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

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Our role

The national information and technology partner to the health and care system
To harness the power of information and technology to make health and care better
Data Access Request Service (DARS)
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.
We process more than 1,000 applications for NHS Digital data each year

Over 500 of those are requests from researchers

There are over 70 data sets available to request from DARS

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 Public Health page and the Health Surveys Service 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 (2009)
- Adult Psychiatric Morbidity Survey (APMS)
- Child Dental Health Survey (2013)
- 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)** – APMS and MHCYP requires DARS application and Data Sharing Agreement (DSA) with NHS Digital's DARS; HSE via UKDS and IAO approval

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

<table>
<thead>
<tr>
<th>Survey</th>
<th>UKDS EUL*¹</th>
<th>UKDS SUL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Dental Health Survey</td>
<td>1988, 1998, 2009</td>
<td></td>
</tr>
<tr>
<td>Child Dental Health Survey</td>
<td>2003, 2013</td>
<td></td>
</tr>
<tr>
<td>Health Survey For England</td>
<td>1991 to 2019</td>
<td>2015, 2018, 2019</td>
</tr>
<tr>
<td>Mental Health of Children and Young People</td>
<td>1994, 2004</td>
<td>2017</td>
</tr>
<tr>
<td>Smoking, Drinking and Drug Use Among Young People</td>
<td>1990 to 2018</td>
<td></td>
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<tr>
<td>Survey of Carers in Households</td>
<td>2009/10</td>
<td></td>
</tr>
<tr>
<td>What About Youth Survey</td>
<td>2014</td>
<td></td>
</tr>
</tbody>
</table>

*¹ 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 (MHCYP and APMS only)

• 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](mailto: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
• HSE SUL is still via UKDS

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 [surveys.queries@nhs.net](mailto:surveys.queries@nhs.net)
• Bespoke requests incur charges
Update on Health Surveys datasets

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

**Mental Health of Children and Young People**
- Three 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. A Wave 3 collection has just finished, and data will be available following publication.

**Smoking, Drinking and Drugs Among Young People** – The 2021 dataset will be available later this year following the 2021 publication.

**Health Survey for England** – data is available for all years under UKDS EUL. 2015, 2018, 2019 data is also available under UKDS SUL, 2016 and 2017 to follow. An ethnicity dataset will also be created following the recent ethnicity publication, and a Q1 2020 dataset.

**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
- New surveys precedent agreed so that approval of some types of surveys data requests can be fast-tracked:
  - Requests must be for not-for-profit research or education, that do not include identifiable data.
  - Can include data linkage to other NHS Digital datasets, including HES, cancer, mortality, MHSDS and IAPT. Exact datasets will be dependent upon the consent recorded from the participant at the time of interview.
  - Commercial requests, or first-of-type linkage, will still follow the standard IGARD approval route
- Types of requests requiring IGARD approval are:
  - HSE blood bank - access to blood bank for left-over serum samples
  - Data Linkage to non-NHS Digital data sets, or first-of-type for NHS Digital data sets
  - Bespoke data requests
  - Requests to re-contact cohorts for follow on research
Thank You

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company/nhs-digital
digital.nhs.uk
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)
# DARS Products

## Secondary Care
- HES (APC, CC, OP)
- ECDS
- SHMI
- SUS PbR

## Mental Health and Community
- MHSDS
- IAPT
- CSDS
- MSDS
- NDA

## Covid-19
- CHESS
- EPMA
- GDPPR
- SGSS, P2, P3
- SSNAP
- CV19 Vaccinations

## “Cohort support”
- Demographics
- Civil Registrations (Deaths)
- Cancer Registrations

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

## 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

- 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]