



Data AccessQuick Guide to



NHS Digital is the national information and technology partner to the health care system with responsibility for standardizing, collecting and publishing data and information from across the health and social care system in England.

This guide will give an insight into the types of data available, how to request access, and data security and delivery requirements.

What types of data does NHS Digital offer?

The platform presents data types including:

- Hospital Episode Statistics (HES) covers diagnostic and procedural information for impatient, outpatient, community care and A&E
- **Secondary Use Service (SUS)** combining HES and payments made for health economic analysis
- Diagnostic imaging metadata provides imaging results in text format (but no images). Also
 includes useful information about referral sources, patient type, and other demographic
 intelligence
- Civil registration and birth rates civil registration covers mortality data
- Mental health datasets from mental health, community health, psychological therapy and maternity services
- Patient Reported Outcome Measures (PROMS) based on Reponses to questionnaires, after surgery, PROMS measures health gain for patients who have undergone hip replacement, varicose vein and groin hernia surgery

Additional datasets will be added during 2020, such as the Adult Social Care Surveys and Emergency Care dataset, so it's worth checking the NHS Digital website regularly for updates on data availability

NHS Digital also manages access to patient surveys – which cover smaller populations and are therefore not always linkable to the other datasets

NHS Digital are also leading the <u>DigiTrial Health Data Research hub</u> for clinical trials. The hub is developing a foundation service to improve the assessment of clinical trial feasibility and will expand this service to provide a mechanism for patient recruitment, outcome reporting and follow up. Users of this

service will be asked for information on the scale of the market and any existing customers in order to assess the suitability of the research for the DigiTrial service.

NHS Digital are part of the recently launched <u>HDR UK Research Alliance</u> of health data custodians who aim to co-ordinate the adoption of standardized tools and techniques to drive the use of health data for research and innovation. As such, the NHS Digital datasets will be discoverable via the <u>HDR UK Innovation Gateway</u>. Users will be able to explore the MetaData Catalogue for information on the structure of the datasets. There is also a HES data dictionary available online.

Navigating the Data Access Request Service

NHS Digital runs the <u>Data Access Request Service (DARS)</u> which assesses, and grants access to selected <u>NHS datasets</u> for certain purposes. The DARS receives around 25 applications per week – from commercial bodies, NHS organizations, government and academia, and most are return customers.

Applying for access:

- To begin the process contact NHS Digital to discuss your requirements. NHS Digital can advise
 on the suitability of your request and how to improve the quality of your application, or whether
 your request can be satisfied through existing published data
- Applicants must sign the NHS Digital Data Sharing Framework Contract which creates a framework of legally binding terms and conditions that will apply on every occasion NHS Digital agree to share data with an applicant
- Once the Data Sharing Framework contract is signed you will then be asked to complete an application (link) to show you are meeting strict data governance standards.
- NHS Digital has produced guidance on the standards of information expected in a data access application, including what to include in each section of the application. These guidelines are used by NHS Digital case officers when reviewing applications so it's well worth closely following the guidance provided

When looking to access routinely collected NHS data, we recommend that a good starting point is the <u>Health Data Toolkit</u> developed by the MRC Regulatory Support Centre. This tool helps researchers understand the approvals and processes required to gain access to NHS health data from an ethical and legal perspective.

Useful Applicant Information

Commercial applicants make up 1/10th of applications, of these two-thirds are granted. It's worth noting that if you're applying as an SME, you need to demonstrate how your research benefits the UK, for example, by publishing outcomes or by demonstrating a clear route to UK patient benefit.

Cost

At the time of publication, applications cost £1030 plus a fee depending on the specific dataset required, There are additional costs for data linkage and bespoke work <u>— you can find out about additional costs</u> on the summary page.

Payment becomes due once the application is approved

Data delivery

NHS Digital are moving to remote data access via a Data Access Environment with embedded analysis tools. The system is live for a limited number of datasets with additional datasets being added over the coming months. In time, this will be the only way to access data without a strong justification for requiring a download of the data (for example if you wish to apply your own analytic tools).

Currently, for those datasets not available via the DAE, the data is delivered as an extract in standard format through Secure Electronic File Transfer

Third parties - for example, Harvey Walsh, Health IQ, CPRD - can repackage aggregated data for other customers, but this must not lead to the possibility of re-identification

It is important to note that if an applicant is engaged with a 3rd party, then the Data Sharing Agreement between parties must comply with the NHS Digital Data Sharing Agreement Terms and Conditions.

Details of approved data releases are listed on the NHS Digital Release Register

Data quality management information is published externally

Data security

Data security is a priority for NHS Digital. So, it's crucial that you can demonstrate how you are going to

Medicines Discovery Catapult Quick Guide: NHS Digital April 2020

protect data. NHS Digital have produced a <u>Data Security and Protection Toolkit</u> that must be used to provide assurance that applicants are practicing good data security

If you are unsure about any data security issues, take a look at NHS Digital's Data Security Centre.