

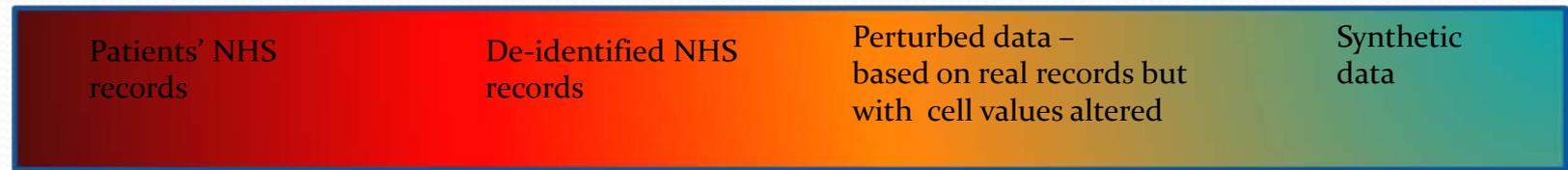
Information Governance

Why is it like this ...?

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Data sensitivity and the risk to individuals' privacy



High risk to patient privacy, high levels of control over data access

Very low risk to patient privacy low levels of control over data access

Using electronic health records (EHRs)

Patient consent

The ideal position is gain participant consent to access their health records

Simple and clear

‘I consent to the xx research team accessing my electronic health records for the purpose of xx for the period xx’

Data Resources by Location

National data - Scotland

BIRTH	Neonatal Record	Dental	Out patients (4.4m annually)	Hospital Admissions (1.4m annually)	Substance misuse	DEATH
Maternity	Child health surveillance	Prescribing (90m annually)	A&E Immunisation	Screening	Suicide	Cancer registrations (47k annually)

BIRTHS

Primary care

Hospital

DEATHS

Smoking	BMI data	Read/Snomed ct data	Imaging data	Pathology	Blood tests	Clinical observations
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BIRTH

Education

Looked after children

Marriage

Housing

Community care

Care homes

DEATH

HMRC
Tax

DWP
Work &
Pensions

Social care

Census
(Scotland & UK)

Challenges in using NHS data without explicit consent

- Who is the data controller?
 - GP
 - Regional Health Board
 - Special/National Health Board
 - An other public sector organisation (Edu SG or LA)
- What will convince them to allow access to the data?
- Understanding the processes and timelines

What are data controllers thinking ...

- Access permission must be done in ways that are:
 - Legal
 - Common law of confidentiality
 - DPA (schedule 2 and for sensitive data schedule 3)
 - Statutes governing data controller
- Carry public support
- May need ethics approval



Common Law Duty of Confidentiality

- Basic principle is that if information is given in situations where a duty of confidence applies, you shouldn't disclose
- However, exemptions to this:
 - consent
 - disclosure necessary to safeguard individual or others, or in the public interest
 - where legal duty to disclose (e.g. court order)
 - In England Section 251



Section 251 (not Scotland)

- Section 251 (NHS Act 2006) allows the Secretary of State for Health to set aside the common law duty of confidentiality for defined medical purposes.
- SoS can enable disclosure of confidential patient information for medical purposes, where it was not possible to use anonymised information and where seeking consent is not practical, having regard to the cost and technology available.
- The Health Research Authority took on responsibility for Section 251 in April 2013, establishing the Confidentiality Advisory Group (CAG) function (Care Act 2014) – CAG advise NHS Digital



DPA: Useful Schedule 2

“Justifications”

- Consent (Condition 1)
- Necessary for compliance with any legal obligation to which Data Controller is subject (but not in a contract (Condition 3))
- Necessary to protect vital interests of individual (but likely to be life or death) (Condition 4)
- Necessary for the exercise of any functions conferred on any person (so either the discloser or the disclosee) by or under an enactment or for the exercise of any other functions of a public nature exercised in the public interest by any person (Condition 5)
- Necessary for purpose of legitimate interests of Data Controller or person to whom data disclosed except where processing unwarranted due to prejudice to rights and freedoms/legitimate interests of individual (Condition 6)



DPA: Useful Schedule 3 “justifications”

- Explicit consent (Condition 1)
- Necessary for the exercise of any functions conferred on any person (so either the discloser or the disclosee) by or under an enactment or for the exercise of any other functions of a public nature exercised in the public interest by any person (Condition 7)
- Necessary for medical purposes, and is undertaken by a health professional or by someone who is subject to an equivalent duty of confidentiality. (Condition 8)



Exemptions: Research (Section 33 DPA)

- Further processing of Personal Data only for “research purposes” in compliance with “relevant conditions” won’t be “incompatible”
- “Research purposes” includes statistical or historical purposes
- “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.
- If meet these requirements, research data can be kept indefinitely (despite 5th DP Principle) and so long as result of research or any resulting statistics not made available in a form which identifies individual, won’t be subject to SAR.



Public Benefit and Privacy Panel (Scotland)

NHS Scotland Health Boards have delegated decision making powers to the PBPP:

- Assess applications to use national level or multiple health board data (non consented) but **NOT** GP data
- Decisions involve balancing the benefit to the public verses the risks to individuals' privacy

<http://www.informationgovernance.scot.nhs.uk/pbpphsc/>

How does PBPP process an application?

**PBPP Full
Committee
(quarterly)**

- Review application and invite applicant to committee meeting to discuss

**PBPP Tier 2 Out of
Committee
(2 week turnaround)**

- Review application and Tier 1 referral reasons
- Approve, refer or reject in current form

**PBPP Tier 1
(2 weekly)**

- Reviewed against proportionate governance criteria
- Approve, refer or reject in current form

eDRIS

- Assist with finalising application for submission
- Submitted to one of the Tier 1 fortnightly panels

Ethics and R&D approval

Ethical review is required by both;

- Confidentiality Advisory Group/NHS Digital
- Public Benefit and Privacy Committee (PBPP)

In Scotland generic ethics approval applies if ;

- Scientific peer review
- Data are to be accessed in the National Safe Haven
- Data are de-identified

In Scotland R&D approval required if health board resources are use.

One way mirror:

Questions in the public's mind

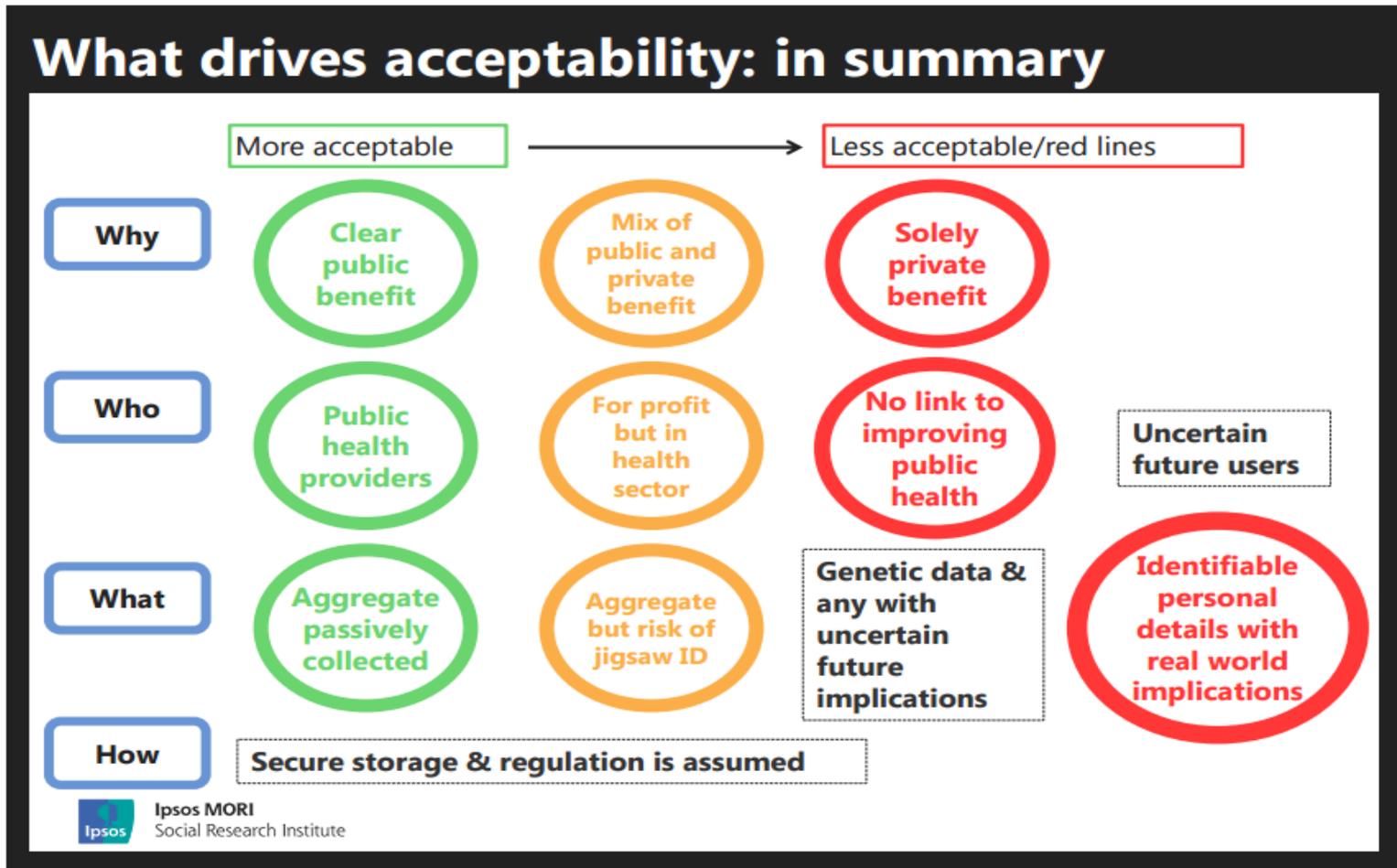
WHY: Is it for a particular public benefit and not just private profit?

WHO: Can the people using my data be trusted to produce a public benefit?

WHAT: Am I giving sensitive data? Could it be linked back to me?

HOW: Are there safeguards in place to keep my data private and secure?

Figure 1.3 – The four 'key tests'; driving acceptability



Scottish Data Access Model

Data controllers opt in to each project

Worthwhile projects
Public Benefit, scientifically and ethically sound
& approved

Safe People

(approved
researchers)

Safe Data

(limited de
identified
data)

Safe Places

(secure
data
centres)

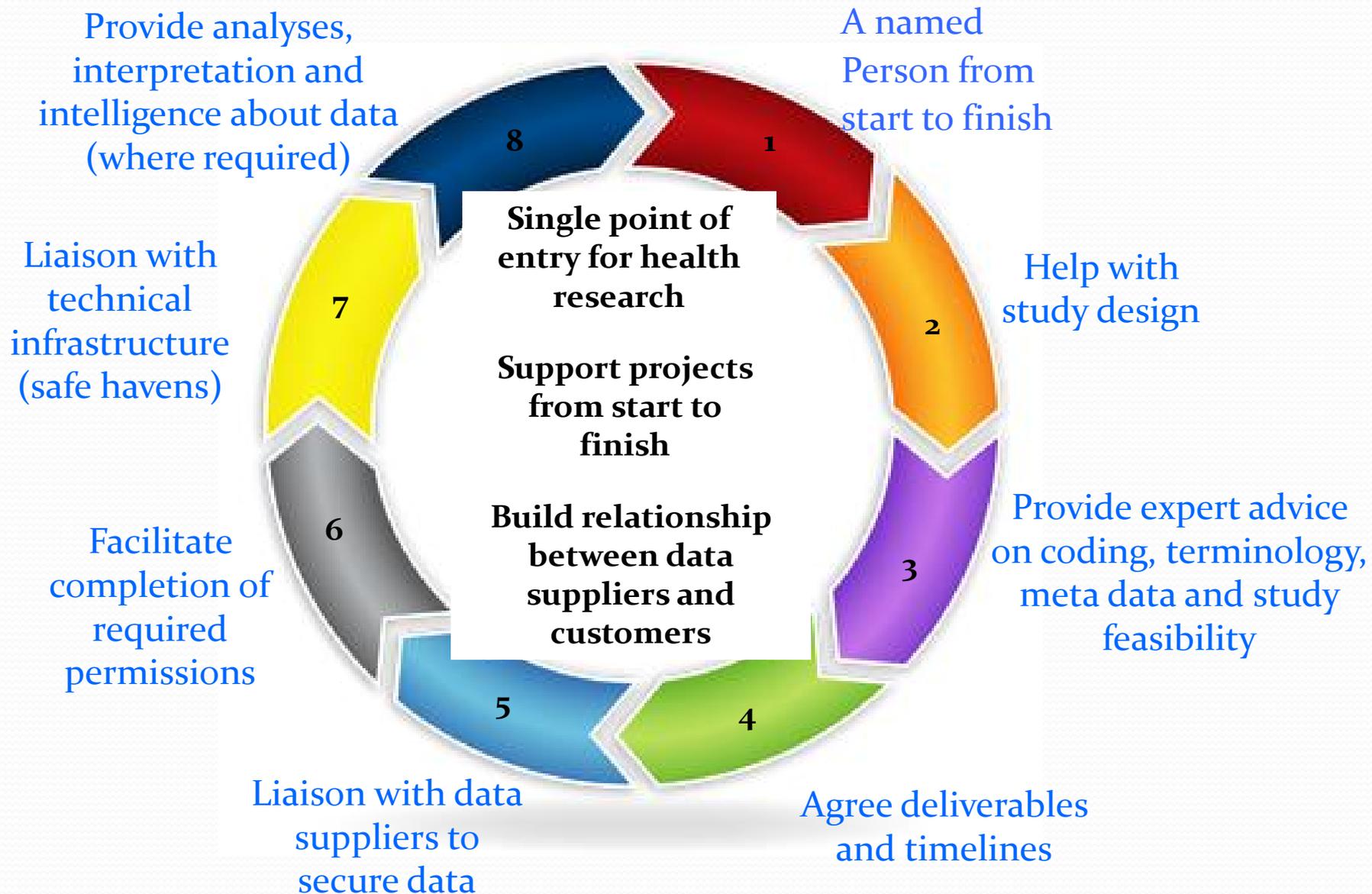
**Safe
Outputs**

(SDC prior
to release
of results)

Data controllers opt in to each project

Public Engagement and Communication

The eDRIS Service - Scotland

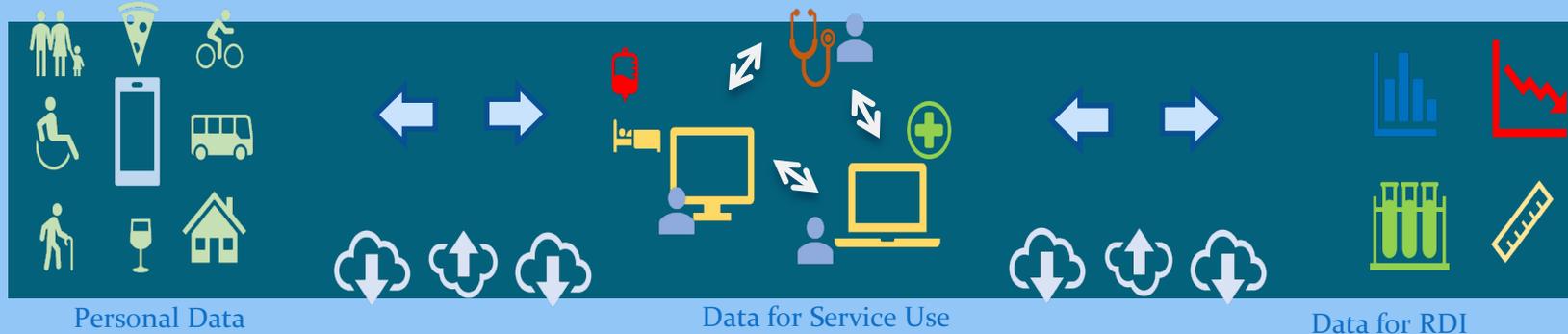


Vision

Wouldn't it be nice if.....

We were able to share information easily and securely to support health improvement, integrated health and social care and health-related research which makes a positive difference to the health and

Mission



Assumes



Challenges



Step Change Ideas

1. Create mutuality of purpose with active public engagement to complete the circle
2. Standardise processes e.g. risk assessments
3. Accreditation of systems, information sharing
4. Evolve IS toolkit
5. Clear, accessible, expert guidance
6. Clear, consistent and swifter processes
7. Once for Scotland resource hub
8. Data events for public and professionals to understand data science & identify risk vs opportunities
9. Increased use of Safe Havens through consistent application
10. Explore options for synthetic data, data mining, open data, safe questions and develop proposals and business case

Alignment

Digital Health & Care, Digital Transformation, Health & Social care integration, Farr, IHDP, Academia, Industry, Open Innovation, Data Hacks, DHI, Data Lab, App Developers, UK wide groups

Thank you for listening

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