

RESEARCH DATABASE

Annual Report to Research Ethics Committee

Research databases with approval from a Research Ethics Committee are required to provide the REC with an annual report on their activities. This form sets out the minimum content of the report and a template format, which may be adapted appropriately.

1. Details of the Chief Investigator of the Research Database (“Data Controller”)

Name:	Julia Hippisley-Cox
Address:	Nuffield Department of Primary Health Care Sciences, Oxford
E-mail:	julia.hippisley-cox@phc.ox.ac.uk

2. Details of the Database

Title:	QResearch Data Linkage Project
Establishment responsible for management of the database:	Oxford
Data Custodian <i>This should be a senior individual, not part of the research database team, who is responsible for oversight of the database within the establishment.</i>	Jane Weinstein Information Governance Manager Department of Primary care Health Sciences, Oxford jane.weinstein@phc.ox.ac.uk
Main REC:	East Midlands – Derby Research Ethics Committee
REC reference number:	23/EM/0166

3. Summary of activity for [period covered by report]

Please provide an overall summary of the database's activities during the year, including:

- *Data collection*
- *Use /release of data*
- *Collaborations with other databases /programmes*
- *Engagement with patients/service users and publicity*
- *Any significant developments in the database's scope, operation or governance.*

3.1 Data collection

More recent data from general practice, cancer registry, civil registry, hospital episode statistics, Intensive Care National Audit and Research Centre (ICNARC) SGSS, the National Immunisation (NIMS) Database and maternity services have been collected during the year and uploaded into the QResearch linked database.

3.2 Use/release of data

Please see appendix for a list of the currently approved projects many of which are using combinations of the GP data linked to HES, cancer registry, mortality, ICNARC and COVID-19 and NIMS COVID-19 vaccination data.

3.4 Database Scope, Operation and Governance.

There have been no major changes to the database scope, operation or governance. There are continual improvements to the QResearch Scientific and the QResearch Advisory Board as follows

QResearch Scientific Committee.

- The committee has both academics and lay representatives from within and external to Oxford. More details on members are published on the relevant section of the QResearch website.
- <https://www.qresearch.org/about/scientific-committee/>.
- Minutes of the Scientific Committee are published [here](#).
- Following a data privacy impact assessment (DPIA) in Spring 2024, the committee has agreed to reduce the information collected from applicants to the essential minimum. For example, CVs are no longer collected as they may have personal information. Instead we request a URL to the institutional web page [see minutes 08.07.2024]. This is better for data protection and also reduces the burden on researchers and administrative staff.
- Similarly, we have simplified the lay summary process to that the information is now only collected once and validated at the point of submission and then directly published to the website. This also reduces administrative burden on applicants, administrative staff and simplifies the scientific review process and makes it easier to maintain

QResearch Advisory Board.

- The advisory board met in July 2024 and provided guidance and advice on a number of initiatives to enhance patient engagement including new data linkages. Further information, including minutes of meetings, is published here <https://www.qresearch.org/about/advisory-board/>

Engagement with patients and service users and publicity

- **Engagement with practices:** we continue to produce a biannual newsletter which is disseminated via social media and our website [QResearch](#) and the Oxford University Website.
- **Engagement with patients:** There are two patient representatives on the QResearch Advisory Board and two on the QResearch Scientific Committee who provide feedback on aspects relevant to patients including information provided to patients, lay summaries of ongoing projects, governance and potential benefits of QResearch, and review applications to access the data for research projects. As a response to these patients, we are now improving the usability of the website for patients.
- **QResearch website lay summary:** A lay summary for all new and ongoing projects continues to be published and is now administered in a more efficient way as noted above. This continues to be reviewed as part of the Scientific Committee review. <https://www.qresearch.org/research/approved-research-programs-and-projects/>
- **QResearch Data Showcase;** We have continued to update the data section on the website which gives a high-level overview of the types of data collected and broad summaries for some major conditions (e.g. the total numbers of patients with cancer on the database). This is intended to provide more information to both services users and researchers interested in using the resource. <https://www.qresearch.org/data/> We also published information about the data on the HDR UK Innovation Gateway in 2022/3 and have reviewed it during 2024. <https://web.www.healthdatagateway.org/collection/4957748719417454>


Use and release of data

- In accordance with our protocol, all data is held on Oxford servers. No data is physically released to researchers – rather researchers who have approved projects and have met the eligibility criteria (including appropriate IG training) are provided with remote access to the server where the relevant subset of data is located. A full list of all current projects (including ongoing projects approved under the previous REC application prior to the move to Oxford) is appended.

4. Applications for access to data

Please append a listing of applications made to the database for release of, or access to, data during the reporting period, together with a lay summary of the purpose of each approved project. Include any releases authorised following a further project-specific application to a REC, as well as those authorised under generic approval.

5. Declaration

Signature of database manager:	
Date of submission:	16 December 2024

Applications for release of data

Please also provide a lay summary (maximum 200 words) for each project for which release of data was approved. Include both projects conducted within the research database team and by external researchers.

Year approved	Reference	Title	Lead investigator	Lead university	status	More information
2024	OX134	A risk prediction model for incident heart failure (RiskHF): validation cohort study	Clare Taylor	Oxford	pending	Awaiting publication
2024	OX162	Undiagnosed HIV, Hepatitis B and Hepatitis C in primary care	Werner Leber	QMUL	pending	Awaiting publication
2024	OX166	Defining the relationship between lipids, statins, and the risk of amyotrophic lateral sclerosis and frontotemporal dementia	Alexander Thompson	Oxford	In progress	see here
2024	OX183	The impact of obesity on survival outcomes following drug treatment for advanced malignancy	Ashley Clift	Oxford	In progress	see here
2024	OX200	SPCR HRT inequalities	Jennifer Hirst	Oxford	In progress	see here
2024	OX201	Identifying socioeconomic and ethnic disparities in key health outcomes by hormone replacement therapy use in women aged 40-80	Jennifer Hirst	Oxford	In progress	see here
2024	OX317	Safety of Medicines in Pregnancy	Julia Hippisley-Cox	Oxford	In progress	see here
2024	OX331	Risk of severe COVID-19 outcomes for people affected by blood cancer.	Julia Hippisley-Cox	Oxford	In progress	see here
2024	OX37	The Integration and Analysis of Data using Artificial Intelligence to Improve Patient Outcomes with Thoracic Diseases (DART)	Julia Hippisley-Cox	Oxford	Completed	see here
2023	OX171	Antibiotic use and survival from breast cancer	Chris Cardwell	QUB	In progress	see here
2023	OX173	Influenza, MenACWY, HPV and COVID-19 vaccines in children: uptake, safety and effectiveness during the COVID-19 pandemic	Julia Hippisley-Cox	Oxford	In progress	see here
2023	OX322	Quantifying disparities in HRT prescribing in the UK. An analysis of routinely collected healthcare data	Jennnifer Hirst	Oxford	In progress	see here
2023	OX330	Comparisons between three clinical research databases (QResearch, CPRD Aurum and CPRD Gold)	Julia Hippisley-Cox	Oxford	In progress	see here
2023	OX333	Analysis of survival from blood cancer in England	Diana Withrow	Oxford	In progress	see here
2022	OX149	Exploring the Long-term health Outcomes following a PrEgnancy with Gestational Diabetes Mellitus (ELOPE-GDM)	Nerys Astbury	Oxford	In progress	see here
2022	OX46	What knowledge would support improving the management of teenagers with dysmenorrhoea in primary care?	Sharon Dixon	Oxford	In progress	see here

2022	OX141	Effects of obesity on COVID in the 2nd wave of the pandemic (including healthcare costs)	Nerys Astbury	Oxford	In progress	see here
2022	OX154	The Psychosis Metabolic Risk Calculator (PsyMetRIC) - Validation, Recalibration and Model Revision Study	Benjamin Perry	Cambridge	In progress	see here
2022	OX164	Co-prescription of antibiotics and oral anticoagulants and risk of bleeding	Haroon Ahmed	Cardiff	In progress	see here
2022	OX309	MAARS Multimodal Active Adaptive Risk Stratification for Cancer	Julia Hippisley-Cox	Oxford	In progress	see here
2022	OX316	Uptake, effectiveness and safety of COVID-19 vaccinations in pregnant women	Julia Hippisley-Cox	Oxford	In progress	see here
2022	OX167	COVID-19 vaccination in children in England: uptake, safety and effectiveness	Martina Patone	Oxford	Completed	see here
2022	OX318	Dynamic evaluation and updating of Covid-19 risk prediction models over time: Methods and pipeline	Julia Hippisley-Cox	Oxford	Completed	see here
2022	OX7	Safety of atypical antipsychotic use in children and adolescents: a cohort study using the QResearch database	Yana Vinogradova	Nottingham	completed	see here
2021	OX128	Exploring the Long Term health outcomes of a Pregnancy with gestational Diabetes (ELOPE-GDM)	Nerys Atsbury	Oxford	In progress	see here
2021	OX136	Long Term Complications of Childhood, Adolescent and Young Adult Cancers	Defne Saatci	Oxford	In progress	see here
2021	OX3	Choosing the right antidepressant for depressive disorder	Andrea Cipriani	Oxford	In progress	see here
2021	OX57	Impact of GP intervention and smoking cessation on secondary prevention of cardiovascular disease in individuals diagnosed with CHD	Angela Wu	Oxford	In progress	see here
2021	OX94	Understanding the early presenting features and long-term complications of childhood and adolescent cancer	Defne Saatci	Oxford	In Progress	see here
2021	OX115	Evaluating diabetes as a risk pathway towards early diagnosis and prognostication of pancreatic ductal adenocarcinoma (PDAC)	Julia Hippisley-Cox	Oxford	Completed	see here
2021	OX30	DELIVER early detection and diagnosis of hepatocellular carcinoma (HCC) among the English population from primary care	Ellie Barnes	Oxford	Completed	see here
2021	OX107	Evaluation of the safety, uptake and effectiveness of COVID-19 vaccines	Julia Hippisley-Cox	Oxford	Completed	see here
2021	OX125	CoMPuTE: Complex Multimorbidity Phenotypes, Trends, and Endpoints	Rafael Perera	Oxford	Completed	see here
2021	OX153	Decision risk tool (QPancreasD) for early diagnosis of pancreatic ductal adenocarcinoma (PDAC) among new-onset diabetes	Pui San Tan	Oxford	Completed	see here
2021	OX300	Optimising NHS blood cancer patient care in the COVID-19 pandemic	Julia Hippisley-Cox	Oxford	Completed	see here
2021	OX69	Seasonal trends in antidepressant prescribing and mental health diagnoses in adolescents and young adults	Ruth Jack	Nottingham	Completed	see here
2021	OX79	OX79 Coronavirus Record Linkage Project	Julia Hippisley-Cox	Oxford	Completed	see here
2020	OX123	The impact of the COVID-19 pandemic on the diagnosis of childhood, teenage and young adult cancers	Defne Saatci	Oxford	In progress	see here

2020	OX29	Maternal depression and anxiety disorders and child mental health outcomes	Catia Nicodemo	Oxford	In progress	see here
2020	OX90	The Impact of Miscarriage on Mental Health Outcomes	Stavros Petrou	Oxford	In progress	see here
2020	OX100	Development and validation of a tool for predicting risk of short-term adverse outcomes from COVID-19	Ashley Clift	Oxford	Completed	see here
2020	OX102	Quantifying the association between ethnicity and COVID-19 outcomes: a population-based study using QResearch linked databases	Julia Hippisley-Cox	Oxford	Completed	see here
2020	OX54	Hepatitis B - natural history and burden of disease	Cori Campbell	Oxford	Completed	see here
2020	OX129	Development and validation of statistical learning models to predict breast cancer diagnosis and breast cancer mortality	Ashley Clift	Oxford	Completed	see here
2020	OX22	Dietary or weight loss advice for hypertension in diabetes in primary care	Carmen Piernas	Oxford	Completed	see here
2020	OX24	Use of HRT and cancer survival	Chris Cardwell	QUB	Completed	see here
2020	OX39	DELTA - integrated diagnostic solution for Early deTection of oesophageal cAncer	Rebecca Fitzgerald	Cambridge	Completed	see here
2020	OX66	Hormone replacement therapy and dementia risk: nested case-control studies using CPRD and QResearch	Julia Hippisley-Cox	Oxford	Completed	see here
2020	OX85	The effect of obesity on incidence and severity of COVID-19	Nerys Astbury	Oxford	Completed	see here
2020	OX86	Associations between COVID-19 infection, tobacco smoking and nicotine use, common respiratory conditions and drugs used for their treatment, : a prospective QResearch-Case Mix Programme data linkage study January-May 2020	Nicola Lindson	Oxford	Completed	see here
2020	OX99	A second wave of crisis in the NHS after the COVID-19 pandemic	Catia Nicodemo	Oxford	Completed	see here