

## **Infections in Oxfordshire Research Database (IORD) Privacy Notice**

**REC reference: 24/SC/0241**

**IRAS project ID: 339234**

**Date of REC approval: 5 September 2024**

### **Name and contact details of organisation**

Oxford University Hospitals (OUH) NHS Foundation Trust, based in the United Kingdom, is the administering authority for the Infections in Oxfordshire Research Database. This database contains anonymised health information from the Oxford University Hospitals NHS Foundation Trust. OUH is the sole data controller in respect of the data in this database, because the database is stored within NHS firewalls at the Trust. The Trust Data Protection Officer can be contacted at [DPO@ouh.nhs.uk](mailto:DPO@ouh.nhs.uk).

Data processors will include other institutions who will receive limited static extracts of specific data items (that is will not have access to the database itself) for specific analyses approved by the IORD Research Database Team and Patient and Public Panel. Researchers will propose infection-related analyses by submitting a project proposal detailing the aims and objectives, analysis plan and necessary data items. The Research Database Team comprises 18 members (majority independent of the National Institutes of Health Research (NIHR) Biomedical Research Centre and Health Protection Research Unit at Oxford, who provide support to the database). The patient and public panel comprises a group of interested and dedicated individuals who have volunteered to be involved with IORD activities in a less formal role than as a member of the research database team but with optimal opportunities to contribute their experiential expertise. Both will approve or reject proposals based on consideration of scope and feasibility, duplication with existing approved projects, possibility of identification of individuals from the requested data set or risk of loss of confidentiality, location where analysis will be conducted, and views from a wider group of patient representatives. Processing will involve analysis of data.

### **Key contact**

The contact is Sarah Walker, Professor of Medical Statistics and Epidemiology, [sarah.walker@ndm.ox.ac.uk](mailto:sarah.walker@ndm.ox.ac.uk).

### **Purpose of study**

IORD is an electronic research database whose primary goal is to use increasingly rich anonymised linked routinely recorded electronic data on hospital administration records (e.g. admission/discharge, ward movement, consultant episodes, diagnostic and procedure codes, demographics and mortality, theatre admissions), electronic medical records (e.g. vital signs, prescriptions), pathology (microbiology, virology, laboratory, histopathology) tests and radiology and other imaging data (e.g. echocardiography results). The aim of this database is to investigate predictors of and trends in incidence of, severity of presentation of, and adverse outcomes following infection (ascertained through microbial isolation or using clinical definitions) and infection-associated syndromes (e.g. pneumonia, sepsis) within Oxfordshire from 1997. This also includes investigation of incidence of and outcomes following infection in populations particularly at risk of infections, including, for example, those with cancer or chronic kidney disease. The overarching aim is for IORD findings to improve the management of infection in UK hospitals. The secondary goal is to use these data together with those from detailed studies (e.g. phenotypic/genotypic strain typing,

diagnostics) undertaken within the NIHR Biomedical Research Centre and Health Protection Research Unit, Oxford, to further elucidate mechanisms of changing microbial virulence at the population level.

### **The lawful basis for processing**

The lawful basis for collecting, storing, and using these personal data, as defined by the EU General Data Protection Regulation (GDPR) is 'Public Task'. These personal data are used for health and social care research, which is a task in the public interest.

### **Categories of data collected**

The anonymised data is obtained from a data-warehouse maintained by the OUH NHS Foundation Trust. The data are routinely collected by them for the purposes of treating patients. The following types of anonymised data are exported into IORD:

- patient administration records, including both inpatient admissions to OUH hospitals, and admissions to Oxfordshire community hospitals, as well as outpatient and "A&E" attendances, and patient details (e.g. gender, ethnicity, date of birth, vital status and date of death)
- pathology (microbiology, virology, laboratory, histopathology – one unified system historically and currently for all four hospitals within the OUH NHS Foundation Trust)
- clinical assessments, including routine measurements and imaging as well as risk factors for infection such as use of invasive devices and wounds, and clinical reviews
- electronic prescribing, including of antibiotics
- interactions with healthcare services outside of secondary care, including GP visits and prescriptions of antibiotics or steroids
- the Oxford maternity database
- infection control databases

### **Details of transfers of personal data**

This database uses existing, routinely collected electronic data. No person identifiable data is included in the database. Under no circumstances are data used for marketing purposes. Data are made available under the agreement that there will be no commercial value and no intellectual property (IP) leading to commercialisation arising from the project. Any project where this is not the case, or where this changes during the course of a project, should approach OUH directly for access to data; IORD data may not be used in these cases. Otherwise, limited static extracts of specific data items will be transferred to third parties for specific analyses approved by the IORD Research Database Team and Patient and Public Panel.

### **Retention details**

Data are being collected from 1997 to date and will be retained for 10 years after the ethical approval for the database expires, and then deleted. The amount of personal (health) data collected is limited to that needed to address research questions related to infections, and are obtained, stored (within the NHS firewall) and transferred securely for legitimate purposes.

### **Rights available to individuals**

All patients can request that their NHS records are not released for secondary use (for example, in Hospital Episode Statistics). Patients who have opted out of sending their hospital records to NHS

Digital would not have information included in this database. Individuals may also opt-out – please email [iord@ndm.ox.ac.uk](mailto:iord@ndm.ox.ac.uk) if you would like to discuss this.

This database has been approved by the South Central Research Ethics Committee (24/SC/0241) and the Confidentiality Advisory Group of the Health Research Authority (19CAG0144).

Making a complaint to the Information Commissioner’s Office (ICO)

If you are unhappy about how your data is being processed by OUH NHS Foundation Trust you may make a complaint to the Information Commissioner’s Office (ICO). You can contact the ICO at <https://ico.org.uk/global/contact-us/contact-us-public/>.