NHS Digital and Research

Monday 12th December 2016

NHS Digital

Information and technology
for better health and care

presented by Richard Langley
Data Access Request Service

# What we've been doing to support research…

- Appointed senior account manager for research

- Established a significantly strengthened team to handle data requests

- Completely revised access processes; introduced triage for quick initial response; allow longer data sharing agreements

- Introduced on-line system for requests

- Introduced a revised single Data Sharing Agreement and an overarching Data Sharing Framework Contract to move repeated queries to organisation level

- Updated and improved guidance and website

- Data Release Register now available within 1 month of end of quarter (most recent due in the week) - see http://content.digital.nhs.uk/dataregister

Data Access Request Service

Customers include NHS and Social care organisations, research, business intelligence companies and the wider life science sector

Over 1500 data disseminations per year, including HES, mental health and PROMS
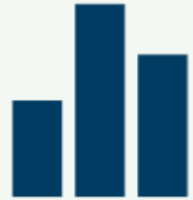
Access to a range of data products, including HES which contains over **1.6bn** records

1400 patient level data releases disseminated per year

20 monthly data extract customers

Over **1000** applications for data received per year

Over **650** data releases for medical research disseminated every year

**397** active medical research studies

What's coming up next…

- Improving support for applicants
  - Context sensitive help & guidance
  - Programme of webinars for applicants
  - Programme of presentations / webinars on dataset developments

- Continual development of DARS on-line

- Additional datasets being made available via DARS on-line

- Working with CAG and others to simplify wider process

Legal Framework

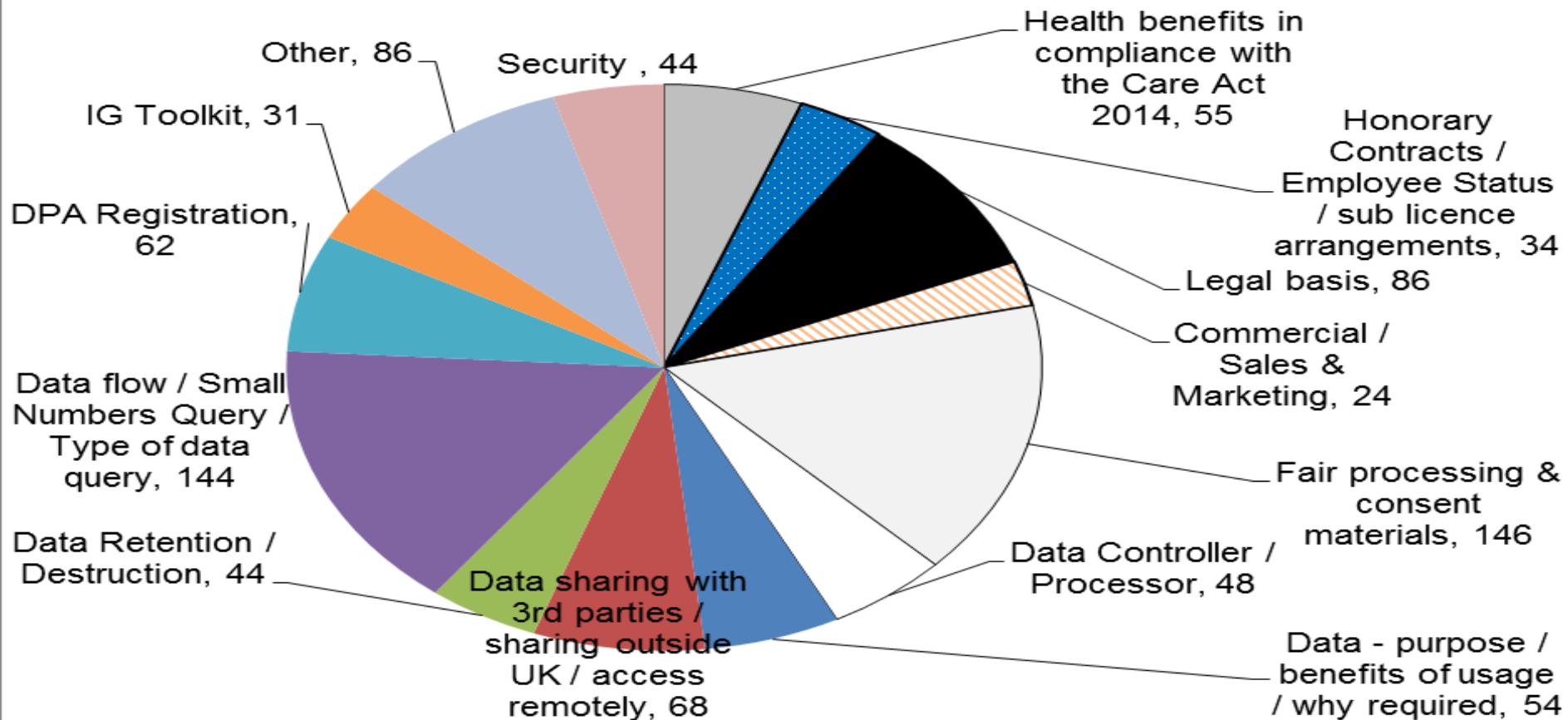Control of data,
legal framework
and constraints

Release of data
to improve health
and social care
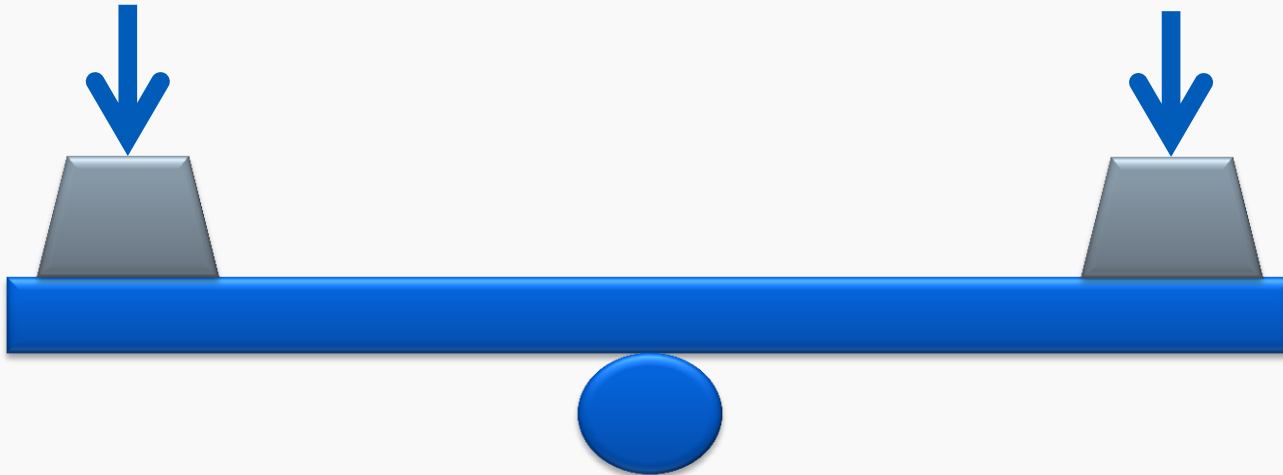
Patient Objections

- If Patient Consent is the legal basis for NHS Digital data dissemination
    - Ensure you allow people to withdraw consent
    - Keep fair processing
    - Type 2 opt outs do not apply

- If s251 is the legal basis
    - NHS Digital upholding objections in line with Department of Health Policy
    - Type 2 opt outs will apply
    - NHS Digital has published statistics on levels of opt out by GP Practice, and impact of opt outs on HES data
    - There can be challenges – case by case

Reasons unable to approve / approve with caveats (Sept 2014 to present)

- Other, 86
- Security , 44
- IG Toolkit, 31
- Health benefits in compliance with the Care Act 2014, 55
- DPA Registration, 62
- Honorary Contracts / Employee Status / sub licence arrangements, 34
- Legal basis, 86
- Commercial / Sales & Marketing, 24
- Data flow / Small Numbers Query / Type of data query, 144
- Fair processing & consent materials, 146
- Data Retention / Destruction, 44
- Data Controller / Processor, 48
- Data sharing with 3rd parties / sharing outside UK / access remotely, 68
- Data - purpose / benefits of usage / why required, 54

Background to the external audit team

The need for greater visibility:

- Value of data comes from sharing and reuse
- Data sharing depends on the public having trust of the system
- The "Review of Data Releases by the NHS Information Centre" produced by HSCIC Non-Executive Director Sir Nick Partridge, June 2014, recommended that the HSCIC should implement a robust audit function that will enable ongoing scrutiny of how data is being used, stored and deleted by those receiving it.
- Audit team established in August 2015 to conduct regular audits
- Audit reports published online

Common Issues - Audits

- Fair processing – principle of "no surprises"
- Lack of clarity around data flows (eg: cross-border)
- Lack of clarity around s251 legal basis
- Lack of clarity around outputs (suggestions on onward sharing / projects)
- Security
- Data minimisation

Breaches

- Do not breach
- If its not explicitly permitted, you cant do it
- Seek permission not forgiveness – ask in advance if in doubt
- If you think you may have an issue, tell us immediately
- Transparency is vital

We are all guardians of patient trust.
Once lost, it is difficult to recover

Basic audit process

Audit preparation / organisation notified

Onsite visit

Headline report (internal)

Draft audit report - auditee and internal review

Audit report published online

Scope of audit

The audit will seek to determine whether:

- The organisation is adhering to, or has the ability to adhere to, the requirements of a data sharing framework contract and a data sharing agreement(s)
- The data handling activities within the organisation pose an unacceptable risk to confidentiality or to NHS Digital
- The organisation conforms to its own policies and procedures

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