Fundamental building blocks to enable data sharing in health and care

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Data sharing…

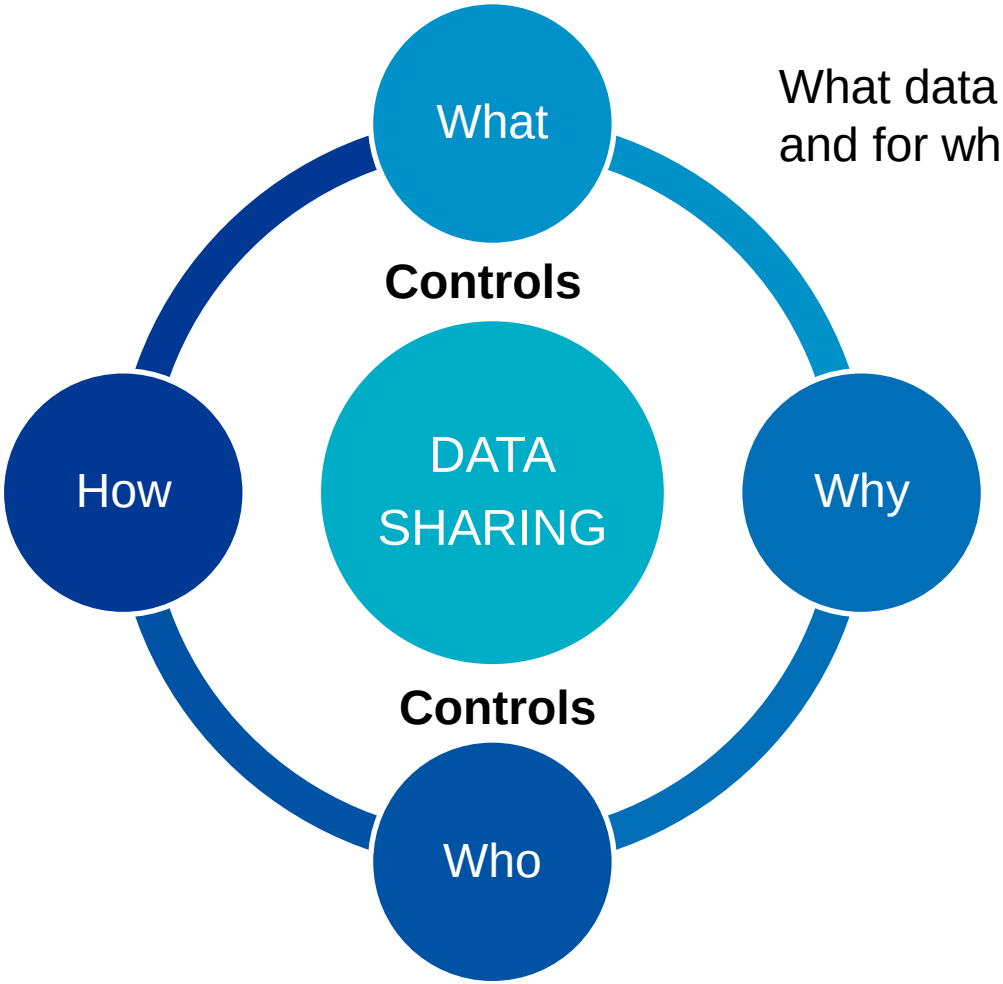
Patient and business benefits

balanced with

Risks and concerns

Data Sharing building blocks

NHS England



What data is necessary and for what purpose?

How do we safely share and use the data, to maintain public trust and confidence?

Why is the data necessary? If necessary – what's the minimum level necessary?

Who needs what data and for what purpose?

What Data?

Over 2000 local and national data flows used by commissioners alone

A single national contract but…
used by:

- 209 CCGs, all setting out different information schedules for local data
- Complex commissioning models all requiring cross validation just to figure out who pays
- Inconsistent application of guidance and standards
- Differing levels of capacity and capability of providers impacting ability to meet information requirements
- National data sets collected by service and not consistently submitted with varying levels of data quality and completeness

Patient level data - classifications (draft)

1. Acute and urgent care
2. Clinical registers
3. Community and out of hospital care
4. Demographic and reference data
5. Diagnostics
6. Drugs and devices
7. Measures of demand
8. Mental health (incl Dementia & LD)
9. Primary care
10. Public health
11. Quality, experience and outcomes
12. Social care
13. Wider determinants of health

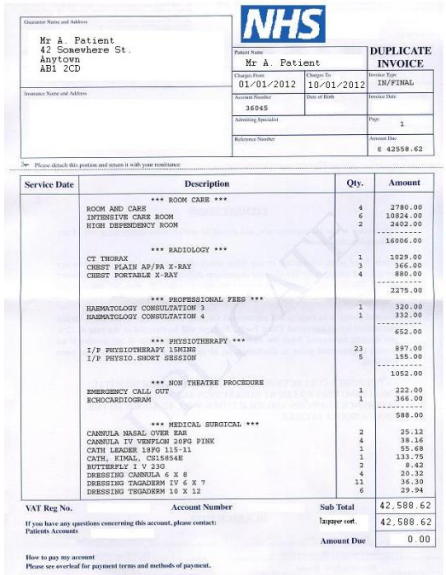
- Provides a more comprehensive view of data necessary to support statutory duties
- Provides flexibility for data type, rather than specific system e.g. SUS data
- Used to describe the purpose and likelihood of linkage

Why commissioners need patient-level data

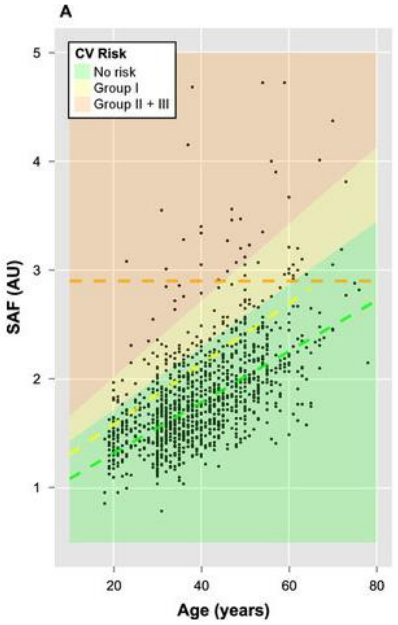
Planning for new models of care

Complex business rules

Case management



Contract management



Risk scoring and profiling

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User scenario – risk stratification

- AS A commissioner I WANT my CSU to apply risk scoring tools to anonymised patient-level data sets to identify groups of patients who may benefit from a particular service SO I CAN commission services and pathways to meet that demand

- AS A clinician I WANT to use the same data sets (with access to the NHS number) to identify specific individuals who are classified as high risk and may require health or social care intervention SO I CAN offer them an assessment

User scenario – invoice validation

- AS A commissioner I WANT my CSU to check that identification rules, tariffing and commissioner assignment have been correctly applied by a provider SO I CAN challenge specific invoices where this is not the case and seek reimbursement

- AS A provider I WANT to know which invoices have been challenged SO I CAN check the details against the patients' records and respond accordingly

User scenario – commissioning activity leading to safeguarding review

- AS A CSU (data processor) I WANT to analyse linked anonymised datasets on behalf of commissioners from multiple organisations SO I CAN provide intelligence about patient pathways and make suggestions to improve delivery of services

- AS A CCG (commissioner) I USE the patient pathway intelligence based anonymised linked datasets but can see that a child has visited several A & E units and there may be a safeguarding issue. I request an identifiable NHS number to be sent to the responsible clinician based using a separate legal basis which supports the disclosure.

How do we balance need for patient level data and maintain public trust and confidence?

- Minimise the use of patient confidential data
- Have controls in place to protect the data

- Make clear what data is collected, how it is used, and who has access
- Make clear how individuals can find out what data is held about them
- Make clear what they can do to find out more, or want do not want data about them to be used for activities other than direct care

How can patient level data be used?

Proposed Solution - Data to be anonymised in line with ICO Anonymisation COP

Requires:

- A consistent and compliant end to end data flow process (business changes)
- Clarity on accountability for controls (roles and responsibilities of data controllers and data processors)
- Strict controls & assurance processes for data recipients (audit / assurance process)
- NHS Digital (DSCRO) anonymise data in line with ICO Anonymisation COP and where there is a separate legal basis, facilitate the disclosure of identifiable data (system capabilities)

Future Operating Model for Data

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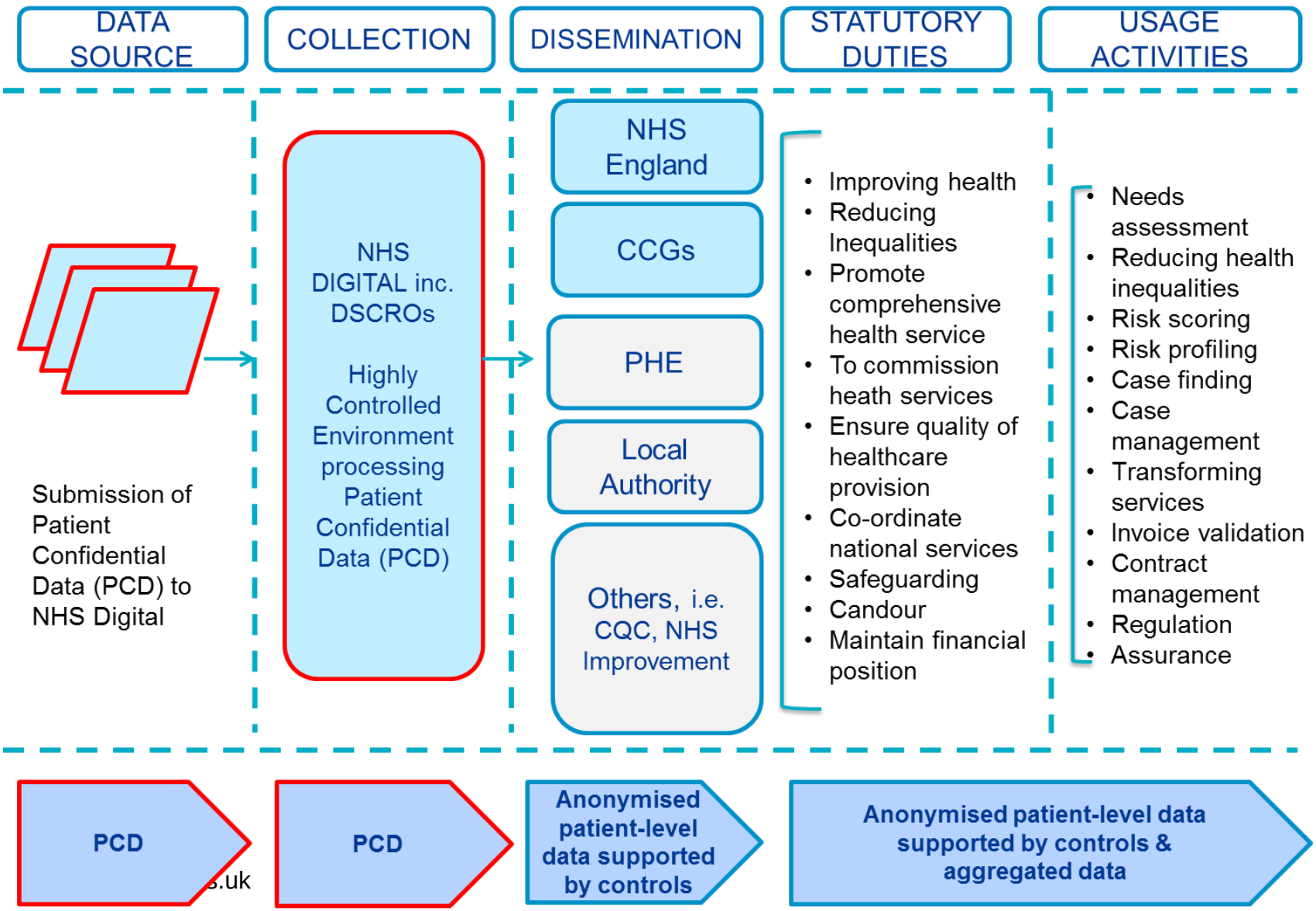


Public Trust and confidence

Actions underway

- Revise and amend fair processing notices and patient information to explain in plain English – what, why, who is involved in data sharing
- Working with NDG and wider systems communications to put for the case for data sharing in NHS
- Implement changes in security and controls, oversight and auditing of organisations receiving and processing patient level data
- Align controls and assurance with accountability – data controllership and processor principles
- Develop and implement new systems to collect, anonymise and disseminate anonymised data in line with ICO anonymisation COP

Collection, de-identification & dissemination via new NHS Digital data platform

NHS England

Provider submissions

All patient level data supported by consistent patient identifiers

Error Reports

Land, Load, Validate

Master Person Service

1. PDS cross-check
2. PDS trace
3. Further Match

De-ID Service
Creates Consistent Commissioning Pseudonym (CCP)

Derivations Service

Dissemination/Access Service

Legal basis

Legal basis

DSP

Anonymised Flow for Commissioning Purposes

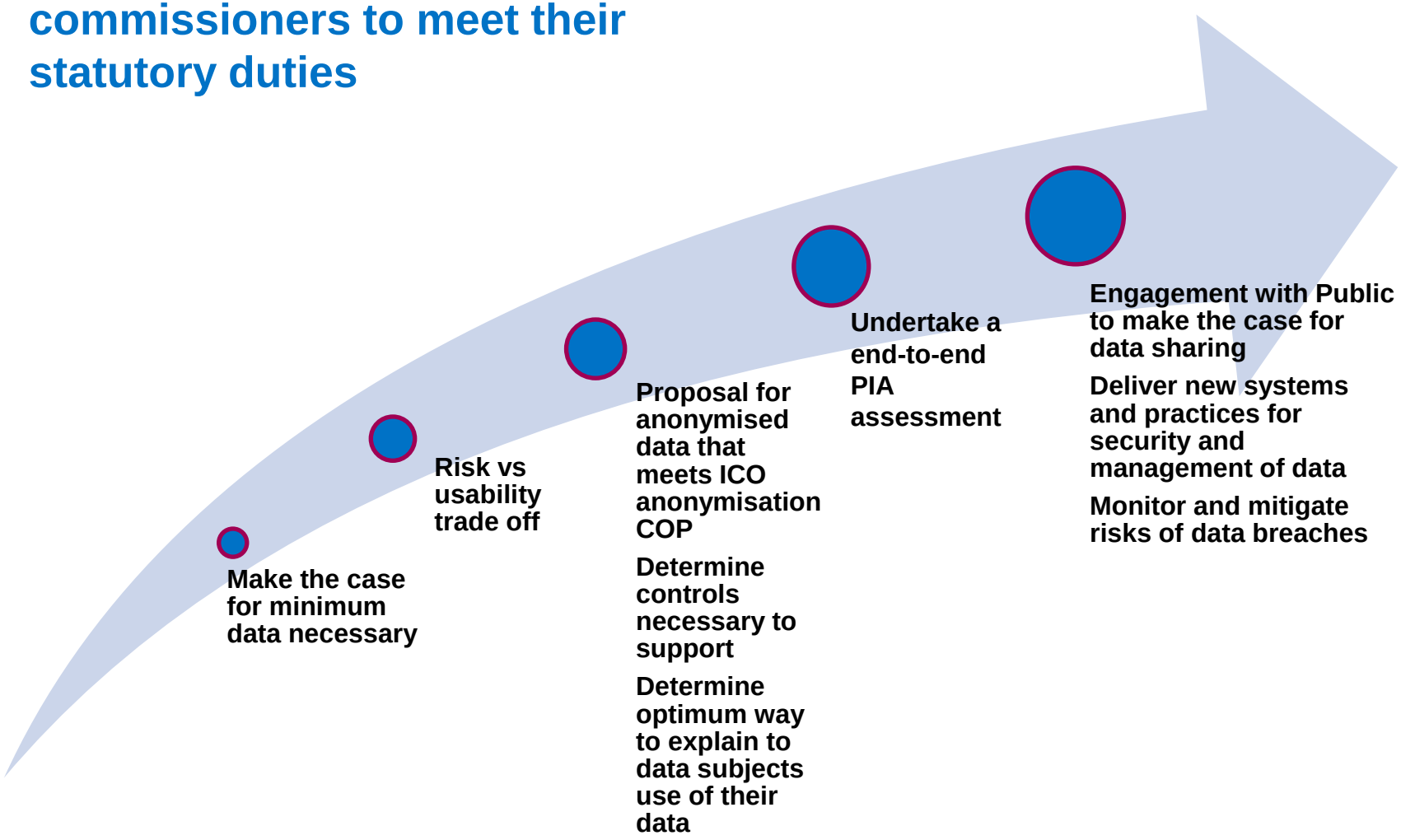
CCP (for linkage)
CCP DQ Flags
Age Derivations
Geographical-Derivations
Local Patient ID
Other data

Identifiable flow for direct care or other legal purposes

NHS Number
Postcode
Date of Birth
Other data

Summary - Our journey

Delivering data to enable commissioners to meet their statutory duties



Summary

- Data sharing is vital for commissioning
- Using ICO anonymisation COP, provides a good way to balance usability with maintaining patient confidentiality
- We have not yet made the case to the public

BUT

- We have a plan and we are closer to delivering the business changes necessary to be successful