

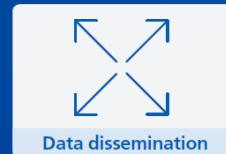
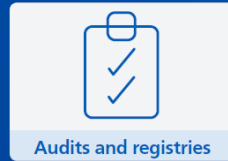
Data Access Request Service (DARS)



Information and technology
for better health and care

September 2019
Fran Hancox, DARS Case Officer

Data, insights and statistics



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**DATA
ACCESS**



Information and technology
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Data Access Request Service (DARS)

- NHS Digital works under legislation, including
 - Health and Social Care Act 2012
 - Care Act 2014
 - Data Protection Act 2018 & GDPR
- Data Access Request Service (DARS) established to enable access for organisations, including clinicians, researchers, commissioners, and commercial companies
- Access provided to patient level data for organisations that :-
 - are legally permitted to have access to the data
 - will look after it according to Information Governance (IG) requirements
 - hold it securely
 - will use it to improve health and care services
 - not solely for commercial use

Data Access Request Service (DARS)

1,000+ active agreements managed through DARS Online



Over **10,000** data disseminations per year, including HES, mental health and PROMS



Working with over

110 Local Authorities and **195** CCGs



Over **1,000** applications for data received per year



Over **1,067** data releases for medical research disseminated each year



A range of data products, including HES which contains over **1.7bn records**



Over **300** active medical research studies



Data Sets available to request now

Hospital
Episode
Statistics

Diagnostic
Imaging Data
Set

Emergency
Care Data Set

Mental Health

Civil
Registrations
(deaths)

Patient
Demographics
Service

SUS PbR

Patient
Reported
Outcome
Measures

National
Diabetes Audit

National Child
Measurement
Programme

Summary
Hospital-level
Mortality
Indicator

Tabulations
(aggregated
data)

Adult Psychiatric
Morbidity
Survey

Maternity
Services Data
Set

Data about...

Patients and their hospital treatments

Information about patient scans

Information about urgent and emergency care

Patients who are in contact with mental health services

Information about patients when they die

Patient names and addresses over time

Cost of care at hospital

Patients undergoing elective in-patient surgery

Information about people with Diabetes

Public health programme about child excess weight indicators

A measure of deaths in hospital within a certain timeframe after leaving hospital

A table of numbers (data)

Information on treated and untreated psychiatric disorder

Information about the maternity care pathway

As an idea of scale... some of the datasets

Hospital Episode Statistics

- Dates back to 1989/90
- Contains over 2 billion records

Mental Health Data

- Dates back to 2006/07
- Fields change year-by-year

Civil Registration (Deaths)

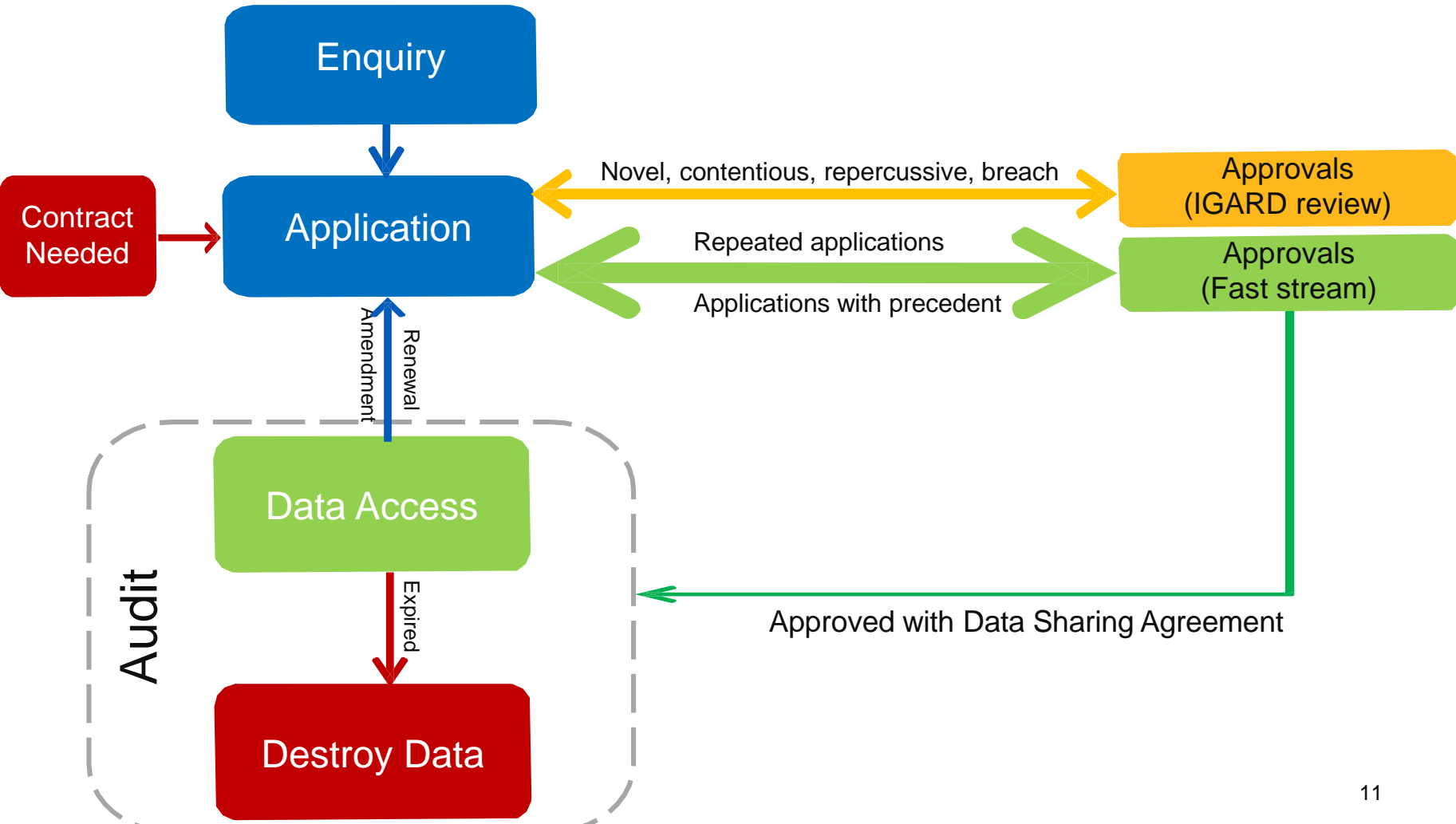
- Contains information on cause of death from civil registration records
- Underlying cause of death is recorded alongside other conditions which may, or may not have directly contributed to the death

Hospital Episode Statistics Data Sets

	HES Admitted Patient Care	HES Outpatients	HES A& E	HES Critical Care
Contains	Data pertaining to inpatient episodes, including diagnostic and operative codes	Data pertaining to outpatient episodes, including diagnostic and operative codes	Data pertaining to A&E episodes, including high level diagnostic groupings	Data pertaining to critical care episodes for adults only
Available since	1989/90 (HESID since 1997/98)	2003/04	2007/08	2008/09
Records per year (2015/16)	~20 million rows	~110 million	~20 million	~300,000
Notes	Contains some maternity data with birth and delivery records (mother and child aren't linked)		Can be linked to corresponding APC episode (AEKEY field) since 2013/14	Can be linked to corresponding APC episode (SUSRECID field)

Data available soon (onboarding)...

- Adult Social Care Survey (ASCS)
- Appointments in General Practice
- Civil Registrations of Births
- Diabetes Prevention Programme (DPP)
- General Practice Workforce
- Health Survey for England (HSE)
- Improving Access to Psychological Therapies (IAPT)
- Mental Health of Children and Young People (MHCYP) 2017
- National Pregnancy in Diabetes Audit (NPID)
- Patient Level Costing Acute Data Set (PLCADS)
- Survey of Adult Carers in England (SACE)
- Survey data sets



How to apply

- Email enquiries@nhsdigital.nhs.uk with a brief description of what type of data you would like to apply for
- You will be given a reference number (e.g. DARS-NIC-12345-ABCDE)
- Our team can answer your initial questions from our DARS email address data.applications@nhsdigital.nhs.uk
- You will be given access to a blank application in DARS Online so that you can log in and begin work on completing the different sections of the application.



What an application must have...

- All relevant sections of the form filled in
- Active Data Sharing Framework Contract for all named data controller(s)
- Evidence that the proposed data flows are lawful
- Security assurance for all data processors
- A clear purpose with information on the planned processing, outputs and expected benefits to healthcare



Common Issues

- Inadequate information in the 'Outputs' and 'Benefits' sections to justify release of the data for the benefit of health/social care
- Data minimisation - insufficient justification for the amount of data requested
- Lack of clarity over roles and involvement of other organisations
- Consent materials do not provide enough clarity about the data and organisations involved; sharing of data with NHS Digital; participants' right to withdraw and the process to withdraw



Making access simpler and faster

Standards

- Published on our website

<https://digital.nhs.uk/services/data-access-request-service-dars/dars-guidance>

- Accessed via the information pop ups when populating an application into DARS Online

<https://dataaccessrequest.hscic.gov.uk/>

- Webinars being published on YouTube

Precedents

- ‘This looks like one we’ve seen before’

- A “fast track” approach to applications using precedents, enabling applications which fit specific criteria to be approved without requiring IGARD review

- Precedents set when applications follow the same basic criteria as multiple other applications.



so how
hard
can it be ?

Breaches

**GPs REVOLT ON
PATIENT RECORDS**

From the Mail, February 6

**Cashing in on patient
records to be banned**

March 1

**Insurers spy
on medical
history of
thousands**

May 28

Legal Framework

Control of data,
legal framework
and constraints



Release of data
to improve health
and social care



Cost recovery

Service components		Unit cost (excluding VAT)
New application		£1,030
Amendment / renewal / extension		£820
Annual review fee		£500
Data production costs	Data volumes	£320 per year, per dataset
	Dissemination	£930 per dissemination
Medical research reports	Per report	£170
	Automatic cohort validation	£420
	Manual cohort validation (per 100 records)	£270
Service required	Bespoke data linkage per dataset per dissemination	£2,060
	Tabulations	£800 per table
HES Online Portal access (per user per year)		£3,200
Permission to sub-licence (per annum)		£10,000

We do this together...

Academia partners:



Citizens and media



Providers/places



Other key partners:



Government:



Research partners:



www.digital.nhs.uk

 [@nhsdigital](https://twitter.com/nhsdigital)

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