

Survey Data: A way forward



Information and technology
for better health and care

Garry Coleman
Associate Director of Data Access

Our mission

To harness the power of information and technology to make health and care better

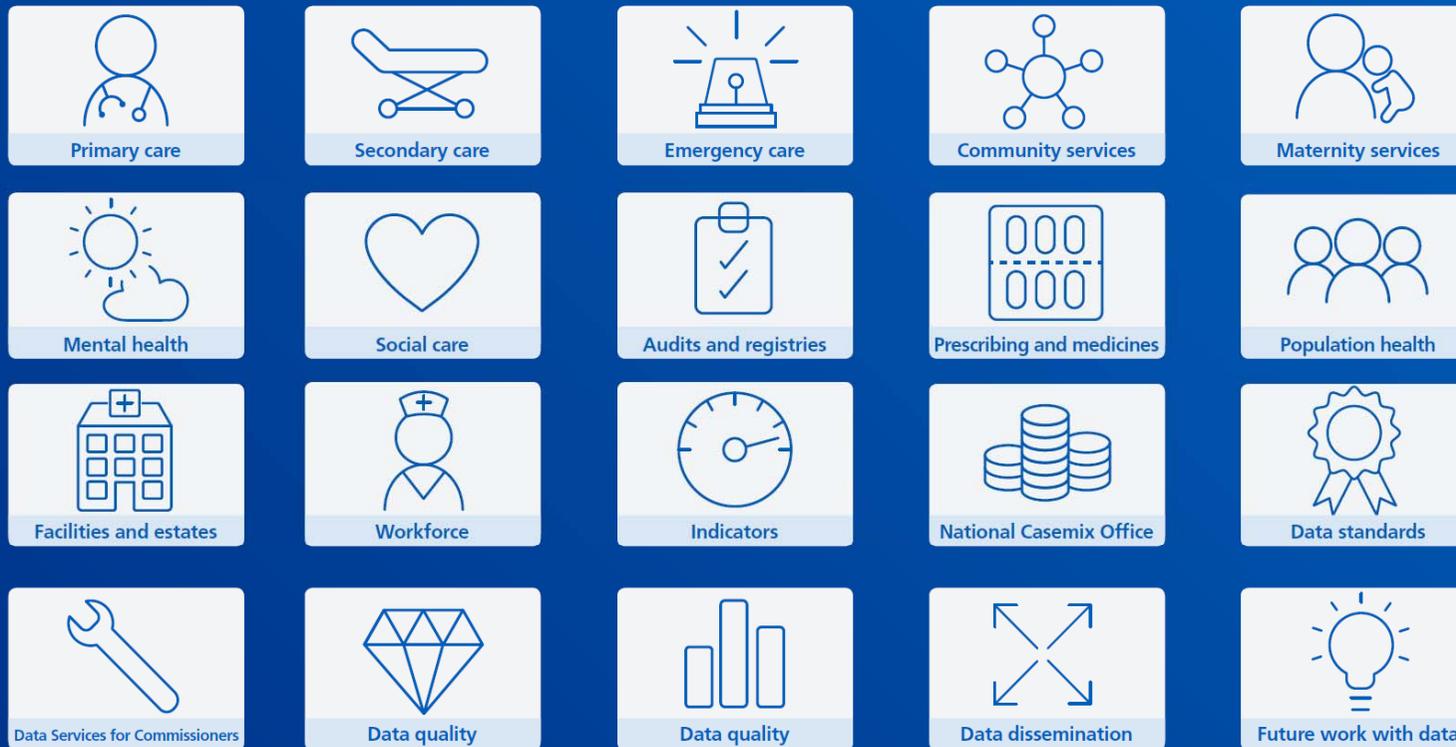
Our role

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



Data, insights and statistics

Copyright © 2019, NHS Digital.



Information and technology
for better health and care

v1.1 Sept 2018

Data Access Request Service (DARS)

- NHS Digital works under legislation, including
 - Health and Social Care Act 2012
 - Care Act 2014
 - Data Protection Act 2018
- 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)

1,084 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

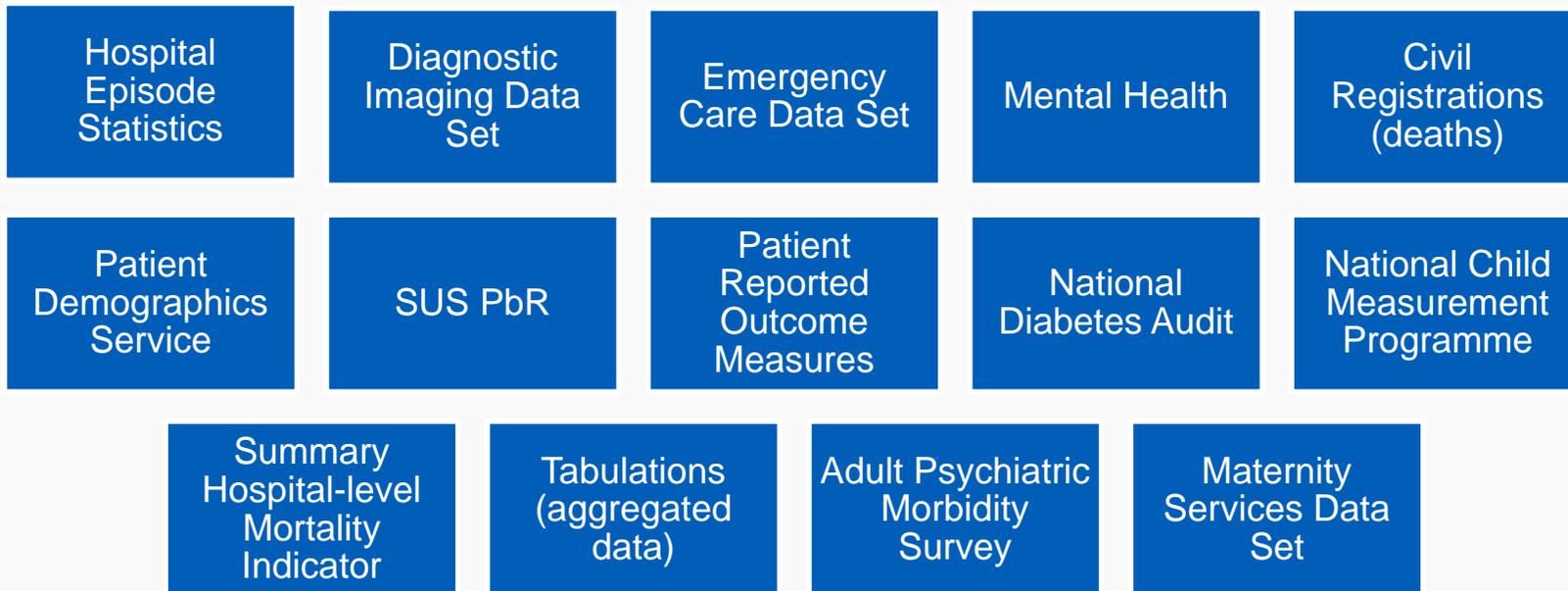
1.7bn records



Over **200** active medical research studies



Data 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

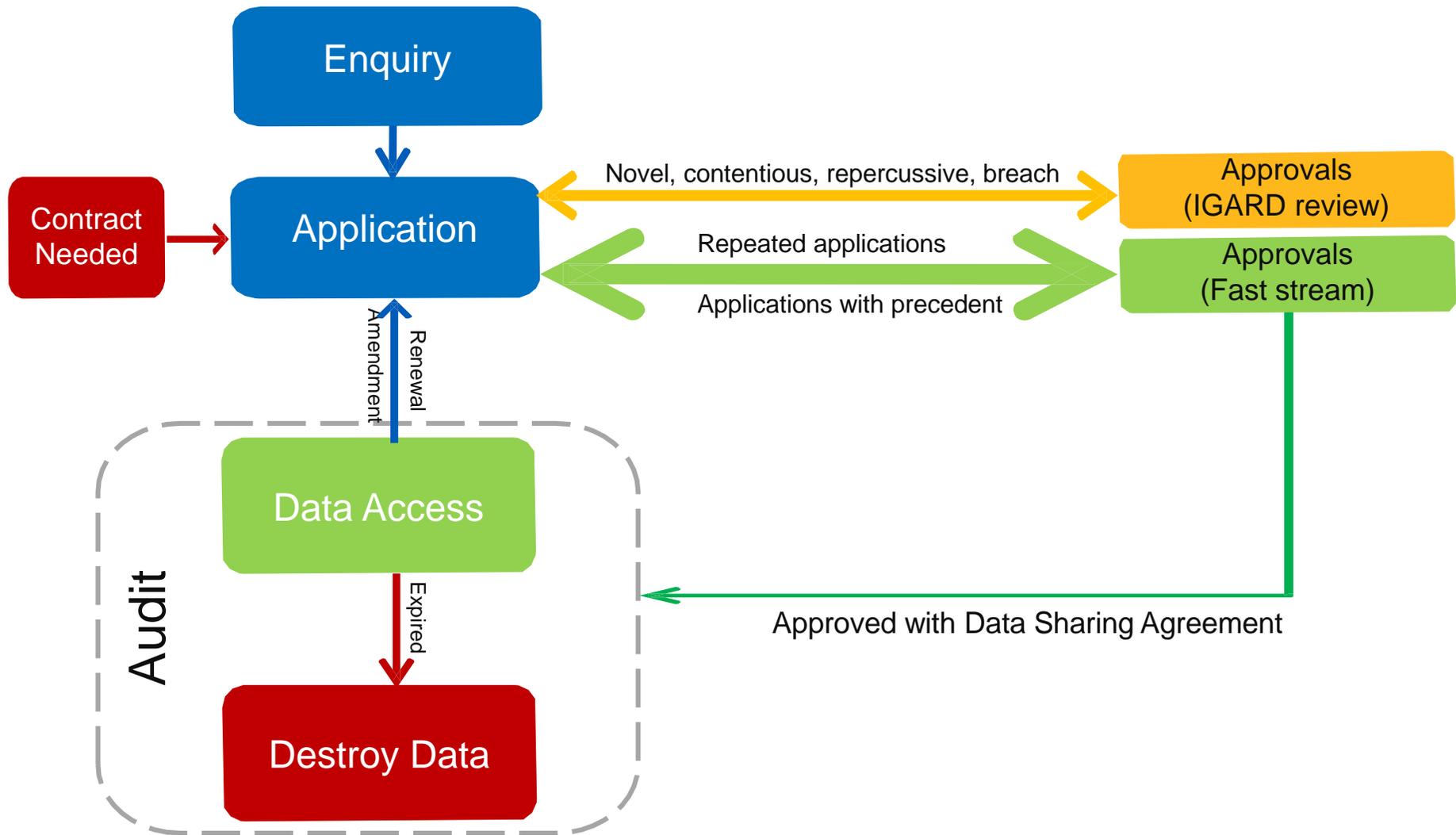
Public health programme about child excess weight indicators

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

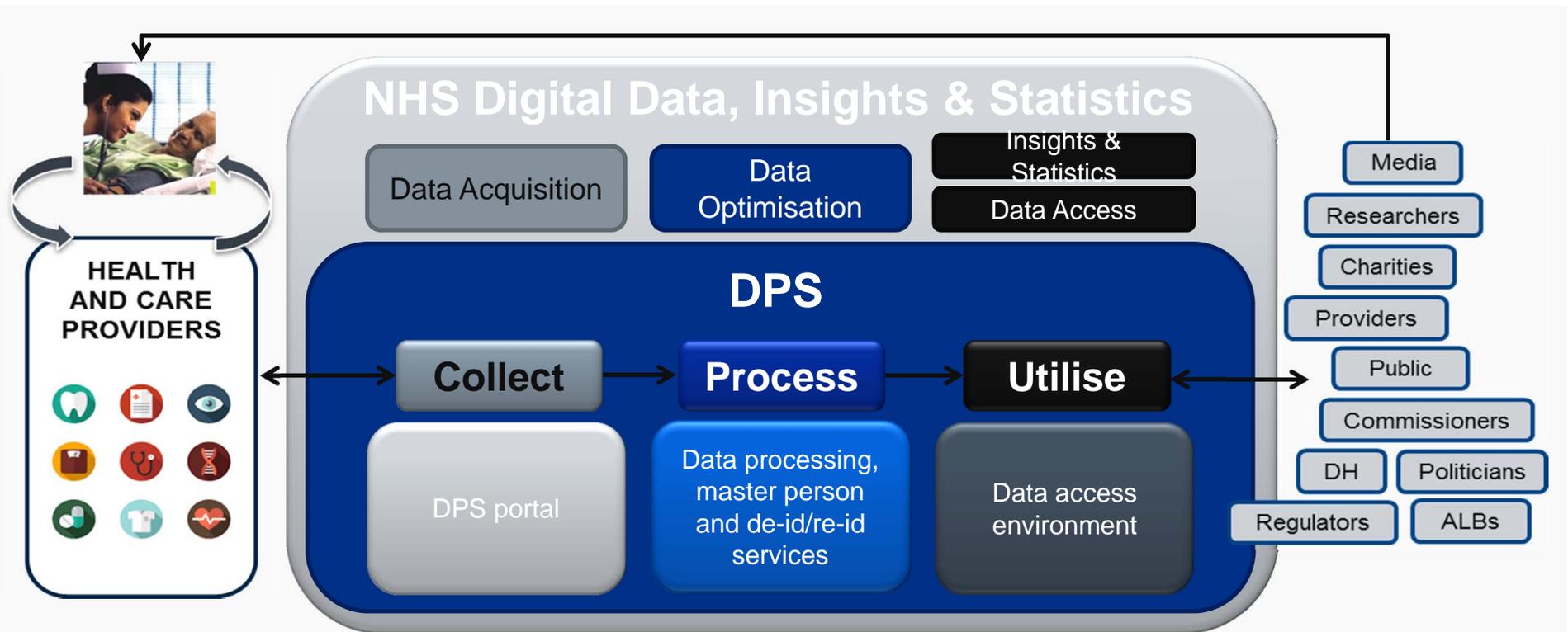
A table of numbers (data)

Information on treated and untreated psychiatric disorder

Information about the maternity care pathway



We're investing in a modern data platform ("DPS")...



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*

Assessing the level of risk in survey datasets

Anonymised

Identifiable



Content: weak or strong identifiers

Context: What other information do you have access to? Is there rare or unusual content

Guidance: <http://www.highlights.rsc.mrc.ac.uk/PIHR/index.html#/? k=b3t8l6>

Current process: UK Data Service & End User Licence

Adult Psychiatric Morbidity Survey: Lessons learned in creating two datasets

Current thinking

- Full survey dataset(s) available through DARS
 - Precedent established
- On-line access through our data access environment
- Data linkable by default to other NHS Digital datasets
- Dataset available through UK Data Service
 - Must include same controls
 - Precedent established
 - Not linkable to other datasets
- Can an anonymous dataset (with value) be created ?

Transition period

- Feedback on proposal, and test / improve application process & systems
- Work with us to:
 - Investigate possibility of an anonymous dataset or alternative solution without compromising utility
 - Develop standard applications for data (precedents)
 - Ensure appropriate guidance and support



www.digital.nhs.uk

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

enquiries@nhsdigital.nhs.uk

0300 303 5678

Information and technology
for better health and care