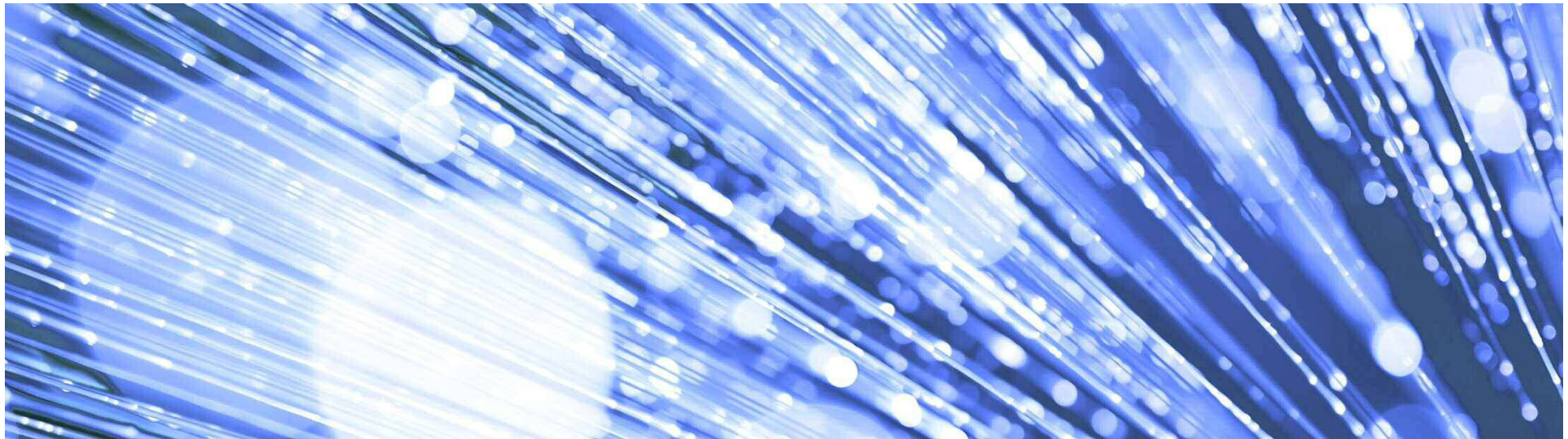


# Update on data access for health surveys



**Information and technology**  
**for better health and care**

**Stuart Blake**  
Information Asset Owner for Surveys

## Data Access Request Service (DARS)

- The Data Access Request Service (DARS) permits clinicians, researchers, commissioners, and commercial companies access to the data required to help improve NHS services.
- The DARS team ensures that we only give access 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 in the UK.

## Data Access Request Service (DARS)

Over **1,200**  
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 **1,000**  
data releases for  
medical research  
disseminated each  
year



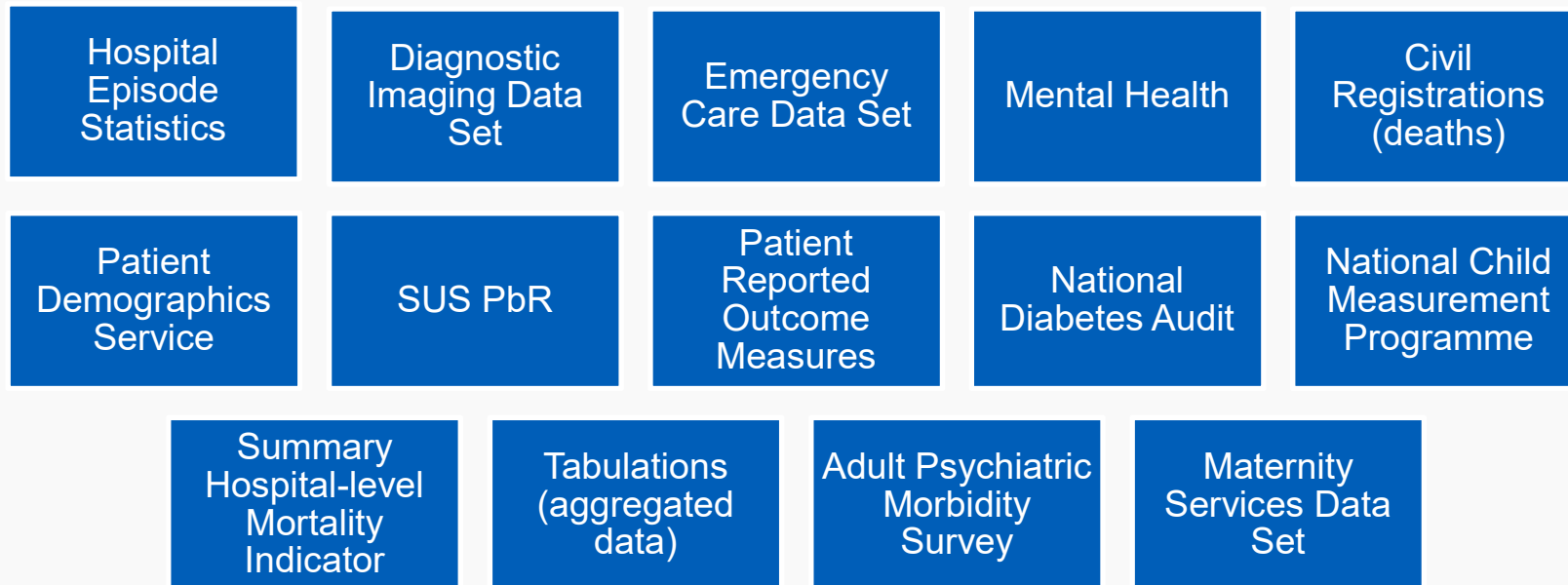
A range of data  
products, including  
HES which contains  
over  
**1.7bn records**



Over **250** active  
medical research  
studies



## Data Sets available to request now



## 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

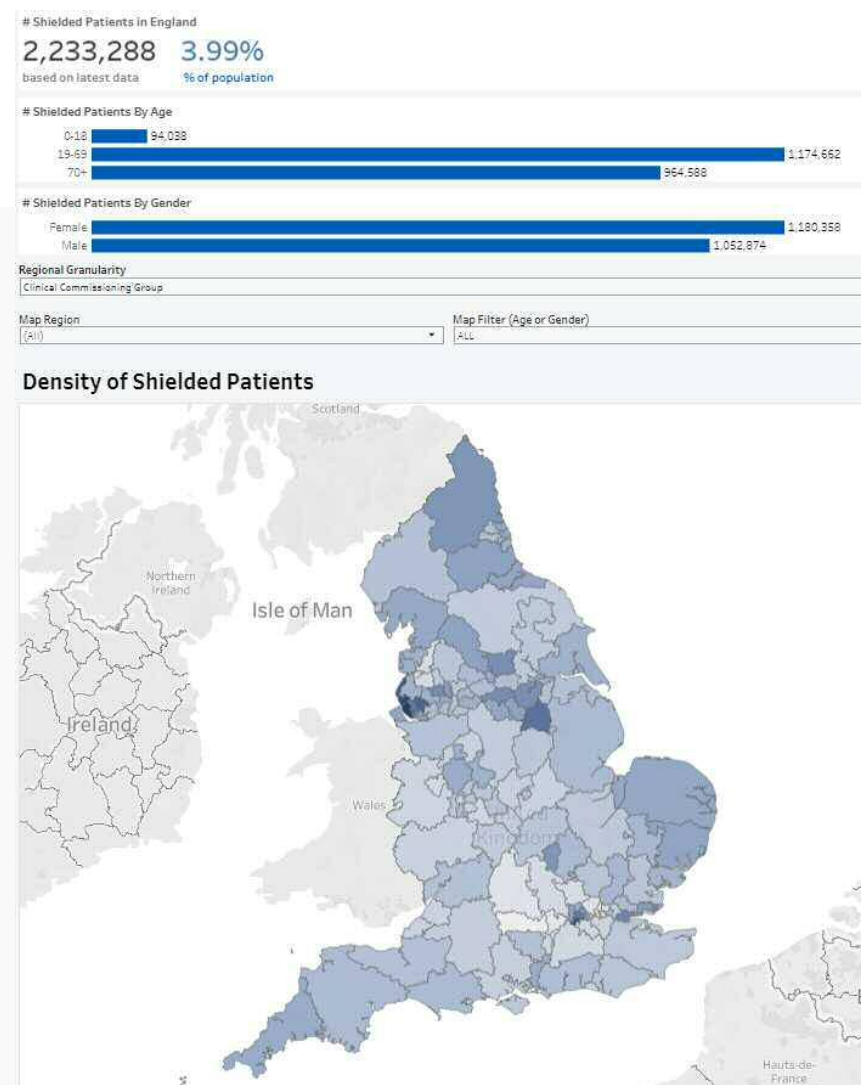
A table of numbers (data)

Information on treated and untreated psychiatric disorder

Information about the maternity care pathway

## NHS Digital COVID-19 response

- Supporting clinical trials, including RECOVERY trial which identified Dexamethasone as a therapeutic low-dose treatment
- Developed HOSTED dataset with PHE to examine transmissions within households
- Onboarding a number of new datasets (Testing, Intensive Care, PHE Surveillance, etc)
- Identified vulnerable citizens: Shielded Patient List
- Developed and published dashboards displaying Open Data



# NHS Digital Health Survey Programme (1 of 2)

## Health Survey for England

*Reports annually*

Face-to-face and self-completion interview

Face-to-face nurse visit

Physical measures such as height and weight, blood pressure, saliva, and blood analytes

Covers general health, disability, obesity, smoking, drinking, fruit and vegetable consumption, health conditions and social care

## Smoking, Drinking and Drug Use among Young People

*Reports biennially*

*[2020 survey suspended]*

Self-completion in schools in England  
Pupils aged 11 to 15

New questions cover wellbeing and life satisfaction measures

# NHS Digital Health Survey Programme (2 of 2)

## **Adult Psychiatric Morbidity Survey**

*Reported in Sept 2016*

Face-to-face interview in households in England  
Covers factors such as mental health and wellbeing, depression, suicidal behaviour, substance dependence

## **Mental Health of Children and Young People survey**

*Reported in Nov 2018*

Covers the prevalence of developmental and mental health conditions, behaviours, bullying and cyberbullying

Age range 2-19 year olds in England

## **Children's Dental Health Survey**

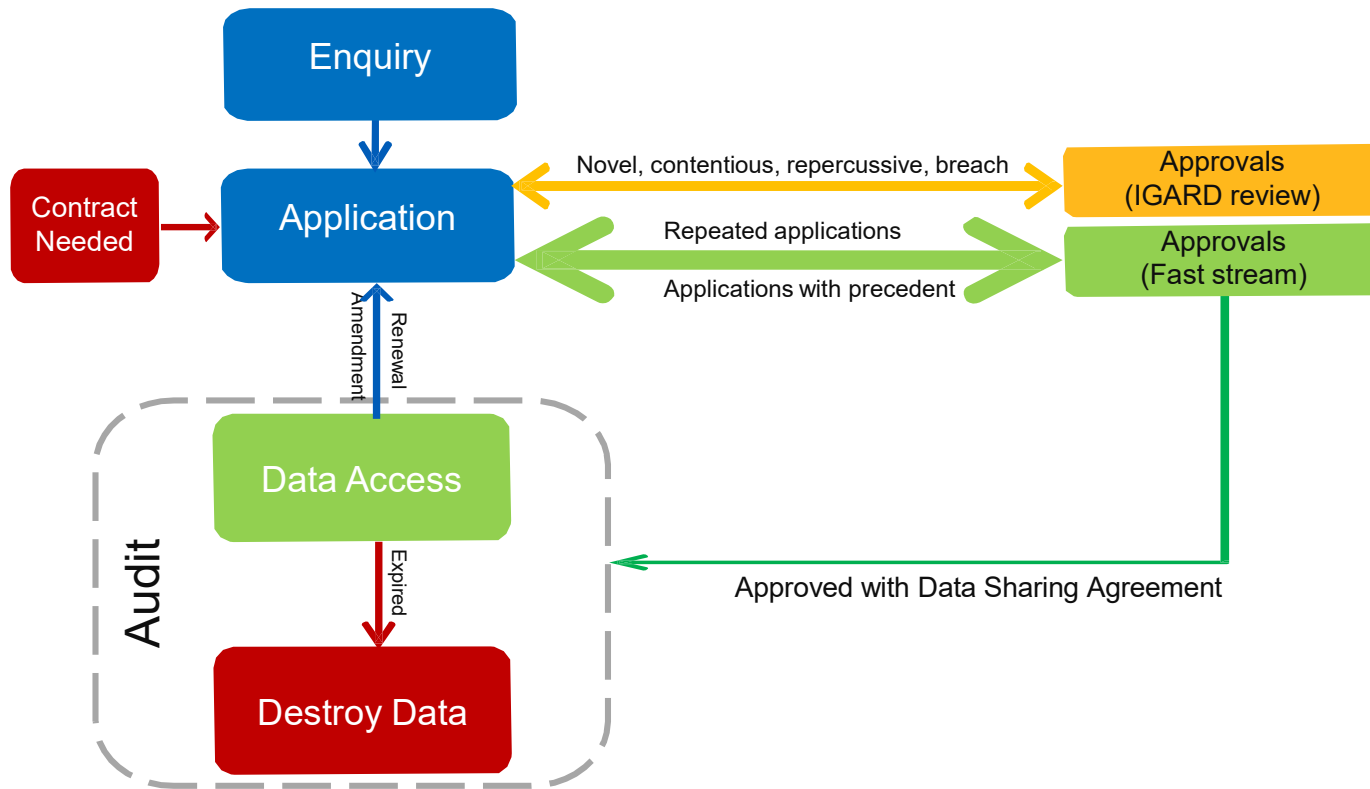
*Reported in March 2015*

Dental examination plus self-completion questionnaires for parents and children in primary and secondary schools in England, Northern Ireland and Wales



## Surveys and latest data reported

Survey Name	Frequency	Most recent publication	Approx sample size
Health Survey for England (Adults and Children)	Annual	2018	10,000
Smoking Drinking and Drug Use among Young People	Biennial	2018	12,000
Adult Psychiatric Morbidity Survey	7 yearly	2014	7,500
Children's Dental Health Survey	10 yearly	2013	9,900
Adult Dental Health Survey	10 yearly	2009	6,500
Mental Health of Children and Young People Survey	Varies: 1999, 2004, 2017	2017	9,100
What About Youth? Survey	Ad hoc	2014	150,000



## Survey data access, the challenge: A balancing act...

Control of data,  
legal framework  
and constraints

Benefits to health  
and social care by  
innovative use of  
data

*"We never killed anyone by using their data. I'm pretty sure we have by not using data."  
Chris Carrigan, UseMYdata*

# Applying the right level of control

- Legislative context: General Data Protection Regulation 2018/ Data Protection Act 2018
- Control of Patient Information (COPI) Notice, March 2020
- Current process: UK Data Service & End User Licence

## Current approach with surveys

- Over time, fields have been removed and/or summarised to remove risk of re-identification
- The resulting dataset has been made available through End User Licence
- Removal and summarisation of fields means some utility is lost
- The challenge is to make the data available in full form: record-level microdata with no changes. This is what data released via DARS will include.

## Surveys onboarding

### Health Survey for England:

- 2018 dataset available via End User Licence
- 2019 dataset – out March 2021 – available via DARS
- Open Data releases to support undergraduate teaching (working with Data Access Working Group)

### Mental Health of Children and Young People

- Progressing Direction to enable dissemination

### Smoking, Drinking and Drugs among Young People

- 2018 dataset available via End User Licence
- Progressing onboarding into DARS

## Planned access:

- Full survey dataset(s) available through DARS
- Online access through our Data Access Environment
- Opportunity for linkage to other NHS Digital datasets
- Standalone, limited dataset (or alternative) available through UK Data Service, End User Licence process

## Publications and further information

NHS Digital publications are available at:  
<https://digital.nhs.uk/data-and-information>

and the HSE series of publications are available at:  
<https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england>





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