Access to data from NHS Digital for biomedical research

Bioinformatics for Biobusiness: Accessing biomedical data for data analysis

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Acknowledgements

Find Recruit Follow / Data for R&D

- Centre for Improving Data Collaboration, NHS England Transformation Directorate
- Science Research and Evidence Directorate, Department of Health and Social Care
- National Institute for Health Research
- UK Research & Innovation

Covid-19 TRE development

- Health Data Research UK
- British Heart Foundation Data Science Centre

NHS DigiTrials Co-development Panel
4,000 staff across NHS Digital

NHS DigiTrials Health Data Research Hub
(Oct 19-Jul 21)

- Health Data Research UK
- University of Oxford
- Microsoft
- IBM

This work uses data provided by patients and collected by the NHS as part of their care and support.

#datasaveslives
NHS Digital is the national digital, data and technology delivery partner for the NHS and social care system.
We support the NHS and the people that it serves

We believe in improving people’s lives through data and technology. To help create better health and care services and solutions, we deliver products, platforms and services, and share national data and insight.

- We collect and disseminate data to improve health and care outcomes
- We design, build and procure new national digital services and systems
- We run critical live services which underpin the health and care system
- We are the cyber security partner supporting health and care providers
Researchers and planners use data from NHS Digital for discovery and insight

We publish 300 official health and care data sets every year, supporting life sciences research, helping local and national planning and enabling accountability

Over 500 billion health and care data points are stored in our records, from Accident & Emergency Admissions to Zero Bed Days
Accessing data from NHS Digital

DATA ACCESS REQUEST SERVICE

Data disseminated to approved users to improve health and social care

Secure Data Environment
Secure access to linked, de-identified health data

NHS DigiTrials
Data enabled clinical research

OUTCOMES
COMMUNICATION
RECRUITMENT
FEASIBILITY
Requests to access data must meet published standards. Details of data sharing agreements and audits are public

Data Access Request Service (DARS) - NHS Digital

### Enquiry
- Initial discussions to discuss requirements and provide advice on feasibility

### Application
- Applicant completes application, detailing: data required; purpose and benefit to health and social care; legal basis; security; how and where data will be processed; etc.
- NHS Digital staff review the application against our published standards with oversight from an independent committee.
- If approved, the application forms the basis for a data sharing agreement (DSA)

### Access
- The DSA is signed by NHS Digital and the data recipient
- The data is produced and checked by NHS Digital
- Data is made available by secure file transfer or in our data access environment

### Audit
- We audit to check that recipients are meeting the obligations in their DSA and publish the outcomes, including post-audit reviews.

### Data deletion
- All data must be deleted when a DSA expires and is not renewed
COVID-19 Secure Data Environment
Minimum viable product supporting academic, NHS, charity and industry users

COVID-IMPACT

Public Health England
• COVID-19 lab test data

Intensive Care National Audit & Research Centre
• Intensive care dataset

NHS Digital
• Hospital data (HESx4 + SUS)
• Death registry data
• Primary care data
• Community dispensing data
• Hospital e-prescribing data
• COVID-19 vaccination data
• Maternity and mental health data

Cardiovascular data
• Cardiology, cardiac surgery, coronary intervention audits (NICOR)
• Stroke audit (SSNAP)
• National vascular registry

NHS Digital link datasets using NHS number and other identifiers

NHS Digital Trusted Research Environment
Secure storage and de-identification of linked datasets
Secure access for approved researchers

CVD-COVID-UK/COVID-IMPACT de-identified linked dataset

Approved researchers

DATA-CAN
Timely and secure access to de-identified cancer data, enabling important COVID-19 related research on rates of cancer referrals, diagnosis and treatment

AstraZeneca
Effectiveness of the Oxford-AZ COVID-19 vaccine, and if there is a causal association of thrombosis with thrombocytopenia syndrome

Department of Health & Social Care
Analysis to inform policy and strategy around COVID-19 pandemic response and recovery

BMJ 2021; 373 doi: https://doi.org/10.1136/bmj.n826
The secure data environment will become the default route for unconsented access to data from NHS Digital

Upgrade of current remote desktop environment
Public beta for prioritised use cases from October 2022

Run code without direct data access
Available by March 2023
NHS DigiTrials – proposition

**FEASIBILITY**
Using national data sets to assess number and location of patients who meet key eligibility criteria

**RECRUITMENT**
Suitable patients identified and invited by the appropriate investigator to participate in a clinical trial

**COMMUNICATION**
Enhancing communications between clinical trialists, patients and their general practitioners before, during and after the trial

**OUTCOMES**
Linkage of trial cohorts to NHS data sources to collect information on relevant medical events providing efficient and comprehensive assessment of clinical safety and efficacy

Find  Recruit  Follow-up
NHS DigiTrials supporting critical health research

- **RECOVERY trial**: Identifying effective treatments that have saved an estimated 1m lives globally
- **PRINCIPLE and PANORAMIC trials**: more than doubled recruitment rates and supported safe prescribing for virtual trials.
- **Vaccine trials**: Novavax completed recruitment in 2 months with 55% volunteers recruited via DigiTrials
- **GenOMICC**: discovery of genes which increase susceptibility to life-threatening COVID-19
- **NHS Galleri**: on track to recruit 140,000 participants with highly representative demographics who will be followed up through routine datasets
“As someone of black African origin I feel it is so important for clinical research to be representative of the population so that treatments can help people from all backgrounds. Services like DigiTrials give anyone who is clinically eligible the opportunity to participate, regardless of their background.”

~ Dolapo Ogunleye
NHS DigiTrials Co-development Panel
Where next

The future is here, it’s just not evenly distributed
Data for R&D Vision

By 2025, have a world leading NHS-wide health data research infrastructure that enhances patient care, sustains the NHS and supports innovation
Data for R&D objectives

- Develop an *England-wide ecosystem of NHS owned and managed infrastructure* to allow researchers access to secure, high-quality, linked datasets, by:
  - *Expanding the scope, capacity and capability* of a national health data infrastructure platform
  - *Developing a network* of sub-national/regional linked health data infrastructure platforms and services
- Enhance *patient and public support and enthusiasm* for use of NHS health data to drive research and development
- *Increase clinical trials capacity* by underpinning clinical trial operations with NHS health data, improving the efficiency of clinical trial set up; and increasing the volume of people recruited to participate in clinical trials
- Expand the ability for researchers to *access a range of genomics datasets through linkage* of sources.
- *Generate returns to the NHS* by applying commercial principles consistently and coherently across the programme to generate value for the NHS.
An interoperable system of TREs

Granular | Agile | Multi-modal | Real-time | Connected to services | Data controller buy-in
AI development, real word studies, translational research etc.

High-level | Coverage | Curated Concierge service | DigiTrials
Priority national trials aligned to ‘Missions’ and pop health

High-value | Enhanced with linkage
Advanced compute
Clinical and research use-cases

NIHR | BioResource
Genomics data assets

Federation

Disease Registries
NHS Digital
Primary care

Sub National TRE System

Example data assets

National TRE

‘Master Aggregator’ research use applications to accredited TREs
Thank You

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Programme on a page

- Data Enabled Trials
  - Find Recruit Follow Up
  - Data Navigation Service
  - Trial Recruitment Capability

- Data Access and Linkage
  - National TRE
  - Subnational TREs
  - Genomics TRE Federation

- Investments
  - Data enabled Clinical Trial Operations

- Enablers
  - Patient and public involvement and engagement
  - Commercial model for Data Access
  - SDE Policy
Setting national policy

**Policy principles**
11 high level guidelines that will guide our approach to SDEs. Published in recent Data Strategy.

**Technical capabilities specification**
Defines technical capabilities required of SDEs, including security, functionality, access and data management.

**Accreditation framework**
Details Information Governance standards that SDEs must adhere to, and how this will be assessed and monitored.

**Roadmap**
A guidance document that explains the transition to SDEs. How the SDE guidelines, tech spec and accreditation should be implemented and over what timeline.
‘Stacked’ throughout the programme, including:

- Learning from others
- PPIE lead within Programme
- Quantitative research
- Representation on governance structures
- Co-design panels
- Citizens juries
- Public deliberations
- National communications
- Engagement with National Data Guardian, Medical Research Charities, and patient lobby groups