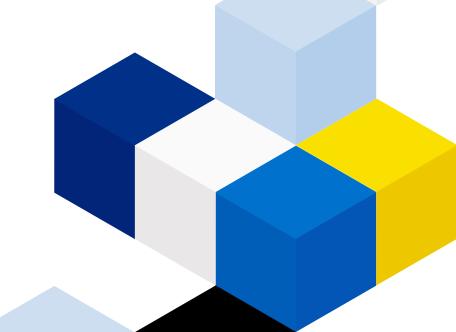


# Update on the Data Access Request Service (DARS) and health survey data access

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The national information and technology partner to the health and care system





# Data Access Request Service (DARS)

### NHS Digital Data Access Request Service - Background

NHS Digital's Data Access Request Service (DARS) enables access to health and social care data for organisations such as clinical and research bodies, academia, commissioners and commercial companies. Its role is to ensure that access to personal data is provided 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;
- will not use it solely for commercial purposes.



### **DARS** key facts and numbers

- We process more than 1,000 applications for NHS Digital data each year
- Over 500 of those are requests from researchers
- There are 47 data sets available to request from DARS
- Since last year, we have onboarded 10 new, Covid-19 related data sets that are used for managing NHS's response to the pandemic; the work continues
- The majority of our data sets cover England, some also devolved nations
- Most of our assets can be linked to other data sets or to cohort data provided by researchers (unless linkage is restricted for legal or practical reasons)
- NHS Digital offers a Clinical Trials service, which can
  - identify an appropriate cohort of patients for the planned clinical trial
  - provide contact details or contact candidates for a trial
  - provide updates on the chosen cohort of patients



## **Survey Data Sets**

## **Population Health Surveys**

- Alongside the data collected from health and social care settings, such as hospitals, clinics, pharmacies or community centres, NHS Digital also offer access to health surveys which have taken place with a representative sample of the population.
- Many of these surveys take place in respondents' homes or via postal/online surveys and are much smaller (in terms of the number of records included) than national and mandated data collections.
- NHS Digital commissions a range of public health surveys, which look into matters of people's health, lifestyle, mental health and behaviours and choices, that may have a lasting impact on their health and healthcare requirements in the future.
- To find out more about these surveys check out the <u>Public Health</u> page and the <u>Health</u> <u>Surveys Service</u> page at NHS Digital.



## Population Health Surveys: data sets

The following health surveys have been commissioned by NHS Digital and are available to researchers via the UK Data Service (UKDS):

- Adult Dental Health Survey
- Adult Psychiatric Morbidity Survey (APMS)
- Child Dental Health Survey
- Health Survey for England (HSE)
- Mental Health of Children and Young People (MHCYP)
- Smoking, Drinking and Drug Use among Young People (SDD)
- Survey of Carers in households
- What About Youth Survey

NHS Digital is the data controller for all of the above Population Health Survey data sets.



## Population Health Surveys: types of access

In most instances, Population Health surveys can be accessed (and downloaded) from the UKDS portal. There are two main types of access and associated approval pathways for surveys deposited with the UKDS:

- UKDS's End User Licence (EUL), which does not require DARS application to be completed
- UKDS's Special User Licence (SUL) requires DARS application and Data Sharing Agreement (DSA) with NHS Digital's DARS

Requests for **bespoke** versions of data require approval from NHS Digital and in most instances a DSA. Bespoke requests are those for:

- data with additional variables not included in the EUL or SUL dataset, bespoke data groupings or derivations
- survey data linked to other assets (applications currently on hold)
- permission to re-contact survey participants
- serum samples from Health Survey for England (applications currently on hold)



## Population Health Surveys: types of access

Survey	UKDS EUL*1	UKDS SUL
Adult Dental Health Survey	1988, 1998, 2009	
Adult Psychiatric Morbidity Survey	1993, 1994, 1997, 2000, 2007	2014
Child Dental Health Survey	2003, 2013	
Health Survey For England	1991 to 2018	2015
Mental Health of Children and Young People	1994, 2004	2017
Smoking, Drinking and Drug Use Among Young People	1990 to 2016	
Survey of Carers in Households	2009/10	
What About Youth Survey	2014	

<sup>\*1</sup> over time greater disclosure control has been applied to EUL variables and also greater restrictions on who can access i.e. must be based in UK or EEA+ from HE/FE, central or local government, NHS, research companies and charities for not for profit education and research purposes only.



## **Accessing Survey data**

#### For EUL

• Create an account with the UKDS, navigate to the Survey and year of choice and select **Access Data**. Add the dataset to your account and to a named project. Select the special criteria and EUL T&Cs. Upon completion you will be able to download the dataset.

#### For SUL

- As above but you will also be prompted that a DARS application is required.
- Complete a NHS Digital Data Access Request Service Application. If you are new to DARS, contact Enquiries
   (enquiries@nhsdigital.nhs.uk or 0300 303 5678) to create an account. If you have previously submitted a DARS application, go to the DARS Online portal.
- Once your application is submitted in DARS Online, you will be allocated a DARS Case Officer who will support you throughout the application and approval process.
- Once application has been approved a data sharing agreement will be created. Electronically sign this. UKDS will be notified that you have met the criteria and access can be granted.
- See the **DARS Application process: guidance (links)** slide for hyperlinks to DARS web sites, guidance and webinars

#### There is no charge for access to either UKDS EUL or SUL datasets.

#### **Bespoke request**

- In the first instance contact the NHS Digital Surveys Team to discuss your requirements <u>surveys.queries@nhs.net</u>
- Bespoke requests incur charges



## **Update on Health Surveys datasets**

Unfortunately due to other Covid-19 priorities we are behind on disseminating survey data however:-

- Mental Health of Children and Young People
  - the embargo on the 2017 dataset has now been lifted, applications can be submitted.
  - Two follow up surveys with the 2017 cohort have taken place Wave 1 in July 2020 and Wave 2 in March 2021. Datasets will be available under UKDS SUL
- Smoking, Drinking and Drugs Among Young People 2018 dataset available later this Summer under UKDS EUL.
- Health Survey for England 2019 dataset will be available under UKDS EUL later this Summer.
- Adult Psychiatric Morbidity Survey 2014 there are plans to create a less reduced dataset to replace the one currently available under UKDS SUL.



#### How are we improving access

- Dedicated Survey dissemination page in DARS to help support access
- Working with IGARD for efficient approval pathway for:-
  - for UKDS SUL datasets
  - Data linkage to other NHS Digital datasets, including HES, cancer, mortality, MHMDS and IAPT. Exact datasets will be dependent upon the consent recorded from the participant at the time of interview. Access for linkage to APMS and MHCYP will probably be first followed by HSE.
- Fully on-boarding HSE into DARS this will allow users to access the UKDS SUL
  datasets for 2016 to 2019 which are currently not available (these include additional
  variables such as household identifiers and single age). Access to blood bank for
  left-over serum samples, and data linkage to other NHS Digital datasets.



# More about DARS

## DARS Application process: guidance (links)

NHS Digital Data Access Request Service (DARS)

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

DARS guidance page (incl. definitions, standards, video webinars)

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

DARS application and approval process: step-by-step (incl. pre-application checklist)

https://digital.nhs.uk/services/data-access-request-service-dars/data-access-request-service-dars-process

DARS products and services (list of data sets and links to data collection pages)

https://digital.nhs.uk/services/data-access-request-service-dars/dars-products-and-services



#### **DARS Products**

#### **Secondary Care**

HES (APC, CC, OP) ECDS SHMI SUS PbR

#### "Cohort support"

Demographics
Civil Registrations (Deaths)
Cancer Registrations

## Mental Health and Community

MHSDS IAPT CSDS MSDS NDA

#### **Primary Care**

Prescribing in Primary Care *GP Data (not yet available)* 

#### Covid-19

CHESS
EPMA
GDPPR
SGSS, P2, P3
SSNAP
CV19 Vaccinations

#### Other

ASCS
BCIR
DID
GP Workforce
PROMS
SACE



#### Data sets: acronym "buster"

- HES Hospital Episode Statistics
  - HES APC Hospital Episode Statistics Admitted Patient Care
  - HES CC Hospital Episode Statistics Critical Care
  - HES OP Hospital Episode Statistics Outpatients
- ECDS Emergency Care Data Set
- SHMI Summary Hospital-level Mortality Indicator
- SUS PbR Secondary Uses Service Payment By Results
- MHSDS Mental Health Services Data Set
- IAPT Improving Access to Psychological Therapies
- CSDS Community Services Data Set
- MSDS Maternity Services Data Set
- NDA National Diabetes Audit
- CHESS COVID-19 Hospitalization in England Surveillance System
- EPMA Electronic Prescribing and Medicines Administration (EPMA) data in Secondary Care for COVID-19
- GDPPR GPES Data for Pandemic Planning and Research

#### Data sets: acronym "buster" (continued)

- SGSS Second Generation Surveillance System
- P2 Covid-19 UK Non-hospital Antigen Testing Results (pillar 2)
- P3 Covid-19 UK Non-hospital Antibody Testing Results (pillar 3)
- SSNAP Sentinel Stroke National Audit Programme
- CV19 Vaccinations Covid-19 Vaccinations: Adverse Reactions & Covid-19 Vaccination Status
- Demographics
- Civil Registrations (Deaths)
- Cancer Registrations
- Prescribing in Primary Care Medicines dispensed in Primary Care (NHSBSA data)
- ASCS (Personal Social Services) Adult Social Care Survey
- BCIR Breast and Cosmetic Implant Registry
- DID Diagnostic Imaging Dataset
- GP Workforce NHS General Practice Workforce
- PROMS Patient Reported Outcome Measures
- SACE (Personal Social Services) Survey of Adult Carers [in England]

