

Research use of NHS and wider administrative data in Scotland **why is it like this?**

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Life, health and our digital footprints



Data Linkage for Research in Scotland

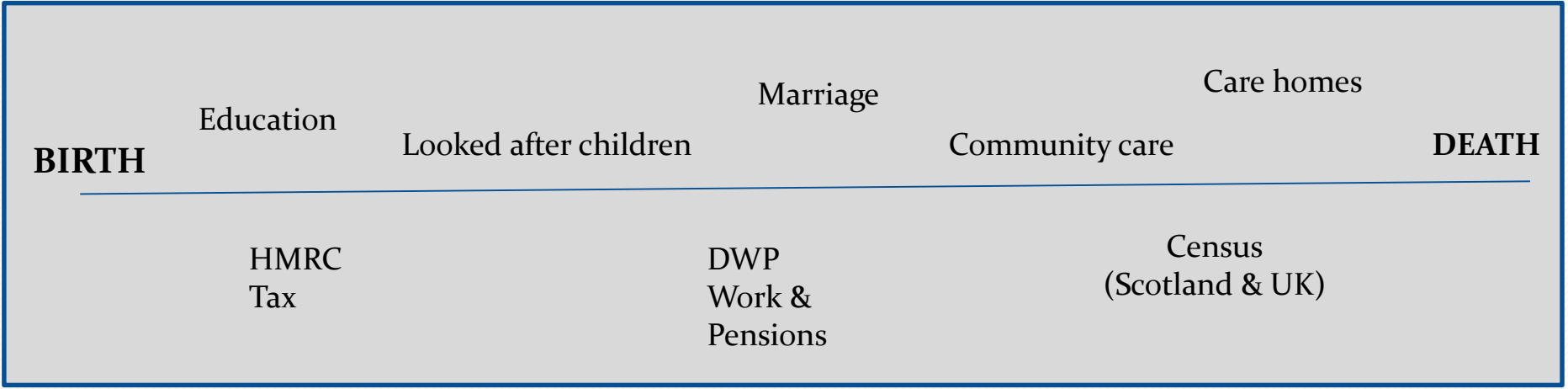
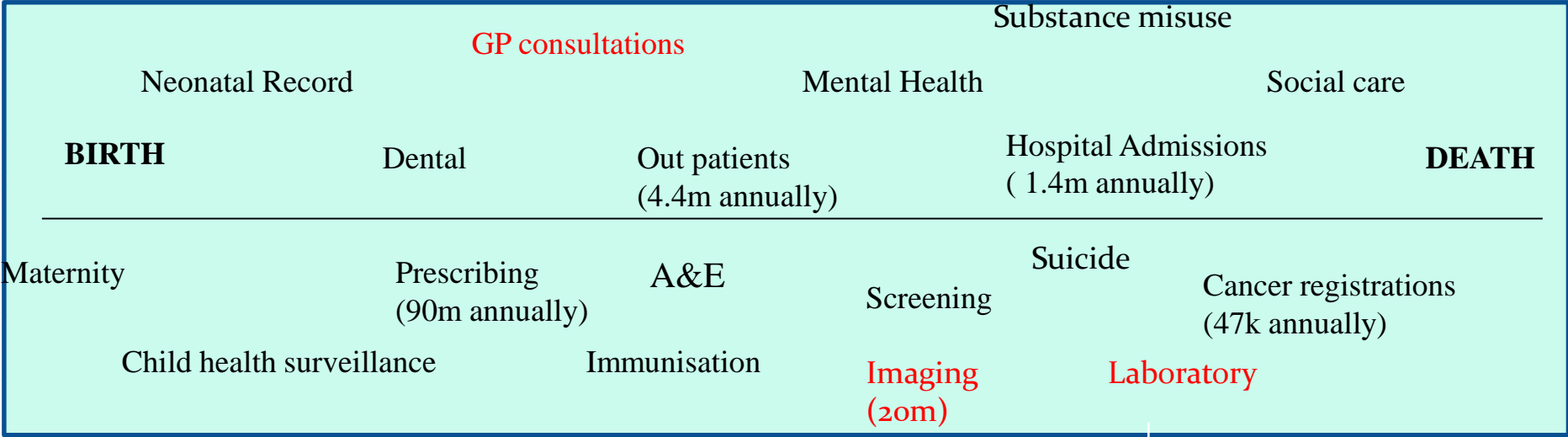
- NHS National Services Scotland linking data for over 20 yrs
- Scottish Health Informatics Programme
 - Empirical research
 - Infrastructural design
 - Public engagement
 - Law and subsequent ‘Guiding Principles’
 - Computing infrastructure (with separation of function)
- Farr Institute (MRC + 9 others funders)
- Administrative Data Research Centre -Scotland (ESRC)
- Scottish Government data linkage
- Urban Big Data Centre

The Farr Institute Vision

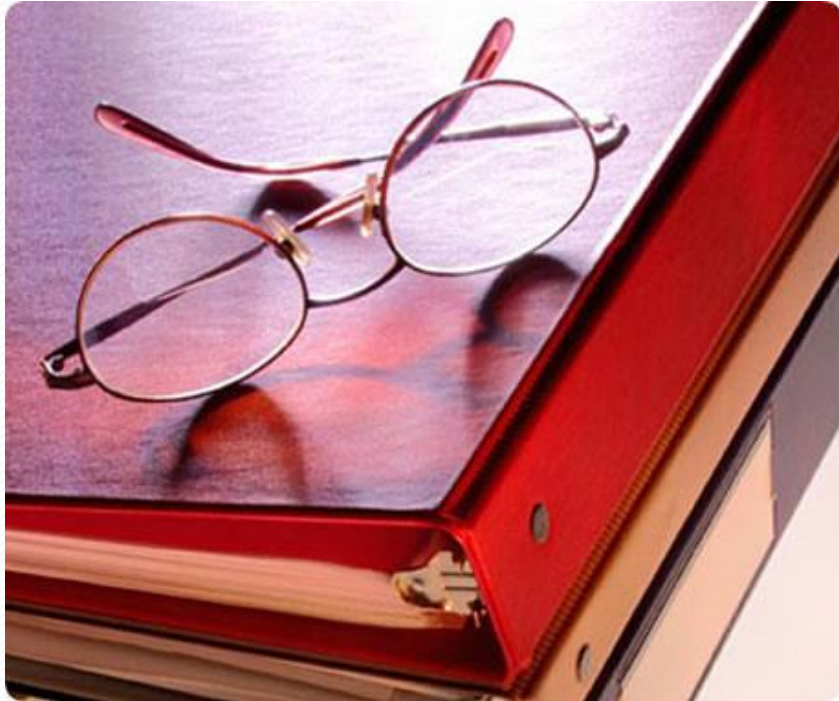
“To harness health data for patient and public benefit by setting the international standard for the safe and secure use of electronic patient records and other population-based datasets for research purposes”



Scottish national level data resources



Two Case Studies



1. Obesity and pregnancy
2. Smoking legislation

BMI and Maternity

- Design
 - 110k women, 124k babies
 - Using maternal records, hospital admissions and NHS cost data
- Outcome measures
 - Number and length of admissions (mum and baby)
 - Health care costs
- Results
 - High BMI: increased risk of hypertension, gestational diabetes, emergency caesarean, longer stays,
 - High BMI: Increased NHS costs



Fiona Denison et al (2013) Royal College of Obstetricians and Gynaecologists

Non-experimental evaluation (policy)

Effect of smoking legislation in Scotland

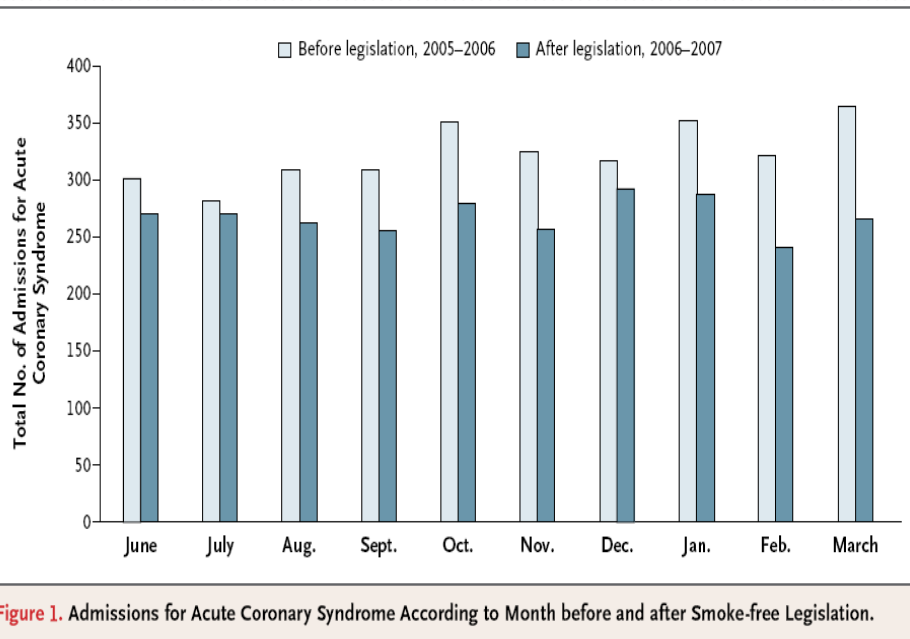


Figure 1. Admissions for Acute Coronary Syndrome According to Month before and after Smoke-free Legislation.

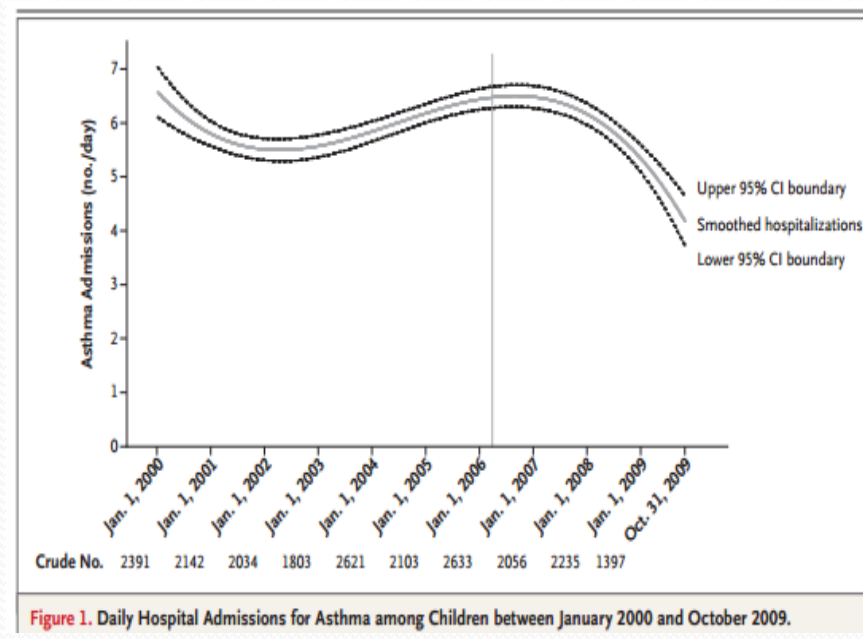


Figure 1. Daily Hospital Admissions for Asthma among Children between January 2000 and October 2009.

Admissions fell by 17% - 67% of reduction was in non-smokers
 Fall in England 4% (no legislation);
 long term trend 3%

Acute Coronary syndrome

Before ban 5.2% increase per annum
 After ban 18.2% decrease per annum

Childhood asthma

Overcoming the challenges in using non-consented data for research



Why do these health data exist?

1. To ensure safe and effective health care
2. To plan and administer our national health service

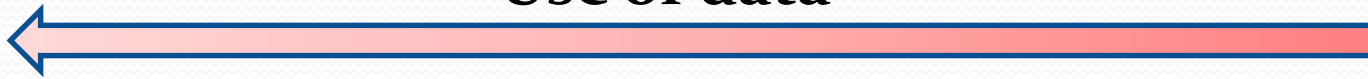
The implications of losing public trust and the withdrawal of data are serious

- Clinical risks
- Planning risks
- Performance risks

Researchers are privileged users of NHS data

Public views on data use for research

Use of data



Better health care

Policy development

Commercial gain

Users of data



Health Service

Academics

Government

Private/commercial



Access to data

3 inter-related elements

1. The law – UK Data Protection Act 1998, the Human Rights Act 1998 (HRA), relevant health service legislation, and the common law duty of confidentiality.

2. Role and function of the organisation that holds the data

3. Organisational policy



NHSS treats de-identified data as though its 'personal data' ...

- 2nd DP Principle states that Personal Data shall be obtained only for one or more **specified** (and lawful) purposes and shall not be further processed in any manner **incompatible** with that purpose(s)
- In other words, if you collect for one specified purpose, you can't just use for a further unspecified purpose.
- How does this fit with research?

Privacy notices

NHS posts 'privacy notices' to inform the public how personal and confidential data will be used for direct and indirect care...but works on an opt-out model

<http://www.england.nhs.uk/wp-content/uploads/2014/03/fair-process-strat.pdf>

(NHS England Fair Processing Strategy 2014)



DPA research exemption: (Section 33)

- Further processing of Personal Data only for “**research purposes**” in compliance with “**relevant conditions**” won’t be “incompatible”
- “relevant conditions” are that data **not processed**:
 - to support measures or decisions with respect to particular individuals; and
 - in such a way that substantial damage or substantial distress is, or is likely to be caused to any data subject.

Policy developments around how NHSS data governed?

- *SG Data Linkage Framework* and **Guiding Principles for Data Linkage**
- Introduction of the **Public Benefit and Privacy Panel** – this makes decisions on National and cross regional projects for secondary care data
- Development of a **National Primary Care Dataset (SPIRE)**

What are the guiding principles?

Public Interest

Protection of privacy, efficient use of data, and scientifically sound and ethically robust research and statistics, are all in the public interest.

Governance and Public Transparency

Clear decision making processes that are open and accountable to the public



What are the guiding principles?

Privacy

The law does not give absolute value to privacy, and a balance is needed between respect for privacy, through the proportionate mitigation of risk, and the potential benefits to all through the use of data.

- consent
- anonymisation
- security



What are the guiding principles?

Access and Personnel

Avoiding any one person or organisation having access to large quantities of personal data.

Linkage using the separation of functions

Sanctions

Where organisations or individuals break the law then legal sanctions apply. Other sanctions should be considered where the Guiding Principles are breached.



Securing Trust: Data Controllers and Public

Data controllers opt in to each project

Worthwhile projects
Public Benefit, scientifically and ethically sound

Data controllers opt in to each project

Safe People

(approved
researchers)

Safe Data

(limited de
identified
data)

Safe Places

(secure
data
centres)

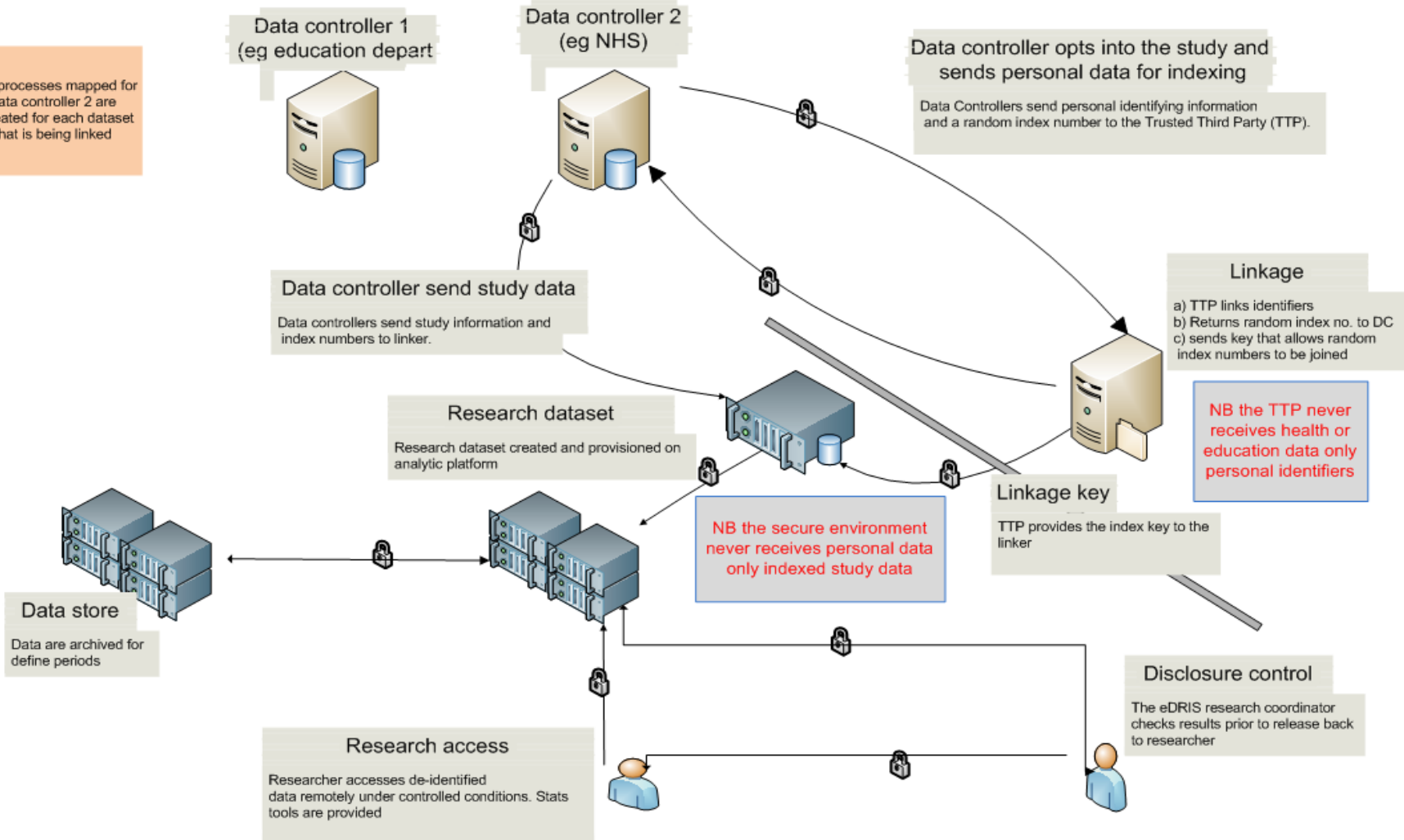
**Safe
Outputs**

(SDC prior
to release
of results)

Public Engagement and Communication

Scottish data linkage using the principle of separation of functions

The processes mapped for data controller 2 are repeated for each dataset that is being linked



Scottish Informatics and Linkage Collaboration

Farr Institute
(MRC)

Administrative Data
Research Centre
(ESRC)

Urban Big Data
Centre ?

Shared
computing
resources at
University of
Edinburgh

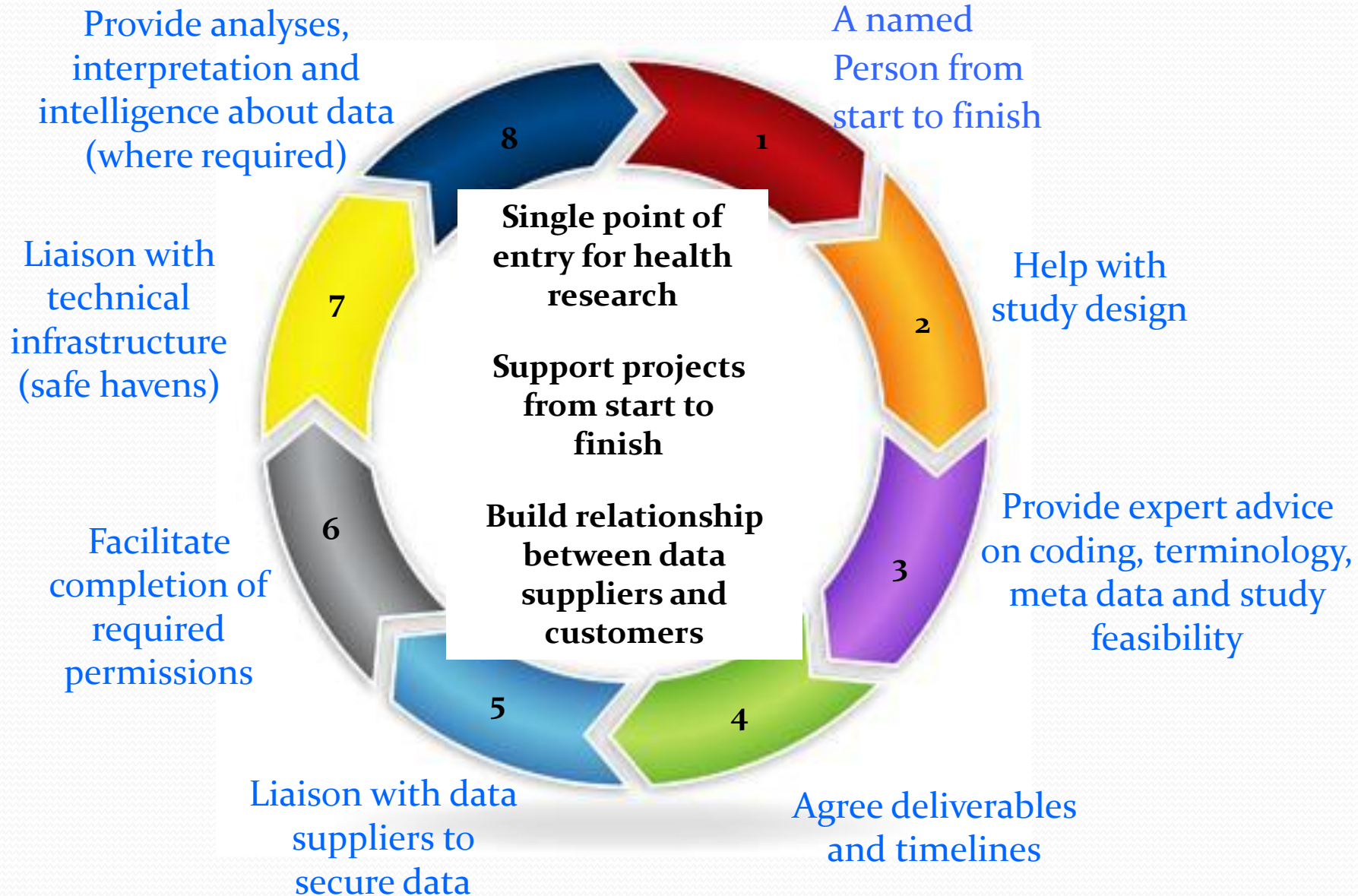
eDRIS
Research
coordination and
advice (NSS)

Shared TTP
Linkage service
at NRS

Shared office
space at
BioQuarter
(UoD and UoE)

SILC
(Shared services for research initiatives that process sensitive data)

The eDRIS Service



Progression to Acute Pancreatitis

National level data

- cohort identified for four NHS Board areas (GG&C, Lothian, Highland, Forth Valley)
- data linked from hospital admissions, outpatient attendances, emergency dept attendances, community prescriptions, critical care units (SICSAG)

Regional level data

- bespoke data collection from NHS systems
- GP data
- laboratory results



Findings:

- a number of previously unknown factors impact on progression to severe acute pancreatitis
- new information on accuracy and clinical diagnosis of 'true acute pancreatitis'
- will contribute to important improvements in patient care and service efficiency

Thanks for listening

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