COVID-UK / COVID-IMPACT Ways of Working v3.0 CVD-COVID-UK / COVID-IMPACT Ways of Working. (n.d.). Available at: <https://bhfdatasciencecentre.org/wp-content/uploads/2023/08/CVD-COVID-UK-COVID-IMPACT-Ways-of-Working-v3.0.pdf> [Accessed 26 Jun. 2024].

¹⁰ British Heart Foundation - Data Science Centre. (2024). Behind the scenes: The CVD-COVID-UK-IMPACT Approvals and Oversight Board - British Heart Foundation - Data Science Centre. [online] Available at: <https://bhfdatasciencecentre.org/news-and-events/behind-the-scenes-the-covid-uk-impact-approvals-oversight-board/>.

¹¹ www.maidenhead-advertiser.co.uk. (n.d.). Maidenhead woman helps shape new study after husband is alerted to heart condition by smartwatch. [online] Available at: <https://www.maidenhead-advertiser.co.uk/gallery/maidenhead/195893/maidenhead-woman-helps-shape-new-study-after-husband-is-alerted-to-heart-condition-by-smartwatch.html> [Accessed 26 Jun. 2024].

¹² Maidenhead couple help gadgets project after health scare. (2024). *BBC News*. [online] 27 Apr. Available at: <https://www.bbc.co.uk/news/uk-england-berkshire-68873606> [Accessed 26 Jun. 2024].

¹³ BHF Data Science Centre Patient and Public Involvement Strategy. (2023). Available at: <https://bhfdatasciencecentre.org/wp-content/uploads/2023/09/BHF-DSC-PPIE-Strategy-23-24.pdf> [Accessed 26 Jun. 2024].

¹⁴ British Heart Foundation - Data Science Centre. (n.d.). For Researchers. [online] Available at: <https://bhfdatasciencecentre.org/for-researchers/> [Accessed 26 Jun. 2024].

¹⁵ British Heart Foundation - Data Science Centre. (n.d.). Public agreement on smartphone and wearable data for cardiovascular research. [online] Available at: <https://bhfdatasciencecentre.org/news-and-events/public-agreement-smartphone-wearable-data/> [Accessed 26 Jun. 2024].

¹⁶ British Heart Foundation - Data Science Centre. (n.d.). Supporting cardiovascular health data researchers to define disease. [online] Available at: <https://bhfdatasciencecentre.org/news-and-events/supporting-cardiovascular-health-data-researchers-to-define-disease/> [Accessed 26 Jun. 2024].

¹⁷ MacArthur, J.A.L., Yong, G.L., Dweck, M.R., Fairbairn, T.A., Weir-McCall, J., Puyol-Antón, E., Meldrum, J., Blakelock, P., Khan, S., Morrice, L., Sudlow, C.L.M. and Williams, M.C. (2023). Cardiovascular imaging research priorities. *Open Heart*, [online] 10(2), p.e002378. doi: <https://doi.org/10.1136/openhrt-2023-002378>

¹⁸ HDR UK (2022). Scientific Conference 2022 - Future priorities. [online] YouTube. Available at: <https://youtu.be/o76dA8dOhmY> [Accessed 26 Jun. 2024].

5. Accelerating research insights to inform patient care and public health. Curate data once, share, use often: Developing re-usable and reproducible data curation tools and resources for research on whole population routinely-collected linked electronic health record (EHR) data to reduce the time, cost and carbon footprint of generating health relevant insights that will improve health and healthcare services.

1	Researcher(s) Name: BHF Data Science Centre health data science team
2	HDR UK Programme: BHF Data Science Centre, Whole Population Data
3	Affiliation(s): BHF Data Science Centre, HDR UK
4	<p>Title of Case Study (150 characters):</p> <p>Accelerating research insights to inform patient care and public health.</p> <p>Curate data once, share, use often: Developing re-usable and reproducible data curation tools and resources for research on whole population routinely-collected linked electronic health record (EHR) data to reduce the time, cost and carbon footprint of generating health relevant insights that will improve health and healthcare services.</p>
5	<p>Summary of the Impact (150 words):</p> <p>Research on whole population electronic health record (EHR) data can be transformative for healthcare, public health, policy-makers, academia and industry providing information on health trends, disease patterns, treatment outcomes and public health interventions. However, EHR data can be messy and so research is time- consuming, takes a lot of computing power and similar tasks are repeated across projects. About 80%¹ of data science research time is devoted to data curation – cleaning and preparing the data ready for analysis to generate high-quality, useful research insights – and usually repeated for every project.</p> <p>We are developing a range of data curation tools, resources and support available to researchers for many different data science projects. By re-using these tools and resources, less time is taken and less computing power used to generate analysis-ready datasets making it faster, cheaper and reducing the carbon footprint of data science research. Team science is key by bringing together expertise and knowledge from different disciplines.</p> <p>¹Goldacre, B & Morley, J. (2022). <i>Better, Broader, Safer: Using health data for research and analysis.</i></p>
6	<p>Underpinning Research (250 words):</p> <p>All resources developed have been driven by project research teams’ requirements carrying out analyses, to reduce duplication of effort and make research quicker and greener. They enable researchers to:</p> <ul style="list-style-type: none"> • Understand what datasets and variables are available and useful, to assess if they can answer their research questions. • Make methods and code, used to make raw data ready for analysis, easier to find and re-use so the time taken to do data curation and analysis is quicker and cheaper. • Use standards/rules to improve research reproducibility e.g. ethnicity coding harmonisation. • Use common curated tables, that can be re-used across many projects e.g. key patient characteristics, so each project does not need to re-run the same code - making it more energy efficient.

	<p>Data curation tools and resources are available to support all research projects carried out as part of the CVD- COVID-UK/COVID-IMPACT programme – investigating the relationship between COVID-19 and all health conditions – and are being developed within NHS England’s Secure Data Environment (SDE). These tools and resources can be used to support many more programmes in the SDE (e.g., DATA-CAN), as well as other research environments (e.g., SAIL Databank for Wales).</p> <p>All code used to develop project pipelines is publicly accessible in the BHF Data Science Centre GitHub and can be used by the wider data science community. Phenotype algorithms that describe things such as a health condition or disease status, are made publicly available in the HDR UK Phenotype Library.</p> <p>Since 2021, CVD-COVID-UK/COVID-IMPACT programme has supported >70 studies using whole-population data from 73 datasets across England, Wales and Scotland for COVID-19 insights, with 19 so far published in The BMJ, The Lancet, Lancet Digital Health, Nature Medicine, and other journals.</p>
7	<p>Description of the Impact (500 words):</p> <p>The data curation tools and resources developed reduce the duplication of effort of repeating the same data curation steps in different projects, accelerating research, making it cheaper and using less computing power. The work has so far supported >70 studies across 50 institutions involving over 400 researchers and >80 analysts. For example, our infrastructure supported a project understanding the relationships between cardiovascular disease and COVID-19², conducted on behalf of the Chief Medical Officers (CMOs) and informed Department of Health and Social Care secondary prevention policies; and the first UK-wide EHR study on COVID- 19 vaccine uptake across the UK³.</p> <p>Resources have been developed for observational, whole population research but have the potential to significantly realise benefits by speeding up many types of research. Resources include:</p> <ul style="list-style-type: none"> ● Notebooks used to share knowledge with researchers about datasets through tutorials, data summaries (>100 notebooks), and data insights (>50 notebooks) from exploratory data analyses. This helps researchers understand the quality of the data and how it can be used without re-doing this work. ● Code re-use and optimisation: <ul style="list-style-type: none"> ○ Code repositories enable researchers to re-use and adapt code developed for previous projects when preparing their data, reducing the time taken to do this work. ○ Green algorithms involves re-use, review and optimisation of code, so it either doesn’t need to run or it does so as efficiently as possible. For example, data curation and analysis code for a project was restructured, reducing the runtime from >7 hours to <10 minutes allowing the project team to analyse a far greater number of diseases. ○ Code list comparison tool is an app to compare phenotype codes, used to define a disease or condition, across code lists from different libraries. This helps researchers determine the appropriate code list for their project and avoids duplication of effort writing code to wrangle and compare code lists. ○ Best practice on managing code and code lists, providing instructions to make it easier for other researchers to access and re-use code in the SDE. Code and protocols from each project are made publicly available in the BHF Data Science Centre’s GitHub repository. ● Common curated tables provide data required by many different research projects in an easily re-usable format so they do not need to re-run this analysis, reducing the time taken to prepare the data, the amount of computer power used and the carbon footprint of research. For example, a table for key patient characteristics (e.g. sex, ethnicity) defined for each individual. ● Dataset Summary Dashboard enables exploration of what data are available and helps researchers assess feasibility of their proposed study by providing an overview of each dataset, e.g., overall counts, data variable descriptions, data coverage, data completeness. ● Data curation pipelines which use existing code repositories and curated tables along with raw data, code lists and the pipeline specification to generate analysis-ready datasets. A range of checks and tables are also produced as part of the data curation pipelines providing essential information for project teams, promoting greater transparency, and accelerating research. ● Data curation pipeline specification templates provide a single source of information needed to prepare data for analysis, e.g., min-max values, selection of phenotypes.

	<ul style="list-style-type: none"> ● Project support by the health data scientist team provides research teams with a range of data curation and analysis expertise based on their needs. Examples: <ul style="list-style-type: none"> ○ Feasibility/Guidance - providing a data curation workflow and stage-by-stage process to analyse health data linked to environmental data (e.g., temperature and air pollution). ○ Partial Project support – creating an app and interactive dashboard to visualise and interpret epidemiological measures (e.g., number of people with a particular) for ~90 cardiovascular diseases (e.g., heart attack and stroke) before, during, and after the COVID-19 pandemic. ○ Full project support – project scoping, protocol input, data curation, analysis and publication writing for a project characterising who in the population (e.g. age, ethnicity, location) has surgery for the narrowing of the aortic valve, the outcomes after surgery and how the COVID-19 pandemic affected who received surgery. <p>²Knight et al, Circulation 2022 ³Kerr et al, The Lancet 2024</p>
8	<p>Role of HDR UK (250 words):</p> <p>The BHF Data Science Centre in HDR UK, led, developed and coordinated development of these tools and resources as well as the CVD-COVID-UK/COVID-IMPACT programme of research.</p> <p>The Centre team worked closely with other teams within HDR UK, including:</p> <ul style="list-style-type: none"> ● National Core Study Data and Connectivity team to make data accessible in national SDEs/TREs and build resources to make data science research quicker and cheaper. ● Senior leadership within HDR UK to ensure the work that has been enabled is visible and of relevance to Chief Medical Officers, policy makers and funders across the 4 nations and provide a conduit for requests for research insights from policy makers and funders. ● UK Health Data Research Alliance, particularly the Diversity in Data - Ethnicity coding working group, Data Officers’ group and OMOP Special Interest group on best practice, harmonisation and standardisation in data science research. ● HDR UK driver programmes – especially Big Data for Complex Disease – to support PhD students and early career researchers. ● Technology team to implement tools and resources more broadly, especially through the Health Data Research Innovation Gateway and Phenotype Library. <p>HDR UK has also provided a platform through meetings and events to share the tools and resources being developed with the wider community.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>This work develops, shares and re-uses tools, pipelines and resources to speed up the time it takes to do data science research. This work supports researchers that are part of CVD-COVID-UK/COVID-IMPACT but is applicable across a wide range of research types and environments.</p> <p>Resources within the SDE could be made available by NHS England to all users of the SDE, e.g., data summary notebooks have been made available for other users of NHS England’s SDE. Much of the code and instructions are exported into GitHub for use by the wider research community. The resources are regularly reviewed and optimised based on the latest research evidence.</p> <p>Updates and knowledge are shared via the CVD-COVID-UK/COVID-IMPACT slack channel and at monthly Consortium Update meetings. A member of the team will meet with analyst(s) at the start of each project to share knowledge and guidance and signpost to the most appropriate resources and will support as required thereafter. The team are developing data notes to be publicly available via the BHF Data Science Centre’s GitHub organisation, which will collate and provide a searchable resource of the key “need to know” information about datasets - from data summary, data insight, and project notebooks, and other useful information for working in the environment. Researchers will be able to contribute and share their own learnings, helping to transfer knowledge between project teams in the Consortium and to the research community more generally.</p> <p>Research results from studies within CVD-COVID-UK/COVID-IMPACT must be published through an open access route.</p>

10	<p>Contribution to Research Culture (250 words):</p> <p>Resources developed are to support all researchers wanting to carry out research using EHRs and based on the requirements of researchers doing this research.</p> <p>The health data science team will tailor support to researchers needs, enabling democratisation of data use. This support can be light touch by providing guidance and support through to carrying out full feasibility, curation and analysis.</p> <p>All resources and tools developed and improvement to the experience of using the SDE have been done in collaboration with multi-disciplinary research teams and the NHS England Data Wrangler Team and Platform Team. By promoting efficient coding the health data science team are helping to ensure that the shared compute resources are used responsibly and as a result continue to meet the needs of the analysts working in the environment.</p> <p>The CVD-COVID-UK/COVID-IMPACT programme is open to all to join. Members must sign up to the principles of participation (available on our website) which advocates team science and open science. All protocols and results/publications are shared with consortium members for input and comment. There is no onus to input but generally those with expertise and an interest in a particular area do provide feedback when relevant.</p>
11	<p>Research Team and Collaborators:</p> <p>Data science expertise, resource development and sharing: BHF Data Science Centre health data science team: Tom Bolton, John Nolan, Mehrdad Mizani, Zach Welshman, Lars Murdock, Fionna Chalmers (ECR), Jamie Farrell (ECR), Jadene Lewis (ECR), Anna Stevenson (ECR)</p> <p>SDE expertise, support resource development and sharing: NHS England Data Wrangler team</p> <p>Data science and domain expertise and input: Director BHF Data Science Centre: Cathie Sudlow Associate Directors, BHF Data Science Centre: Angela Wood (Whole Population Data); Spiros Denaxas (Defining Disease); Will Whiteley (Stroke Catalyst); Reecha Sofat (Cohorts); Ewan Pearson (Diabetes Catalyst)</p> <p>Contribution to developing resources, data science and methodology expertise, clinical domain expertise: CVD-COVID-UK/COVID-IMPACT consortium members</p> <p>Project management and coordination: Project Manager: Rouven Priedon</p> <p>Patient and public input to research projects: public members of the BHF Data Science Centre public advisory group</p>
12	<p>Funding:</p> <p>The health data science team are funded by the British Heart Foundation Data Science Centre (grant SP/19/3/34678), awarded to Health Data Research UK;</p> <p>Other funding: HDR UK Director's Discretionary Fund award (from HDR UK QQ1 core funding), Data and Connectivity National Core Study, led by Health Data Research UK in partnership with the Office for National Statistics and funded by UK Research and Innovation (grant ref: MC_PC_20058).</p>

6. First UK whole-population study shows risks of severe COVID-19 outcomes in under-vaccinated people

1	Researcher(s) Name: Steven Kerr, Stuart Bedston, Genevieve Cezard, Alexia Sampri, Siobhan Murphy, Declan T Bradley, Kirsty Morrison, Ashley Akbari, William Whiteley, Christopher Sullivan, Lynsey Patterson, Kamlesh Khunti, Spiros Denaxas, Thomas Bolton, Samaira Khan, Alan Keys, David Weatherill, Karen Mooney, Jan Davies, Lewis Ritchie, Jim McMenamin, Frank Kee, Angela Wood, Ronan A Lyons, Cathie Sudlow, Chris Robertson, Aziz Sheikh
2	HDR UK Programme: HDR UK COALESCE Consortium – a partnership between Scotland’s EAVE II project and British Heart Foundation’s Data Science Centre (part of Health Data Research UK)
3	Affiliation(s): University of Edinburgh
4	Title of Case Study (150 characters): First UK whole-population study shows risks of severe COVID-19 outcomes in under-vaccinated people
5	Summary of the Impact (150 words): The first study of everyone over the age of five across all four nations of the UK has demonstrated the risk of severe outcomes – hospitalisations and deaths – posed by under-vaccination against COVID-19. Between a third and a half of the populations of the four UK nations had not received the recommended number of COVID vaccinations and boosters by summer 2022. Mathematical modelling indicated that 7,180 hospitalisations and deaths out of around 40,400 severe COVID-19 outcomes during four months in summer 2022 might have been averted if the UK population was fully vaccinated.
6	Underpinning Research (250 words): Before the COVID-19 pandemic, the data infrastructure was not at the point where it was possible to perform full-population analyses using individual-level electronic health records. Multiple advancements needed to occur to enable the discoveries that can now be made using data from the whole population of the UK. One of the main ambitions of COALESCE was as a proof of principle for performing analyses on data from the whole population across all four nations of the UK. Prior to this, the research team had done large population studies into COVID-19 vaccine safety and waning using large datasets that covered Scotland, Wales and Northern Ireland but none that used data across the whole population of the UK. Only partial coverage of England was available early in the pandemic but it became apparent that improved access to electronic health records in England was needed, especially when looking at rare adverse effects or conditions. <ul style="list-style-type: none"> • https://doi.org/10.1016/S0140-6736(22)01656-7 • https://doi.org/10.1371/journal.pmed.1003927 • https://doi.org/10.1093/ije/dyac199
7	Description of the Impact: Early COVID-19 vaccine rollout began strongly in the UK, with over 90% of the population over the age of 12 vaccinated with at least one dose by January 2022. However, rates of subsequent booster doses across the UK were not fully understood until the COALESCE study. The research team based across the UK studied securely-held, routinely collected NHS data from everyone over 5 years of age during June 1 to September 30 2022. People were grouped by vaccine status, with under-vaccination defined as not having had all doses of a vaccine for which that a person was eligible. Published in <i>The Lancet</i> , the COALESCE study estimated that 7,180 hospitalisations and deaths out of around 40,400 severe COVID-19 outcomes during four months in summer 2022 might have been averted, if the UK population was fully vaccinated. Under-vaccination was associated with an increased rate of severe COVID-19 outcomes – hospitalisations and deaths – across all age groups studied, with under-vaccinated people over 75 more than twice as likely to have a severe COVID-19 outcome than those who were fully protected.

	<p>The highest rates of under-vaccination were found in younger people, men, people in areas of higher deprivation, and people of non-white ethnicity.</p> <p>The HDR UK COALESCE study was set up to provide UK and devolved governments with data-driven insights into COVID-19 vaccination coverage and establish data pooling methods and infrastructure to pave the way for future UK-wide studies. Members of the public and patients were involved in the shaping of this work.</p> <p>With COVID-19 cases on the rise and a new variant strain recently identified, this research provides a timely insight into vaccine uptake and hesitancy which could inform policymakers. This study also marks a significant milestone in HDR UK’s mission to unite the UK’s health data to enable discoveries that improve people’s lives and demonstrates the value and potential of population-wide health data studies.</p> <p>The research team engaged in a briefing with the Science Media Centre and the work was subsequently covered in national and international media outlets. Professor Cathie Sudlow was also invited on the BBC Radio 4 Today programme to discuss the work.</p>
8	<p>Role of HDR UK (250 words):</p> <p>The research relied on secure access to anonymised health data for the entire UK population across all four nations, which was only made possible by the ability to access and link datasets during the COVID-19 pandemic through the HDR UK-led National Core Studies Data and Connectivity programme. Funded by the UK Government, this programme was set up with the aim to make COVID-19-relevant data available for research with greater speed, efficiency and scale.</p> <p>The development of NHS Digital’s TRE for England with the BHF Data Science Centre and the CVD-COVID-UK/COVID-IMPACT Consortium was a gamechanger for the capacity to perform whole population analyses. In addition, collaboration between HDR UK Wales and Northern Ireland enabled remote access to health and social care data for the Northern Ireland population.</p> <p>Looking forward, this work will play an integral role in the HDR UK research driver programmes – in particular the Inflammation and Immunity programme and Big Data for Complex Disease. COALESCE has demonstrated the ability to bring together each UK nation’s data and generated findings on the process of this that will benefit future efforts to do whole- population scale studies for other public health challenges.</p> <p>Genevieve Cezard has been awarded a fellowship with the Big Data for Complex Diseases programme.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>The analysis code can be found at https://github.com/HDRUK/COALESCE. The phenotyping and analysis code in England can be found at https://github.com/BHFDSC/CCU051_01. The data that were used in this study are de-identified and are only available to approved researchers, not available publicly. Code was also shared within the research team throughout the study, enabling others to adapt and use what had already been drafted to improve efficiency in carrying out the work.</p> <p>Knowledge was frequently exchanged between members of the research team across the four nations at different institutes.</p> <p>On a weekly basis, the analysts from each country would get together on a call to share issues encountered and support each other with solutions from experience. This way of working improved the efficiency of the research and supported the development of new skills.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>Everyone on the team was working towards a common goal and – although geographically dispersed across the UK – maintained frequent communication to support each other through the project. Through weekly meetings, learnings were shared that both improved the efficiency of the project and supported individual skills development.</p> <p>The team became friends with each other, meeting socially in Edinburgh and elsewhere outside of working hours.</p> <p>There was no specific focus on equity, diversity or inclusion. We simply wanted to do good research, and everything else flowed from that.</p>
11	<p>Research Team and Collaborators:</p> <ul style="list-style-type: none"> • Steven Kerr – Chancellor’s Fellow, University of Edinburgh • Stuart Bedston - Research Officer and Data Scientist, Health Data Science at Swansea University • Genevieve Cezard - Research Associate, University of Cambridge • Alexia Sampri - Postdoctoral Research Associate in Health Data Science, University of Cambridge • Siobhan Murphy - Research Fellow, Queen’s University Belfast • Declan T Bradley - Lecturer, Queen's University Belfast • Kirsty Morrison – Scientist, Public Health Scotland • Ashley Akbari - Senior Research Manager and Data Scientist, Swansea University

	<ul style="list-style-type: none"> • William Whiteley - BHF Data Science Centre Associate Director and Theme Lead for the Stroke Catalyst • Christopher Sullivan • Lynsey Patterson – Lead Data Analyst for NI, Queen’s University Belfast • Kamlesh Khunti – Professor of Primary Care Diabetes and Vascular Medicine, University of Leicester • Spiros Denaxas - Professor of Biomedical Informatics, UCL • Thomas Bolton - Senior Health Data Scientist at BHF Data Science Centre • Samaira Khan - Public Involvement and Engagement Manager for the BHF Data Science Centre • Alan Keys - PPIE representative • David Weatherill – PPIE representative • Karen Mooney - PPIE representative • Jan Davies - PPIE representative • Lewis Ritchie - Mackenzie Chair of General Practice, University of Aberdeen • Jim McMenamin - Interim Clinical Director of Health Protection Scotland, part of Public Health Scotland • Frank Kee - Director of the Centre for Public Health in the School of Medicine, Dentistry and Biomedical Sciences at Queen’s University Belfast • Angela Wood - Professor of Health Data Science at the Victor Phillip Dahdaleh Heart & Lung Research Institute, University of Cambridge and Associate Director of the British Heart Foundation Data Science Centre • Ronan A Lyons - Clinical Professor of Public Health at Swansea University, and Co-director at the SAIL Databank • Cathie Sudlow - Chief Scientist at Health Data Research UK and Director of the British Heart Foundation (BHF) Data Science Centre • Chris Robertson - Professor of Statistics, University of Strathclyde • Aziz Sheikh - Director of the Usher Institute at the University of Edinburgh, HDR UK Research Director
12	<p>Funding:</p> <p>In addition to support from the National Core Studies: Data and Connectivity programme, funded by UK Research and Innovation, this research received HDR UK core funding and from the British Heart Foundation, through work at the BHF Data Science Centre at HDR UK.</p>

7. Advancing interoperable sensitive data research infrastructure through community group funding

1	<p>Researcher(s) Name: DARE UK delivery team:</p> <ul style="list-style-type: none"> • Balint Stewart, Programme Manager DARE UK • Fergus McDonald, Senior Programme Manager, DARE UK • Rob Baxter, Technical Lead, DARE UK • Michelle Amugi, Programme Manager, DARE UK • Westley Igbo, Senior Communications and Engagement Manager, DARE UK • Emily Jefferson, Interim Director, DARE UK
2	<p>HDR UK Programme: DARE UK</p>
3	<p>Affiliation(s): UKRI, MRC, ADR UK</p>
4	<p>Title of Case Study (150 characters):</p> <p>Advancing interoperable sensitive data research infrastructure through community group funding</p>
5	<p>Summary of the Impact (150 words):</p> <p>Community-driven approaches are essential for advancing interoperable sensitive data research infrastructure. However, resource constraints hinder the formation and activities of these groups. To address this, DARE UK funded four community groups up to £40,000 each over five months (Nov 2023 - Apr 2024). Key impacts include:</p> <ol style="list-style-type: none"> 1. Building communities by enabling new collaborations and rapid growth, exemplified by the UK TRE community tripling in size and forming multiple additional working groups. 2. Securing community input and buy-in for new tools and standards, ensuring they meet community needs. For instance, the SDC-REBOOT (Statistical Disclosure Control- Reducing Barriers to Outputs from TREs) group facilitated feedback and adoption of (semi)-automated output checking tools. 3. Creating community resource hubs to consolidate and align efforts, such as PEDRI's on Public Patient Involvement and Engagement resources, launching in October 2024. <p>This funding initiative has shown how just a little funding can go a long way.</p>
6	<p>Underpinning Research (250 words):</p> <p>The DARE UK Sprint exemplar and Driver projects demonstrated how critical partnership working is in solving the complex technical and governance challenges around cross-domain sensitive data sharing and analytics, with the funded projects overwhelmingly involving multiple partner organisations. These partnerships were key in bringing together the necessary infrastructure, research expertise, and data together, and without exception included public involvement throughout.</p> <p>Given this need for partnership working, the DARE UK programme launched its Community Groups initiative in April 2023. However, an identified challenge was resource constraints among participants, both in terms of the time needed to coordinate and run the groups as well as undertake the group-driven activities themselves. DARE UK therefore made small funds of up to £40,000 available per community group to support community group management, administration and events over a 5-month period from November 2023 – end March 2024.</p> <p>The call specification was designed to encourage communities that brought together diverse and inclusive networks, mandating community groups to be open and inclusive with co-chairs from multiple organisations. Alignment with the DARE UK vision and objectives was facilitated by defining needs in the selection criteria in priority areas including infrastructure technology, data standards, governance models, and effective public engagement strategies. Finally, the assessment panel were encouraged to consider the portfolio of funded community groups - helping to ensure a balanced overall spread across the priority strategic themes and included a public contributor to help the selection of proposals best aligned with public priorities.</p>

7	<p>Description of the Impact (500 words):</p> <p>Partnership working and community-driven approaches are critical for driving innovation in interoperable sensitive data research infrastructure. However, resource constraints hinder the formation of community groups both in terms of the time needed for individuals to coordinate and run the groups as well as to undertake the group-driven activities themselves. The DARE UK programme therefore ran an open funding call for community groups, ultimately funding four groups up to £40,000 over a five-month period from November 2023 – April 2024. Even over a short period of time and with small amounts of funding, these community groups are already having an impact on the sensitive data research landscape.</p> <p>Funding support has enabled:</p> <ul style="list-style-type: none"> • Strengthening of the community: support to buy out individuals’ time for community management and coordination, as well as to run events, has enabled the join-up of new configurations of people and institutions and has driven the rapid growth of these communities. For example, since DARE UK support the UK TRE community has tripled in size to 300 members from ~100 organisations (as of June 2024). Subsets of highly engaged members have formed over half a dozen working groups out of this community on critical areas such as TRE cybersecurity, funding and sustainability, and terminology, clearly demonstrating wider appetite for community enterprises given access to a wider, engaged community of practice. • Community input and buy-in for new tools, standards, and recommendations, ultimately supporting adoption: The development of new tools and standards in research infrastructure depends crucially on wider community input and buy-in. This helps to ensure that the tools and standards that are (co)developed are fit for the purposes of the community, and therefore support adoption by the community. The SDC-REBOOT community group, for example, enabled community feedback and the generation of resources to help community adoption of tools to support output checking, widely seen as one of the most challenging and resource-intensive aspects of TRE operations. Similarly, the AI Risk Evaluation Working group used the funding to run workshops with different stakeholders (researchers, data owners, and members of the public) for community input into a set of recommendations for the training and release of AI models from secure environments. • Community resource hubs: Some groups also opted to generate community resource hubs. Bringing together and signposting relevant domain-specific resources not only provides benefits for the wider community, but also helps to avoid duplication of effort and supports alignment across community activities. For example, PEDRI (Public Engagement in Data Research Initiative) used funding to develop a new website which will house a resource hub on Public Patient Involvement and Engagement (PPIE) in data and statistics, due to launch in October 2024. <p>As these community groups mature, they will form a critical mass of community expertise in their particular domain. This will help drive and sustain innovation in cross-domain sensitive data research infrastructure.</p>
8	<p>Role of HDR UK (250 words):</p> <ul style="list-style-type: none"> - HDR UK contracts supported with grants contracting - HDR UK comms supported with publicising the funding call - HDR UK Finance supported grant award delivery and monitoring - HDR UK events provided a platform for community groups to present their work at the HDR UK conference - The community groups themselves are also leveraging HDR UK infrastructure and networks. For example, the SDC-REBOOT community group reached an agreement to host their resources for output checking via HDR UK.
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>Openness: Membership to DARE UK Community Groups is open to all interested individuals who subscribe to the DARE UK programme vision. DARE UK community group meetings and processes are open, and the deliverables of DARE UK community groups are made available and publicly disseminated through open access platforms such as Zenodo.</p> <p>Open source first, non-profit, and technology-neutral: The DARE UK programme and its community groups do not promote, endorse, or sell commercial products, technologies, or services and the development of open and re-usable recommendations and outputs as part of the DARE UK programme is mandatory. All foreground IP generated through an interest or working group are shared as open source under a Massachusetts Institute of Technology (MIT) or other equivalent permissive license.</p>

10	<p>Contribution to Research Culture (250 words):</p> <p>The DARE UK Community Group Code of Conduct provides detailed guidance for community groups and their membership on expectations for DARE UK community group member behavior and policies, as well as mechanisms for dealing with infringements. This helps to ensure DARE UK community groups contribute positively to the wider research culture.</p>
11	<p>Research Team and Collaborators:</p> <p><u>The DARE UK Delivery Team</u></p> <ul style="list-style-type: none"> • Balint Stewart, Programme Manager DARE UK • Fergus McDonald, Senior Programme Manager, DARE UK • Rob Baxter, Technical Lead, DARE UK • Michelle Amugi, Programme Manager, DARE UK • Westley Igbo, Senior Communications and Engagement Manager, DARE UK • Emily Jefferson, Interim Director, DARE UK
12	<p>Funding:</p> <p>This research was funded as part of the DARE UK Phase 1b funding, from UK Research and Innovation (UKRI) as part of the Community Driven Pathways work stream.</p> <p>In Phase 1b, the DARE UK programme was allocated £4,250,000 of which £2,750,000 was earmarked for Community Driven Pathways. Following the Phase 1b Driver Projects funding call, £2,541,527 of this was allocated towards the DARE UK Driver Projects. This left an underspend of £208,473.</p> <p>Following discussions, the DARE UK Programme Board agreed for this underspend to be allocated towards further Community endeavors. Therefore, a proposal was made by the Delivery Team for how these funds might be deployed in a useful way through other community building activities, including this open funding call.</p>

8. Driving forward sensitive data research in the UK: The DARE UK Driver Projects

1	<p>Researcher(s) Name:</p> <p>DARE UK Delivery Team</p> <ul style="list-style-type: none"> • Westley Igbo • Fergus McDonald • Balint Stewart • Rob Baxter • Michelle Amugi <p>Driver Projects Principal Investigators:</p> <ul style="list-style-type: none"> • SATRE, Standardised Architecture for Trusted Research Environments - Dr Christian Cole, University of Dundee • TELEPORT, Connecting researchers to big data at light speed - Professor Simon Ellwood-Thompson, University of Swansea • SACRO, Semi-Automated Checking of Research Outputs -Professor Jim Smith, University of the West of England • TRE-FX, Delivering a federated network of trusted research environments to enable safe data analytics- Professor Carole Goble, University of Manchester • SARA, Semi-Automated Risk Assessment of Data Provenance and Clinical Free-text in trusted research environments- Dr Arlene Casey, DataLoch, University of Edinburgh
2	<p>HDR UK Programme: DARE UK</p>
3	<p>Affiliation(s): UKRI, MRC, ADR UK, HDR UK, University of Manchester, University of Dundee, University of Swansea, University of Edinburgh, University of the West of England</p>
4	<p>Title of Case Study (150 characters):</p> <p>Driving forward sensitive data research in the UK: The DARE UK Driver Projects</p>
5	<p>Summary of the Impact (150 words):</p> <p>In Phase 1b of the DARE UK Programme, following an open funding call, five Driver Projects were funded from February 2023 to October 2023. Through these projects, DARE UK has taken significant steps towards achieving its vision – to deliver a more joined-up, efficient UK data research infrastructure for public benefit. The outcomes of the Driver Projects provided valuable insights, addressing challenges including defining Trusted Research Environment capabilities; exploring how to simultaneously analyse data held within different TREs; and making efficiencies in checking outputs leaving secure environments. A number of the solutions developed by the Driver Projects have already been implemented by TREs, both in the UK as well as internationally. From the eager engagement of the UK research community to the effectiveness of sprint-style project portfolios, the lessons learned offer a roadmap for ongoing and future efforts. Dedicated resources, community-led collaborations, and a robust public involvement and engagement strategy have emerged as critical components for success.</p>

6	<p>Underpinning Research (250 words):</p> <p>In order to ensure that the projects which secured for funding would be impactful, the delivery team set out four areas of focus:</p> <ul style="list-style-type: none"> • Trusted research environment (TRE) reference architecture • Core federation services • Federated identity management across TREs • Partial automated risk assessment at data access request <p>The funding opportunity was publicised via the UKRI Funding Finder website, with a launch webinar to share information and answer questions. This helped to make the scope of the call clear to ensure that proposals submitted were addressing relevant challenges. This event was extensively promoted through a variety of channels to encourage interdisciplinary reach.</p> <p>An independent selection panel, consisting of technical experts and two public contributors, was formed to assess proposals. The panel reviewed the applications, identifying whether they were relevant, innovative and economical. The assessment had two stages: initial review and scoring of applications, followed by a panel meeting where applicants were questioned further by a PIE lead reviewer and a technical lead reviewer to ensure thorough evaluation. Following this, the panel recommended funding five of the eight eligible applications received.</p> <p>Post-launch, projects showcased their progress and outcomes to key stakeholders through showcase events and to the public in online webinars. This was done at the beginning and the end of the projects. A final report outlining the impact of their work and how it was achieved (including PIE) was submitted at the end of the projects.</p> <p>All reports are available on Zenodo:</p> <ul style="list-style-type: none"> • SATRE • TRE-FX • TELEPORT • SARA • SACRO <p>The DARE UK Delivery Team summarized the cross-learnings and outcomes from the projects in a report and also conducted a PIE evaluation. The findings from this PIE evaluation will inform future funded work and have been used to update DARE UK PIE guidance for future funded work.</p>
7	<p>Description of the Impact (500 words):</p> <p>Phase 1 of the DARE UK programme sought to address critical challenges in the UK's sensitive data research landscape. By undertaking a series of exploratory projects and consulting with the data research community and the public, DARE UK made significant strides towards creating a more cohesive and efficient data research infrastructure for public benefit. The DARE UK Driver Projects were a crucial step in this journey. Building on the insights from earlier Sprint Exemplar Projects, these five Driver Projects utilised the Five Safes framework to inform the design and delivery of a UK-wide network of Trusted Research Environments (TREs) for sensitive data research.</p> <p>The SARA project focused on semi-automated risk assessment of data provenance (a documented data trail from its origin to where it has moved to and where it is presently) and clinical free-text (e.g., GP records), within trusted research environments, improving data reliability and accessibility.</p> <p>The SACRO project implemented semi-automated checks on research outputs, ensuring research outcomes protect individual privacy while easing the manual burden on TRE staff. The project created a statistical framework and the 'ACRO' engine (a software framework that provides a guide and set of tools for researchers and output checkers) to automate disclosure risk checks, significantly reducing the need for manual inspection.</p>

Other projects like TRE-FX and TELEPORT developed mechanisms for federated data analysis and swift data access. TELEPORT's approach gives the research user direct access or sight of the de-identified data to carry out their analysis, and importantly the combined dataset is presented to the research user through a single view or interface. Through this a researcher will be able to log into a single TRE and be able to carry out analysis working directly with deidentified data from multiple TREs. Amongst other things, TRE-FX developed and showcased a scalable approach, allowing for the streamlined access of analysis tools to multiple TREs. TRE-FX has opened new avenues for researchers to conduct analyses across diverse TREs efficiently.

SATRE created a set of principles and capabilities for establishing and managing TREs to ensure data privacy, security, and streamlined research operations and defined the functional specification TREs should possess to ensure consistency and seamless collaboration in a shared network.

Each of the solutions developed will help make cross-domain sensitive data linkage easier for researchers. This will allow more research to be done to benefit the public.

Since the conclusion of the projects in October 2023, many of the Driver Projects have had a positive impact on the Research Community:

SATRE

Major impacts to date:

- Industry: Several commercial TRE providers are using SATRE
- Scotland: All Scottish TREs are evaluating themselves against SATRE
- England: NHS Secure Data Environment network using SATRE as a baseline
- SATRE working group formed driving forward further implementation and improvement to the SATRE specification as a community

TRE-FX

Major impacts to date:

Initiatives adopting and enhancing the TRE-FX solution:

- BY-COVID project
- EOSC-ENTRUST, a European Network of TRUSTed research environments
- Genomic Data Infrastructure (GDI) (proposal phase)
- Dementia's Platform Australia + Dementia's Platform + Alzheimer' Disease Data Initiative (proposal phase)

TELEPORT

Major impacts to date:

- Teleport is being deployed between SAIL and DPUK for a project, application going through approval
- Ongoing discussion with other groups working with SeRP who require federation.

SARA

Impacts to date:

- The wider Data Safe Haven community have expressed great interest in seeing SARA's solution developed and deployed across all projects.

	<p><u>SACRO</u></p> <ul style="list-style-type: none"> • SACRO's solutions are being tested and adopted across the UK and internationally (Germany and Michigan, USA) • SDC Statistical Disclosure Control - Reducing Barriers to Outputs from TREs (SDC-REBOOT) interest group formed to facilitate feedback and adoption of (semi)-automated output checking tools. <p>The outcomes of these projects provided valuable insights for the DARE UK Delivery Team:</p> <ul style="list-style-type: none"> • Community demand: There is a strong demand for advanced TRE capabilities to support impactful scientific research. • Project portfolios: Sprint-style projects are effective for early-stage conceptualization, but real-world application requires sustained efforts. • Collaboration: Continuous support for community-driven collaborations and idea development is crucial. • Public involvement and engagement (PIE): Delivering high-quality PIE is challenging but essential, requiring a coordinated approach.
8	<p>Role of HDR UK (250 words):</p> <p>HDR UK provided support to the DARE UK delivery team in the following ways:</p> <ul style="list-style-type: none"> • Promoted the Driver Projects funding opportunity through HDR UK social media channels • HDR UK Comms team supported with the promotion of all events • Promoted the work of some of the Driver Projects and their impact at the HDR UK conference • HDR UK contracts team gave advice and support on how best to run the funding call- as a research grant or as a service • HDR UK contracts supported with reviewing the initial grant award letter • Public Involvement and Engagement team gave guidance and support on how to PIE involvement • The Mid Project Showcase Day was hosted at the HDR UK office in London
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>Open source first, non-profit, and technology-neutral: The DARE UK programme and its Driver Projects do not promote, endorse, or sell commercial products, technologies, or services and the development of open and re-usable recommendations and outputs as part of the DARE UK programme is mandatory. All foreground IP generated through an interest or working group shall be shared as open source under a Massachusetts Institute of Technology (MIT) or other equivalent permissive license.</p> <p>All projects were published on Zenodo (links above) and all project outputs are opensource.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>There were several ways in which the DARE UK Delivery helped to contribute towards a positive research culture through the Driver Projects:</p> <ul style="list-style-type: none"> • Setting out clear requirements in the call -specification such as diversity of organisations and co-investigators which would encourage a good research culture. • Promoting innovation and forward thinking by providing funding to stimulate improvements. • Using the DARE UK Landscape review to identify requirements and ensuring that the work we funded was innovative, needs-based and surfaced some of the challenges known to exist in the sensitive data research landscape. • Including PIE as integral component throughout the assessment process. • Steering projects to address PIE at all reporting stages and to provide separate reports specifically focused on PIE

	<ul style="list-style-type: none"> Public contributors on the panel with specific PIE criteria to focus on. They looked at value for money and public benefit in particular. All projects had to report on PIE at all project review points. PIE evaluation was conducted at the end of the projects. Transparency- An FAQ document, updated weekly, ensured all potential applicants had access to the same information. Encouraged a collegiate research environment by holding off cross-project meetings and setting up spaces to share documents and have discussions across projects.
11	<p>Research Team and Collaborators:</p> <p>The DARE UK Delivery Team</p> <ul style="list-style-type: none"> Balint Stewart, Programme Manager DARE UK Fergus McDonald, Senior Programme Manager, DARE UK Rob Baxter, Technical Lead, DARE UK Michelle Amugi, Programme Manager, DARE UK Westley Igbo, Senior Communications and Engagement Manager, DARE UK <p><u>SATRE</u></p> <p>Principle Investigator: Dr Christian Cole</p> <p>Co-Investigators :</p> <ul style="list-style-type: none"> Prof. Sonya Coleman - Ulster University (UU) Prof. James Hetherington - University College London (UCL) Prof. Emily Jefferson - Health Data Research UK (HDRUK) Dr Dermot Kerr - Ulster University (UU) Dr Martin O'Reilly - The Alan Turing Institute (ATI) Dr Justin Quinn - Ulster University (UU) Dr James Robinson - The Alan Turing Institute (ATI) Layla Robinson - Research Data Scotland (RDS) Hari Sood - The Alan Turing Institute (ATI) <p>Researcher Co-I:</p> <ul style="list-style-type: none"> Dr Cian O'Donovan (UCL) <p>Project Partners:</p> <ul style="list-style-type: none"> Jillian Beggs - Lay participant Antony Chuter - Lay participant <p><u>SACRO</u></p> <p>Principal Investigator: Professor Jim Smith</p> <p>Co-investigators:</p> <ul style="list-style-type: none"> Dr Ben Derrick: UWE Professor Emily Jefferson: Health Data Research, UK Professor Felix Ritchie: UWE Amy Tilbrook, University of Edinburgh Professor Paul White: UWE Sebastian Bacon: Bennett Institute, University of Oxford Dr James Liley: University of Durham Dr Richard Preen: UWE Dr Simon Rogers: NHS Scotland Peter Stokes: Bennett Institute, University of Oxford Dr Christian Cole: University of Dundee Katherine O'Sullivan: University of Aberdeen Michael Sibley: Electronic Data Research & Innovation Service (eDRIS), Public Health Scotland

	<ul style="list-style-type: none"> • Jess Morley: Bennett Institute, University of Oxford • Layla Robinson, Research Data Scotland (RDS) <p>TELEPORT:</p> <p>Principal Investigator: Professor Simon Ellwood-Thompson</p> <p>Co-Investigators:</p> <ul style="list-style-type: none"> • Professor Mark Parsons, Director, EPCC University of Edinburgh • Carole Morris, Head of Service eDRIS Public Health Scotland <p>TRE-FX</p> <p>Principal Investigator: Professor Carole Goble</p> <p>Co-investigators:</p> <ul style="list-style-type: none"> • Stian Soiland-Reyes - ELIXIR UK / Technical Architect, Dept. of Computer Science, The University of Manchester • Dr Philip Quinlan. Director of Health Informatics. School of Medicine, University of Nottingham • Dr Thomas Giles. Team Leader, Digital Research Service, University of Nottingham • Mr Jonathan Couldridge, Senior Digital Research Scientist, Digital Research Service, University of Nottingham • Professor Emily Jefferson - Chief Technology Officer (CTO), HDRUK • Dr Christian Cole - Senior Lecturer, School of Medicine and Research Lead at Health Informatics Centre (HIC), University of Dundee • Professor Simon Thompson - Director of Secure e-Research Platform & Technical lead for SAIL Databank, University of Swansea • Prof Elizabeth Sapey Director of PIONEER, The HDR UK Hub in acute care • Dr Rebecca Wilson PI DataSHIELD, University of Liverpool • Suzy Gallier, Technical Director, PIONEER Health Data Research Hub for Acute Care <p>SARA</p> <p>Principal Investigator: Dr Arlene Casey, Senior NLP Development Scientist, DataLoch</p> <p>Co-investigators</p> <ul style="list-style-type: none"> • Prof. Nicholas Mills, BHF Chair of Cardiology • Dr Stuart Dunbar, Engagement Manager, DataLoch University of Aberdeen • Katherine O’Sullivan, Grampian Data Safe Haven Operational Lead • Dr Milan Markovic, Research Fellow, Computing Science • Dr Ana Ciocarlan, Lecturer, Computing Science • Katie Wilde, Grampian Data Safe Haven Director Greater Glasgow and Clyde (West of Scotland) Safe Haven • Dr Charlie Mayor, Safe Haven Manager Greater Glasgow and Clyde Glasgow Safe Haven • Dr Elizabeth Ford, Reader in Health Data Science, Brighton and Sussex Medical School, University of Sussex
12	<p>Funding:</p> <p>DARE UK (Data and Analytics Research Environments UK) is a programme funded by UK Research and Innovation (UKRI) . The DARE UK Driver Projects were funded as part of the DARE UK Phase 1b funding, from UK Research and Innovation (UKRI). In Phase 1b, the DARE UK programme was allocated £4.25 million with £2.75 million for funding work with the community such as the Driver Projects.</p> <p>SATRE Funded amount: £614,112 TRE-FX Funded amount: £566,457 TELEPORT Funded amount: £462,933 SARA Funded amount: £383,147 SACRO Funded amount: £514,878</p>

9. Scientific use cases for cross-domain sensitive data research in the UK reveal transformational potential for public benefit

1	<p>Researcher(s) Name:</p> <p><u>The DARE UK Delivery Team:</u></p> <ul style="list-style-type: none"> • Balint Stewart, Programme Manager DARE UK • Fergus McDonald, Senior Programme Manager, DARE UK • Rob Baxter, Technical Lead, DARE UK • Michelle Amugi, Programme Manager, DARE UK • Westley Igbo, Senior Communications and Engagement Manager, DARE UK • Emily Jefferson, Interim Director, DARE UK <p><u>The Public Service Consultants (The PSC):</u></p> <ul style="list-style-type: none"> • Mark Ray, Associate consultant • Fiona Jamieson, Manager • Katie Burns, Associate Partner • Antonio Weiss, Senior Partner
2	<p>HDR UK Programme: DARE UK</p>
3	<p>Affiliation(s): UKRI, MRC, ADR UK</p>
4	<p>Title of Case Study (150 characters):</p> <p>Scientific use cases for cross-domain sensitive data research in the UK reveal transformational potential for public benefit</p>
5	<p>Summary of the Impact (150 words):</p> <p>This work brought together over 50 interdisciplinary researchers, policymakers, and public members to identify 52 use cases for integrating diverse data types at scale. This revealed significant potential public benefits for health and wellbeing, addressing both longstanding and emerging societal challenges such as productivity, social inequality, climate change, obesity, and mental health crises. Benefits modeling estimated substantial economic gains, projecting £319.11bn (+/- £79.14bn) by 2050 from just 10 use cases, bolstering the economic rationale for cross-cutting research to solve intersectional societal problems. While there is considerable focus on the risks and safeguards of using public data, this research emphasizes the vast public benefits that can be realized if data is used responsibly. These findings will guide DARE UK’s future funding calls for real-world projects leveraging sensitive data research infrastructure innovation.</p>
6	<p>Underpinning Research (250 words):</p> <p>On 8 February 2024, DARE UK, supported by The PSC, brought together 48 UK-based researchers and seven public participants to explore use cases for linking sensitive data. The full-day workshop aimed to answer the question: “If all sensitive data in the UK could be linked and accessible at scale, how could we use it to benefit the public?”</p> <p>Participant recruitment was through invitation and an open call for expressions of interest. Researchers represented seven different Research Councils, showcasing the diverse expertise present. Over half of the researchers worked across multiple research councils, indicating their engagement in interdisciplinary research. Realizing the full value of data for public benefit necessitates public involvement; thus, seven public participants contributed to the workshop activities and the planning of the session.</p> <p>The workshop featured four interactive activities: identifying types of sensitive data, pinpointing key societal challenges, surfacing use cases by combining data types to address the identified challenges, and voting on a subset of use cases through a 3-minute “Dragon’s Den” style pitch. This process enabled the prioritization of 10 use cases for detailed benefit analysis.</p> <p>The inclusive approach underscored the importance of involving diverse voices in data-related initiatives. The findings and the high-priority use cases identified will inform future research and funding decisions. Full details of the use cases and their potential benefits are available in the workshop report, which aims to guide further innovation in sensitive data research infrastructure.</p>

7	<p>Description of the Impact (500 words):</p> <p>The grand challenges facing society today are increasingly complex and interconnected. Tackling these will require intersectional research that brings together various types of data about people. This project focused on the opportunities that could be unlocked for research in the public good if researchers had access to linked sensitive data at scale.</p> <p>Diversity of Data</p> <p>Participants identified 52 use cases that were notable for their diversity, potential impact, and innovative approaches. The 52 use cases integrated 80 different kinds of data, grouped into 10 higher-level domains. Cross-cutting approaches were prominent, with 69% of use cases combining data from three or more domains. Health data featured in 85% of use cases but were typically cross-cutting and aimed at improving public health, wellbeing, and productivity rather than targeting specific clinical interventions.</p> <p>Addressing Societal Challenges</p> <p>The use cases aimed to understand and address some of the UK's most pressing societal challenges. Over half of the use cases tackled longstanding issues dating back to the 1970s and '80s. Key focus areas included:</p> <ul style="list-style-type: none"> • Social inequality (27% of use cases) • The Productivity Paradox (23% of use cases), addressing the stagnation of UK productivity since the 2008 financial crash • Climate change (15% of use cases) <p>Additionally, several use cases explored modern challenges, such as the impact of digital technologies and social media on the wellbeing of children and young people.</p> <p>Innovative Approaches</p> <p>Innovative methods for linking data were a hallmark of the use cases. Notably, 38% of use cases combined data at the family or household level to analyze the influence of social environments on health and life outcomes.</p> <p>Economic and Social Benefits</p> <p>The potential economic benefits of addressing these challenges were significant. Benefits modeling estimated a gain of £319.11bn (+/- £79.14bn) by 2050 from just a subset of the identified use cases. This projection underscores the substantial public benefits achievable through targeted data linkage initiatives.</p> <p>Future Directions</p> <p>To realize these benefits, further work is needed to translate research findings into policies and actions. However, the economic modeling illustrates the tremendous potential impact of even a small subset of the use cases.</p> <p>As the DARE UK programme advances, it is crucial to support real-world interdisciplinary data research that spans traditional boundaries and enhances our understanding of societal challenges. This work will inform future funding opportunities, guiding research teams aiming to tackle the identified use cases.</p> <p>In conclusion, the workshop underscored the importance of linking sensitive data to address key societal issues effectively. By fostering innovative, interdisciplinary research, DARE UK aims to drive substantial public benefits, both socially and economically. This initiative will shape the future of data-driven research and policy, ensuring that the benefits of linked sensitive data are realized for the public good.</p>
8	<p>Role of HDR UK (250 words):</p> <p>HDR UK provided support to the DARE UK delivery team in the following ways:</p> <ul style="list-style-type: none"> - Guidance on PIE involvement - Support in recruitment of public contributors for the workshops - Supported with publicising the call for expressions of interest - The workshop was hosted in-person at HDR UK Head Office at the Wellcome Trust

	<ul style="list-style-type: none"> - HDR UK Contracts team supported with the contracting of the PSC - HDR UK Comms team reviewed the report and provided feedback
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>Transparency: All methodological details are provided in the report together with references to source data wherever relevant for the desk-based research parts.</p> <p>Knowledge exchange: a preliminary version of the report’s findings was presented back to workshop participants in an online plenary session for their input and feedback before the final publication of the report.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>Diversity of participants: Recruitment of participants was through an open call for expressions of interest, as well as by direct invitation. All those that submitted an expression of interest for the workshop were subsequently invited to attend the workshop. Recruitment through invitation helped to ensure a diverse spread of participants by research councils, gender, and locality. This diversity was essential for the objectives of the workshop: to work across disciplinary boundaries to surface use cases that address society’s most intersectional and complex challenges.</p> <p>Public involvement: Public participants contributed to activities throughout the workshop, in addition to contributing valuable insights for the planning of the workshop session itself.</p> <p>Recognition: All workshop participants were acknowledged by name at the end of the report.</p>
11	<p>Research Team and Collaborators:</p> <p><u>The DARE UK Delivery Team</u></p> <ul style="list-style-type: none"> • Balint Stewart, Programme Manager DARE UK • Fergus McDonald, Senior Programme Manager, DARE UK • Rob Baxter, Technical Lead, DARE UK • Michelle Amugi, Programme Manager, DARE UK • Westley Igbo, Senior Communications and Engagement Manager, DARE UK • Emily Jefferson, Interim Director, DARE UK The Public Service • <u>Consultants (The PSC):</u> • Mark Ray, Associate Consultant • Fiona Jamieson, Manager • Katie Burns, Associate Partner • Antonio Weiss, Senior Partner
12	<p>Funding:</p> <p>This research was funded as part of the DARE UK Phase 1b funding, from UK Research and Innovation (UKRI) as part of the Community Driven Pathways work stream.</p> <p>In Phase 1b, the DARE UK programme was allocated £4,250,000 of which £2,750 000 was earmarked for Community Driven Pathways. Following the Phase 1b Driver Projects funding call, £2,541,527 of this was allocated towards the driver projects. This left an underspend of £208,473.</p> <p>Following discussions, the DARE UK Programme Board agreed for this underspend to be allocated towards further Community endeavors. Therefore, a proposal was made by the Delivery Team for how these funds might be deployed in a useful way through other community building activities, including this research on scientific use cases.</p>

10. New policy approaches and research methodologies around anticipating seasonal demand and avoidable attendances and admissions in urgent & emergency care

1	Researcher(s) Name: Jen Lewis, Richard Jacques, Rebecca Simpson, Suzanne Mason
2	HDR UK Programme: Regional Linked Data Programme
3	Affiliation(s): Division of Population Health (formerly SchARR), The University of Sheffield
4	<p>Title of Case Study (150 characters):</p> <p>New policy approaches and research methodologies around anticipating seasonal demand and avoidable attendances and admissions in urgent & emergency care.</p>
5	<p>Summary of the Impact (150 words):</p> <p><u>1: Informing decision making</u></p> <p>a) Our research revealed that assumptions about factors underpinning winter pressures in emergency care are not supported, with significant implications for policy-making regarding pressure mitigation. Our findings have potential to support urgent care systems better manage demand, capacity and patient flow.</p> <p>b) Considerable variation in potentially avoidable emergency department (ED) attendances and acute hospital admissions among patients with ambulatory sensitive care conditions (ACSCs) may indicate a lack of alternatives to admission, and/or failures of care in pre-hospital settings, highlighting a need for more robust management of ACSCs.</p> <p><u>2: Improving health and wellbeing</u></p> <p>Implementation of policy changes based on our findings has potential to improve patient experience and outcomes. Better demand management and alternatives to ED and admission will support patients to get appropriate, timely emergency healthcare, reduce unhelpful avoidable admissions, and support staff wellbeing via more manageable workloads.</p> <p><u>3: Advancing methods and technology</u></p> <p>Our novel approach to analysis has potential to generate fast and impactful outcomes and may be utilised to address a wide range of research questions in health and health policy. A new collaborative network has been established through this project. The approach was successful for aggregating real-world hospital data for analysis but challenges remain.</p>
6	<p>Underpinning Research (250 words):</p> <p>We used a collaborative ‘federated’ analysis approach to examining two research questions:</p> <ul style="list-style-type: none"> • What is the nature of seasonal variation in demand for emergency care across England? • What regional variation exists in patterns of avoidable emergency department attendances and acute hospital admissions?

	<p>Researchers at seven research centres took part in this study which utilised routinely collected emergency care data covering 1/11/2021-31/10/2022. The study was coordinated by a lead research centre (Sheffield), who supplied a list of required data and analysis to all other centres. Each centre established ethics, data sharing and acquisition processes with their local NHS trusts. Researchers at each centre analysed local data and supplied summary results to the lead centre. Results were aggregated to give a national and regional picture of seasonal and regional variation in avoidable admissions and demand for urgent care.</p> <p>Our research revealed no consistent variation in either the number or nature of ED attendances or acute hospital admissions in winter (https://doi.org/10.1136/emj-2023-RCEM.39). This suggests:</p> <ul style="list-style-type: none"> • High demand and pressure keeping EDs and acute wards at or near capacity are experienced all year, and not strongly associated with winter; • Experiences of increased demand during winter is not due to notably higher demand, but may be the result of minor fluctuations causing a shift from EDs and acute wards ‘just coping’ to ‘not coping’. <p>We also identified considerable variation in potentially avoidable emergency department attendances and acute hospital admissions for ambulatory care sensitive conditions (ACSCs) (https://zenodo.org/records/10522846). This may indicate a lack of alternatives to admissions within hospital trusts, the pre-hospital environment and wider healthcare system, and that initiatives such as Same Day Emergency Care (SDEC) services may not be fully functioning as intended.</p> <p>PPI feedback for this project was very positive, and helped ensure the focus remained on understanding and improving services and avoided placing undue responsibility on the patient for making an avoidable attendance or increasing pressure on services.</p>
7	<p>Description of the Impact (500 words):</p> <p>There are multiple pathways to impact from these novel findings.</p> <p><u><i>Informing decision making</i></u></p> <p>There are clear policy implications emerging from this work.</p> <p>Since current mitigation measures against seasonal pressure are not supported by our findings, current measures are unlikely to represent an optimal approach to handling seasonal pressure. Our research points to new and better approaches to managing the experience of seasonal demand. The introduction of new target capacity limits year-round are suggested, as current targets do not appear to be sufficiently robust to cope with small fluctuations in demand. The adoption of effective measures to apply new targets are necessary and could include measures such as Virtual Wards and certain GP-ED models.</p> <p>The work exploring avoidable admissions and attendances found there were high rates of patients attending ED with ACSCs, and High proportions of potentially avoidable admissions from ED. This may signify a failure of care in pre-hospital settings, such as primary and community care, and that initiatives such as current Same Day Emergency Care (SDEC) services may not be functioning as intended. Policy implications include the need for robust management of ACSCs as an important way to reduce avoidable demand for acute beds, and re-examination of existing mitigation services to ensure they are meeting patient needs.</p> <p><u><i>Improving health and wellbeing</i></u></p> <p>Our work addresses current NHS priorities (1,2) and is a matter of importance to the public (3,4). Resulting policy changes have the potential to support NHS targets by providing more flexibility for small fluctuations in demand which may currently create unmanageable levels of pressure, leading to clear benefit for hospital staff in terms of manageable workload and wellbeing, and for patients, for whom the best pathways of care will be available for their needs regardless of locality or seasonality. This has the potential to improve health and quality of life outcomes, by improving access to emergency care, reducing avoidable admissions, enabling supported healthcare in the home and ensuring timely care delivery regardless of season, addressing the impact area.</p>

	<p>Where our research revealed commonly understood definitions of ‘Winter Pressures’ (e.g., increased attendances to the emergency department) to be inaccurate, we have also defined new priorities for research to investigate to understand what is driving the subjective experience of higher demand. Targets include qualitative explorations of emergency care staff perceptions of drivers of pressure in winter, prospective evaluations of the efficacy of demand management measures, and quantitative analysis to identify ‘tipping points’ that result in unmanageable demand.</p> <p>Our work exploring avoidable admissions has identified that variation in how admissions are managed is an important target for research which will support endeavours to create a more egalitarian emergency healthcare system and reduce avoidable admissions and attendances which can adversely affect patients’ health and wellbeing.</p> <p><i>Advancing methods and technology</i></p> <p>This work has established a new infrastructure and research network across England comprising a large interdisciplinary collaborative team. This has resulted in more rapid access to and analysis of routine emergency healthcare data and is leading to new standard practice and research projects for key and priority areas.</p> <p>A policy briefing was provided to DHSC (attached) and the work has been disseminated through talks at the Royal College of Emergency Medicine (RCEM) conference (https://doi.org/10.1136/emj-2023-RCEM.39) for the Office of National Statistics (Online, 9/5/24), and via publicly accessible reports (https://zenodo.org/records/10522846). Further collaborations have been established which will provide further detail on drivers of, and mitigations for, demand. This includes local collaborations with the South Yorkshire Community of Practice of Advanced Analytics opening access to new data pipelines which will contextualize future planned research in this area.</p> <p>References:</p> <ol style="list-style-type: none"> 1. NHS England (2023) <i>Major plan to recover urgent and emergency care services</i>. Online https://www.england.nhs.uk/2023/01/major-plan-to-recover-urgent-and-emergency-care-services/ Retrieved 17th June 2024 2. NHS England (2023) 2023/24 Priorities and operational planning guidance V1.1. Online https://www.england.nhs.uk/wp-content/uploads/2022/12/PRN00021-23-24-priorities-and-operational-planning-guidance-v1.1.pdf Retrieved 17th June 2024 3. The Guardian (2024) NHS in summer crisis of emergency care waits, doctors say. Online https://www.theguardian.com/society/article/2024/jun/20/nhs-summer-crisis-emergency-care-waits-royal-college-of-emergency-medicine Retrieved 20th June 2024 4. The Independent (2023) NHS using AI to reduce ‘avoidable’ hospital admissions this winter. Online https://www.independent.co.uk/news/health/nhs-artificial-intelligence-waiting-list-b2446744.html Retrieved 15th June 2024
8	<p>Role of HDR UK (250 words):</p> <p>In addition to funding this work, HDR UK were important to the impact of this project by supporting co-ordination between the research team and policy representatives from the Department for Health and Social Care (DHSE) and the UK Health Security Agency (UKHSA) through a ‘buddying’ scheme. This allowed us to focus our work on areas important to healthcare policy bodies.</p> <p>HDR UK were instrumental in convening meetings of the Regional Linked Data Group involved in this large-scale project. They also supported communications within the group, with dedicated HDR UK staff members organising, chairing, and helping to direct meetings. HDR UK also helped co-ordinate PPIE, and supported decision-making on research priorities and projects to be delivered.</p> <p>HDR UK also co-ordinated the dissemination of a policy briefing covering the main findings and clinical implications of this work. HDR UK have also helped enable additional dissemination and collaboration, such as through the recommendation of the project to be featured in an Office for National Statistics webinar.</p>

9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>This highly collaborative project has raised the profile of the novel, federated data analysis approach and highlighted the potential of this approach to impact health policy and decision making more rapidly than would be possible with standard approaches. Lessons learned through the course of this project, which will be documented in an upcoming research paper, will allow future research exploiting this approach to be undertaken more quickly and efficiently.</p> <p>While significant restrictions on data access were necessary due to the sensitive nature of the data, code to support consistent data pipelines, checking and processing was developed collaboratively between multiple research centres and made available on GitHub (https://github.com/MattStammers/hdruk_avoidable_admissions_collaboration_docs and https://github.com/MattStammers/outcomes_project). This process facilitated productive exchange of ideas and expertise regarding best practices around handling and processing data, and its hosting on a publicly accessible repository demonstrates commitment to open science practices.</p> <p>The project has also led to the establishment of new collaborations and a growing research network that is eager to work together on future projects and continuing to address strategic research questions in other healthcare domains using large data resources.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>The nature of the project, including a large interdisciplinary team of many staff with different levels of seniority and expertise, encouraged a supportive, collaborative working environment. All sites were encouraged to feed into the project plan and best practice and methodologies for execution. Different sites were proactive in taking responsibility for different aspects of project delivery. Many staff involved were early career, and everyone, including junior staff, was encouraged to share insights and suggestions during weekly meetings. The project allowed junior staff members an opportunity to collaborate with a broad range of clinicians and researchers from a range of institutions, increasing their active research networks and affording opportunities for future development.</p> <p>All research centres showed a willingness to collaborate with a new and sometimes complex process involving multiple sets of governance and ethics guidelines, and different data pipelines and acquisition processes. Sites collaborated on plans to extract data and worked together to produce a common data validation process which was made publicly available. Senior staff were supportive and offered guidance throughout a complex process.</p>
11	<p>Research Team and Collaborators:</p> <p>Many researchers were involved in this project from a large number of research centres. In the interests of brevity only staff from the lead site (Sheffield) are listed here, and the collaborative indicates the other research institutions involved.</p> <p>University of Sheffield:</p> <p>Suzanne Mason: Professor of Emergency Medicine. Project oversight and clinical lead.</p> <p>Jen Lewis: Medical statistician. Co-lead and primary analyst for the Winter Pressures project. ECR at the time of the project.</p> <p>Richard Jacques: Senior Lecturer in Medical Statistics. Co-lead and analyst for the Avoidable admissions project.</p> <p>Rebecca Simpson: Lecturer in Medical Statistics. Co-lead and analyst for the Avoidable admissions project.</p> <p>Simone Croft: Project Manager. Co-ordinated research sites and data sharing agreements and ethics for South Yorkshire NHS Trust.</p> <p>Susan Croft: Emergency Medicine Consultant. Supported project development and advised on strategic clinical direction.</p> <p>Madina Hasan: Data Manager. Management and data processing for South Yorkshire NHS Trust data. ECR.</p> <p>Ross McMurray: Research Data Manager. Managed secure data environment for processing and analysis of South Yorkshire Data</p> <p>Other institutional members of the HDR UK Regional Linked Data Consortium:</p> <p>HDR UK</p> <p>Barts Health NHS Trust</p> <p>University of Bristol</p>

	Imperial College London Lancashire Teaching Hospitals NHS Foundation Trust PIONEER Research Hub Birmingham University Hospital Southampton NHS Foundation Trust
12	Funding: This work was funded by HDR UK Data & Connectivity (Regional linked data programme) and HDR UK Grant WP0011.

11. Speaking the same language: harnessing highest quality data in all four nations to improve UK respiratory outcomes

1	<p>Researcher(s) Name:</p> <p>Professor Jenni Quint, Chris Orton</p>
2	<p>HDR UK Programme:</p> <p>Inflammation and Immunity Driver Programme</p>
3	<p>Affiliation(s):</p> <p>Imperial College London, Swansea University, University of Edinburgh, Queen’s University Belfast</p>
4	<p>Title of Case Study (114/150 characters):</p> <p>Speaking the same language: harnessing highest quality data in all four nations to improve UK respiratory outcomes</p>
5	<p>Summary of the Impact (150/150 words):</p> <p>Data curation is 80% of the effort in most health data research projects. We provided methods for consistent curation of harmonised, research-ready respiratory datasets in primary and linked secondary care data in England, Northern Ireland, Scotland and Wales. Algorithms and code lists are replicable in different data environments and clinically validated, saving significant time. These resources for asthma and chronic obstructive pulmonary disease (COPD) in all 4 nations, and interstitial lung disease (ILD) in England, Scotland and Wales, are a key data improvement for industry, charity, academic and NHS use, and a critical foundation for federated analyses. They underpin future capability to run consistent reports at the touch of a button on incidence, prevalence and health utilisation for common respiratory conditions across the UK for policy and advocacy activities. This provides a starting point for curation of equivalent respiratory datasets in other EHR databases in the UK and potentially internationally.</p>
6	<p>Underpinning Research (248/250 words):</p> <p>The goal to improve respiratory datasets and provide access to the highest quality curated data and cohort profiles for COPD, ILD and asthma, was initiated in 2019 as a key activity for the BREATHE Hub for Respiratory Health. This was discussed first with lay members in the BREATHE Curiosity Group, to obtain views on the usefulness of the project. Initial work was in the primary and linked secondary care data in the Clinical Practice Research Datalink (CPRD; for England) and the Secure Anonymised Information Linkage (SAIL; for Wales), and was extended with NIHR Imperial BRC funding to include NHSE data. MRC Capital Funding enabled work in 2022 to include DataLoch (for SE Scotland), and also the provision of GPIP data linked through the Honest Broker Service (HBS) for coding of a directly comparable respiratory cohort and variables for asthma and COPD in Northern Ireland.</p> <p>Completed work in England, Wales and Scotland was recently published. Data processing of the newly created HBS primary and linked secondary care resource is in its final stage.</p> <p>By working in parallel on the curation methodology for CPRD, SAIL and DataLoch, we were able to highlight key differences in coding languages, processes and recording between the databases, and identify solutions to enable valid clinical comparisons. All codelists used, including cohort definitions and variables, can be found on GitHub and in the Health Data Research UK Phenotype Library to re- create these cohorts for different time periods and provide a starting point for other EHR databases.</p>
7	<p>sharing of codelists and algorithms for easy reproduction and replication, generating consistent phenotype and variable definitions regardless of the coding system, is a vital step for the advancement of health data methods and technology in respiratory research. We have helped “sort the data”, resulting in several areas of impact:</p> <p>Shared learning and quality assurance. The use of EHR databases to carry out research into common respiratory diseases like asthma, COPD and ILD is growing, but until now there has been no systematic approach and little opportunity to learn</p>

	<p>from others. By comparing data across secure data / trusted research environments (SDEs/TREs), embedding clinical validation, and sharing methodology, we have generated important insights on UK EHR data quality. Lessons learned can now be used to improve curation processes more widely e.g. with other disease conditions and as part of wider HDR UK goals to harmonise datasets across the UK.</p> <p>Saving time and greener computing. Data cleaning and curation is a hugely time-consuming part of the analysis process (estimated at 80% of the whole project). The provision of research-ready datasets with built-in clinical validity, and code/algorithms to use these easily in different circumstances means that there is no need to start from scratch each time, leading to faster and more efficient research for industry, academia, charity and NHS. For example, two Respiratory Registry projects recently approved by DataLoch are led by clinicians with an interest in improving NHS services.</p> <p>More efficient UK-wide research. Models like the Observational Medical Outcomes Partnership (OMOP) Common Data Model have been highlighted as an enabler of efficient cross-region/nation research studies, but there is a loss of granularity with OMOP which undermines respiratory analyses. Our harmonised approach is being used to validate and further develop federated analytics tools to deliver quality research across several SDEs/TREs without loss of granularity.</p> <p>Capacity development. By sharing code and methods, we have enabled those without specialist respiratory knowledge to run quality health data studies e.g. to link with other types of data to address novel questions, or to create routine reports for policy impact. As examples, the resources are being used to investigate respiratory syncytial virus (RSV) infection in children and its association with asthma development, to predict respiratory exacerbations in primary care, and to explore health inequalities associated with respiratory conditions across the UK. These developments support the stated aims of Asthma + Lung UK and the National Respiratory Audit Programme (NRAP; England) to improve the data used by health commissioners and government policy makers.</p> <p>Driving positive system change with direct patient benefits. Our lay members have emphasised the importance of consistency across the UK for research data access and data security. Our work has highlighted differences regionally and nationally, which helps hold SDEs/TREs and associated policy makers to account, and drive change in the system for patient benefit.</p>
8	<p>Role of HDR UK (250/250 words):</p> <p>BREATHE was one of a number of HDR UK funded Health Data Research Hubs in QQ1 that were established to provide a rich toolkit of healthcare datasets, infrastructure and expertise to enable users to identify, access, understand and use data to improve people’s lives. HDR UK’s strategic focus on FAIR (Findable, Accessible, Interoperable, Reusable) data during QQ1, enabled and validated this foundational work through BREATHE, emphasising shared tools and methodologies for wider benefit.</p> <p>The work that HDR UK began with BREATHE has leveraged other funding to build on the original objectives. This has been reinforced further in QQ2 with the HDR UK Inflammation and Immunity (I&I) Driver Programme, and feeds directly into the development of federated analytics, building on DARE UK pilot studies.</p> <p>Data foundations from BREATHE have become embedded in a range of partnerships – including with industry and NHS as well as wider research teams – and are now vital keystones for new I&I work to describe and predict patient and health system impacts from a range of common respiratory diseases. In time, this vital foundational work to “sort the data” will be the basis for predictive algorithms and data-led trials and quasi-experimental studies that can evaluate health interventions in different settings. Planning for this next stage is a current area of focus in I&I.</p> <p>This work will be scaled across HDR UK via a new data design authority (led by Monica Jones and supported by Chris Orton) to establish connection with UK data providers as a core infrastructure offering.</p>

9	<p>Contribution to Open Science and Knowledge Exchange (246/250 words):</p> <p>As previously stated, the use of EHR databases to carry out research into common respiratory diseases is growing, but clinical validity of the methodologies and resulting data used was variable. By sharing all code lists used, including cohort definitions and variables, on GitHub and in the Health Data Research UK Phenotype Library, we are reducing the barriers for researchers to work in this area. In line with HDR UK’s aims to make research more open, collaborative and responsive, the shared learning and open-source code lists provide a consistent best practice foundation for any researchers in this area, as well as those needing quality-assured data and methods for health audit needs.</p> <p>HDR UK aims to develop scalable solutions for important policy areas. Our recent work with Chief Medical Officers across the UK, Asthma + Lung UK, and NRAP, have all demonstrated that the quality of data and reports that have been available to evaluate NHS respiratory pathways, and provide most effective guidance to patients, have been inadequate. This has been emphasised in particular by Asthma + Lung UK, which has found it difficult to create effective levers to improve respiratory health outcomes, due in part to a lack of up-to-date information about incidence, prevalence, health utilisation and outcomes. Well-curated, validated and harmonised data registries across the UK will provide the necessary foundations in the future for charities and policy makers to run reproducible federated analyses at the push of a button, and efficiently generate updated estimates when needed.</p>
10	<p>Contribution to Research Culture (230/250 words):</p> <p>This work was led from Imperial and Swansea but carried out collaboratively and iteratively with colleagues in Edinburgh and Belfast. The authors on the publication reflect this cross-institution collaborative working, as well as a diversity of backgrounds and skills. In line with our publication strategy, the first authors on the publication are those who did the intensive work of data preparation, data cleaning, coding and statistical analysis. Neither of them have PhDs. Lead author Sarah Hatam was given the opportunity to work in different TREs (CPRD and DataLoch) for this project, supporting her wider career development.</p> <p>This area of development was influenced positively by the many and varied discussions with charity, NHS and industry colleagues about quality of data and the challenges of running routine reports. Our lay members have been a key part of this journey and have had considerable input into these discussions and shaping the focus of the work. Much of the focus in BREATHE was on developing opportunities for joint working with industry in health data science, but reproducible “quality” data sets are a clear need for all data users to help answer a range of questions more efficiently in relation to diagnosis, treatment and disease progression. The availability of open code lists and algorithms, together with detailed methodology to replicate this, ensures quality and consistency as the basis for future research practice with all stakeholders.</p>
11	<p>Research Team and Collaborators:</p> <p>BREATHE and I&I Steering Groups</p> <p>Prof Jenni Quint, School of Public Health, Imperial College London</p> <p>Chris Orton, Head of Business Development Services, Population Data Science, Swansea University Prof Aziz Sheikh, Usher Institute, University of Edinburgh</p> <p>Dr John Busby, Senior Lecturer in Medical Statistics, Queen’s University Belfast Antony Chuter, PPI Lay Lead, BREATHE</p> <p>Alex Brownrigg, PPI Lay Lead, BREATHE Karen Mooney, PPI Lay Lead, I&I Programme Anna Grosse, PPI Lay Lead, I&I Programme</p> <p>Katie Kissick, Chief Operating Officer, BREATHE, Usher Institute, University of Edinburgh</p> <p>Dr Wendy Inglis Humphrey, Chief Operating Officer, I&I Programme and BREATHE Capital Projects, Usher Institute, University of Edinburgh</p> <p><u>Research team</u></p> <p>Sara Hatam, Data Scientist, Usher Institute, University of Edinburgh Sean Scully, Data Officer, SAIL Databank, Swansea University</p> <p>Dr Sarah Cook, Research Fellow, School of Public Health, Imperial College London Hywel Evans, Research Officer, SAIL Analytical Services, Swansea University Alastair Hume, Population Data</p>

	<p>Science, Swansea University</p> <p>Dr Constantinos Kallis, Research Associate, School of Public Health, Imperial College London Dr Ian Farr, Senior Research Officer, Population Data Science, Swansea University</p> <p>Dr Adriana Kramer Fiala Machado, Research Fellow, School of Medicine, Queen’s University Belfast</p>
12	<p>Funding:</p> <p>The initial work was supported by BREATHE - The Health Data Research Hub for Respiratory Health (MC_PC_19004). BREATHE was funded through the UK Research and Innovation Industrial Strategy Challenge Fund with additional support from the Medical Research Council and delivered through Health Data Research UK.</p> <p>Infrastructure support was provided by the NIHR Imperial Biomedical Research Centre (BRC) and MRC Capital Funding (MC_PC_22006). SAIL Databank receives core funding from the Welsh Government’s Health and Care Research Wales. DataLoch is core-funded by the Data-Driven Innovation programme within the Edinburgh and South East Scotland City Region Deal (ddi.ac.uk) and the Scottish Government Chief Scientist Office (http://www.cso.scot.nhs.uk).</p> <p>Completion of the work in Northern Ireland is supported by Health Data Research UK (HDRUK2023.0027), which is funded by the Medical Research Council (UKRI), the National Institute for Health Research, the British Heart Foundation, Cancer Research UK, the Economic and Social Research Council (UKRI), the Engineering and Physical Sciences Research Council (UKRI), Health and Care Research Wales, Chief Scientist Office of the Scottish Government Health and Social Care Directorates, and Health and Social Care Research and Development Division (Public Health Agency, Northern Ireland).</p>

12. Developing the leaders of tomorrow – a model for successful capacity building

1	<p>Researcher(s) Name:</p> <p>Professor Gwyneth Davies</p>
2	<p>HDR UK Programme:</p> <p>Inflammation and Immunity Driver Programme (I&I)</p>
3	<p>Affiliation(s):</p> <p>University of Edinburgh, Imperial College London, Swansea University, Queen’s University Belfast, Alder Hey Children’s Hospital</p>
4	<p>Title of Case Study (150 characters):</p> <p>Developing the leaders of tomorrow – a model for successful capacity building</p>
5	<p>Summary of the Impact (147/150 words):</p> <p>Our Training and Capacity Building Programme represents impact in progress. Modelling this on an existing UK-wide capacity building programme allows us to bring together successful elements from 10 years of learning. The core tenet of cross-institutional supervision fosters true collaborative working across our driver programme. Embedding PPI from the outset – including a lay mentoring programme – ensures high impact. We have forged a vibrant community of students and early career researchers (ECRs) through UK-wide face-to-face meetings, frequent stand-up meetings and a co- created webinar programme. We will nurture future leaders with opportunities including an ECR co- leading the programme, student/ECR leads on our steering group, ECRs encouraged to lead work programmes and an ECR developing black internship training. We open our webinars across HDR UK and beyond to promote shared learning.</p> <p><i>PhD Student: “For me, it’s about climate and culture: there is an intentional generosity and encouragement in the system.”</i></p>
6	<p>Underpinning Research (247/250 words):</p> <p>Our approach was modelled on the Asthma UK Centre for Applied Research (AUKCAR) Training Programme, co-led by Professor Gwyneth Davies (AUKCAR Impact Report 2014-2024):</p> <ul style="list-style-type: none"> • Collaboration: Cross-institutional supervision is a core requirement and all leadership team members give feedback through a panel-based approach. <i>PhD student: “When we see senior colleagues, there is a warm atmosphere: collegiate, encouraging and purposeful.”</i> • Early career perspectives and decision-making: one student and one ECR representative are on the I&I Steering Group (roles rotate annually). • Embedding PPI from the outset: direct feedback on lay summaries and introduction of a lay mentoring programme. • Early career webinars: a co-created programme based on ECR feedback and AUKCAR learning, which is open to all HDR UK ECRs. Topics have included Systematic Reviews and PPI, with Choosing Independent Variables and Machine Learning next. <i>PhD student: “The PPI webinar changed how I am thinking about doing work in the future. It is so easy to get wrapped up in the data and not look at patients.”</i> • Soft skills and confidence: Students and ECRs take turns at chairing webinars and presentations

	<p>Building on the AUKCAR model:</p> <ul style="list-style-type: none"> • ECRs helped to shortlist and interview Black Internship Programme (BIP) candidates. Clinical Fellow: <i>"I really enjoyed it. It helped me understand what is important in applications and interviews."</i> • ECRs will line manage black interns and students will provide mentorship. • An ECR has developed our BIP webinar programme. We have a publication strategy that emphasises, celebrates and promotes ECRs and students in terms of authorship and leadership development opportunities.
7	<p>Description of the Impact (499/500 words):</p> <p>Submitted as <i>impact in progress</i>, this builds directly on principles and rich benefits seen in AUKCAR, and demonstrates generalisability and potential for other programmes.</p> <p>Positive culture of team and open science. Everyone benefits from breadth of experience and dialogue in our cross-institutional supervision framework. Students / ECRs (currently 14, expected to grow to 30+) feel more connected as a cohort, and to I&I goals / HDR UK strategy, through regular interactions. Lay involvement reminds us that every piece of data is a person. We are fostering broad mindsets, sharing networks and including affiliated mid-career researchers. Peer-led activities are emerging, e.g. presentation and Q&A practice, cross-institution peer review. This will underpin collaborative practices needed for future pooled or federated analyses, as well as building interdisciplinary leadership networks.</p> <p><i>PhD Student: "This kind of peer group is very helpful and I really appreciate it."</i></p> <p>Promotion of equality, diversity and inclusion. Our team – interns, students, ECRs, senior researchers, lay leads, professional services – brings diverse experiences personally and professionally. Those from a pure data background can explore data issues and research questions with clinical colleagues as well as lay members. This influences the framing of clinical questions, successful engagement with data providers and dialogue with community organisations like Social Action for Health who focus on health inequalities. Our black interns will bring a different set of lived experiences, and we are particularly looking forward to discussions with them this summer. An ECR has developed their training programme, which will also welcome students, ECRs and lay members, and frame discussions on clinical inequalities and use of health data to influence change. ECRs who are passionate about EDI can legitimately bring their experiences to bear on intern mentorship and develop themselves through this. A leadership decision to track PPI and impact on all projects will encourage everyone to consider patient impact in their work.</p> <p><i>PhD student: "The opportunity to discuss my project with people who have been directly affected by asthma has changed how I approach my research questions."</i></p> <p>Training and education across all career stages. The I&I training programme is still a relatively unique offering in terms of sharing knowledge, skills and tools in a safe and supportive environment. AUKCAR noted the direct influence of training on next steps: insights into career options, a sounding board for career ideas, an influential professional network, and opportunities to become co-applicants on major collaborative projects and grant applications. As we begin to explore opportunities for new funding for interventional studies, we are actively reaching out to mid-career researchers (some already affiliated) to become more involved with programme development and future leadership, as well as to offer webinar topics for students and ECRs. They are vital role models and an important part of our growing network.</p> <p><i>PhD student: "Presenting at full team meetings is absolutely terrifying, but everyone is so supportive and if you can practice on people who are senior leaders in the field, it makes it less scary when you do it at conferences in the future."</i></p>
8	<p>Role of HDR UK (231/250 words):</p> <p>As part of its QQ2 strategy, HDR UK:</p> <ol style="list-style-type: none"> 1. actively encouraged provision of funding for a core set of studentships and early career fellowships in the Research Driver and Infrastructure Programmes. 2. prioritised a core theme around Training and Capacity Building to develop new capabilities, interdisciplinary skills and development opportunities. <p>Together, these encouraged the I&I Steering Group to establish a specific cross-cutting capacity building theme, integrated</p>

	<p>with HDR UK’s Capacity Building Programme through the BIP and training network leads, and feeding learning into the Trust and Transparency Pillar from lay mentorship and integrated PPI feedback. Training and Capacity Building is discussed actively in Steering Group meetings and reported on quarterly. This emphasises its importance in everything that we do, and builds actively on previous learning.</p> <p>The strategic emphasis by the HDR UK impact committee as part of its impact framework on “improving research culture and capacity” continues to drive forward a particular focus on this area. There is a clear steer by HDR UK to all of those funded through QQ2 that training and capacity building is a shared responsibility.</p> <p>Clinical Fellow: <i>“Doing a PhD can be quite lonely if you don’t have a network around you. The first half of my PhD was not funded by this programme and our research team is very small at the moment, so it is nice to have other people around doing similar work.”</i></p>
9	<p>Contribution to Open Science and Knowledge Exchange (247/250 words):</p> <p>HDR UK aims to make research more open and collaborative. Our cross-institution approach to PhD supervision nurtures collaboration from the grass roots. By embedding students and ECRs in leadership meetings, involving them in recruitment for the BIP, and giving opportunities to chair sessions, we are providing insight into the environment beyond immediate areas of study or work, and also giving opportunities to learn from each other. Webinars are open to HDR UK Drivers and regional networks.</p> <p>Working side-by-side with lay members and patients provides an important lesson in bringing different voices into the research environment and learning directly from a variety of life experiences. Lay involvement in delivery of training and student mentoring further develops PPI ability to provide effective feedback on this work, and embeds the principle of doing research “with” and not “to” or “for” patients and the public.</p> <p>The inclusion of a lay panel member for the Black Internship Programme and PhD recruitment processes has helped raise awareness of patient and public interests in our work, and enabled discussions about how outputs from research can be presented in ways that are easy to understand.</p> <p>Our plans to bring new mid-career affiliates to this programme will further contribute to an environment where all our health data scientists can flourish as part of a distributed but collegiate team.</p> <p>PhD students: <i>“It sets a climate in which we can risk and try things out.”</i> <i>“It feels like quite a safe space to make mistakes and get feedback.”</i></p>
10	<p>Contribution to Research Culture (250/250 words):</p> <p>Regular meetings online and in person enable the team to get to know and lean on each other as colleagues, regardless of institution, background, seniority, or area of research. As well as the webinar programme, the entire team is encouraged to attend a fortnightly stand-up meeting where everyone shares progress and challenges. There is something about seeing each other (online) regularly that helps to develop a stronger sense of team, and reminds everyone that they are facing similar issues, everything is interconnected and they are not working alone. As a result of this, students are starting to meet up more informally and to collaborate / support each other with specific areas of work, whether this is academic (scoping reviews), technical/skills (data analysis) or wider skills (tips for multi-tasking).</p> <p><i>PhD Student: “What we are doing is arising from all of us. Everyone has added to how we are working together and encouraging one another.”</i></p> <p>These collaborative opportunities will only grow and develop as the programme evolves, but the fundamentals laid in the first year are the foundation for the future.</p> <p>Combining intern and wider capacity building in the summer will further encourage team porosity, align training needs, and improve equality, diversity and inclusion in research across career stages. This will be exciting and invigorating for interns, support additional ways to build rapport in the team, and provide a range of leadership / mentorship development opportunities. A training session on health inequalities and interaction with lay members will further promote responsible research.</p>

11	<p>Research Team and Collaborators:</p> <p>Professor Gwyneth Davies, Professor of Respiratory Medicine, Swansea University Medical School (I&I Training Lead) Dr Mohammad Al Sallakh, Health Data Scientist, Population Data Science, Swansea University (ECR) (I&I Training Co-Lead) Dr Hannah Whittaker, HDR UK funded Early Career Research Fellow, Imperial College London (ECR) (ECR Representative on I&I Steering Group) Cedric Burden, PhD student, Population Data Science, Swansea University (ECR) (PhD Representative on I&I Steering Group) Dr Wendy Inglis Humphrey, Programme Manager, I&I Programme Lily Quinlan, Programme Administrator, I&I Programme</p> <p>PhD panel supervisory team</p> <p>Dr Ting Shi, Chancellor’s Fellow, Usher Institute, University of Edinburgh</p> <p>Professor Sir Aziz Sheikh, Professor of Primary Care Research and Development, Usher Institute, University of Edinburgh Professor Jenni Quint, Professor of Respiratory Epidemiology, School of Public Health, Imperial College London Professor Liam Heaney, Professor of Respiratory Medicine, Queen’s University Belfast Dr John Busby, Senior Lecturer in Medical Statistics, Centre for Public Health, Queen’s University Belfast Professor Ian Sinha, Consultant Respiratory Paediatrician, Alder Hey Children’s Hospital Dr Olufemi Olajide, Head of Data Science, Alder Hey Children’s Hospital</p> <p><u>Black Internship Programme line managers</u></p> <p>Dr Olufemi Olajide, Head of Data Science, Alder Hey Children’s Hospital Dr Hannah Whittaker, HDR UK funded Early Career Research Fellow, Imperial College London (ECR) Dr Karen Jeffrey, HDR UK funded Research Fellow, Usher Institute, University of Edinburgh (ECR) Dr Adriana Kramer Fiala Machado, HDR UK funded Research Fellow, Queen’s University Belfast (ECR) Dr Mohammad Al Sallakh, Health Data Scientist, Population Data Science, Swansea University (ECR) <u>PPI team and Lay mentors</u> Dr Tracy Jackson, Senior Research Fellow, Usher Institute, University of Edinburgh (ECR) Karen Mooney, PPI Lay Lead, I&I Programme Anna Grosse, PPI Lay Lead, I&I Programme Laura Gonzalez Rienda, PPI Research Assistant, Usher Institute, University of Edinburgh</p>
12	<p>Funding:</p> <p>The foundations for this work came from the Asthma UK Centre for Applied Research, which was funded by Asthma + Lung UK (AUK-AC-2012-01 and AUK-AC-2018-01 from 01/05/2014 – 31/01/2025). All delivery with the current cohort of researchers is funded by the Inflammation and Immunity Driver Programme, with support in kind (Swansea University) for leadership from Professor Gwyneth Davies.</p>

13. Innovative community engagement approaches in research to identify shared priorities and inform COVID-19 vaccination programmes in Brazil

1	<p>Researcher(s) Name:</p> <p>Dr. Fernando Bozza, PI, DP-EFFECT – ‘Effectiveness of COVID-19 vaccination in Brazil Using Mobile Data’</p>
2	<p>HDR UK Programme: International COVID-19 Data Alliance (ICODA)</p>
3	<p>Affiliation(s): Evandro Chagas National Institute of Infectious Disease, Oswaldo Cruz Foundation, Rio de Janeiro, Brazil</p>
4	<p>Title of Case Study (150 characters - currently 146):</p> <p>Innovative community engagement approaches in research to identify shared priorities and inform COVID-19 vaccination programmes in Brazil.</p> <p>A short, easy-to-understand title in plain English that describes the impact of the research (not the research itself).</p>
5	<p>Summary of the Impact (150 words – currently 157):</p> <p>A concise overview, avoiding jargon and technical language, clearly articulating the main impacts (and their reach and significance) as aligned to HDR UK’s Impact Framework.</p> <p>The summary should clearly and coherently describe the relationship between the research, the outcome or impact, and the nature of the benefits arising (whether potential or realised).</p> <p>Impact falls under ‘Forming Public Trust’, ‘Research Culture’ and ‘Improving Health and Well Being’ of the HDR UK’s Impact Framework.</p> <p>HDR UK’s ICODA programme enabled international researchers to use existing data to provide rapid insights to help manage the COVID-19 pandemic. One of the ICODA research projects, DP-EFFECT, used different types of data to consider the effectiveness of COVID-19 vaccines in Brazil in protecting individuals and communities from severe disease. The research team invested significant time and resources in engaging with a socially vulnerable community living in Rio de Janeiro’s favelas. They participated in a COVID-19 vaccination programme, Vacina Maré, being delivered in the favelas by a local NGO, and built trust with the community through this direct engagement, ensuring the community’s priorities were addressed through the research, and that they understood how the results could improve disease outcomes. The approach was one of shared leadership, using tailored communication methods to engage the community in an ongoing dialogue about the research, and informing COVID-19 vaccination programmes to improve health outcomes for all.</p>
6	<p>Underpinning Research (250 words – currently 247):</p> <p>The ICODA programme enabled 12 exemplar studies to use existing data to address major research questions relating to the COVID-19 pandemic. One study, DP-EFFECT, ran from July 2021-Oct 2022, and used different types of data to quantify the effectiveness of COVID-19 vaccines in Brazil in protecting individuals and populations from infection and severe disease. The research team determined vaccine effectiveness in protecting individuals by using an approach called test-negative design to compare the severity of respiratory disease in COVID-19 patients from 43 hospitals. They analysed vaccination rates in adults in 5,500 Brazilian municipalities, finding that socioeconomic disparities impacted on first dose vaccination and disease protection, with primary healthcare proving critical in providing more equitable access to vaccines in vulnerable locations.</p> <p>The DP-EFFECT team also carried out a cohort study in a vulnerable favela community in Rio de Janeiro, demonstrating the ChAdOx1 vaccine was effective in reducing symptomatic COVID-19 infection in this community. The research team engaged extensively with the community and worked with NGOs and community members to help shape the study and ensure it met their needs, and communicated the benefits of the study and vaccination programmes. This had a major impact on</p>

	<p>vaccination rates in the favela community and produced a significant number of outputs in a short timeframe, including a publication on self-care mental health strategies for vulnerable populations. The team subsequently developed a toolkit for community engagement that can be used by health researchers more widely, impacting positively on both public trust and research culture.</p>
7	<p>Description of the Impact (500 words – currently 475):</p> <p>The DP-EFFECT study ran between July 2021 and October 2022 and rapidly produced insights on the effectiveness of the COVID-19 vaccination programmes in Brazil, which highlighted differences in protection of individuals and communities from severe disease, relating to inequity and vaccination campaign approaches. The study produced important insights that informed local and regional vaccination programmes; and these findings were communicated widely via many channels to a range of stakeholders, particularly to vulnerable communities, at a time when public communication about the pandemic and vaccination approaches was limited. Findings of the study were communicated via social media, reaching more than 2 million viewers, with over 500 media insertions in local and international news.</p> <p>The research team took a shared leadership approach to involvement and engagement from the outset, and the project involved academia, non-governmental organisations, public and private sectors, and critically, was embedded in local communities. This included engagement with vulnerable communities in the favelas in Rio de Janeiro through the Vacina Maré vaccination programme. The team brought together community members to identify research priorities and develop trustworthy approaches to research; and have since developed a toolkit and run workshops for researchers in other countries and regions on community engagement in wider global health research studies. They have also produced resources that are openly available for other researchers to use.</p> <p>This study and the approach taken have formed the foundation for subsequent studies, and the results and findings have created new opportunities for funding and collaborations with other supporting institutions. Cohort studies from the Vacina Maré project have extended to include additional analyses beyond impact of the pandemic and vaccination programmes, supported by the Instituto Todos Pela Saude (ITPS). This includes the Long COVID-19 cohort, which has enrolled more than 800 participants and is a collaborative study with the International Severe Acute Respiratory and Emerging Infection Consortium (ISARIC), supported by Wellcome. Another study focuses on the impact on mental health during the COVID-19 pandemic, supported by the USA’s Center for Disease Control. Importantly, the Vacina Maré project has resulted in new studies that focus on vulnerable populations, such as primary healthcare assistance evaluation and strengthening in Alto Xingu, Mato Grosso, Brazil, and monitoring national vaccination coverage trends in Brazil.</p> <p>A further impact and legacy of DP-EFFECT is the website developed for the Vacina Maré cohort study, providing general information about wider research studies on vaccine effectiveness for individuals and populations, cohort studies and impact. Along with the social media strategy for communicating insights, the website serves as an ongoing contact channel for communities in the Maré district in Rio de Janeiro, as well as research collaborators and partners, forming part of the framework laid down for the community and health practitioners to work together on other health priorities and engage in future research in a trustworthy and systematic way.</p>
8	<p>Role of HDR UK (250 words – currently 265):</p> <p>HDR UK convened the ICODA programme, with funding from the Gates and Minderoo Foundations. This programme identified and supported 12 driver projects that helped pilot and shape data infrastructure and governance approaches for participating research teams, including policies, processes and tools. HDR UK also managed a global funding call that resulted in identification of 10 driver projects, including DP-EFFECT. Criteria for selection included: potential to produce rapid insights to manage the COVID-19 pandemic; research equity, involvement and benefits for LMICs; and community and wider stakeholder engagement.</p> <p>HDR UK provided key enablers to facilitate rapid generation of research insights from DP-EFFECT and the other driver projects, building on HDR UK’s approach for the UK, including the Five Safes and:</p> <ul style="list-style-type: none"> • Provision of a trusted research environment (TRE) to facilitate safe and trustworthy data access and analysis, especially for multi-country teams, standard data sharing agreement and streamlined processes for researcher accreditation • Ethics and Governance Framework to provide guidance to driver project teams on ethical and trustworthy approaches for their research

	<ul style="list-style-type: none"> • Policies for output review, attribution, publication • Sharing the projects’ metadata on the Health Data Research Innovation Gateway • Project management support. <p>HDR UK also provided support on community and wider stakeholder engagement for all driver projects, including workshops and guidance on best practice, a webinar delivered with experts for longlisted research teams, and a mid-programme workshop for knowledge sharing. These contributions supported the DP-EFFECT team by: a) helping them develop effective engagement strategies in their study design; b) providing opportunities to discuss any challenges and learnings; and c) ‘testing’ their engagement methodology for a short project to generate key learnings.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>All policies and processes produced to enable the 12 ICODA driver projects were made publicly available on the ICODA web pages. Adhering to FAIR principles, the driver projects, including DP-EFFECT, also made metadata and code, available on the ICODA website and HDR UK’s Innovation Gateway. The HDR Global team helped coordinate the Global Health Data Science Digital Hub and publications and outputs from the driver projects and ICODA generic policies and processes were shared via the Hub’s Resources page.</p> <p>The ten Grand Challenges ICODA driver projects were invited to participate in the wider Grand Challenges (GC) community, (a global community of Data Science chapters in India, Brazil and Africa), through use of Synapse, an online forum. The DP-EFFECT team were also invited to the Grand Challenges Data Science Annual Convening Meeting on the 22 November 2021 in Cape Town, and Dr. Bozza shared insights from the DP-EFFECT research study with attendees.</p> <p>ICODA provided support and guidance for Stage 2 long-listed applicants to the BMGF GC funding call on best practice in community and stakeholder engagement via two workshops. Mid-way through delivery of the driver projects, ICODA also convened a knowledge sharing meeting focused on community and stakeholder engagement.</p> <p>Broader lessons learned from the ICODA initiative, including on community and stakeholder engagement, were published in a manuscript in The Lancet Digital Health. Since the ICODA funding ended, Dr. Bozza has gone on to collate the approaches taken by his research team to community engagement in the favelas in Rio de Janeiro, in a toolkit, which has been published and is openly available for other researchers to use.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>ICODA driver projects were required under the terms of their award to make their research findings openly and freely accessible when published. ICODA provided support and guidance to the GC ICODA research teams to be able to make their findings openly and freely accessible using the Gates Open Research platform, which is available to use free of charge for all BMGF awardees (use of this platform is now mandatory for any recipient of funding from the BMGF). Two publications from the DP-EFFECT study can be found on the platform.</p> <p>The overall governance approach taken by the DP-EFFECT study of bringing together different stakeholders from the outset (NGOs, health practitioners and communities) demonstrates a commitment to fostering a healthy and collaborative research culture, the benefits of which can be seen in the rapid generation of insights as well as the empowerment of communities and stakeholders. This project team championed a multi-disciplinary, multi-institution approach, with the inclusion of the community in all aspects of design and delivery of the research, an approach which inverted the standard system of non-researchers not being involved in study design. The team called this approach ‘inverting the research triangle’, with effective communication at its heart; amongst other things, the team produced multiple community <i>newsletters</i>, delivered mobile announcements, and worked with community leaders).</p>
11	<p>Research Team and Collaborators:</p> <ul style="list-style-type: none"> • Dr. Fernando Bozza. Principal Investigator • Dr. Silvio Hamacher, responsible for the strategic project design and supervision • Dr. Fernanda Baião, responsible for the conceptual and technical design of the project, including the definition of the data analysis and machine learning techniques

	<ul style="list-style-type: none"> • Dr. Paola Maçaira, main Statistician Researcher and responsible for the design and concept of the project, and the definition and analysis of statistics techniques • Dr. Otavio Ranzani (MD MSc (Epi) Ph.D), member of the research team • Dr. José Cerbino (MD MSc Ph.D), member of the research team • Dr. Leonardo S.L. Bastos, member of the research team • Dr. Rudi Rocha, member of the research team • Dr. Soraida Aguilar, member of the research team • Beatriz Rache, member of the research team
12	<p>Funding:</p> <p>The project was funded by the Bill & Melinda Gates Foundation and Minderoo Foundation and was made available through ICODA and a global Grand Challenges funding call. The ICODA initiative ran from July 2020 – October 2022 and the total funding received was \$6, 515, 399.</p> <p>The DP-EFFECT research study was awarded \$98,340 under the GC ICODA global funding call for a 12-month project.</p>

14. Equitable approaches to health data research across ten countries: understanding the impact of COVID-19 on health services and institutional mortality

1	Researcher(s) Name: Dr. Catherine Arsenault
2	HDR UK Programme: International COVID-19 Data Alliance (ICODA)
3	Affiliation(s): Department of Global Health, Milken Institute School of Public health, George Washington University, Washington, DC, USA
4	<p>Title of Case Study (150 characters):</p> <p>Equitable approaches to health data research across ten countries: understanding the impact of COVID-19 on health services and institutional mortality.</p>
5	<p>Summary of the Impact (150 words – currently 114 words):</p> <p>(This impact case study relates to ‘Research Culture’, ‘Advancing methods and Technology’, ‘Improving Health and Well-being’ and ‘Informing decision-making’ themes of HDR UK’s Impact Framework).</p> <p>HDR UK’s ICODA programme enabled international researchers to use existing data to provide rapid insights that helped manage the COVID-19 pandemic. One of the ICODA research studies, DP-REHCORD, used standardised data from 31 health services in ten countries (low-, middle- and high-income) to assess the impact of COVID-19 on health service delivery and institutional mortality. Insights from this study informed decision-making on health policy and practice in each country by helping to identify priorities for restoring service levels after the pandemic, and for improving health service resilience. Critically, the study used equitable approaches to health data research and multi-country collaboration that provided rapid insights, enabled knowledge sharing, and contributed to a strong research culture.</p>
6	<p>Underpinning Research (250 words):</p> <p>The ICODA programme enabled 12 exemplar studies to use existing data to address major research questions relating to the COVID-19 pandemic. One study, DP-REHCORD, ran from July 2021-July 2022, and measured the effect of the COVID-19 pandemic and associated containment policies on the quality of health care and mortality rates from non-COVID conditions in 31 health services in ten countries. They extracted and prepared data from health management information systems spanning Jan 2019 – Dec 2020 from Chile, Ethiopia, Ghana, Haiti, Laos, Mexico, Nepal, South Africa and South Korea. The team used an interrupted time series to assess the effect of the pandemic on health service delivery, and statistical techniques to assess the effect of containment policies on healthcare demand, such as patient appointments.</p> <p>DP-REHCORD produced rapid insights that informed decision-making on priorities for resuming essential health service provision following the pandemic in each participating country and health system. These insights also informed future planning to modernise healthcare services and strengthen health system resilience, such as the National Strategy for Health Systems Recovery in Mexico. Overall, the study found the pandemic resulted in healthcare service disruption in every country, with no patterns associated with country income or pandemic intensity. Healthcare services most affected in all countries were cancer screenings, TB screening and HIV testing, with outpatient visits to hospitals significantly reduced.</p> <p>The multi-country research team took an equitable and highly collaborative approach to the design, delivery and governance of the study, and engaged with key stakeholders in each country. This enabled the development and sharing of common tools and approaches, resulting in rapid insights and a strong research culture.</p>

7	<p>Description of the Impact (500 words):</p> <p>The DP-REHCORD study ran from July 2021 – July 2022 and rapidly produced insights on the effect of the COVID-19 pandemic and associated containment policies on the quality of healthcare services and mortality rates from non-COVID conditions in ten countries (South Africa, Ethiopia, Ghana, Mexico, Chile, Haiti, Thailand, Laos, South Korea, Nepal), using health management information systems data. The study produced important insights which informed decision-making in each country on: restoring essential healthcare services post-pandemic, modernising and adapting current health systems, and strategies for better health system resilience for future emergencies.</p> <p>The equitable approach taken to governance and collaboration between researchers from low-, middle- and high-income countries in this study was exemplary. The team adopted an equitable approach for study design and governance, and developed shared approaches, such as common code books, shared tools for data harmonisation of data, and a version control system for statistical code. Overall, these enabled the team to generate rapid and rich research insights in each country, as well as comparative research across multiple countries during the pandemic, with strong engagement with policy makers ensuring research insights were used to inform healthcare policy and practice.</p> <p>Key engagement and impact opportunities included the following: Following completion of the study the team held an organised session to present their findings at the Seventh Global Symposium on Health Systems Research (HSR 2022), Bogota, Colombia, 31 Oct- 4 Nov 2022. The session included five panellists from the REHCORD study from South Africa, Ethiopia, Nepal, Mexico and the USA, and was moderated by Catherine Arsenaault, the PI of DP-REHCORD.</p> <p>In South Africa, the team presented their findings as a policy brief to the Kwa-Zulu Natal government highlighting the negative impact of COVID-19 on maternal and child health outcomes. Through discussion, the team developed a proposal for a community-based intervention, including women’s groups and community health workers, to support the health system’s resilience interventions. This was presented to the senior management committee in the Provincial Ministry of Health, as a response to the direct and indirect impact of covid-19 in Kwa-Zulu Natal.</p> <p>In Haiti, a dashboard developed through the DP-REHCORD study was presented to stakeholders at the Ministry of Public Health and Population to raise awareness of the decline in service use during the COVID-19 pandemic. The team made people in the vaccination programme aware of the low vaccination coverage and officials of the Ministry of Health aware of the effects of the pandemic on national programmes such as malaria, tuberculosis and HIV. Using the data, the immunisation unit at the Ministry of Health are working on a Polio and diphtheria campaign, to improve coverage of the service.</p> <p>In Mexico, following publication of the first BMJ Global Health article showing large declines in essential health services, several discussions were held with the Mexican Institute for Social Security (IMSS) directors about these results and the DP- REHCORD team contributed to the development of a new National Strategy for Health Services Recovery to modernise the health system and overcome the disruptions highlighted through the research.</p>
8	<p>Role of HDR UK (250 words):</p> <p>HDR UK convened the ICODA programme, with funding from the Gates and Minderoo Foundations. This programme identified and supported 12 exemplar or driver projects that helped pilot and shape data infrastructure and governance approaches for all participating research teams, including policies, processes and tools. In addition, HDR UK managed a global funding call that resulted in identification of 10 driver projects, including DP-REHCORD. Criteria for selection included: potential to produce rapid insights to manage the COVID-19 pandemic; research equity, involvement and benefits for LMICs; and community and wider stakeholder engagement.</p> <p>HDR UK provided key enablers to facilitate rapid generation of research insights from DP-REHCORD and the other driver projects, building on HDR UK’s approach and activities for the UK, including the Five Safes and</p> <ul style="list-style-type: none"> • Provision of a trusted research environment (TRE) to facilitate safe and trustworthy data access and analysis, particularly important for multi-country teams such as DP-REHCORD, standard data sharing agreement and streamlined processes for researcher accreditation • Ethics and Governance Framework to provide guidance to driver project teams on ethical and trustworthy approaches for their research

	<ul style="list-style-type: none"> • Provision of policies for output review, attribution, publication • Sharing the projects' metadata on the Health Data Research Innovation Gateway including guidance on requirements • Project management support. <p>HDR UK ran two workshops for long-listed applicants at Stage 2 of the global funding call and provided support and guidance on designing effective approaches to engagement of policy makers. HDR UK also helped disseminate DP-REHCORD statistical codes to make these accessible to a wider range of researchers.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>All policies and processes produced to enable the 12 ICODA driver projects were made publicly available on the ICODA web pages. Adhering to FAIR principles, the driver projects, including DP-REHCORD also made metadata and code available on the ICODA website and HDR UK's Innovation Gateway. The HDR Global team helped coordinate the Global Health Data Science Digital Hub and publications and outputs from DP-REHCORD and other driver projects as well as ICODA generic policies and processes were shared via the Hub's Resources page.</p> <p>DP-REHCORD researchers were invited to participate in the Gates' Grand Challenges (GC) community, (a global community of Data Science chapters in India, Brazil and Africa), through use of Synapse, an online forum. They were also invited to the Grand Challenges Data Science Annual Convening Meeting on 22 November 2021 in Cape Town, and the PI, Dr. Catherine Arsenault shared insights from the DP-REHCORD research study with attendees. Broader lessons learned from the ICODA initiative were published in a manuscript in The Lancet Digital Health, with Dr. Arsenault contributing to this manuscript.</p> <p>Dr. Arsenault also shared her knowledge more widely through participation in The People's Voice Survey on Health System Performance: This survey offers a fresh perspective, centred on patient and public experiences, rather than traditional performance indicators used in hospital performance tracking. The six papers, (published in The Lancet Global Health) in this Series highlight the innovative measures featured in the People's Voice Survey, including confidence in public primary healthcare, system competence in preventive care, and user experience.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>Under the terms of their award, ICODA driver projects were required to make their research findings openly and freely accessible when published. ICODA provided support and guidance to the driver projects' research teams, including DP-REHCORD, to be able to make their findings openly and freely accessible using the Gates Open Research platform, which is available to use free of charge for all BMGF awardees (use of this platform is now mandatory for any recipient of funding from the BMGF).</p> <p>The equitable approach taken to governance and collaboration between teams from low-, middle- and high-income countries was exemplary in DP-REHCORD and facilitated the generation of rich research insights in each country. Research insights have all been published open access, and additionally, the team used the GitHub repository to share the statistical code used in the project: https://github.com/catherine-arsenault/HS-performance-during-covid-do-files The team's data cleansing and preparation protocols and methods are also described on the platform as the team felt that they may be helpful to others who want to use data from health management information systems in their research.</p>

11	<p>Research Team and Collaborators:</p> <ul style="list-style-type: none"> • Dr. Catherine Arsenault, Principal Investigator • Dr. Sebastian Bauhoff, Co-Principal investigator • Professor Margaret E. Kruk, Co-Principal investigator • Dr. Svetlana Doubova, Project Lead for Mexico and Data Custodian • Dr Munir Kassa Eshetu, Co-project Lead for Ethiopia • Dr. Roody Thermidor, Project Lead for Haiti and Data Custodian • Dr. Suresh Mehata, Project Lead for Nepal and Data Custodian • Dr. Shogo Kubota from the WHO Lao country office and collaborators at the University of Health Sciences in Vientiane. Data custodians at the Lao Ministry of Health were also involved indirectly • Data custodians and collaborators at the University of KwaZulu-Natal and at the Medical Research Council of South Africa • Data custodians from Ghana Health Services including health information specialists.
12	<p>Funding:</p> <p>The project was funded by the Bill & Melinda Gates Foundation and Minderoo Foundation and was made available through ICODA and a global Grand Challenges funding call. The ICODA initiative ran from July 2020 – October 2022 and the total funding received was \$6, 515, 399.</p> <p>The DP-REHCORD research study was awarded \$100,000 from the Grand Challenges ICODA global funding call for a 12-month project.</p>

15. The impact of digital technology in care homes

1	Researcher(s) Name: SUZANNE MASON
2	HDR UK Programme: NORTHERN PARTNERSHIP
3	Affiliation(s): UNIVERSITY OF SHEFFIELD
4	Title of Case Study (150 characters): THE IMPACT OF DIGITAL TECHNOLOGY IN CARE HOMES
5	<p>Summary of the Impact (150 words):</p> <p>Many emergency admissions from care homes are avoidable- causing distress for residents and their families, placing pressure on NHS and social care. This project aimed to streamline residents' care by giving staff the tools to remotely monitor and submit observations digitally to NHS Clinical teams when concerned about their wellbeing. Using a digital technology called HealthCall, observations are fed to remote clinical staff to triage referrals to help patients get the most appropriate care first time. The 3-year study evaluated 8702 residents across 118 care homes. Data was linked from care homes via the HealthCall technology with acute hospital data to evaluate care outcomes. Impacts measured change in emergency department attendance and hospital admission. Key findings include:</p> <ol style="list-style-type: none"> 1. 11% reduction in emergency department attendance 2. 25% decrease in emergency hospital admissions 3. 11% reduction in the length of stay, with a further month-by-month decrease of 28% 4. Reduction of £57 per resident in 2018, increasing to £113 per resident in 2021 5. High levels of staff and resident satisfaction with the HealthCall technology
6	<p>Underpinning Research (250 words):</p> <p>This was a mixed methods multi-centre evaluation of a digital technology (HealthCall) introduced into care homes in the North East between 2018-2021. 118 care home settings were evaluated including 8702 residents. The study included 4 workpackages:</p> <p><u>WP1:</u> The study involved 118 care homes across the North East from 2018-2021. Routinely collected NHS secondary care data from County Durham and Darlington NHS Foundation Trust was linked with data from the HealthCall technology App. Three outcomes were modelled monthly using Generalised Linear Mixed Models: counts of emergency attendances, emergency admissions, and length of stay of emergency admissions.</p> <p><u>WP2:</u> Stakeholder consultation used survey and interviews to explore experiences of using the new technology. 35 interviews with variety of care home staff, local authority staff, NHS clinicians, care home residents and their family members. Data was synthesised into 3 themes: challenges in implementation of the technology, communication and training for care home staff in using the technology, improving skills of staff and being able to enhance care delivery.</p> <p><u>WP3:</u> Economic evaluation to identify change in health care costs in adopting the HealthCall system using the routine data to identify where costs may have changed due to HealthCall changing the decision to admit residents to hospital. The impact of HealthCall was tested on each outcome using the Generalised Linear Mixed Models.</p> <p><u>WP4:</u> Synthesise findings, disseminate, prepare publications and other outputs.</p>

7	<p>Description of the Impact (500 words):</p> <p>The research generated a lot of interest in how digital technologies can be implemented in care home settings and benefit residents and care home staff by reducing avoidable hospital admissions, upskilling staff and providing a seamless route to contacting NHS clinicians for advice when it is needed. A number of outputs were prepared including peer reviewed publications and conference presentations (outputs 1-7), an animation aimed at care homes, providers and lay audiences (output 8) and press releases raising awareness of the study findings (outputs 9-11).</p> <p>The digital care homes project reported findings directly to NHSX in order to inform their roll out of technologies into care home settings. The learning care homes team also worked with the Yorkshire and Humber AHSN to develop synergistic evaluation methods that can be applied across care homes introducing similar, but different technology support.</p> <p>Awards, 2021</p> <ul style="list-style-type: none"> • ‘Best Health Tech Solution for Patient Safety’ award • Excellence in ‘Supply Award for Patient Experience’ • Finalist for the Nursing Time Awards for ‘Technology and Data in Nursing’ <p>PAPERS</p> <ol style="list-style-type: none"> 1. Garner, A., Preston, N., Caiado, C. C. S., Stubington, E., Hanratty, B., Limb, J., . . . Knight, J. (2024). Understanding health service utilisation patterns for care home residents during the COVID-19 pandemic using routinely collected healthcare data. <i>BMC Geriatrics</i>, 24. doi:10.1186/s12877-024-05062-6 2. Cockshott, Z., Russell, S., Stocker, R., Knight, J., Mason, S., Hanratty, B., & Preston, N. (2024). ‘In the shower crying...but we came back in the following day and did it all again’. Distress and resilience in care home staff during the COVID-19 pandemic– A qualitative interview study. <i>BMC Geriatrics</i>, 24(1). doi:10.1186/s12877-024-04804-w 3. Garner, A., Lewis, J., Dixon, S., Preston, N., Caiado, C. C. S., Hanratty, B., . . . Mason, S. M. (2024). The impact of digital technology in care homes on unplanned secondary care usage and associated costs. <i>Age and Ageing</i>, 53(2). doi:10.1093/ageing/afae004 4. Garner, A., Preston, N., Caiado, C., Stubington, E., Hanratty, B., Limb, J., . . . Knight, J. (2023). Understanding Health Service Utilisation Patterns for Care Home Residents During the COVID-19 Pandemic using Routinely Collected Healthcare Data. doi:10.1101/2023.07.11.23292499 5. Garner, A., Lewis, J., Dixon, S., Preston, N. J., Caiado, C. C. S., Hanratty, B., . . . Mason, S. M. (2023). The Impact of Digital Technology in Care Homes on Unplanned Secondary Care Usage and Associated Costs. doi:10.1101/2023.06.13.23291324 6. Russell, S., Stocker, R., Cockshott, Z., Mason, S., Knight, J., Hanratty, B., & Preston, N. (2023). Use of a digital application to enhance communication and triage between care homes and National Health Service community services in the United Kingdom: a qualitative evaluation. doi:10.1101/2023.03.02.23286669 7. Abstract: https://emj.bmj.com/content/39/12/A974.1 8. Health Data Research (HDR) UK. The Healthcall app. <i>An animation</i>. https://vimeo.com/manage/videos/8348983. Accessed 3/5/2024. 9. Health Data Research (HDR) UK. Remote health monitoring smartphone app reduces emergency hospital admissions from care homes by 25%. <i>News story</i>. https://www.hdruk.ac.uk/news/remote-monitoring-app-reduces-emergency-hospital-admissions-from-care-homes/. Accessed 3/5/2024. 10. https://nhshealthcall.co.uk/news/digital-remote-monitoring-technology-care-home/ 11. Press Release: https://eusem.org/news/802-digital-technology-linking-care-homes-to-clinical-advice-hubs-reduces-a-e-attendances
8	<p>Role of HDR UK (250 words):</p> <p>HDRUK funded the project through the Better Care programme as part of the HDRUK Northern partnership. HDRUK also supported through facilitating a press release (Output 9).</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p>

10	<p>Contribution to Research Culture (250 words):</p> <p>Working with colleagues in HealthCall and the care sector to share data, participate in the evaluation and contribute to the research.</p> <p>Accessing the TRE in Durham and working with NHS colleagues to develop Data Sharing Agreements, share data and link data to that collected in care homes</p> <p>Using routine health data to drive evaluations of healthcare interventions and describe effectiveness and impact</p>
11	<p>Research Team and Collaborators:</p> <p>Suzanne Mason, Professor of Emergency Medicine Academic Lead, University of Sheffield. Principal Investigator, Project Lead, Conceptualisation, Funding acquisition, Project administration, Supervision, Writing - review & editing</p> <p>Alex GARNER – PhD Student/Senior Research Associate, Lancaster University (Early career researcher). Data scientist/statistician. Lead quantitative analyst and first author for quantitative papers. Conceptualisation, Investigation, Methodology, Formal Analysis, Writing - original draft, Writing - review & editing</p> <p>Jen LEWIS, Statistician, University of Sheffield. Data Analysis, writing, review, editing</p> <p>Simon Dixon, Professor of Health Economics, University of Sheffield, Economic Analysis, writing, review, editing</p> <p>Nancy Preston Co-Director in the International Observatory on End of Life Care within the Faculty of Health and Medicine, University of Lancaster. Supervision, Writing - review & editing</p> <p>Jo Knight Chair in Applied Science Data Analysis Lead, University of Lancaster . Conceptualisation, Funding acquisition, Project administration, Supervision, Writing - review & editing</p> <p>Barbara Hanratty, Professor of Primary Care, University of Newcastle. Barbara Hanratty - Writing - review & editing</p> <p>Camila Caiado Associate Professor of Statistics University of Durham. Data curation, Project administration</p>
12	<p>Funding:</p> <p>HDRUK BETTER CARE FUND</p> <p>DHSC/UKRI COVID-19 Rapid Response Initiative: IMPACT OF COVID-19 PANDEMIC ON CARE HOME PATHWAYS, OUTCOMES AND SAFETY OF CARE</p>

16. Reallocation of time between device-measured movement behaviours and risk of incident cardiovascular disease

1	Researcher(s) Name: Aiden Doherty, Shing Chan
2	HDR UK Programme: QQ1: Reproducible Machine Learning
3	Affiliation(s): University of Oxford
4	Title of Case Study (150 characters): Reallocation of time between device-measured movement behaviours and risk of incident cardiovascular disease
5	Summary of the Impact (150 words): The study advances our understanding of the association between movement behaviours and health by employing wearable sensors (accelerometers) to obtain accurate and objective measures of human activity, analysed using compositional data analysis to quantify the effects of substituting one activity for another. By demonstrating a clear link between reallocating time towards more moderate-to-vigorous physical activity (MVPA) and reduced risk of CVD, this work has implications for public health strategies. It informs the development of interventions and guidelines aimed at reducing sedentary behaviour and increasing physical activity, thus potentially lowering CVD incidence on a population scale. The findings empower healthcare professionals and policymakers with data-driven insights to promote healthier lifestyle choices, contributing to better health outcomes and reduced healthcare costs associated with CVD.
6	Underpinning Research (250 words): This research utilized free-living accelerometer data from 152 participants to develop a machine-learning model capable of classifying various movement behaviors—ranging from sedentary to vigorous activities and sleep. The model was trained and validated using a leave-one-participant-out method, obtaining high accuracy (88%) and reliability (Cohen's kappa of 0.80). The study then expanded its analysis to 87,498 participants from the UK Biobank, applying the machine-learning model to assess movement behaviors over a week-long period. The novel approach of compositional data analysis within Cox regression allowed for the examination of how time reallocation among different behaviors influenced the incidence of CVD. The rigorous methodology and expansive data set underpin significant findings about lifestyle behaviors and their direct correlation with health outcomes, particularly the impact of physical activity levels on cardiovascular health.
7	Description of the Impact (500 words): By establishing a quantitative link between reallocation of movement behaviors and the risk of cardiovascular disease (CVD) in a large cohort, the study provides a compelling case for the real-world application of technology in health monitoring and intervention. The use of wearable sensors and machine learning methods allow for objective and accurate assessments of physical activity levels in large populations, a critical factor in scaling up preventive health strategies. The finding that reallocating 20 minutes a day to moderate-to-vigorous physical activity (MVPA) from less active behaviors can reduce CVD risk by 9% presents a practical and achievable guideline for individuals and health practitioners. Similarly, the association between increased sedentary time and higher CVD risk underscores the need for public health campaigns focused on reducing sitting time and promoting more active lifestyles. The implications for public health policy are significant. Health departments and policymakers can use these insights to formulate guidelines that encourage more active lifestyles. For instance, urban planning can incorporate more green spaces and pedestrian areas to promote physical activity. Workplaces can introduce wellness programmes that encourage regular breaks for physical movement, potentially improving employee health and reducing healthcare costs related to CVD.

	<p>Furthermore, the research has implications for the development of personalized medicine. With the ability to track and analyze individual movement patterns accurately, healthcare providers can offer tailored advice to patients on how to adjust their daily routines for optimal health benefits. This personalized approach not only enhances the effectiveness of health interventions but also increases patient engagement and compliance.</p> <p>Educational campaigns can also benefit from these findings by providing clear, evidence-based messages about the health benefits of regular physical activity. Schools and universities can integrate more physical activity into their curricula, helping to establish healthy habits early in life.</p> <p>The economic impact is also notable. By reducing the incidence of CVD through effective preventive measures, healthcare systems can save on the costs associated with treating advanced cardiovascular conditions. Insurance companies might also adjust premiums and coverage options based on customers' engagement with physical activity, incentivizing healthier behaviors through financial benefits.</p> <p>In conclusion, this research not only advances scientific understanding of the link between physical activity and cardiovascular health but also provides actionable strategies that can be implemented at individual, community, and policy levels to improve public health outcomes. The integration of wearable sensors with traditional epidemiological approaches offers a promising way forward in the prevention and management of modern diseases, showcasing a successful marriage of technology and health science.</p>
8	<p>Role of HDR UK (250 words):</p> <p>HDR UK supported the work described above, now culminated in a publication in the British Journal of Sports Medicine (BJSM). It also contributed to the creation and the maintenance of software packages that are central to our research. These include the Biobank Accelerometer Analysis Tool (https://biobankacanalysis.readthedocs.io/en/latest/index.html) and EpiCoda (https://github.com/OxWearables/epicoda), which have facilitated distribution and replication of our methodologies.</p> <p>Further, HDR UK's support was crucial in the development of training materials through platforms like DNANexus (https://blog.dnanexus.com/uk-biobank-rap-researcher-spotlight-february-2023).</p> <p>HDR UK has been a key supporter of an annual short course on machine learning for wearable technology, which recently welcomed 25 participants, with 13 receiving financial support from HDR UK. In addition, they have helped set up a yearly workshop that's now a regular part of the CDT programme. HDR UK has also backed the creation of software templates to ensure that research can be consistently replicated.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>We made our tools and datasets openly available, facilitating their use in research. This move supports wider health data research and encourages collaborative improvements and validations. In particular, we returned our processed variables to the UK Biobank to reach the 40,000 registered research users, made our software tools available via GitHub (no registration required), and created training materials via DNANexus.</p> <p>https://blog.dnanexus.com/uk-biobank-rap-researcher-spotlight-february-2023</p> <p>https://biobank.ndph.ox.ac.uk/showcase/label.cgi?id=1020</p> <p>https://biobankacanalysis.readthedocs.io/en/latest/index.html</p>

10	<p>Contribution to Research Culture (250 words):</p> <p>We conduct workshops and seminars to advocate for open science and reproducibility. These initiatives help shape a research environment that values transparency and cooperation.</p>
11	<p>Research Team and Collaborators:</p> <p>Aiden Doherty, Principal Investigator</p> <p>Shing Chan, Postdoctoral researcher</p>
12	<p>Funding:</p> <p>Our research was funded by Health Data Research UK (HDR UK).</p>

17. Industrial Centre for Artificial Intelligence Research in Digital Diagnostics (iCAIRD)

1	<p>Researcher(s) Name: LA Anderson, CF De Vries, G Lip, S Colosimo, RT Staff</p>
2	<p>HDR UK Programme:</p>
3	<p>Affiliation(s): ¹Aberdeen Centre for Health Data Science, Institute of Applied Health Sciences, University of Aberdeen, Scotland. ²NHS Grampian, Aberdeen, Scotland.</p>
4	<p>Title of Case Study (150 characters): Industrial Centre for Artificial Intelligence Research in Digital Diagnostics (iCAIRD) - Identifying AI workflow gains for breast screening pathways</p>
5	<p>Summary of the Impact (150 words):</p> <p>This multidimensional interdisciplinary team has brought together industry, the NHS, and academia with a shared focus on overcoming the obstacles to implementing AI in breast screening. The team has provided award-winning innovation and collaborative leadership between industry, the NHS and academia. The group has worked hard through stakeholder questionnaires, newspaper articles, public speaking, television appearances, public events, and social media to discover the public's take on AI's introduction and report our findings. We have discussed our findings with government officials and given our views on the next steps needed to implement AI into the breast screening programme. The team has a curated dataset for others to use for benchmarking and performance evaluation.</p> <p>Retrospective and prospective studies have been undertaken, facilitated the production of a novel generic image-processing platform to allow the review of AI tools, and used a patient anonymisation tool to maintain image integrity.</p>
6	<p>Underpinning Research (250 words):</p> <p>The project's broad aim is to answer the question, 'What would it take to get AI into breast screening?' Early on, the group investigated patient acceptance of such an introduction using a self- completed questionnaire published in the <i>Journal of Medical Screening</i> (DOI: 10.1177/09691413211001405). This demonstrated broad acceptance but with some reservations.</p> <p>This was followed by a study looking into mammographic readers' views. Published in <i>Insights into Imaging</i> (DOI: 10.1186/s13244-022-01322-4), the study confirmed the broad acceptance of AI's introduction but went on to describe the types of evidence that these key stakeholders would require for implementation. In addition, a stakeholder analysis was also performed (<i>BMC Health Services Research</i>: DOI: 10.1186/s12913-024-10926-z), highlighting the ambition for such an introduction. Collectively, these have guided our analysis plans. We have modelled AI's introduction at points in the screening pathway that are acceptable to stakeholders. First, we performed a retrospective analysis of 4 years of routine screening data using the Grampian Data Safe Haven (<i>Radiology Artificial Intelligence</i>: DOI: 10.1148/ryai.220146).</p> <p>The study highlighted the risk of using such tools 'out of the box' without testing and the need for local tuning. Moreover, the results also indicated an issue with longitudinal robustness. That is, upstream changes, such as software upgrades, to the mammography x-ray sets shifted performance. These findings guided the group's prospective analysis of consecutively acquired real-world data (<i>EPOS</i>: DOI:10.26044/ecr2023/C-14767). The results of this study will be submitted for publication shortly. Our findings indicated an 10.4% increase in cancer detection and 30-40% reduction in human mammographic reads (resource savings).</p>

7	<p>Description of the Impact (500 words):</p> <p>The programme focuses on operational outcomes: Our questionnaire publications represent a bottom-up approach to technology transfer and experimental design by asking how this technology might be acceptably used and what evidence stakeholders require. These findings have influenced and supported study design in Denmark, Italy and Columbia and have been repeated in Norway and Italy. Similarly, these outcomes have influenced our own analyses and study designs. Executing studies with large clinically acquired real-world data has presented security, privacy, and governance issues. The group used a 'hidden in plain sight' (DOI:10.23889/ijpds.v7i3.2023) approach to anonymisation and constructed with our partners a data safe haven equivalent for industry and researchers interested in accessing anonymised NHS images and reports to allow them to develop, test, and validate AI algorithms. The Safe Haven Artificial Platform (SHAIP:doi:10.23889/ijpds.v7i3.2056), designed by Canon Medical Research Europe Ltd, supports the development of sophisticated AI components.</p> <p>Several industrial partners have used it to undertake exemplar projects in stroke, breast screening, and x-ray interpretation for limb fracture and chest and researchers at the University of Aberdeen are using it for Natural Language processing tasks for large population-based data analytics. These researchers have been supported by the Grampian Data Safe Haven's governance processes. SHAIP became the first research environment directly linked to the Scottish National PACS archive enabling evaluation and development of AI tools in medical imaging.</p> <p>Our work has secured funding to support and extend our mammography dataset within this facility, attracting new vendors to test and benchmark their products. The current mammography facility provides readily available safe, fast, and regulatory-compliant resources, with associated staffing support to advise, collaborate and perform such testing and benchmarking. The burden of regulatory and governance oversight involved in curating such a large patient dataset cannot be underestimated. All permissions for this took two years to acquire. However, the groups' perseverance has added value with all new users and projects not requiring such an extensive permissions pathway, easing access and accelerating discovery. Although our work is focused on and has been successful with mammographic data, the model can be extended to all NHS-acquired imaging data.</p> <p>Our retrospective mammographic project, published in 2023, a collaboration between the NHS, the University of Aberdeen, and Kheiron Medical Technologies Ltd., has yielded evidence for potential operational and clinical gains, identified potential operational risks such as upstream X-ray machine changes and issues with generalizability, and provided a basis for prospective studies. These results have been used to support guidance for developing, purchasing, implementing, and monitoring AI Tools in Radiology in North America (RSNA), Europe (ESR) and Australia & New Zealand (RANZCR). Beyond academic presentations, these findings have been featured in the mainstream press, radio, and television, appearing on the BBC show AI-What next?</p> <p>The retrospective findings contributed to the design and execution of a tripartite prospective study (GEMINI). Although our peer-review publication is in-press as a conference presentation, it has generated interest with the results discussed with NHS England and the Department of Health and Social Care in the context of running a large multi-centered randomised controlled trial. The results have even been commented on by the Chancellor of the Exchequer, Jeremy Hunt, who wrote on X that "<i>innovations like this that can drive huge improvements in productivity in our public services.</i>"</p> <p>The authors of this project have spoken on adopting AI at multiple local, national and international conferences and stakeholder meetings moving beyond radiology into digital health. Dr Lip has also spoken as an international advisor to other countries considering introducing AI into their screening programmes.</p>
8	<p>Role of HDR UK (250 words):</p> <p>iCAIRD builds on a long history of collaboration in health data science and imaging in Scotland through the Scottish Health Informatics Programme, the Farr Institute, and HDR UK. Professor Corri Black (Co-applicant) and Professor Lesley Anderson (iCAIRD Lead in Grampian) are HDR UK Scotland Associate Directors and Katie Wilde, DaSH Director, is the current Deputy Director of DHR UK Scotland. The project itself has relied on the principles of health data research and innovation for public benefit championed by HDR UK. The data for analysis was delivered by the Grampian Data Safe Haven (DaSH), an HDR UK Alliance member, enabling sensitive data research in a secure data environment. DaSH facilitated each of the complex data extractions, de-identification and linkage for researchers to analyse within the trusted research environment. Moreover, the development of the SHAIP platform across NHS Grampian and DaSH enables a novel data de-identification technique, 'hidden in plain sight', which allows de-identification of images, structured and unstructured data (e.g. free text) whilst retaining the original data structure for AI algorithm development to facilitate deployment in clinical environments.</p> <p>As an HDR UK Alliance member, DaSH is committed to the ethical and responsible use of health data for research, best practice in information governance, infrastructure development, health data science, accessibility and transparency to drive innovation and research to improve healthcare, clinical service delivery and determinants of health. These values are reflected throughout this project and demonstrate the role that HDR UK plays, even where the research has not been funded directly by HDR UK.</p>

9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>The group embraces the principles of open science and actively engages in knowledge exchange. Its work has been presented to the public, peers, the third sector, and government throughout the UK and Europe as proffered papers, webinars and invited presentations. Although we support open access to data, the nature of our NHS data prohibits us from publishing it for ‘free’ access; however, we have curated the dataset, including images and longitudinal follow-up, for access via the</p> <p>Grampian Data Safe Haven for academic and industry use. Our public engagement work has complemented the publication stream in open-access journals detailed above, resulting in television segments, press articles, and digital media such as YouTube. The group has participated in local Science promotion events such as Techfest (techfest.org.uk) and events around the Royal Institution Christmas Lecture 2023 involving school and other youth groups. The governance of this project and dataset has been extensive. In addition to interaction with the familiar governance groups, ethics, sponsors, and Caldicott guardians, the group engaged with The NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP).</p> <p>This patient advocacy panel scrutinises applications for access to NHS Scotland health data for non-direct care. Its role is to ensure that applicants have considered the proposal's public benefit and privacy implications. Our position is that extensive knowledge exchange with such groups is essential to realise the potential of NHS data such as this. Increasing their knowledge and understanding is a crucial investment for the future.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>iCAIRD has significantly contributed to the national and local research culture providing leadership in AI in Healthcare in Scotland. This project is across organisations and sectors; an interdisciplinary collaboration that has integrated skills and expertise from Radiology, Medical physics, data science, mathematics, computer science, economics, public health, digital health and NHS and industry Research and Development. This has led to regular interdisciplinary meetings to facilitate knowledge sharing and cross-pollination of ideas and methodologies including formation of the AI Healthcare Collaborative group in NHS Grampian. It also includes funded student training in medicine, public health, health economics, data science and medical physics and mentorship for junior investigators, leading to an Advancing Healthcare Awards 2024, Rising Star (Dr de Vries). The group has been recognised locally, with Professor Anderson receiving a Positive Research Culture Award and Nationally receiving awards at the Holyrood Digital Health and Care Awards, the Scottish Knowledge Exchange Awards and the Scotland’s Life Sciences Awards. As discussed elsewhere, this project puts patients’ views at its core, using their views to guide our analysis plan. The group has shown leadership in the national debate through our exemplary publications and promotion of our results to peers, the public, and the government.</p>
11	<p>Research Team and Collaborators:</p> <p>Professor Lesley Anderson, Chair in Health Data Science, Aberdeen Centre for Health Data Science, University of Aberdeen. Dr Clarisse de Vries, Postdoctoral Research Fellow, Aberdeen Centre for Health Data Science, University of Aberdeen. Dr Gerald Lip, Clinical Director North East of Scotland Breast Screening Centre, NHS Grampian Professor Roger Staff, Head of Imaging Physics NHS Grampian Dr Samantha Colosimo, Clinical Scientist, NHS Grampian iCAIRD Consortium collaborators Kheiron Medical</p>
12	<p>Funding: Harrison, Blackwood, Anderson. The Industrial Centre for Artificial Intelligence Research in Digital Diagnostics https://icaird.com/. Extension bid (2022-2023). Innovate UK. £1,611,191. Total iCAIRD project grant £9,970,020</p> <p>Anderson, Lip, Staff, De Vries. Grampian's Evaluation of Mia an Innovative National Breast Screening Initiative (GEMINI). Kheiron Medical Technologies Limited under NIHR Phase 4 AI Award. 2022-2023, £413,68</p> <p>Anderson, Lip, Staff, De Vries. ANCHOR Breast Imaging Dataset, Friends of Anchor, 2024-2028. £69,408.69.</p>

18. Improving equitable access to specialist child and adolescent mental health services in Grampian

1	Researcher(s) Name: William Ball ^{1,2} , Katherine O’Sullivan ^{1,3} , Irmina Zborowska ¹ , Jessica Butler ^{1,4}
2	HDR UK Programme: HDR UK Scotland
3	Affiliation(s): ¹ Aberdeen Centre for Health Data Science, University of Aberdeen, ² School of Nursing, Midwifery and Paramedic Practice, Robert Gordon University, ³ Grampian Data Safe Haven, ⁴ NHS Grampian
4	Title of Case Study (150 characters): Improving equitable access to specialist child and adolescent mental health services in Grampian
5	Summary of the Impact (150 words): Our multidisciplinary team of university researchers, NHS analysts and clinicians, city council staff, and PPIE partners analysed regional trends in mental health services and prescribing for children and young people, focusing on the outcomes of people on the Child Protection Register - those with experience or at risk of significant harm. This work had extensive press coverage, and resulted in targeted staff recruitment, and the establishment of a multi-agency programme of work to support childcare in Grampian. The integration and linkage of datasets across organisations was challenging and required significant advancements in methodologies and governance frameworks. This resulted in government-level discussions on data sharing, and policy changes to enable future multi-agency data linkage. In addition, this project strengthened the collaboration between academia, NHS and local authorities, and has kickstarted the sharing of skills and experiences across sectors, that will enable further projects aiming to tackle health inequalities in the region.
6	Underpinning Research (250 words): Our project, conducted through 2022-2023, found a substantial increase in mental health prescribing and referrals to specialist outpatient psychiatric services among children over the past decade as well as persistent inequalities based on area deprivation. We also found that children with experience of child protection procedures were up to 5-times more likely to seek or receive professional support for their mental health. We aimed to investigate social inequalities in childhood mental health services using routinely available healthcare administrative data. We worked closely with a joint working group (consisting of individuals from local authorities, the health board, education and justice sectors) with an interest in childhood health and well-being to develop the project and share our findings to influence service planning and future research. We also involved the Aberdeen Centre for Health Data Science PPIE group, made up of 9 local people with diverse backgrounds, throughout the research process. They provided valuable insights into the best way to interpret and present our findings to a range of audiences. The PPIE group helped us identify a group of advocates for children, who work in a range of roles to support children, to provide feedback and useful insights on our findings which we shared with the local CAMHS clinical team and Aberdeen City Council to inform service planning and future research priorities. The work was funded by the Health Foundation’s Networked Data Lab grant, who published a policy briefing paper on the topic: https://www.health.org.uk/publications/reports/improving-children-and-young-peoples-mental-health-services . Our work has also been published in two journal articles: https://doi.org/10.1186/s12888-022-04438-5 ; https://doi-org.ezproxy.rgu.ac.uk/10.1016/j.socscimed.2024.117057 . Summary data and analysis code are openly available online: https://doi.org/10.5281/zenodo.6655991 ; https://doi.org/10.5281/zenodo.10245708 .

7	<p>Description of the Impact (500 words):</p> <p>For the first part of the work, that looked at inequalities in children’s mental health, we joined the multi-agency Child Neglect Group, and worked with groups within the Aberdeen City Council (Data, Governance, Social Work, Police, Education) and NHS Grampian (Childrens Lead, Health Intelligence, Governance) to create a safe space to discuss needs and challenges. This resulted in targeted staff recruitment to address needs in this area, and transformation of data capture within the service. This is a quote from one of the CAMHS clinicians: “This analysis has allowed us to prioritise our service development to match the areas of need. It has allowed us to join our services and tailor care.”</p> <p>For the work on the Child Protection Register, our team was embedded within NHS Grampian Health Intelligence; we established a Childrens’ Data Steering Group, met regularly with the Data Lead for the Aberdeen City Council, and shared learning with national analysts working on child health data. As a result, a programme of children’s data analysis was established to support childcare in Grampian. “What you presented represents everything we are striving for to help us shape public services with and for our most vulnerable communities.” – member, NHS Grampian and Aberdeen City Children’s Cumulative Neglect Group.</p> <p>The work on the Child Protection Register was more technically complex, because of the datasets involved. The common unique identifier in most health datasets of patients in Scotland is the Community Health Index (CHI) number, but the Aberdeen City Council Child Protection Register does not have CHI numbers attached to the records. Our work demonstrated that CHI matching children and young people is critical in understanding the health needs of vulnerable children. As a result, there has been a Scotland-wide policy change to work towards CHI-seeding all local authority records, including children and young people, to facilitate faster and easier linkage to health data to better support all vulnerable populations.</p> <p>We presented our findings to a Cross-Party Group on Health Inequalities at Scottish Parliament on February 2024. The goal was to highlight the need for a Scotland-wide policy on multi-agency data sharing to minimise time in accessing data and to facilitate complex data linkage. The Health Foundation, based on our work and that of the other Networked Data Labs, have submitted evidence to national reviews, including the DHSC consultation on the 10-year mental health and wellbeing plan in 2022, and the Sudlow Review in 2024.</p> <p>We have had extensive local press coverage of this work: BBC Radio Scotland Interview: https://www.bbc.co.uk/sounds/play/m001gwjm; Scotsman article: https://www.scotsman.com/news/people/mental-health-prescriptions-for-children-up-nearly-60-percent-3987828; Sunday Post Article: https://www.sundaypost.com/news/scottish-news/mental-health-prescriptions-for-children-on-the-increase-research-shows/; Press and Journal Article: https://www.pressandjournal.co.uk/fp/news/aberdeen-aberdeenshire/5259277/university-study-reveals-59-rise-in-anti-depressant-prescriptions-for-children-in-grampian-since-2015/; Opinion pieces: https://www.pressandjournal.co.uk/fp/opinion/6358588/mental-health-crisis-nhs-grampian-young-people-rgu-opinion/; https://www.researchdata.scot/news-and-insights/big-data-is-interesting-but-small-data-has-real-impact/</p>
8	<p>Role of HDR UK (250 words):</p> <p>Our work has drawn from the principles of health data research and innovation for public benefit championed by HDR UK. The data for analysis was delivered by the Grampian Data Safe Haven (DaSH), an HDR UK Alliance member, enabling sensitive data research in a secure data environment. DaSH facilitated each of the complex data extractions, de-identification and novel data linkage for researchers to analyse within the trusted research environment. The DaSH team also undertook the probability matching of City Council records to health records, which involved extensive cross-referencing of data between disparate sources without a linkage ID to establish identities. This work contributed to the policy change to CHI-seed all local authority records.</p> <p>As an HDR UK Alliance member, DaSH is committed to the ethical and responsible use of health data for research, best practice in information governance, infrastructure development, health data science, accessibility and transparency to drive innovation and research to improve healthcare, clinical service delivery and determinants of health. These values are reflected throughout this project and demonstrate the role that HDR UK plays, even where the research has not been funded directly by HDR UK.</p>

	<p>The Networked Data Lab at the University of Aberdeen and NHS Grampian builds on a long history of collaboration in health data science, novel data linkage and health determinants in Scotland through the Scottish Health Informatics Programme, the Farr Institute, and HDR UK. Professor Corri Black (Lead Investigator) is an HDR UK Scotland Associate Director and Katie Wilde, DaSH Director, is the current Co-Director of HDR UK Scotland.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>Besides sharing our code and summary data from our publications, we have also produced an analysis of CAMHS referrals/wait list open data: https://will-ball.github.io/CAMHS/</p> <p>The successful collaboration in this project between academia, the NHS and Aberdeen City Council, has been a model for other collaborative work, notably the Health Determinants Research Collaboration (HDRC). This programme, funded by the National Institute for Health and Care Research to Aberdeen City Council in partnership with NHS Grampian, the University of Aberdeen, and Robert Gordon University, aims to address the wider drivers of population health and health inequalities of groups and areas within the city. We share learning, best practice, and analytics skills with HDRC partners. Councillor John Cooke, Vice-Chairperson of the Integrated Joint Board, said: “We are pleased to be leading on this hugely important collaboration and for this tremendous opportunity for sharing skills and experiences between sectors. Working with our partners, we will be able to utilise the enhanced research evidence to inform our decision making aimed at improving wellbeing and tackling health inequalities across the city.”</p> <p>As part of this work, we facilitated training for ACHDS PPIE partners, strengthening this group of public advocates for health data research. We provided training materials and harnessed their feedback to develop a training pack for new members and researchers planning to involve the public. We have agreement with members of the PPIE group to develop our own training materials and hope to do that in partnership with HDRUK.</p> <p>Following the success of this project, we have agreed to create a real-time CAMHS data quality assurance and analysis pipeline in collaboration with the NHS Grampian Health Intelligence team. This pipeline will implement the data linkage and analysis that we have done for this project, but within the NHS secure setting, so the results can be presented at the level of individual patients without anonymisation. All code and methods for the pipeline will be standardised for use across Scotland and will be made publicly available.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>The Aberdeen Centre for Health Data Science, where this project is based, is a collaboration between the University of Aberdeen, and NHS Grampian. It is interdisciplinary by design, and our members greatly value Team Science. We ensure proper credit attribution, and we treat all team members as equal research partners. For example, our Safe Haven staff, who are in non-traditional academic roles, take active part in research, including securing research funding, giving research presentations, and authoring papers. We have a dedicated “Culture Committee” that aims to foster an inclusive environment, address concerns, help develop our Ways of Working framework, and evaluate its effectiveness. It consists of members in a range of roles and career stages, to ensure all perspectives are considered and heard.</p> <p>This project has shaped a PPIE culture in the Centre for Health data Science. Our PPIE members have provided input for other projects (e.g., an AI project and cancer detection PhD project), and PPIE activities have been included in new project proposals and community initiatives (e.g., inequalities in chronic kidney disease care, One HealthTech Aberdeen). PPIE has been incorporated into our MSc programme in Health Data Science.</p>

11	<p>Research Team and Collaborators:</p> <p>Our team for this work involved members from academia, NHS, Aberdeen City Council, and PPIE:</p> <p>Will Ball (Chancellor’s Fellow at Robert Gordon University) and Jessica Butler (Lead Data Scientist at NHS Grampian) led the research; Corri Black (Clinical Chair at the University of Aberdeen and Public Health Consultant in NHS Grampian) helped secure the funding, administer the project, and support earlier career staff; Irmina Zborowska (Project Administration Coordinator) collected the evidence of impact; Magdalena Rzewuska (Advanced Research Fellow) and Sharon Gordon (ACHDS programme coordinator) set up our PPIE group; Barbala Ostrowska is a representative of the PPIE group; our Safe Haven team (represented by Katie Wilde, Katherine O’Sullivan, Helen Rowlands, and Michael Lackenby) provided access (including information governance and agreements across organisations) and data linkage; Elaine Thompson and David Ritchie (NHS Grampian) curated the health datasets; and Caroline Anderson and Martin Murchie (Aberdeen City Council) curated the Child Protection Register data.</p> <p>CRedit taxonomy for author contributions for both our publications is included as supplementary material.</p>
12	<p>Funding:</p> <p>The work was supported by the Health Foundation Networked Data Lab Programme.</p>

19. Improved measurement of multimorbidity in research

1	<p>Researcher(s) Name:</p> <p>Iris S-S Ho Amaya Azcoaga-Lorenzo Ashley Akbari Corri Black Jim Davies Peter Hodgins Kamlesh Khunti Umesh Kadam Ronan A Lyons Colin McCowan Stewart Mercer Krishnarajah Nirantharakumar Sophie Staniszewska Bruce Guthrie</p>
2	<p>HDR UK Programme:</p> <p>Multimorbidity national resource</p>
3	<p>Affiliation(s):</p> <p>University of Edinburgh (ISSH, PH, SM, BG) University of St Andrews (AAL, CM) Swansea University (AA, RAL) University of Aberdeen (CB) University of Oxford (JD) University of Leicester (KK, UK) University of Birmingham (KN) University of Warwick (SS)</p>
4	<p>Title of Case Study (150 characters):</p> <p>Improved measurement of multimorbidity in research</p>
5	<p>Summary of the Impact (150 words):</p> <p>Multimorbidity research is constrained by considerable variation in how researchers define and measure multimorbidity. This work has characterized the extent and implications of this variation, and developed international consensus guidance for researchers which is already widely cited in academic papers with increasing numbers of researchers aligning methodological choices to the guidance. The immediate impact is to improve the consistency and reproducibility of a very rapidly growing research field internationally, which addresses one of the key challenges for healthcare worldwide.</p>

6	<p>Underpinning Research (250 words):</p> <p>The research found very large variation in how researchers conceptualise and measure multimorbidity (the presence of multiple long-term conditions), and used a systematic consensus process to develop recommendations to improve the consistency, comparability and reproducibility of future research. The project involved a large systematic review of the scientific literature to <i>understand</i> variation in how multimorbidity is conceptualized and measured in research, followed by an international Delphi consensus study to <i>recommend</i> improvements in research in this field. The systematic review included 566 studies, and found very wide variation in how researchers measured multimorbidity, for example that the number of conditions included in measures ranged from two to 285 (median 17), with considerable under-representation of mental health conditions (https://doi.org/10.1016/S2468-2667(21)00107-9). This variation means that comparison of findings of different studies is difficult which constrains the field (https://doi.org/10.1136/bmjopen-2021-057017). The Delphi consensus study made a number of recommendations for measuring multimorbidity in research and for reporting standards, including 24 conditions which should always be included in multimorbidity measurement and 35 conditions which should usually be included unless there is a good reason not to (https://doi.org/10.1136/bmjmed-2022-000247). There was public involvement in the design of the study (particularly the development of the Delphi consensus material), and the consensus study had both a professional and a public/patient panel to ensure that both perspectives underpinned guidance for researchers.</p> <p>https://doi.org/10.1016/S2468-2667(21)00107-9 (published June 2021, cited 102 times as of 26/6/24)</p> <p>https://doi.org/10.1136/bmjopen-2021-057017 (published April 2022, cited 43 times as of 26/6/24)</p> <p>https://doi.org/10.1136/bmjmed-2022-000247 (published July 2022, cited 54 times as of 26/6/24)</p>
7	<p>Description of the Impact (500 words):</p> <p>The impact of the work is both in changing understanding of the problem of measurement in multimorbidity research (the two systematic review papers) and in changing how research in this important field is done (the Delphi study that created consensus guidance for researchers). The three papers published in 2021 and 2022 are highly cited (199 times as of 26/6/24) and we have responded to multiple queries from researchers from several countries seeking advice on how to implement the recommendations in their work. There is therefore immediate impact in terms of improving the validity and reproducibility of research, as well as research efficiency since historically individual research teams would spend considerable time making idiosyncratic choices (<i>Advanced Methods and Technology</i> impact area). The consensus study was deliberately designed to have both a professional and a public panel, with final consensus agreed across both, which ensures that recommendations draw appropriately on public perspectives (<i>Forming Public Trust</i> domain). In the longer term, more consistent and reproducible research will support more rigorous research in this important field, and facilitate more rapid translation of research findings into impact on patients and the public (<i>Improving Health and Well-being</i> impact area).</p> <p>Systematic reviews</p> <p>https://doi.org/10.1016/S2468-2667(21)00107-9 (published June 2021, cited 102 times as of 26/6/24)</p> <p>https://doi.org/10.1136/bmjopen-2021-057017 (published April 2022, cited 43 times as of 26/6/24)</p> <p>Delphi study making consensus recommendations for researchers</p> <p>https://doi.org/10.1136/bmjmed-2022-000247 (published July 2022, cited 54 times as of 26/6/24)</p>

8	<p>Role of HDR UK (250 words):</p> <p>The work was done by the collaboration in the HDR UK National Multimorbidity Research, so was HDR UK funded and facilitated.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>All three papers were published in an open access journal with particular attention paid to graphical summaries of the findings to support their use. We rapidly respond to researcher queries about how to implement the consensus recommendations, for example by steering people to tools to support them such as the HDR UK Phenotype Library.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>The project team was a collaboration across eight UK universities, with a commitment to a Team Science approach, and respecting each other's varying disciplinary perspectives and priorities. We have subsequently published other work together in a variety of different collaborations.</p>
11	<p>Research Team and Collaborators:</p> <p>Iris S-S Ho (PDRA, early career). Amaya Azcoaga-Lorenzo (Honorary Senior Lecturer) Ashley Akbari (Professor of Health Data Science) Corri Black (Professor of Public Health) Jim Davies (Professor of Software Engineering) Peter Hodgins (Clinical Fellow, early career) Kamlesh Khunti (Professor of Primary Care Diabetes and Vascular Medicine) Umesh Kadam (Professor of General Practice and Public Health Research) Ronan A Lyons (Professor of Public Health) Colin McCowan (Professor in Health Data Science) Stewart Mercer (Professor of Primary Care and Multimorbidity) Krishnarajah Nirantharakumar (Professor in Health Data Science and Public Health) Sophie Staniszewska (Professor of Health Research) Bruce Guthrie (Professor of General Practice)</p> <p>All of the team contributed to the conceptualisation and design of the study, interpretation of findings and writing of papers. ISSH led the day to day conduct of the study, working with BG, and with the support of PH for the systematic review.</p>
12	<p>Funding:</p> <p>HDR UK funding for the national multimorbidity resource.</p>

20. Improving patient flows through emergency departments through better patient selection for Same Day Emergency Care (SDEC)

1	Researcher(s) Name: Professor Elizabeth Sapey
2	HDR UK Programme: PIONEER, the HDR UK Hub in Acute Care
3	Affiliation(s): University of Birmingham (UoB), University Hospitals Birmingham NHS Foundation Trust (UHB)
4	<p>Title of Case Study (150 characters):</p> <p>Improving patient flows through emergency departments through better patient selection for Same Day Emergency Care (SDEC).</p>
5	<p>Summary of the Impact (150 words):</p> <p>Overcrowding in Emergency departments leads to poor patient outcomes and long delays. To address this, NHS England developed Same Day Emergency Care (SDEC), where patients receive emergency assessments and treatments without overnight admission. Our national survey showed that how patients are selected for SDEC varies, with recommended tools being inaccurate.</p> <p>We improved patient selection for SDEC, building a patient selection tool using data and stakeholder’s input. Analysing >500,000 patient records, a new scoring system was developed using artificial intelligence that could predict SDEC suitability in 80% of patients. Factors improving accuracy included combining patient factors such as age, how unwell they were on arrival to hospital and their symptoms. This scoring system is now being tested in other healthcare settings. Working with stakeholders, we co-produced an informative SDEC leaflet with the public to explain patient selection. This is now being translated into locally prevalent languages to increase accessibility.</p>
6	<p>Underpinning Research (250 words):</p> <p>The project commenced in January 2023 and initial with policy recommendations were submitted by 31st March 2023.</p> <p>By combining features from both the current SDEC scoring systems, acuity scores and presenting complaint, we developed a tool that more accurately selected patients for SDEC using both traditional statistics and machine learning. Validation on a separate dataset further confirmed the superiority of the ML models in identifying patients for SDEC in a diverse and urban population. This tool offers a more accurate method to enhance patient triaging for SDEC, improving patient flow through urgent and acute care settings. The model was reviewed throughout its development by key stakeholders including patients, clinical staff working in emergency care and SDEC settings, GPs and policy makers, to ensure end-users though the tool was useful and deployable. This work is continuing as we assess the ability of this tool to accurately identify patents for SDEC services in different hospital settings.</p>
	<p>Further information and publication timelines:</p> <ul style="list-style-type: none"> • Dataset has been made available via HDR UK Innovation Gateway to support Open Science approach. (https://web.www.healthdatagateway.org/dataset/7af96f17-5ab6-4275-b8ef-61a3e053d342). • Infographic summarising dataset produced. (https://www.pioneerdatahub.co.uk/wp-content/uploads/SDEC-V3-Infographic-page-001.jpg) • Paper – a manuscript is currently being drafted for publication based on the development and validation of the tool. • Patient Leaflet – revised version, following additional patient and hospital feedback is being amended to trial in 2 differing SDEC areas. Once this trial is complete, plan is to translate in prevalent written languages (Arabic, Cantonese, Urdu, Somali, Polish) as well as accessible formats (large print). The leaflet will then be shared through Society for Acute Medicine.

7	<p>Description of the Impact (500 words):</p> <p>The Problem</p> <p>Same Day Emergency Care (SDEC) aims to reduce hospital admissions by providing hospital-led urgent investigations and treatments without hospital admission.</p> <p>The challenges we addressed include:</p> <ul style="list-style-type: none"> • How to best choose patients for SDEC, building tools which stakeholders have confidence in. • How to optimally staff SDECs, given the varying flow of patients over the day and trends in referrals over time. • How to explain to patients what SDEC is. <p>Impact of the Research</p> <p>We developed a new tool to select patients for SDEC using health data from >500,000 patients, working with healthcare professionals, patients and policy makers. We tested the tool in end-user workshops. We are validating this tool in different hospital settings, modelling the workforce needed against exact and predicted patient flows. We co-designed a leaflet explaining what SDEC is. This is now being piloted across SDECs regionally and being translated into different languages.</p> <p>Advancing Methods and Technology</p> <ol style="list-style-type: none"> 1. Scalable Tool for NHS: A tool created for testing and adoption across English acute care settings, designed to accommodate different levels of digital maturity. 2. Expedited Decision-Making: This tool streamlines the decision-making process, enabling more patients to receive timely care. 3. Strategic Partnerships: Established strategic partnerships with the Society for Acute Medicine (SAM) and NHS England (NHSE) to embed the validated tool in upcoming SDEC guidance. <p>Forming Public Trust</p> <ol style="list-style-type: none"> 1. Co-designed Patient Materials: To explain the concept of SDEC and address concerns about this pathway. 2. Collaboration with Stakeholders: Including healthcare professionals, policy makers, patients, and the public ensured the new tool met the needs and expectations of end-users. <p>Improving Health and Well-being</p> <ol style="list-style-type: none"> 1. Better Selection for Patients: Utilising evidence readily available within the first hour of patient presentation to hospital, enhancing patient outcomes and experience by ensuring timely and appropriate care. 2. Reduced Unnecessary Bed Moves: Improving bed planning to minimise unnecessary patient bed moves, enhancing comfort, continuity of care, and patient safety. 3. Improved Patient Flow: Enhancing patient flow to the SDEC service, ensuring patients are seen at the right time and place, thereby increasing overall capacity and addressing emerging health needs. 4. Reduction in health disparities: The tool was designed using PIONEER's diverse data and with diverse stakeholders, ensuring it is fit for purpose. <p>Informing Decision Making</p> <ol style="list-style-type: none"> 1. Policy Maker Collaboration: HDR UK facilitated a pairing with policy experts from the Department of Health & Social Care. A short policy briefing was sent to DHSC. 2. Primary Beneficiaries: Patients and the public, while also having a positive impact on healthcare professionals, organisations, and policy/government plans. This has resulted in collaborations among several NHS Acute Trusts, namely Plymouth and Norfolk and Norwich, with a focus on optimising pathways. The Executive Team at UHB has agreed to implement additional changes to the front-door pathways, based on this work, with the PIONEER team serving as a living-lab to assess impact and ensure near-real-time optimisation.
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	<p>Improving Research Culture and Capacity</p> <p>National Working Group to build upon the project’s work and continue to develop the SDEC service and associated tools.</p>
8	<p>Role of HDR UK (250 words):</p> <p>PIONEER was part of HDR UK's Digital Innovation Hub (DIH) Programme, which demonstrated strong collaboration between the NHS, academia, industry, and the public. The programme was supported by UK Research and Innovation's (UKRI) Industrial Strategy Challenge Fund from 2019-2023. PIONEER has continued to maintain sustainability, utilising our expertise and datasets to drive healthcare improvements.</p> <p>During the COVID-19 pandemic, HDR UK established the COVID-19 Data and Connectivity programme, which included PIONEER representing the West Midlands. In partnership with the Alan Turing Institute and UKRI, this initiative funded nine studies to enhance understanding of the pandemic and inform policy responses. One such study, led by Professor Elizabeth Sapey at University Hospitals Birmingham NHS Foundation Trust, is the focus of this Impact Case Study.</p> <p>HDR UK's contribution was crucial in securing this funding and ensuring the project's impact on enhancing decision-making, improving patient flow, and optimising resource use within the NHS. Our project, coordinated and supported by HDR UK with funding from the National Institute for Health and Care Research (NIHR), provided PIONEER with the opportunity to undertake this key research.</p> <p>This project exemplifies the value of HDR UK's collaborative approach, which used Alliance links to Government and Policy Makers to ensure their involvement. Furthermore, the report was used to support Winter Planning and future strategic development around these services.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>The PIONEER HDR UK Hub in Acute Care has significantly advanced health data research through open science practices and knowledge exchange.</p> <p>Open Science Practices:</p> <ol style="list-style-type: none"> 1. Transparency and Data Sharing: PIONEER makes research data accessible to approved users, enhancing reproducibility and enabling secondary analyses. The datasets used to build this tool are advertised on the HDRUK Innovation Gateway. 2. Collaborative Research: This project engaged healthcare professionals, policy makers, patients, and the public, ensuring ethical and relevant research. 3. Co-design and Participation: Involving patients and the public in research design ensures patient-centered studies that address real needs and concerns. <p>Knowledge Exchange:</p> <ol style="list-style-type: none"> 1. Cross-Sector Partnerships: PIONEER facilitates collaboration between the NHS, academia, industry, and the public, leading to innovative solutions and shared best practices. 2. Educational Initiatives: Workshops, seminars, and training sessions have been delivered to build research capacity and foster a research-positive culture in acute care. 3. Research Outputs and Dissemination: PIONEER produces and disseminates peer-reviewed publications, reports, and policy briefs to inform a broad audience. <p>Evidence of Impact:</p> <ol style="list-style-type: none"> 1. Grant Activity and Research Applications: PIONEER has supported over £41M in grant activity and more than 100 research applications, demonstrating its capability to attract significant funding. 2. COVID-19 Response: As part of HDR UK’s COVID-19 Data and Connectivity programme, PIONEER contributed to national efforts, improving pandemic understanding and informing policy. Improved Clinical Practice: This project has led to better patient flow and optimized resource use in acute medical departments, directly enhancing patient outcomes and healthcare efficiency.

10	<p>Contribution to Research Culture (250 words):</p> <p>We embed collaboration and inclusivity in our work by involving various stakeholders, including healthcare professionals, policy makers, patients, and the public. This ensures that all perspectives and needs are considered, fostering mutual respect and shared objectives.</p> <p>Our research is transparent and open. We co-designed tools and materials with stakeholders to ensure clarity and accessibility, building trust and encouraging active participation. Data access approval by our Data Trust Committee and our publicly accessible data use registry ensure public oversight of data sharing decisions. The team promotes a research-positive culture among the multi-disciplinary team, making research an integral part of clinical practice.</p> <p>Continuous learning and professional development are promoted through strategic partnerships and knowledge sharing. By establishing a national working group and partnering with organizations such as the Society for Acute Medicine (SAM) and NHS England (NHSE), skills are developed and capacity is built across the healthcare sector.</p> <p>The collaboration between technical expertise, academic leadership, and researchers has led to significant grant activity and research applications in acute care topics. This integration enhances the project's impact and fosters a culture of innovation and excellence.</p> <p>PIONEER's success in securing funding and delivering impactful results demonstrates our commitment to sustainability and long-term impact. It sets a benchmark for future research initiatives and contributes to a resilient and dynamic research environment.</p>
11	<p>The members of our research team were as follows.</p> <ol style="list-style-type: none"> 1. Professor Elizabeth Sapey, Director of PIONEER, the Health and Research Data hub for Acute Care, Consultant in Acute and Respiratory Medicine, University of Birmingham – Lead for the project, Director of PIONEER and strategic leadership around academic and clinical methods. 2. Dr Catherine Atkin, Assistant Clinical Professor in Acute Medicine, University of Birmingham – Early Career Researcher and clinician supporting link with health and academic interfaces, and engagement with the Society for Acute Medicine. 3. Suzy Gallier, Technical Director of PIONEER, the Health and Research Data hub for Acute Care, University Hospitals Birmingham NHS Foundation Trust – overarching management of delivery and technical leadership 4. Dr Lily Li, Senior Data Scientist, PIONEER, the Health and Research Data Hub for Acute Care, University Hospitals Birmingham NHS Foundation Trust – undertook the machine learning approach to the analysis. 5. Felicity Evison, Principal Clinical Informatician, University Hospitals Birmingham NHS Foundation Trust – provided senior statistical and analytical support. 6. James Hodson, Statistician, University Hospitals Birmingham NHS Foundation Trust – undertook the traditional statistical analysis work. 7. The Society for Acute Medicine (SAM) – contribution to review and feedback around methodology. SAM will also work to embed this work in other acute trusts and disseminate tool and patient-facing materials. 8. Adam Dryden, Senior Statistical Officer, Department of Health & Social Care – provided Policy and links with DHSC. <p>Patient and public workshop contribution – involved from initiation throughout, to ensure contribution to methodology, approach as well as co-authoring public-facing materials.</p>
12	<p>Funding:</p> <p>This research was supported from joint NIHR and HDR-UK funding aimed at easing NHS winter pressures. In order to support these pioneering projects the Health and Social Care Secretary added £800,000 of government funding.</p>

21. Linking data from health and education to transform research to improve the lives of children and the adults they become

1	<p>Researcher(s) Name:</p> <p>Prof. Katie Harron</p>
2	<p>HDR UK Programme:</p> <p>Social and Environmental Determinants of Health Driver Programme</p>
3	<p>Affiliation(s):</p> <p>University College London</p>
4	<p>Title of Case Study (150 characters):</p> <p>Linking data from health and education to transform research to improve the lives of children and the adults they become</p>
5	<p>Summary of the Impact (150 words):</p> <p>The Education and Child Health Insights from Linked Data (ECHILD) Research Database has unlocked the power of administrative data from health, education, and children’s social care services for understanding the complex relationships between health and education.</p> <p>We created ECHILD, a linked data resource to help generate critical evidence for shaping early-years policy. ECHILD is the largest dataset of its kind, capturing detailed information on 20 million children in England, from birth to adulthood, and is the first ever comprehensive linkage of health, education and social care data for all children born in England since 1984. Cross-sector partnerships have been built to safely and securely open this pioneering resource for research with clear public benefit for the provision of healthcare and education.</p> <p>Enabling reuse of ECHILD’s pseudonymised data and resources leads to gains in productivity for research, removes the need for linkage using personally identifiable information, and delivers public value for money, removing data requests from government departments.</p> <p>ECHILD is a ground-breaking example of public good arising from access to large health and education datasets, with appropriate measures in place to safeguard privacy and data security, which will ultimately lead to improved services for millions of children in England.</p>
6	<p>Underpinning Research (250 words):</p> <p>We have created a national data resource for England – the ECHILD database (Education and Child Health Insights from Linked Data). ECHILD represents a step-change in research capability for children and young people, built on an academic-government partnership. Our efforts to establish a governance framework for linkage at NHS England and data access via the Office for National Statistics means that this data resource is now open to UK researchers who aim to answer policy-relevant research questions to benefit the public.</p> <p>Since 2021, the data has been used for research to inform public policy. For example, we used the data to show that children in contact with social care services or those with Special Educational Needs were most affected by COVID-19 and associated lockdowns in terms of hospital admissions [1, 2, 3], to show that each week of gestational age at birth is associated with improved outcomes at school age [4]. Ongoing research is being conducted to understand whether special educational needs provision in schools can improve health outcomes [5]. Other research includes evaluating how childhood chronic liver disease, cancer, and congenital anomalies are related to cognitive development, and evaluating mortality in children in contact with social care services [6, 7, 8].</p> <p>Our data development and research has been underpinned by extensive patient and public engagement. For example, we created a video for the PEDRI initiative to describe how linked data are being used for research for children and families and commissioned lay input on the ECHILD website material.</p> <p>A comprehensive summary of ECHILD outputs, including peer-reviewed publications, protocols, and other resources, is attached to this document.</p>

7	<p>Description of the Impact (500 words):</p> <p>Advancing Methods and Technology: ECHILD drives research and innovation by offering secure and anonymised data access. Through the implementation of enhanced transparency standards, researchers have benefited from streamlined practices, including easier and transparent data access, resources, a supportive GitHub community, and a new website.</p> <p>Forming Public Trust: ECHILD established a Lay Public Involvement and Engagement group comprising 20 members. These individuals contributed to the digital content and design of the ECHILD video animation and illustrations.</p> <p>Improving Health and Well-Being: ECHILD provides evidence on which groups of children to target for early intervention to ensure that all children have the best possible start in life. This evidence will lead to the development of evidence-based guidelines and inform decisions about the information that should be shared across services.</p> <p>Informing Decision Making: ECHILD is a core resource for the NIHR funded Children and Families Policy Research Unit (CPRU), which undertakes research to inform decision-making by government and arms-length bodies. CPRU works closely with the Department of Health and Social Care (DHSC) to determine priorities and provide evidence directly to the Secretary of State for Health, government departments and arms-length bodies. ECHILD is also a core component of the Data Improvement Across Government (DIAG) initiative, which is a programme of work funded by HM Treasury Shared Outcomes Fund and led by the Department for Education. It is designed to improve the way data are used and shared across government to improve the outcomes for vulnerable children and families.</p> <p>Improving Research Culture and Capacity: ECHILD training has equipped participants with essential skills for navigating and maximizing the use of the dataset. We host seminars that foster community learning and collaborations and promote interdisciplinary exchanges and partnerships. These initiatives support team science, open practices, and diverse research outputs while ensuring sustainable leveraging of funding. ADR UK funded Research Fellowships have been highly sought after for ECHILD; 3 fellowships were awarded in 2023, with additional awards anticipated in 2024.</p> <p>Enhanced Visibility and Credibility ECHILD is regularly mentioned by external organizations and government bodies. This recognition attracts more researchers, influences policy, helps secure funding, builds partnerships, and expands the dataset's use:</p> <ul style="list-style-type: none"> • House of Lords Preterm Birth Committee 2024: ECHILD given as an example of the type of data that should be used to better understand the determinants and outcomes of preterm birth. • The Academy of Medical Sciences: ECHILD highlighted as a key initiative to improve access to and use of data to improve health in the early years. • NIHR funding calls: ECHILD highlighted as a key data resource. • Department for Education report on government policy on information sharing: ECHILD highlighted as a key dataset for informing policymaking. • Office for Statistics Regulation report on the importance of including children and young people in official statistics: ECHILD given as a good practice example. • Support for ECHILD from young people, parents and children's charities has been voiced during many events and consultations, including a stakeholder meeting which included representatives from 15 charities, the Children's Commissioner's Office, and other groups. • Administrative Data Research UK: ECHILD recognized as one of their flagship datasets. <p>Beneficiaries of the impact Children and young people and their families will benefit from the more detailed information that can be generated from the huge sample size of ECHILD on likely outcomes for children with specific conditions. Clinicians and educational / early years</p>
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	<p>services professionals will also benefit from ECHILD, as they can use this information to inform decisions about clinical follow up for specific groups of children. These data will help develop evidence-based policies, better planning, and quality improvement of services.</p> <p>Reach of the impact</p> <p>ECHILD is an internationally unique resource thanks to its scale and population coverage. It is being sought to be replicated in other countries where administrative data linkage is currently being developed, e.g. Chile. Partnerships between ECHILD and other jurisdictions with similar data have been established with Ontario.</p>
8	<p>Role of HDR UK (250 words):</p> <p>HDR UK are directly supporting the team who are establishing ECHILD as a national sovereign data asset for research that benefits the provision of healthcare and education. Advancing ECHILD is a central aim for the HDR UK Social and Environmental Determinants of Health Driver Programme.</p> <p>ECHILD has been building upon methods, privacy protection and public involvement developed by HDR UK. With the HDR UK Public Advisory Board and Trust and Transparency teams, ECHILD is co- producing learning modules for the HDR UK Futures platform. These will inform on best practice principles for administrative data use and on public confidence in data security. The work also aims to define a framework for informing and capturing public and other stakeholder views on the perceived value, concerns and acceptability of linked administrative health data for research.</p> <p>The UK Health Data Research Alliance and Transparency Standards have enabled the development of a robust framework to improve openness and understanding of ECHILD. This has included activities and a platform to actively promote public awareness, where researchers can also effectively discover ECHILD's data and tools.</p> <p>Throughout the ECHILD project, through forums and opportunities for knowledge exchange, the HDR UK leadership and community have raised ECHILD's profile as an intersectoral data resource. This wealth of expertise has been harnessed and contributed to the ECHILD project realising its objectives. One such example is the research partnership with the Molecules to Health Records Driver Programme starting 2024, with further driver program collaborations planned throughout HDR UK's second Quinquennial.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>ECHILD makes a significant contribution to health data research through its extensive dataset covering 20 million children in England, encompassing health, education, and social care data. This resource enables researchers to conduct detailed studies on factors influencing child development and health outcomes. Emphasizing open science principles, ECHILD ensures transparency and data sharing to promote collaboration and verification of research findings across disciplines.</p> <p>In addition to managing data rigorously, ECHILD hosts seminars, training courses and User Day events. These educational initiatives are designed to equip researchers, policymakers, and healthcare professionals with the skills to effectively utilise ECHILD data in their work. To further promote community engagement and open science, ECHILD maintains a GitHub section on their website, where tools, code, and resources are shared openly to facilitate collaboration and innovation. By fostering knowledge exchange and capacity building, ECHILD supports evidence-based decision- making in child health and social care policies. These efforts not only strengthen the reliability and relevance of health data research but also contribute to improving outcomes for children and families throughout England.</p>

10	<p>Contribution to Research Culture (250 words):</p> <p>ECHILD promotes open science principles by prioritising transparency, reproducibility, and robust data management. Researchers are encouraged to adhere to rigorous standards in data manipulation and analysis, ensuring that findings are accessible and verifiable. This commitment to open science not only strengthens the credibility of research outcomes but also fosters trust among stakeholders, including policymakers, healthcare professionals, and the public.</p> <p>In addition to promoting collaboration and open science, ECHILD invests in capacity building and professional development. ECHILD offers training courses, seminars, and educational resources designed to enhance researchers' skills in data analysis, methodology, and ethical research practices. These initiatives support researchers at all career stages, empowering them to conduct rigorous and impactful research using ECHILD data.</p> <p>Overall, ECHILD's commitment to fostering a healthy research culture through collaboration and open science, underscores its role in advancing knowledge and improving outcomes in child health and social care research. These efforts contribute to creating an inclusive and innovative research environment that benefits the broader scientific community and society.</p>
11	<p>Katie Harron, Professor of Statistics and Health Data Science. Lead for the ECHILD Research Dabase</p> <p>Ruth Gilbert, Professor of Clinical Epidemiology. Co-Director, Children and Families Policy Research Unit; Deputy lead for ECHILD, member of Child Health Informatics Group; Lead for the HOPE study; Co-director, Social and Environmental Determinants of Health Driver Programme, HDRUK</p> <p>Ruth Blackburn, Senior Research Fellow, Senior Research Fellow in Public Health Data Science; Associate Director, Social and Environmental Determinants of Health Driver Programme, HDRUK.</p> <p>Vincent Nguyen, Research Fellow Kate</p> <p>Lewis, Research Fellow Tony Stone,</p> <p>Data Scientist</p> <p>Farzan Ramzan, Data Scientist</p> <p>Ania Zylbersztein, Senior Research Fellow</p> <p>Bianca De Stavola, Professor of Medical Statistics Matt Jay, Data</p> <p>Scientist</p> <p>Difei Shi, Research Assistant ECR</p> <p>Louise Mc Grath-Lone, Senior Research Fellow</p>
12	<p>Funding:</p> <p>ECHILD is supported and funded by ADR UK (Administrative Data Research UK), an Economic and Social Research Council (part of UK Research and Innovation) programme (ES/V000977/1, ES/X000427/1 and ES/X003663/1).</p> <p>This work was supported by Health Data Research UK (HDRUK2023.0029 and HDRUK2023.0453).</p>

References

- [1] <https://adc.bmj.com/content/107/10/e29> Changes in adolescents' planned hospital care during the COVID-19 pandemic: analysis of linked administrative data.
- [2] <https://bmjopen.bmj.com/content/13/6/e071973> Number and timing of primary cleft lip and palate repair surgeries in England: whole nation study of electronic health records before and during the COVID- 19 pandemic
- [3] <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/covid19related-school-closures-and-patterns-of-hospital-admissions-with-stressrelated-presentations-in-secondary-schoolaged-adolescents-weekly-time-series/01955547EB2F5DE4DAD42F5A27479813> COVID-19-related school closures and patterns of hospital admissions with

stress-related presentations in secondary school- aged adolescents: weekly time series

[4] <https://academic.oup.com/ije/article/52/1/132/6589377> Gestational age at birth, chronic conditions and school outcomes: a population-based data linkage study of children born in England.

[5] <https://pubmed.ncbi.nlm.nih.gov/37918923/> Evaluation of variation in special educational needs provision and its impact on health and education using administrative records for England: umbrella protocol for a mixed-methods research programme.

[6] <https://ijpds.org/article/view/2340> Primary-school recorded special educational needs in children born with major congenital anomalies in England: A population-based study using the Education and Child Health Insights from Linked Data database.

[7] https://adc.bmj.com/content/108/Suppl_2/A37.2 Special educational needs and school readiness of children with neurodevelopmental conditions: a national cohort using linked health and education records.

[8] https://adc.bmj.com/content/108/Suppl_2/A225.1 Educational outcomes in children with chronic liver disease in England are inferior to peers: evidence from 5 million children.

22. Public Advisory Board and researcher co- development of learning content on public involvement in health data science using unique property reference number (UPRN)

1	Researcher(s) Name: Ruth Blackburn on behalf of the Social and Environment Determinants of Health (SEDH) Driver Programme Team
2	HDR UK Programme: SEDH Driver Programme
3	Affiliation(s): University College London
4	Title of Case Study (150 characters): Public Advisory Board and researcher co-development of learning content on public involvement in health data science using unique property reference number (UPRN).
5	Summary of the Impact (150 words): During its first year the SEDH Driver Programme has consolidated information on how UPRNs are used in UK health data research, what the governance considerations are, and to develop technical guidance on privacy-preserving methods at each point of the research pipeline. In addition to traditional scientific publications these findings are being developed into a researcher-facing learning module that is freely accessible via the HDR UK Futures platform. Co-developing the module has brought together researchers from the Driver Programme with expert lay members from the HDR UK Public Advisory Board (PAB), with the resulting knowledge exchange informing best practice for governance and public involvement for health research using UPRN. Bringing together researcher and expert lay advisors has shaped the content, tone and delivery of the training material, thereby promoting public voices in research culture whilst developing resources for health data science methods that will ultimately build public trust.
6	Underpinning Research (250 words): The SEDH Driver Programme is enhancing largescale, longitudinal datasets with place-based data including unique property reference number (UPRN) to investigate the impact of environmental (e.g. air pollution) and social exposures (e.g. household groupings) on health across the life course. UPRN encodes address data that is openly available and is therefore highly sensitive and disclosive when combined with health or personal data. It is paramount that research using UPRN embeds privacy preserving steps into all parts of the research pipeline, and that public benefit, support and involvement is clearly demonstrated throughout. During its first year, the SEDH Driver Programme has worked to establish how UPRNs are used in UK health data research, what the legal and governance considerations are, and to develop technical guidance on privacy preserving methods within the pipeline (e.g. masking cohort UPRNs during transit, use of salt for scalable UPRN encryption). This research is well progressed but not yet published. The research outlines guidance on encryption methods that are both scalable and which support linkable flows of encrypted data from different sources. These findings are informing the development of the learning module and the specification of research pipelines developed by the Driver Programme, across HDR UK, and beyond.

7	<p>Description of the Impact (500 words):</p> <p>Process: The process of developing learning materials on public involvement for health data research using UPRNs has brought together researchers in the SEDH Driver Programme and six expert lay advisers from HDR UK’s Public Advisory Board (PAB). Co-developing the materials reflected a series of discussions between researchers and the PAB, with considerable time between meetings spent creating and reviewing written/visual material. These meetings include an initial approach to identify interested PAB members to form a working group, followed by the development of draft training material and 4 meetings (each 60-90 minutes in length) to plan and develop content. Concrete milestones in the process include forming a working group (Feb 2024), agreeing the approach to PAB training on UPRNs and co-developing the materials (April 2024), sharing written training materials on UPRNs and discussing the content outline and structure (May 2024), developing key messages for public involvement for health research using UPRN (June 2024). Upcoming milestones are filming (summer 2024) and editing (early autumn 2024), with the module expected to go live later in the year. Both researchers and volunteers from the PAB will be filmed and feature in the learning module.</p> <p>Impact: Although not yet complete, this work has already had considerable impact. Firstly, by raising awareness that there are specific concerns related to place-based data, that need to be addressed throughout the data pipeline, in order to maintain geoprivacy. Secondly, through creating an effective partnership for knowledge exchange that is improving understanding of the geoprivacy challenges, and thereby enable detailed discussions about potential solutions. Our approach started with sharing knowledge gained through Driver Programme activity (how UPRNs are used in research, what the risks are, how these can be managed) with the PAB. These research findings were then enriched with the PAB’s invaluable insight and experience to critique how public involvement for health data science using UPRNs should be approached, and to define best practice in this area. These discussions provided valuable insight and a deep level of scrutiny that is independent of the research, as well as a space where solutions could be explored. For example, how members of the public can be involved in monitoring and governance of the research using UPRNs. We have also extended existing HDR UK PPIE materials to better reflect aspects of PPIE that are specific to the use of UPRNs. Impact reflects a shift in the knowledge and perspectives of HDRUK researchers, public advisors and HDR UK staff – whilst the number of individuals may be small (~20 people), the reach of the partnership is significant and of strategic importance for data science. The learning material (when completed later this year) will reach a much larger audience of researchers, with key messages to be disseminated through Public Engagement in Data Research Initiative (PEDRI). Furthermore, as the PAB feels that there is a lack of public facing resources that adequately address management of risks relating to UPRN, there are also plans for public-lead podcasts to be developed in the future. Together, this will improve research practices and help to earn public trust through meaningful PPIE, governance and addressing privacy concerns.</p>
8	<p>Role of HDR UK (250 words):</p> <p>This work arises from a partnership between the PAB and researchers working on the SEDH Driver Programme. It would not have been possible without HDR UK networks, funding and facilitation. In particular, working group meetings have been organized and facilitated by Ester Bellavia (and supported by Tara Dowd), resulting in a thoughtful and constructive series of discussions in which members of the PAB have acted as critical advisors and producers of the content. The initial approach to the PAB was co-ordinated by Doreen Tembo to identify interested PAB members to form a working group. The HDR UK Learning Team, including Rosie Wakeham and Sam Wise have supported the researchers in how to refine the structure and scripting of the material and will continue to support the final phase of work in which the content will be filmed.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>The resulting learning module will be made available, without a pay wall, via HDR UK Futures and will inform the perspectives and practices of researchers and wider health data science community.</p>

10	<p>Contribution to Research Culture (250 words):</p> <p>The process of creating this learning module has created a partnership between the PAB and researchers that will positively impact on the research culture of HDR UK, and amplified the public voice within researcher training materials. The discussions have shaped how researchers will plan, manage and communicate research that uses UPRNs, with PPIE and governance positioned at the heart of the research process.</p>
11	<p>Research Team and Collaborators:</p> <p>All members of the SEDH Driver Programme have contributed to the research. Huge thanks to ECRs Julia Shumway (PhD Candidate, UCL GOS Institute of Child Health) and Oluwaseyi Arowosegbe (Research Associate, Imperial College London) who have supported the development of learning materials.</p> <p>This work would not have been possible without the invaluable advice, support and critical appraisal of the Public Advisory Board: Aisha Kekere-Ekun, Alan Holcroft, Gavin Malloch, Mandy Rudczenko, Munisa Hashimi and Sara-Jane McAteer who have input into the development of the materials.</p> <p>We thank all HDR UK staff who supported this work including: Ester Bellavia, Tara Dowd, Doreen Tembo, Rosie Wakeham and Sam Wise.</p>
12	<p>Funding:</p> <p>The research was funded by the HDR UK SEDH Driver Programme with all Public Advisory Board time and input to learning materials funded through HDR UK central PPIE and training funding.</p>

23. Provenance and integrity of key national datasets characterized through a clinical trialist secondment with NHS DigiTrials

1	Researcher(s) Name: Dr Macey Murray
2	HDR UK Programme: Transforming Data for Trials
3	Affiliation(s): University College London (MRC Clinical Trials Unit [MRCCTU])
4	Title of Case Study (150 characters): Provenance and integrity of key national datasets characterized through a clinical trialist secondment with NHS DigiTrials.
5	<p>Summary of the Impact (150 words):</p> <p>The project investigated whether data held by NHS Digital/England (NHSE) is considered “source data” as defined by trial regulations. Sponsors need to show that all data in a trial are reliable, complete, and the systems that manage it support its integrity. This includes healthcare systems data that may be used for participant identification and outcome ascertainment. Detailed investigation with data architects and NHSE teams enabled the secondee to document the lifecycles of two frequently accessed datasets and assess their integrity: the Civil Registration of Deaths, and the Admitted Patient Care of Hospital Episode Statistics. Initial findings were presented in a position paper and shared with the Real-World Data (RWD) guideline working group at MHRA. Following discussion with MHRA during Jul-Oct2021, it was agreed that both datasets are “reliable, transcribed copies of the original data, suitable for use in clinical trials, subject to relevance”. The paper was subsequently revised and published in Feb2022 on Zenodo, along with a commentary in Aug2022.[1,2] The project improves transparency of data processes within NHSE, supporting trust in using these data for trials.</p> <ol style="list-style-type: none"> 1. Murray ML, Pinches H, Mafham M, et al. Use of NHS Digital datasets as trial data in the UK: a position paper. Zenodo 2022; published online 11 February 2022. https://www.doi.org/10.5281/zenodo.6047155 2. Murray ML, Love SB, Carpenter JR, et al. Data provenance and integrity of health-care systems data for clinical trials. Lancet Digital Health 2022; 4: E567-E568. https://doi.org/10.1016/S2589-7500(22)00122-4 <p>Underpinning Research (250 words):</p> <p>Consultation with key data teams (SUS, AHAS, HES, HES Data Quality, Corporate Metadata) and information gathering took approximately 6 months to complete. The secondment enabled access to confidential information about data platforms, quality, and processes. Metadata and lineage information recorded in NHSD and ONS publications and data dictionaries were also reviewed, and relevant details were extracted for each of the three lifecycle stages (submission, production, releasable) and described in the position paper. There was no PPIE input as this work was mainly technical descriptions of data processes and metadata. The UK medicines regulator, MHRA, was approached for input. The paper initially drafted in Apr 2021 was revised several times by the collaborative group before it was sent to MHRA in Jul 2021 for comment. A second meeting with MHRA was held in Oct 2021, during which it was agreed that the two datasets are reliable, transcribed copies of the original source data, suitable for use in trials, subject to relevance. The final position paper was published in Feb 2022 following detailed comments from the MHRA RWD group,[1] and a commentary about the work was published in Lancet Digital Health in Aug 2022, urging other data providers to provide provenance and integrity information to data users and trial sponsors.[2] Further work was funded by the Directors Innovation Fund in 2022.</p> <ol style="list-style-type: none"> 1. Murray ML, Pinches H, Mafham M, et al. Use of NHS Digital datasets as trial data in the UK: a position paper. Zenodo 2022; published online 11 February 2022. https://www.doi.org/10.5281/zenodo.6047155 2. Murray ML, Love SB, Carpenter JR, et al. Data provenance and integrity of health-care systems data for clinical trials. Lancet Digital Health 2022; 4: E567-E568. https://doi.org/10.1016/S2589-7500(22)00122-4

7	<p>Description of the Impact (500 words):</p> <p>The key impacts are 1) demonstrating that two important NHSE datasets are reliable, transcribed copies of source data, and are suitable for use in trials (subject to relevance), and 2) developing an approach to describe the provenance and assess the integrity of health data that can be used by other data providers. As of 17th Jun 2024, the paper has had 1355 unique downloads and 1757 unique views, boosted when the commentary in Lancet Digital Health was published in Aug2022.</p> <p>In addition, there were other impacts from the secondment, including providing trialist input into DigiTrials service development (feasibility testing, recruitment, outcomes).</p> <p>National reach and impact</p> <p>After publication of the commentary, other UK data providers were directly approached to discuss data provenance and integrity of their products. Ten providers met with the secondee and recognized the importance of such work. However, most of these had limited resources (staff time), but at least 2 agreed to prioritize gathering information on data provenance and integrity for data users: NNRD and Clinical Practice Research Datalink (CPRD). Both data providers share their data for clinical trials purposes. Negotiation with CPRD’s Senior Management Team to allow project initiation is ongoing (first reviewed in Apr2024).</p> <p>The secondee and NHSE also extended provenance work following funding from the Director’s Innovation Fund (DEDICaTe project, Jun2022-Mar2023) to develop NHSE’s Central Metastore, considered the “single source of truth” about NHSE data. The secondment continued until just before the merger of NHS Digital with NHS England. The project was successfully completed in Mar2023 with a publicly available website with outputs of the project, comprising lineage diagrams of 4 datasets (including the two from the original position paper, and HES Critical Care and HES Outpatients), videos explaining lineage, an operating manual to allow others to learn how to ingest lineage/provenance information using a metadata tool. Early results were presented at the International Clinical Trials Methodology Conference in Oct2022, where the secondee was runner up of the UKCRC CTU Directors’ Award for the presentation with the ‘Greatest Potential for Future Impact’. A manuscript describing the work has undergone peer review and will be published in the Health Informatics Journal later in 2024. Further work to capture the lineage of SACT (Systemic Anti-Cancer Therapy) in the Central Metastore was commissioned by CRUK (through the Cancer Data Collaborative) and completed by an independent consultant in Mar2024.</p> <p>International reach and impact</p> <p>The paper has international reach as trialists and clinical researchers in Canada (Ontario Health, University of Toronto) and Australia (Population Health Research Network, Australian Clinical Trials Alliance) have approached the lead researcher for advice and collaboration on subsequent projects.</p>
8	<p>Role of HDR UK (250 words):</p> <p>HDR UK funded the researcher through the HDR London site (clinical trials focus), so clinical trials expertise and resources were provided to NHS DigiTrials during the secondment (Dec2020-Dec2022). NHS DigiTrials was funded by HDR UK as a hub, enabling the strategic partnership between the MRCCTU and NHSE, and the convening of the Healthcare Systems Data for Clinical Trials Collaborative Group (a collaboration between MRCCTU, NHSE, and the Nuffield Department of Population Health, University of Oxford – all involved in the HDRUK Trials programme). The timing of the secondment was during the early development of DigiTrials service offerings, so the embedded trialist was able to advise and influence planning and development such as: test the feasibility dashboard service (launched Feb2023), critique plans for the recruitment service, and provide user-input in the re-design of the DARS online application system (launched Jan2024).</p> <p>Subsequent work funded by the Director’s Innovation Fund (DEDICaTe project; Jun2022-Mar2023) was initiated with the Corporate Metadata team at NHSE to populate a centralized repository of metadata and lineage information of 4 NHSE datasets, known as the Central Metastore, and to share access publicly for data users via a website (https://dedicate.healthandcaremetadata.uk/).</p>

9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>The paper supports transparency and trust in the use of the two datasets as users (trialists, other researchers, regulators) can see how the data are managed by NHSE. The publication of the position paper was through the open-access Zenodo platform, and it has had 1355 unique downloads and 1757 unique views, boosted when the commentary in Lancet Digital Health was published. The paper has national and international reach as trialists and clinical researchers in Canada and Australia have approached the lead researcher for advice and collaboration on subsequent projects.</p> <p>The MHRA reviewed the paper before publication and stated that the two datasets were considered as “reliable, transcribed copies of original source data, suitable for use in trials subject to relevance.” Although no reference to the paper was made, the MHRA RWD guideline on RCTs was updated after consultation with our group to say “all-cause mortality and inpatient hospitalisations are known to be well recorded in the UK general population”.</p> <p>Dissemination was also through invited presentations in the UK (Mar2022-Sep2023) to audiences such as statisticians (NIHR Statistics Group), trial managers (UK Trial Managers Network, individual trials units), cancer researchers (National Cancer Research Institute), data providers, UK government, including SDE commissioners (Clinical Research Recovery, Resilience and Growth Data and Digital Subgroup), national webinars (BHF Data Science Centre, TMRP), and national and international conferences. Some of these presentations were recorded webinars that have been shared on YouTube.</p> <p>The work has already directly supported ongoing clinical trials needing to provide documentation of assurance on data provenance and integrity of these datasets at regulatory agency audit, including the RECOVERY trial. Dissemination to clinical trial teams will be enhanced by the ongoing work of the Transforming Data for Trials programme.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>A collaborative group was formed between academic researchers at UCL, Oxford (Nuffield Department of Population Health) and NHSE for this work (convened by the lead researcher). This shows that mutually beneficial partnerships between different stakeholders can advance knowledge using health data, thus aiding trust and transparency for data users. Similar collaborations with other data providers are already in development such as with CPRD.</p> <p>The outputs of the secondment (position paper, commentary, subsequent HDR DIF project) has enabled discussion with data providers about the provenance of their datasets and consider what they need to support similar characterizations. A number of these providers are active in the HDR UK Transforming Data for Trials programme through the Stakeholder Prioritization Forum, because of these discussions around data integrity.</p>
11	<p>Research Team and Collaborators:</p> <p>Healthcare Systems Data for Clinical Trials Collaborative Group</p> <p>MRCCTU: Dr Macey Murray (Senior Research Fellow), Professor Matt Sydes (now NHS England), Associate Professor Sharon Love, Professor James Carpenter, Professor Max Parmar (Director).</p> <p>NHS Digital/England: Heather Pinches (formerly Head of Clinical Trials Service 2019-2024), Prof Michael Chapman, Tom Denwood (former Director of Research and Clinical Trials), Suzanne Hartley (formerly senior trial manager at Leeds CTRU and NHS DigiTrials secondee, now at Data Access Request Service).</p> <p>Nuffield Department of Population Health, University of Oxford: Professor Sir Martin Landray, Associate Professor Marion Mafham.</p> <p>Other collaborators</p> <p>NHS DigiTrials: Andy Rees (Programme Manager), Annie Walker (Technical Lead).</p> <p>Corporate Metadata team, NHSD/E: Laura Sato (Head), Jaspal Panesar (Project Manager), Rebecca Lee (Data Architect).</p>

12	<p>Funding:</p> <p>HDRUK QQ1 funded the research fellow at UCL (Macey Murray) from Nov2019 to Mar2023, which allowed her to be seconded from Dec2020 to Dec2022 for 2 days/week. The secondment ended just before the merger of NHS Digital with NHS England.</p> <p>HDR UK Director’s Innovation Fund (Jun 2022-Mar 2023) supported the follow-on project, Demonstrating Data Integrity of routinely collected healthcare systems data for Clinical Trials (DEDICaTe). Much of the funding supported a data architect in the NHSE’s Corporate Metadata team. The outputs are available via a public-facing website hosted by NHS England (previously NHSD) https://dedicate.healthandcaremetadata.uk/</p>
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24. Science Festivals: New places, new activities, new audiences

1	Researcher(s) Name: Anna Woolman (not a researcher!)
2	HDR UK Programme: Patient and Public Engagement and Involvement (PPIE) team
3	Affiliation(s): NA
4	Title of Case Study (150 characters): Science Festivals: New places, new activities, new audiences
5	Summary of the Impact (150 words): In response to HDR UK public contributors request for more public engagement opportunities beyond London, the PPIE team have been trialing new approaches to engaging audiences with health data at science festivals across the UK. Festivals have so far included Humber Science Festival and Northern Ireland Science Festival, with Orkney International Science Festival (Scotland) and Bridgend Fun Day (Wales) on the horizon. Already, the learnings and impact of attending science festivals has been broad. For many audiences, taking part in HDR UK activities was the first time they were coming across the concept and impact of health data research. For the HDR UK team, it was an opportunity to collaborate with regional HDR UK partners and public advisory board members to develop and deliver new science engagement activities for non-specialists, platforming the science and public contributor stories. This also created ready-made content for future public engagement opportunities and strengthened relationships.
6	Underpinning Research (250 words): After discussion and development of HDR UK's public engagement strategy, it was decided to pilot attendance at science festivals across the UK's four nations between 2023 and 2024. The Public Advisory Board (PAB) and HDR UK Voices Network emphasised the need to reach younger audiences who do not typically engage with science, leading to the decision to primarily target science festivals taking place outside of university towns and cities where possible. Humber Science Festival (September 2023) and Northern Ireland Science Festival (February 2024) were the first two events HDR UK attended. Because of the ambition to reach younger audiences, family-friendly activities were developed and delivered alongside the Public Advisory Board, other public contributors, researchers and HDR UK partners. They ranged from using lego to demonstrate how data is sorted, to a ring toss game illustrating the difficulties of finding cures for heart disease, loaned by the British Heart Foundation, a 'data jigsaw' created in collaboration with HDR Northern Ireland, hook-a-duck and competitions. Audiences also had the opportunity to speak to HDR UK public contributors and sign-up to the HDR UK Voices network. Upcoming festivals in Scotland and Wales respectively are Orkney International Science Festival, suggested by the PAB and Bridgend Fun Day. In Orkney the team are trialing a conversational-style panel event with scientists and public contributors aimed at adults in addition to family-friendly activities.

7	<p>Description of the Impact (500 words):</p> <p>Across both festivals, many audiences reported this was the first time they were hearing about health data research. Despite this, there were at least 34 sign-ups to the HDR UK Voices public contributor network suggesting the activities were successful in engaging people. The events also led to a doubling in HDR UK Voices webpage visits.</p> <p>Internally, approaches to evaluation improved upon between festivals. For example, while there were difficulties in understanding audience numbers at the first festival (Humber), this was addressed at the second (Northern Ireland) where over 400 members of the public engaging with the activities.</p> <p>Audience and staff feedback demonstrated which activities proved popular and those that didn't work so well, meaning they are being re-considered for the future.</p> <p>Participating in science festivals has been the first time PPIE HDR UK team have conducted an in- person public outreach campaign. Although the project is only half-way through, it has already enabled the team to collaborate with different people and organisations to develop activities, forging new relationships and strengthening existing ones. Going forward, the learnings from it will be invaluable in developing HDR UK's approach to understanding and engaging with new audiences.</p>
8	<p>Role of HDR UK (250 words):</p> <p>The HDR UK PPIE team are leading on science festival involvement. However, it could not be fully realised without the involvement of the Public Advisory Board, HDR UK Voices, other public contributors, HDR UK Northern Ireland, Scotland and Wales researchers, partner organisations and other HDR UK colleagues who co-developed and -delivered activities.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>Our approach to public engagement places knowledge exchange front and centre. Throughout the process, from attending and choosing science festivals, to developing and delivering activities, we have taken a collaborative approach involving public contributors, HDR UK researchers and other public engagement professionals.</p> <p>The PPIE team have pro-actively shared reflections and learnings from the science festival activities, including in a blog which as been viewed 62 times since it was published in February 2024. Between NI Science Festival and Humber Science Festival, we shared 20 posts across X and LinkedIn with a total of 19486 views.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>Our public engagement work, by nature, aims to improve research culture through the involvement of researchers <i>and</i> public contributors in developing and delivering engagement activity. We hope this approach will lead by example, encouraging our research communities to value the role of collaboration and public involvement in health data research.</p> <p>The Public Advisory Board have been directly involved in deciding the festival locations as well as determining which activities were best to develop further. Our HDR UK Voices network have also been involved in attending the festivals and sharing their stories. Researchers reached through regional HDR UK networks have also been involved in our events, enabling them to have two-way dialogue with the public and enabling them to take part in public engagement in a safe space.</p>

11	<p>Research Team and Collaborators:</p> <p>HDR UK Patient and Public Involvement Team HDR UK Public Advisory Board HDR UK Voices Network</p> <p>HDR UK Northern Ireland, HDR UK Scotland, HDR UK Wales Project leads:</p> <ul style="list-style-type: none"> ● Anna Woolman (HDR UK Public Engagement Manager) – new lead ● Rachel Edwards (HDR UK Public Engagement Officer) – previous lead Event support: ● Ester Belavia (HDR UK PPIE Manager) ● Tara Dowd (HDR UK PPIE Officer) ● Doreen Tembo (HDR UK Head of PPIE) ● Debs Barber (HDR UK Communications Manager) ● Eilidh Ferguson (HDR UK Procurement Manager) ● Westley Igbo (DARE UK Engagement and Communications Manager) ● Dona Reddiar (HDR UK Doctoral and Internship Programme Manager) ● Rachael Bazuaye (HDR UK PPIE Officer) ● Holly McKenna (BHF Data Science Centre Communications Manager) ● Cathie Sudlow (HDR UK Chief Scientist) ● Sara-Jane McAteer (Public Advisory Board) ● Jan Speechley (Public Advisory Board) ● Sarah Markham (Public Advisory Board) ● Tony Plant (Public Advisory Board) ● Sonia Patton (Public Advisory Board) ● Theano Stoikidou (HDR UK Voices) ● Justin Greenwood (HDR UK Voices) ● Nicola Monk (BHF Data Science Centre Public Advisory Group) ● Chris Monk (public contributor) ● Emma Cassinelli (Queens University Belfast) ● Laura McGowan (Queens University Belfast) ● Mome Mukherjee (University of Edinburgh) Science festival collaborators: ● Sarah Jones (NI Science Festival) ● Aoife Earley (NI Science Festival) ● Stephanie Garner (NI Science Festival) ● Jillian Thompson (NI Science Festival) ● Mark Lorch (Hull Science Festival) ● Charlotte Pinkerton (Hull Science Festival)
12	<p>Funding:</p> <p>HDR UK core funding.</p>

25. Co-development and Adoption of Transparency in Data Access Standards: Process, Implementation, and Impact

1	<p>Researcher(s) Name:</p> <p>Yemi Macaulay (Information and Research Governance Manager) and Ester Bellavia (Patient and Public Involvement and Engagement [PPIE] Manager), on behalf of the HDR UK Legal Trust and Ethics team</p>
2	<p>HDR UK Programme:</p> <p>Pan-UK Data Governance Steering Group Five Safes Action Force Working Group with nominated organisations from the following organisations (HDR UK Public Advisory Board members, Office for National Statistic, Public Health Scotland, OpenSafely, UK Longitudinal Linkage Collaboration, NHS Digital Independent Group Advising on the Release of Data (IGARD), Health and Social Care Northern Ireland (HSCNI), Health Research Authority (HRA), SAIL Databank, Kings College London AI Centre, BHF Data Science, NHS BUCKINGHAMSHIRE, OXFORDSHIRE AND BERKSHIRE WEST ICB, NHS England, University of Dundee- School of Medicine</p>
3	<p>Affiliation(s):</p> <p>HDR UK</p>
4	<p>Title of Case Study (150 characters):</p> <p>Co-development and Adoption of Transparency in Data Access Standards: Process, Implementation, and Impact</p>
5	<p>Summary of the Impact (150 words):</p> <p>The development of Transparency Standards began in early 2023 as part of a multi-stakeholder collaboration. This initiative followed the release of the Clear communication on data access procedures standards by HDR UK’s Public Advisory Board (PAB) and its alignment with the focus of the Five Safes Action Force Working Group. Since its inception, the initiative has (a) advanced methods in data access through cross-sector partnerships and research networks; (b) enhanced public trust by including public members; (c) improved research culture and capacity by emphasising cross-sector collaboration and public involvement; and (d) increased capacity with additional funds. The HDR UK funds and successful Medical Research Council (MRC) funding bid have enabled the implementation of these standards across different contexts. Outputs from the 19 awarded projects demonstrates the value of dedicated resources in improving local realities and contributing to the broader research field, highlighting both immediate and potential impacts.</p>
6	<p>Underpinning Research (250 words):</p> <p>In 2021, the National Data Guardian released a report emphasising transparency throughout the data life cycle—from collection, storage, assessment, and use—and advocated for inclusive governance. Following this, HDR UK’s PAB investigated public involvement practices within the UK Health Data Research Alliance (the Alliance), finding missed opportunities on health data policies and inconsistent data access procedures.</p> <p>A 2022 follow-up review of Alliance members websites revealed further issues such as inaccessible language, incomplete information, and outdated formats. In response, the PAB created the Clear communications about data access procedures standards, presented to Alliance members in the form of recommendations. These recommendations were divided in two categories: ‘core standards’, which outline the essential activities that should be standard practice, end ‘enhanced standards’, which suggest desirable activities to further increase transparency and public trust in data access processes.</p>

	<p>Simultaneously, the Five Safes Action Force Working Group reviewed the accessibility and transparency of the data access application processes across Alliance members in 2022. They assessed whether custodians published data access application forms, outlined the steps of the process on their websites, and communicated adherence to the Five Safes framework. These reviews informed the initial draft of the Transparency Standards, developed through consultations with PAB and Five Safes Action Force Working Group members, and published in August 2023.</p>
7	<p>Description of the Impact (500 words):</p> <p>The impact of this project has been diverse and continues to unfold, with a particular focus on four key areas:</p> <ul style="list-style-type: none"> - Advancing methods for data access: A critical achievement of this project has been the co-development of Transparency Standards, to enhance the accessibility, availability, and transparency of health data custodians' processes. These standards were collaboratively shaped by the Five Safes Action Force Working Group and PAB members, aiming to streamline the process of accessing health data for research purposes. The introduction of open access application forms (Standard 1), transparent application processes and criteria (Standard 2), clear website navigation (Standard 3), value of target audience (Standard 4), regular website content review (Standard 5), and transparency of data use and auditing (Standard 5) has already shown significant improvements in accessibility and use for stakeholders, as demonstrated by the outputs of the 19 projects funded. - Enhancing public trust through inclusive practices: Central to the team's efforts has been the active involvement of public members in every stage of project development. This inclusive approach ensures that outputs meet diverse community needs and strengthens the social contract between research organisations and the public. By integrating public perspectives into decision-making processes, including creating and reviewing research materials, the team was able to uphold the principles of the social license theory, fostering greater accountability and transparency in ways of working. - Improving research culture and capacity through stakeholder engagement: The adoption of Transparency Standards has promoted consistency among data custodians, encouraging organisations to standardise and streamline their data access protocols. Through funding initiatives, numerous organisations have successfully implemented these standards, demonstrating remarkable agility and innovation in enhancing their operational frameworks. This flexibility has empowered recipients to tailor their approaches to meet specific standards, resulting in substantive improvements across the sector. - Increasing capacity through strategic funding: The funding initiative and subsequent showcase event have provided a valuable platform for knowledge exchange among participating organisations. By sharing good practices and showcasing successful implementations of the standards, these forums have promoted broader adoption and innovation within the sector. Moreover, the initiative has underscored the transformative potential of modest financial support in encouraging organisations to adopt novel practices, such as public disclosure of committee minutes and rejected applications. These initiatives not only strengthen organisational transparency but also raise public trust in research practices. <p>In conclusion, the impact of these initiatives extends beyond immediate improvements in data access and transparency; they have also contributed to a more inclusive and accountable research environment.</p>

8	<p>Role of HDR UK (250 words):</p> <p>Below is an overview of HDR UK’s role in this project and its significant contribution to impact:</p> <ul style="list-style-type: none"> - HDR UK manages and provides funds for the Alliance, which established the Pan-UK Data Governance Steering Group (Steering Group) in 2022. The Steering Group includes representatives from data custodians, policymakers across the four nations, data science professionals, government data owners, and public members. Its focus is on simplifying and streamlining data access governance processes through four ‘Action Forces’. The Action Force involved in this project is the Five Safes Action force. HDR UK draws on the expertise of its PAB members, who provide strategic and operational guidance. Managed and funded by HDR UK’s PPIE team, the PAB ensures that stakeholder perspectives are integral to decision-making processes. HDR UK submitted a bid to the MRC for additional funding for the Transparency Standards project, which supported its implementation. - HDR UK has actively supported and funded dissemination efforts, including the following: organising a showcase event publicised via email and through social media; arranging for the publication of projects abstracts and posters in the International Journal of Population Data Science; submitting a proposal for, and being shortlisted for, presentation of project process and impact at the quarterly Shared Commitment to Public Involvement Learning and Sharing meeting; and developing bitesize videos featuring various perspectives, which will soon be available online. These efforts have helped raise awareness of the initiative, its value, and its impact beyond the HDR UK community through various channels and dedicated resources.
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>This initiative has significantly contributed to open science and knowledge exchange in health data research through several key achievements:</p> <ul style="list-style-type: none"> - Development and publication of Transparency Standards: These standards provide clear guidelines to promote transparency in health data research, demonstrating the research team’s commitment to open science practices. - Continuous public involvement: Throughout the project, the research team worked closely with the public to address their interests and concerns. This partnership ensured that public perspectives were integrated into the health data research process, extending beyond the scope of this initiative. - Collaboration with various stakeholders: The collaboration with and between PAB members and the Five Safes Action Force Working Group highlighted the importance of diverse perspectives in research practices. - Secured additional financial support: Through a successful MRC funding bid, the initiative expanded the implementation of Transparency Standards across various contexts. This funding also facilitated public involvement in the projects, thereby promoting research inclusivity and ensuring broader societal relevance. - Participation in showcase event: Representatives from over 100 Alliance members attended the showcase, there they were able to review posters detailing project background, objectives, Transparency Standards implemented and their impact on public and researchers, and any transferable insights. - Recognition with a best poster award: PAB members assigned this award in acknowledgement of excellence in presentation quality, poster aesthetics, contributions to the field, and other outstanding components.
10	<p>Contribution to Research Culture (250 words):</p> <p>Based on the information documented above, this research project initiative has significantly advanced research culture by promoting open science and transparency, fostering public involvement, facilitating multi-stakeholder collaboration and knowledge sharing, supporting capacity building through additional funding, and gaining recognition through publications, poster showcases, and awards. These efforts collectively contribute to a research environment where integrity, collaboration, and innovation thrive.</p>

11	<p>Research Team and Collaborators:</p> <p>Legal Trust and Ethics team member Yemi Macaulay led the project, supported by Ester Bellavia who ensured continuous involvement of HDR UK's PAB. Cassie Smith and Andy Boyd, HDR UK Trust and Transparency pillar leads, played a key role in initiating and facilitating collaboration among stakeholders to advance this initiative. They also successfully secured additional funds from the MRC to implement the standards. The Alliance team led by Paola Quattroni. provided significant support in shortlisting projects for funding, while the HDR UK Contract team, led by Crysta Kaczmarek, ensured a clear, fair, and transparent process from funding shortlisting to assignment. Additionally, the HDR UK Communication team, led by Jonathan Wood, was instrumental in creating online content and promoting knowledge sharing before and after the transparency standard showcase. In addition to these efforts, several members of the HDR UK community from various teams volunteered to support the organisation of the showcase.</p>
12	<p>Funding:</p> <p>HDR UK provided funding for the development and dissemination of the Transparency Standards. The implementation of these standards across 19 different projects was supported by the MRC, with each project eligible to apply for up to £15,000.</p>

26. Principles of data access, providing the foundation for a standardised Data Access Agreement (DAA) template, designed for use across the network of Trusted Research Environments (TREs) and Secure Data Environments (SDEs) in the UK. By providing a familiar format and terms, the template aims to build trust amongst data owners and the UK public and to provide clarity to researchers on their obligations to protect the data. Widespread adoption is intended to accelerate health data research by enabling faster times from project approval to data access

1	<p>Researcher(s) Name:</p> <p><u>TRE Legal Toolkit Action Force members:</u></p> <p>Rachel Brophy, Cassie Smith, Andy Boyd, Edel McNamara, Yemi Macaulay, Paola Quattroni, Stephen Burrows, Andrew Morris [HDR UK]</p> <p>Alan Harbinson, Alison Afrifa [Honest Broker Service, Northern Ireland] Alison Knight [Health Research Authority (HRA)]</p> <p>Allison Noble [Research Data Scotland]</p> <p>Amir Mehrkar, Liam Hart, Juliet Underdown [OpenSAFELY / Bennett Institute, University of Oxford] Carole Morris [Public Health Scotland]</p> <p>Dauids Evans [NHS Transformation Directorate]</p> <p>Ishbel MacPherson [Burness Paull LLP, previously HDR UK]</p> <p>Katharine Evans [UK Longitudinal Linkage Collaboration (UK LLC), University of Bristol] Kevin Willis, Amy Ogborne [NHS England]</p> <p>Konstantinos Kaouras, Meave Groot Bluemink, Our Future Health]</p> <p>Pamela Linksted [DataLoch, NHS Lothian]</p> <p>Liz Merrifield [Wales Cancer TRE, Cardiff University]</p> <p>Pete Stokes [The Data Lab, previously Office for National Statistics] Sharon Heys [Secure Anonymised Information Linkage (SAIL) Databank]</p> <p><u>Other Collaborators (Patient representatives, Contracts Subgroup, Industry Representatives):</u></p> <p>Munisa Hashimi, Amanda Rudczenko, Tony Plant, Roger Gibb [HDR UK Public Advisory Board (PAB)]</p> <p>Marie Devlin [Queen’s University, Belfast]</p>
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	<p>Rajive Sharma, Mary Fitzgerald [University of Bristol]</p> <p>Doug Akins [University of Southampton]</p> <p>Sophie Baines [University of Oxford] Brian</p> <p>Berry [University of Nottingham]</p> <p>Janet Valentine, James Squires [The Association of the British Pharmaceutical Industry (ABPI)] Claire</p> <p>Edgeworth [NECS]</p> <p>Ruth Boardman, Laura Goold, Lucy Turner [Bird & Bird]</p> <p>Adam McArthur, Laura Marchant, Matthew Bonam [Astra Zeneca]</p>
2	HDR UK Programme: Trust & Transparency
3	Affiliation(s): (As above in brackets)
4	<p>Title of Case Study (150 characters):</p> <p>Principles of data access, providing the foundation for a standardised Data Access Agreement (DAA) template, designed for use across the network of Trusted Research Environments (TREs) and Secure Data Environments (SDEs) in the UK. By providing a familiar format and terms, the template aims to build trust amongst data owners and the UK public and to provide clarity to researchers on their obligations to protect the data. Widespread adoption is intended to accelerate health data research by enabling faster times from project approval to data access.</p>
5	<p>Summary of the Impact (150 words):</p> <p>In providing an open-source output in the form of a template DAA the aim is to streamline and standardise data governance, preventing the need for DAA development and legal resource at each TRE/SDE Host Organisation and/or TRE/SDE Coordinator Organisation. By providing a standard template which will become familiar, review times and burden on contracting teams at the User Organisation should also reduce, offering cost and time-effectiveness, leading to faster data access from the point of project approval. All parties involved in the contracting process will have clarity in their roles and obligations to protect the data, including approved researchers in the form of click-through Terms and Conditions upon access to the TRE. Cross-sector partnerships, bringing together stakeholders from the health and non-health data domains, non-commercial and commercial, ensure all are working to the same robust standards and to the same principles of data access. Involvement of members of the public in the development of the underpinning principles and DAA will help build trust in the way data is accessed in TREs and the associated governance controls, and in that the public voice has been incorporated into the work.</p>
6	<p>Underpinning Research (250 words):</p> <p>The template Data Access Agreement (DAA) is available as an open resource on Zenodo: TRE Data access agreement template (zenodo.org) and the methodology behind the development and the underpinning principles have been published in the International Journal of Population Data Science (IJPDS): https://doi.org/10.23889/ijpds.v8i4.2169. The intention is for widespread adoption of the DAA template and to foster an understanding of the potential impact via the published article. We are working with established TRE hosts, including UK LLC), SAIL Databank, Our Future Health, and those in setup, such as the NHS Subnational SDE network and BHF Data Science Centre Cohorts TRE, to assess the feasibility and operational implications of adoption of the template and to collect metrics on time from approval of a project to time to data access before and after the introduction of the template. The template and principles of data access have been mapped against the Five Safes Framework and were initially formulated by conducting a benchmarking exercise of DAAs in place for established</p>

	<p>TREs. Core clauses have been formulated and extensively reviewed where there is a need for commonality and clarity in the TRE network, and flexibility is accounted for in the customisable annexes, each with guidance on what to include and whether each annex is mandatory or optional depending on the TRE model. The TRE Legal Toolkit Action Force, consisting of members of the Pan-UK Data Governance Steering Group of the UK Health Data Research Alliance have all contributed to the development and refinement of the template. A workshop was held with members of HDR UK’s Public Advisory Board to discuss the principles, and feedback was received via email following this, and incorporated into the data access principles.</p>
7	<p>Description of the Impact (500 words):</p> <p>The template DAA has been viewed over 1000 times and downloaded over 800 times to date on Zenodo. The published article on data access principles and development of the DAA is available via the IJPDS, an open-access peer-reviewed journal. An abstract on streamlining contracting to advance public benefit research has been accepted for oral presentation at the International Population Data Linkage Network (IPDLN) conference in Chicago in September 2024, with the purpose of sharing progress with an international audience. The HDR UK Early Career Impact Committee selected the principles/DAA paper as the top impact of the quarter in November 2023, and the DAA template received a Reproducibility Recognition at the HDR UK Conference in March 2024. Some feedback from the Early Career Impact Committee included:</p> <p><i>“Such a great overview of the TRE landscape and so well written that it was worth book-marking to continually refer to.”</i></p> <p><i>“I’ve saved it so inevitably when I have no idea what’s going on, I can go back to it”</i></p> <p><i>“Everyone should read this for fun - it’s a very useful guide to the TRE landscape”</i></p> <p><i>“Had pretty much top marks for me, good PPI engagement and involvement of all UK nations.”</i></p> <p><i>“This is very important in informing the research environment, helping to clarify processes.”</i></p> <p>The DAA template has been integrated into Aridhia Digital Research Environment (DRE) as a best practice example of a data use agreement: https://www.aridhia.com/blog/ensuring-control-of-data-with-data-use-conditions-in-the-aridhia-dre/</p> <p>The DAA template has also been included on a blog post on ‘Sector Standards Contracts: UK R&D’ by a Commercial Contracts Lawyer: https://thomasmorgan.substack.com/p/sector-standard-contracts-uk-r-and</p> <p>A news article summarizing the work was also published on the IJPDS website to point to the publication of the paper: ‘Unlocking the potential of data research through standardised access agreements’.</p> <p>Feedback on the ambitions of the work was received during the public involvement workshop with members of the HDR UK Public Advisory Board (PAB) and included in the published article along with many constructive quotes. A comment on the overall aims was:</p> <p><i>“Overall, I think it is a fantastic idea which could potentially streamline data access, but also ensure that a universal system and standards are in place.”</i></p> <p>Direct feedback to the authors was also received from a member of the PAB:</p> <p><i>“This really is a shining example of best practice in relation to PPIE.”</i></p>

	<p><i>"I am sure you have seen the many times I have used this piece of work as an example of PPIE best practice."</i></p> <p>HDR UK Voices is a network of public contributors, and the following blog post made reference to this work:</p> <p>HDR UK Voices blog post by Munisa Hashimi, Public Advisory Board member:</p> <p><i>"Throughout this process, I felt that my feedback was taken on board. I co-authored the journal article, with my comments being quoted, and I had a material impact on the template itself. I also felt supported and valued for both the positive comments I provided and the critiques on how to improve. The DAA template was a great example of how PPIE can be embedded and used to make meaningful change to health data projects. The DAA template also displayed the value of involving PPIE from a project's inception and the incredible impact that can be achieved when facilitated correctly."</i></p> <p>Research Contracts Leads from Russell Group universities have fed into the development of the DAA template as a TRE Legal Toolkit subgroup, via workshops and written feedback to ensure suitability for academic institutions.</p> <p>Ongoing discussions and collaborative working with NHS SDE network, Data for R&D, the Health Research Authority, and the Four Nations Contracts Leads are focusing on suitability for adoption across the NHS.</p> <p>Discussions have also been held with Industry representatives from representatives from Astra Zeneca and the Association of the British Pharmaceutical Industry (ABPI) and feedback incorporated into the DAA template, to ensure suitability for commercial partners.</p> <p>The DAA template will be included in the Office for Statistics Regulation report on Data Sharing and Linkage for the public good, as an example of where progress has been made.</p>
8	<p>Role of HDR UK (250 words):</p> <p>The TRE Legal Toolkit Action Force is a working group of the Pan-UK Data Governance Steering Group, an expert group of stakeholders involved in TRE data governance from across the four nations, with partners at the UK's Office for National Statistics. The TRE Legal Toolkit group and the associated outputs are coordinated by HDR UK's Information and Research Governance Manager, with all outputs receiving review and significant input from HDR UK's Head of Legal, Trust and Ethics, also Co-Lead of the Trust and Transparency Pillar of HDR UK's work, alongside significant input from the other Co-Lead (HDR UK and Director of the UK Longitudinal Linkage Collaboration). Input to the development of the contract template and paper was also received by HDR UK's Information Governance Manager and HDR UK's Data Protection Lead. HDR UK's Public Involvement Manager was instrumental in coordinating the public involvement element of the work and contributed to the paper. HDR UK's Head of Alliance and Alliance Engagement Programme Officer, Alliance Community and Engagement Officer and Alliance Delivery Manager have all contributed to sharing developments and outputs of the TRE Legal Toolkit group across the UK Health Data Research Alliance, including over 100 members across the UK. HDR UK's Programme Director for the Driver Programmes has also coordinated the sharing of knowledge across the Regional networks, and HDR UK's Programme Director for Infrastructure Services has shared across the Hubs. The Director of Infrastructure and Services has worked to develop coordinated working with the Data for R&D programme, to provide joined up communication and realisation of benefits of the outputs to the SNSDE network and connections to other workstreams such as commercial operations and technology. HDR UK's Head of Contracts has provided advice on the development of the DAA template.</p>

9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>The publication of the data access principles and DAA template as open access resources allows the sharing of knowledge and best practice across the UK, with the aim of streamlining and simplifying data governance processes. Frequent presentations to interested groups on the work enhances understanding and potential impact. Feedback will be sought from adopters of the template on areas which prompt requests for clarification or raise concerns, and that feedback will be used to further iterate the template in future.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>The multiple collaborators on this work from across the four nations, working in health and non-health data domains and from commercial and non-commercial organisations supports a healthy cross-sector research collaboration. The suitability of the DAA template as a resource across the ecosystem of TREs/SDEs aims to ensure all are working to the same standard in terms of data protection obligations and efficiency. The projected impact on research culture, in terms of cost and time effectiveness aims to accelerate data access, prevent unnecessary delays and frustrations in the research contracting process, while setting and maintaining robust data governance safeguards.</p>
11	<p>Research Team and Collaborators:</p> <p>The paper in the IJPDS was co-authored by Rachel Brophy, Cassie Smith, Ester Bellavia, Yemi Macaulay, Edel McNamara, Paola Quattroni, Andrew Morris (all HDR UK), Maeve Groot Bluemink (Our Future Health), Katharine Evans, Andy Boyd (UK LLC), Munisa Hashimi, Amanda Rudczenko (HDR UK PAB), Allison Noble (Research Data Scotland).</p> <p>The development of the DAA template was conducted by the TRE Legal Toolkit Action Force of the Pan-UK Data Governance Steering Group, with members from the following organisations: Bennett Institute for Applied Data Science (University of Oxford, England), DataLoch (Scotland), Health and Social Care (HSC) (Northern Ireland), Health Data Research UK (HDR UK), NHS England, NHS Health Research Authority (HRA), Office for National Statistics (ONS), OpenSAFELY, Our Future Health, Public Health Scotland, Research Data Scotland, Secure Anonymised Information Linkage (SAIL) Databank (Swansea University, Wales), UK Longitudinal Linkage Collaboration (University of Bristol, England), and Wales Cancer TRE Project (Cardiff University, Wales).</p> <p>The TRE Legal Toolkit Contracting Subgroup has members from the following institutions: University of Southampton, University of Bristol, University of Oxford, University of Nottingham.</p> <p>We have engaged with representatives from the ABPI and Astra Zeneca for an Industry perspective and sought legal advice from external law firms.</p> <p>Four members of HDR UK’s PAB were involved in the development of the principles and template.</p> <p>The Early Career Research Impact Panel reviewed and provided feedback on the template and paper.</p>
12	<p>Funding:</p> <p>HDR UK Core Funding.</p>

27. Policy Impact of the Trust and Transparency Team.

1	Researcher(s) Name: Edel McNamara
2	HDR UK Programme: Trust and Transparency
3	Affiliation(s): HDR UK
4	Title of Case Study (150 characters): Policy Impact of the Trust and Transparency Team.
5	Summary of the Impact (150 words): The team is focused on data access requirements to health data for research projects in the public good. We promote (a) enhanced public trust through the involvement and engagement of public members (b) Informing decision making through our support to researchers in understanding the importance of compliance with government, regulatory and health services policies when undertaking their research projects, and (c) Improve research culture and capacity ensuring the relevant stakeholder views (policy makers, public and patient members, data custodians) are considered when policy makers are implementing new practices, and our work is at the very core of providing vital support Public members and patients need to be involved in policies and decisions around how data is accessed to ensure that such policies are rules governing data access are acceptable and clear to them. Involving a variety of stakeholders in these decisions promotes trustworthiness and promotes transparency in data access.
6	Underpinning Research (250 words): In order for research to be trustworthy meaningful PPIE needs to be embedded at each step in the process including the underlying policies. To promote policies that make data available, underlying strategies and practices need to balance being trustworthy, with being permissive in allowing data to be used subject to controls that protect privacy and ensure use of data in the public good. The team, primarily through the work of the Pan-UK Data Governance Steering Group , have been reviewing and responding to open consultations and actively engaging with regulators and the NHS in order to impact research policies. This is to enable researchers, public and patients views and concerns to be taken into account and to ensure these policies will work for the research community and are suited towards the researchers using them. Enabling them to comply with requirements they need to adhere to (with a goal of making information more accessible in a less burdensome way). When responding to these consultations the team engaged with a number of parties including members the UK Health Data Research Alliance , the Pan UK Data Governance Steering Group, HDR UK's Public Advisory Board and the wider HDR UK community. The team engages with all these parties to enhance the voice of the research community, public and patients to enable their views to be shared with policy makers and their experiences to be considered.

7	<p>Description of the Impact (500 words):</p> <p>HDR UK have responded to several consultations including:</p> <ul style="list-style-type: none"> • The ICO Consultation: Transparency in Health and Social Care guidance • ICO Consultation: UK GDPR and DPA 2018: The Research Provisions • ICO Consultation: Anonymisation, pseudonymisation and privacy enhancing technology guidance • Public consultation on reforms to the UK's data protection regime: Data a New Direction • Call for Evidence The right to privacy digital data <p>ICO:</p> <ul style="list-style-type: none"> • The ICO adopted several points raised in our response to the Transparency consultation in the final guidance including: <ul style="list-style-type: none"> ○ Defining and separating the organisations that need to comply ○ Updated definition of transparency information ○ Include reference to opt-out policies and Common Law ○ Clarity that the guidance that being transparent about the benefits of using data to public health, as well as the risks promoting trust. ○ Expanding on the different communication methods that can be used in providing transparency information. • The ICO adopted Frascati definition of research, expanded the definition of research to include data preparation, data wrangling and other ancillary activities necessary to prepare and utilize data for research in response to our response of the Research Provisions. • The team is actively engaging with the ICO after the submission to our response on anonymisation, pseudonymisation and PETs through a case study focused on the use of data for research with a Trusted Research Environment. • The team is actively engaging with the ICO after the submission to our response on anonymisation, pseudonymisation and PETs. We have submitted a case study to them focusing on the anonymisation on data within a TRE. This case study was done in collaboration with a number of parties from the Steering Group (inc. MRC, HRA, RDS, NHS E, and SAIL) <p>Govt:</p> <ul style="list-style-type: none"> • The team responded to the written call for evidence on the right to privacy: digital data and Andrew Morris gave oral evidence to the Science, Innovation and Technology Committee. It was noted that the UK is well placed to make a meaningful and distinct contribution to global health data science and to fully realise the benefits of health data we must include all relevant parties and demonstrate that data can be used in a safe and secure manner. HDR UK promotes data access process for research using the Five Safes Framework which enables the right to privacy while unlocking the power of data. <p>NHS E</p> <ul style="list-style-type: none"> • The Steering Group facilitated a meeting where NHS E presented the new NHSE Value Sharing Framework followed by an opportunity for questions and discussion. This included presentations from NHS E on the Value Sharing Framework and a presentation by a member of HDR UK's Public Advisory Board followed by an opportunity for researchers and others to ask questions. A summary is available here. • The Steering Group were involved in and influenced the streamlining the accreditation framework for the SDE network, ensuring the researcher environments are aligned and accredited under the existing UK Statistics Authority Framework. This work was done in collaboration with the Alliance and HDR UK's Public Advisory Board.
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8	<p>Role of HDR UK (250 words):</p> <p>HDR UK manages and provides funds for the Alliance, which established the Pan-UK Data Governance Steering Group (Steering Group) in 2022. The Steering Group includes representatives from data custodians, policymakers across the four nations, data science professionals, government data owners, and public members. Its focus is on simplifying and streamlining data access governance processes through four ‘Action Forces’</p> <p>The team led of drafting all these responses which included reviewing the guidance and any other documents provided in detail and responding to them. The level of engagement for each of these responses varied depending on the nature of the consultation and the timescale needed to respond. For the ICO consultation of research the team brought the definitions of research to the wider HDR UK institution for feedback. When NHS E were seeking feedback on their draft Value Sharing Framework, HDR UK convened an event with members of the Alliance, Steering Group and Public Advisory Board to enable them to bring their thoughts and questions directly.</p> <p>HDR UK’s Public Advisory Board has been very involved in all our policy work, the team have presented and sought their feedback on several issues. For example, the NHS E Value Sharing Framework was brought to a HDR UK PAB meeting, where PAB discussed and gave their feedback, this was summarised by a member of PAB who presented their feedback on at the event. We have followed a similar pattern of bringing ICO consultations to the PAB and gathered and consolidated their feedback into our written responses.</p>
9	<p>Contribution to Open Science and Knowledge Exchange (250 words):</p> <p>We publish all our responses broadly sharing them with all of our partners including the Alliance and our wider community, a number of these policies have been published and shared online (e.g. Data a New Direction, Transparency Consultation, Submission UK Parliament Inquiry).</p> <p>The trust and transparency team aim to simplify and streamline data access processes through Pan-UK Data Governance Steering Group, which represents data custodians, policymakers, and public contributors across the four UK nations. In all our responses HDR UK promotes principles and best practices to enable ethical research for the public good, this includes promotion of the Five Safes Framework and active and meaningful engagement with and involvement of patients and the public. We promote and encourage regulators and policy makers to engage with frameworks and best practices that the research community undertakes e.g. guidance from the National Data Guardian.</p> <p>Our team is keen that transparency be embedded into all aspects of our work and we make outputs publicly available in order to share knowledge and expertise and to enhance collaboration by making it easy for parties to see our views and stance on topics. This enables us to promote changes with policy makers by unifying a number of voices.</p>
10	<p>Contribution to Research Culture (250 words):</p> <p>Data access processes and their underlying policies, regulations, and laws need to be trustworthy but also permissive. Meaningful engagement with the relevant communities, public and patients is necessary to achieve this. Transparency underpins good research culture, and we have engaged heavily with the ICO on their guidance on this and the progress achieved by the Transparency Standards. It is necessary that researchers and the health data science community and involved with shaping and feeding into the policies that govern their research and we convene working groups and workshops, create guidance, resources and facilitate partnerships to facilitate discussion</p> <p>This work has sought to embed the voice of researchers and member of the public in policy initiatives. The team engages with partners across the health data ecosystem landscape including partners from each of the four nations. There are numerous regulations, laws and policies all need to be adhered to when conducting health data science research projects.</p> <p>Through this work the team brings researchers voices and experiences to policy makers so that their experiences can impact policy makers and their work can be taken into account when policies and processes are updated.</p>

11	<p>Research Team and Collaborators:</p> <p>HDR UK Public Advisory Board, members of the Health Research Data Alliance, the communications team.</p> <p>The Steering Group consists of members from The Association of the British Pharmaceutical Industry (ABPI), Administrative Data Research UK (ADR UK), Advisory Group for Data, British Medical Association (BMA), Clinical Practice Research Datalink (CPRD)Data and Analytics Research Environments UK (DARE), ESRC UKRI, Genomics England, Health Research Authority, Medical Research Council (MRC), National Data Guardian Office (NDG), NHS E, Northern Ireland Health Social Care, Office Life Sciences, ONS, Our Future Health, HDR UK Public Advisory Board, Public Health Scotland, Research Data Scotland, Secure Anonymised Information Linkage Databank (SAIL), UK Longitudinal Linkage Collaboration (UK LLC), UK Stats Authority, UWE Bristol and the Welsh Government</p>
12	<p>Funding:</p>