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Payment Innovation and Local Support (PILS) Information Governance Workshop

24th July 2014

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Welcome & Introductions

Bruno Desormiere

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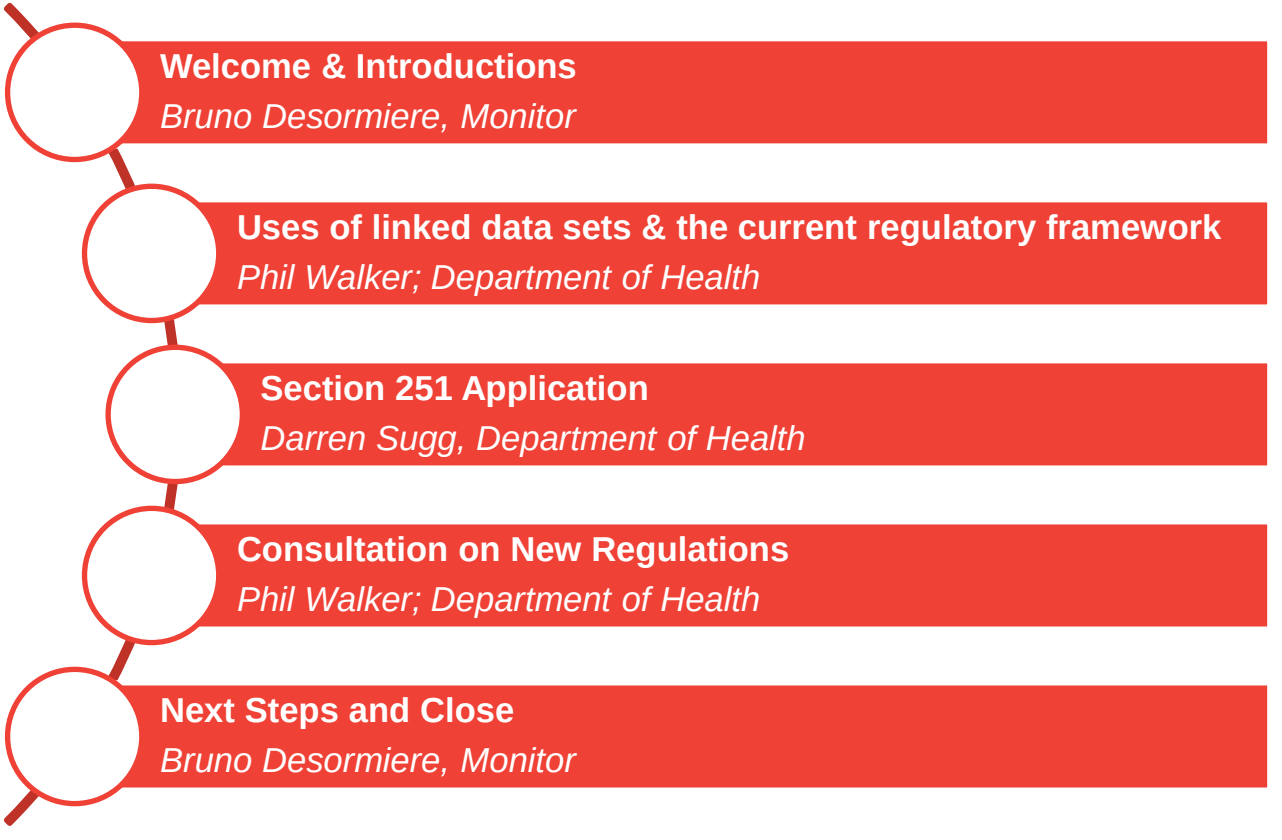
Outline of the workshop



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Recap – Payment Innovation & Local Support (PILS)

- Commissioners, providers and clinicians within a local care economy would benefit from an improved understanding of the resource utilisation and associated costs of care across the various health and social care providers for the populations they serve
- Poor visibility of how different patients (or a sub-groups of patients) use the health and social care systems is frequently noted as a barrier to commissioning and delivering patient centred co-ordinated care
- Linked data at the patient level is a key enabler to improved care and is required in order to describe a complete patient population resource map across all providers of integrated care
- There are some local examples of successfully linking data across providers and of using this data to support improvement in the delivery of co-ordinated care; however, this practice is not well understood or widely adopted across the country.
- This project aims to provide local support on how to develop linked patient level data sets. It will also clarify the value of this information and demonstrate the analytical potential of rich data sets in identifying, delivering and commissioning more integrated care for patients

User guide for linking patient level data

- Worked with subject matter experts and 5 partner sites who already have experience of linking data to produce a draft user guide
- Shared with our 8 test sites a very early draft of the guide
- Information Governance identified as the main area requiring troubleshooting for test sites. Workshop today designed to provide clarity on the current regulatory framework and what may be possible going forward.

Partner Sites

- Somerset
- North West London
- Tower Hamlets
- Barking, Havering & Redbridge
- Kent

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Uses of linked data sets & the current regulatory framework

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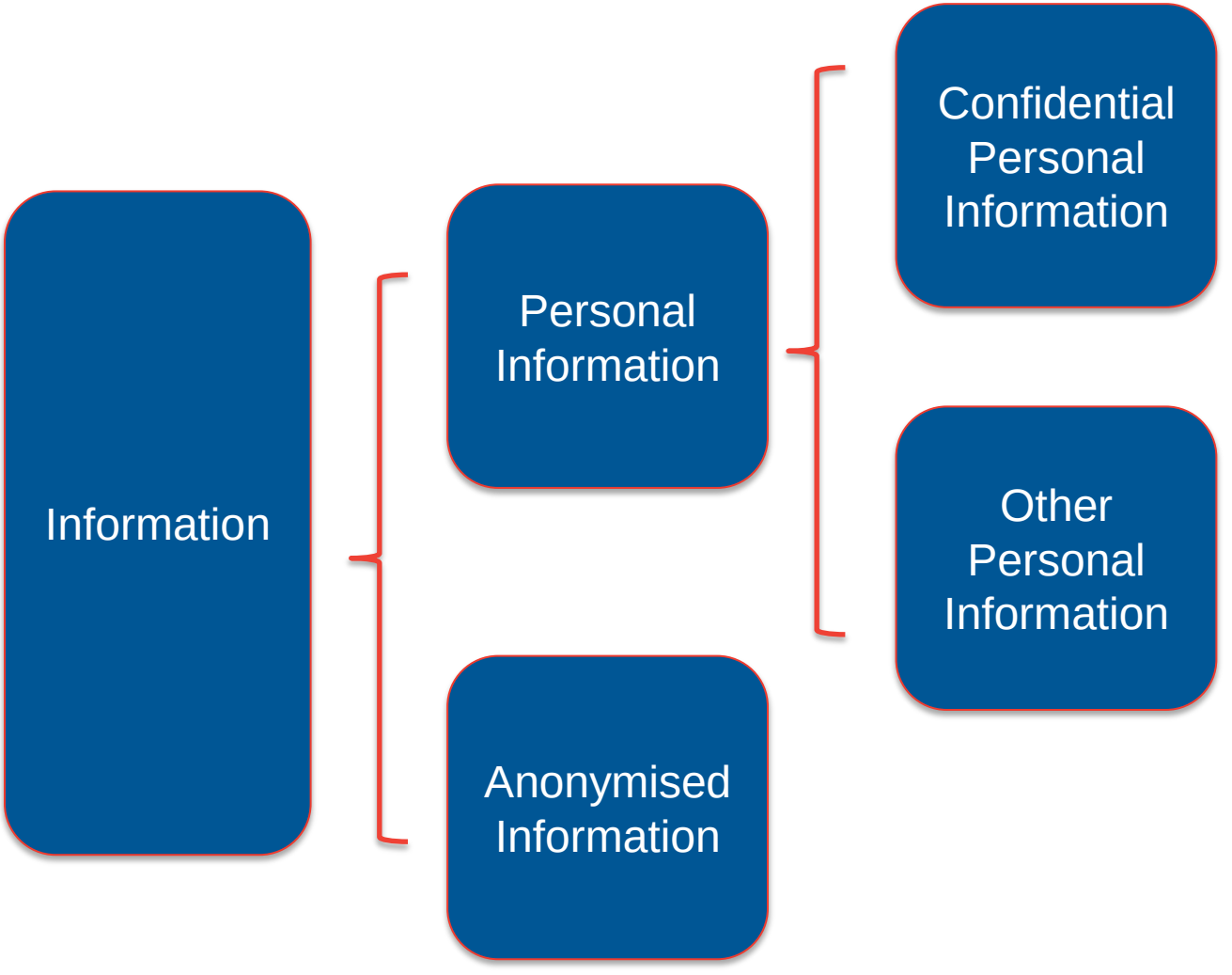
Information Governance Requirements



PCD – Personal Confidential Data

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Non-confidential personal information

- Cannot contain or be used to link to anything that informs about clinical or social care matters
- Can include demographic information
- Can be used for purposes that support analysis, e.g. NHS Number tracing
- People must be informed in broad terms about how information that identifies them may be used

Anonymised information

- Cannot contain anything that might lead to re-identification in the context that applies
- If meets the requirements of the HSCIC ‘Anonymisation for Publication’ standard it may be published
- For most organisations anonymised data can be used for any purposes desired

Sharing Confidential Personal Information for Care

- Confidential personal information is protect by law and should not normally be shared against the wishes of the individual concerned, whether for care or any other purpose.
- However, it is generally accepted that people who use health and social care services understand that social workers, doctors, nurses and other professionals will need to share confidential information among the care team and with other professionals along the care pathway in order to provide effective care.
- When an individual consents to receiving treatment or care the common law duty of care imposes a duty to share the information necessary to deliver what is needed.
- When someone expresses concern or surprise it is important that the reasons for sharing information are explained and more generally it is good practice to keep all individuals informed about who is involved in their care and how their personal and confidential information is used.
- People have the right to say no even if this results in a worse outcome for them

Examples of care and non-care purposes

Use	Description	
A. Individual access to own medical record and history[1]	Allows people to view their own medical record and become more involved in their own care	Direct Care
B. Creating and sharing co-ordinated care plans	Co-ordinated care plans for people identified with high levels of specialised need for use across providers and setting	
C. Sharing of patient medical records and care history	Sharing patient medical records and care history for all patients to support their care	
D. Risk stratification	Risk stratification used to identify patients or patient cohorts that would benefit from proactive preventative care.	Not Direct Care
E. Identifying gaps in clinical data	For example data can be analysed to determine whether a patient is receiving the correct care for their diagnosis	
F. Piloting new care models and observing outcomes	Allows for the impact of care interventions to be measured in other settings of care, i.e. does an intervention in Primary Care reduce hospital admissions?	
G. Understanding current and future population needs and resource utilisation	For example, assessing where the highest areas of demand and cost are to assess where efficiency can be targeted.	
H. Tracking Outcomes, and meeting outcome targets	Linked data can be used for outcome tracking and outcome based payment across care settings	
I. Capacity planning	Through providing a picture of trends across settings of care to identify pressures across the whole locality	
J. Designing and implementing new payment models	Identifying the average spend associated with segments of population can be used as basis for population-based payments	

When using or sharing confidential personal information for purposes other than care, there needs to be a clear lawful basis

This requires that:

- fully informed and explicit consent has been gained from the individual concerned.

OR

- There is a legal obligation to share the confidential information for a particular purpose (e.g. HSCIC power).

OR

- the law allows the sharing of confidential information for a particular purpose. This can be because there is a public interest justification or through permissive legislation (e.g. s251 Regulations).

Summary

Three choices:

- Explicit consent
- Support under s251 Regulations
- Anonymised/pseudonymised data

Example: Risk Stratification requires confidential personal information but is not a direct care purpose

"Risk stratification tools can help determine which people in a population are at high risk of experiencing outcomes, such as unplanned hospital admissions, that are simultaneously: undesirable for patients; costly to the health service; and potential markers of low-quality care.

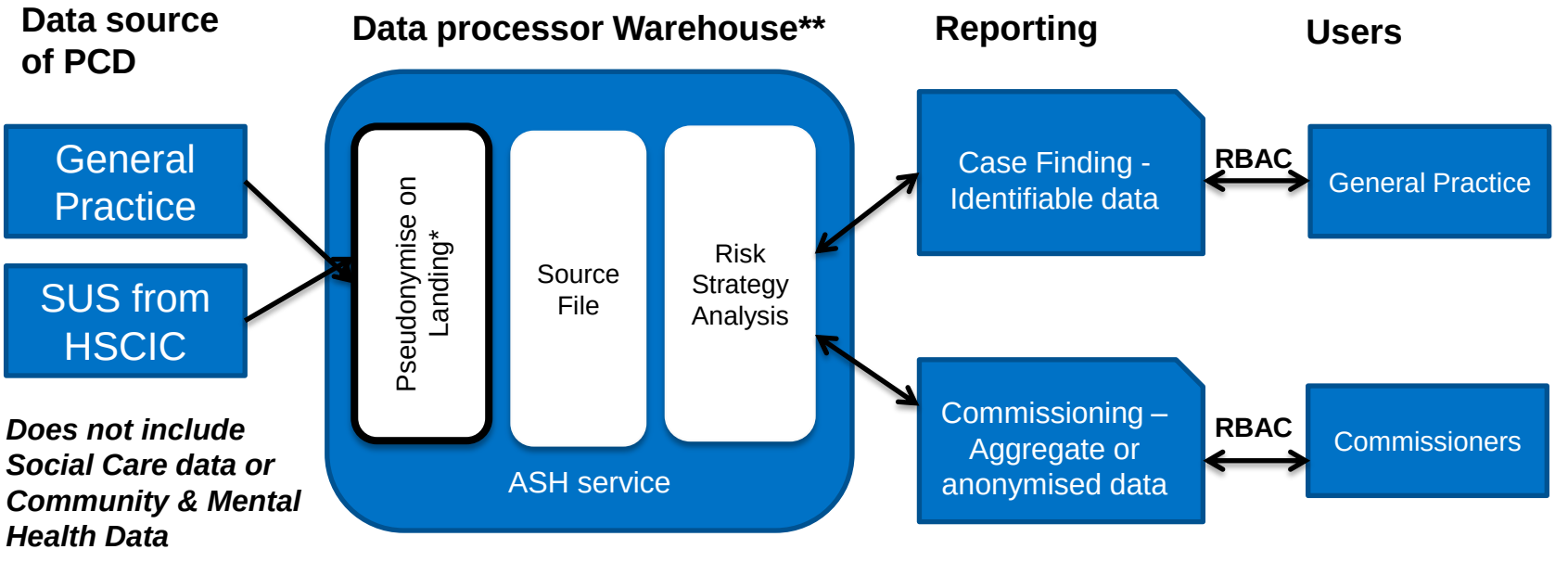
Also known as predictive risk models, these tools are used widely in the NHS, both for:

- *Analysing the health of a population ("risk stratification for commissioning") and*
- *Targeting additional preventative care interventions, such as the support of a community matron, to high-risk patients ("risk stratification for case finding")"* [1]

[1] NHS England, Information Governance and Risk Stratification: Advice and Options for CCGs and GPs http://www.england.nhs.uk/wp-content/uploads/2014/02/ig-risk-ccg-gp-2.pdf

Generic Risk Stratification Process under s251 Regulations

Figure 1 **IG compliant approach – Legal basis provided by (CAG 7-04(a)/2013). Patient Consent is not required whilst this is valid.**



An additional CAG approval is being pursued to allow inclusion of Social Care PCD for Risk Stratification purposes for the Southend Pioneer

PCD – Personal Confidential Data,
ASH – Accredited Safe Haven,
RBAC – Role Based Access

**May also use weakly pseudonymised data, defined as the following data elements NHS Number as the single identifier and include age, partial postcode, presence of date of death and sensitive items of gender and ethnicity*

*** Processing of data for risk stratification takes place under the constraints set in place by the approval of the Section 251 by the Secretary of State. This means that processing can only be undertaken by accredited organisations, either already under contract to the NHS with a proven track record on managing data for risk stratification or by Commissioning Support Units, effectively part of NHS England, that have achieved (Stage 1) ASH status*." P16 http://www.england.nhs.uk/wp-content/uploads/2014/03/priv-imp-assess.pdf

Source: Adapted from "Privacy Impact Assessment Risk Stratification, IG Taskforce Consultation Paper CP-02", Figure 1 (March 2014) http://www.england.nhs.uk/wp-content/uploads/2014/03/priv-imp-assess.pdf

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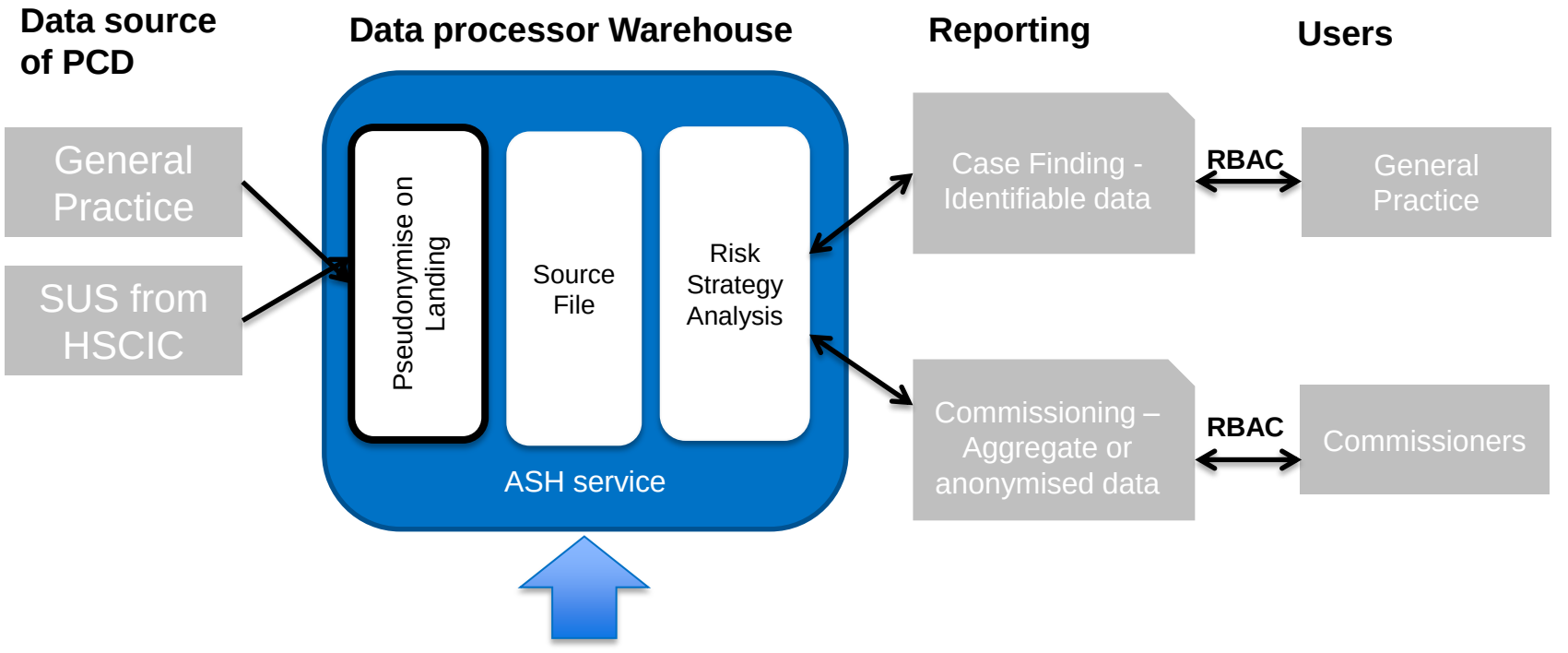
Generic Risk Stratification Process under s251 Regulations – Further explained



What analysis can take place here for commissioning purposes?

- Making data less identifiable
- Data linkage
- audit, monitoring, & analysis of healthcare provision

For what purpose?

The aim supported was to target vulnerable patient groups and offer them appropriate services. The aim of risk stratification is to reduce hospital readmissions and target clinical interventions to high risk patients.

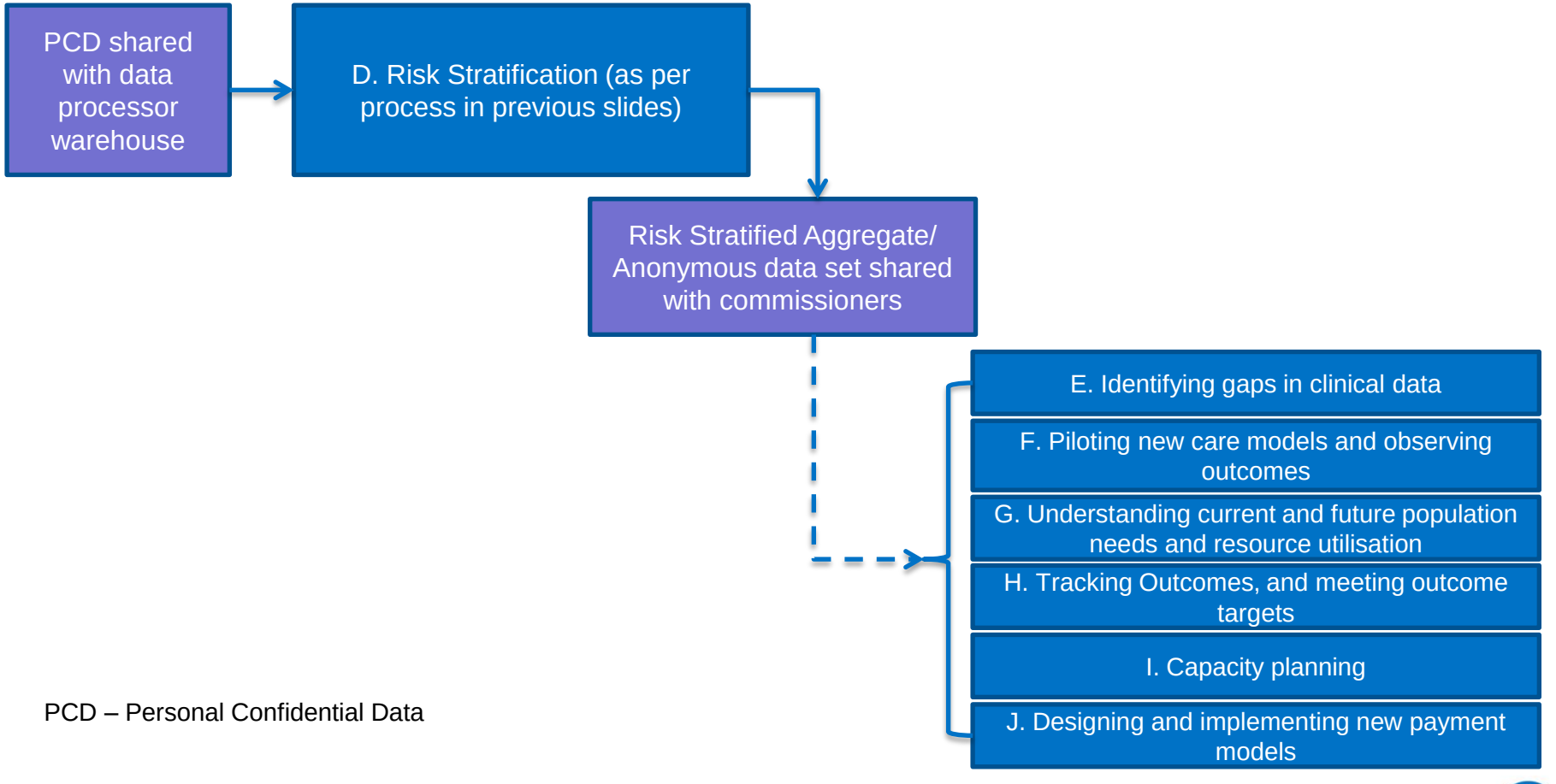
Summary: Linking Data for Risk Stratification Purposes under a s251 approval

- CAG 7-04(a)/2013 provides a legal basis for sharing of GP data and SUS data for the purpose of risk stratification*.
- The CAG approval grants temporary permission until 23/07/2014 for data processors working on behalf of GP Practices. To be compliant they must complete an Assurance Statement; available at: http://www.england.nhs.uk/wp-content/uploads/2014/02/rsa-state-02-141.pdf
- *"The existing approval applies only to GP data and SUS data. Social care data needs a separate legal basis at the present time – either consent, a separate s251 application of techniques which don't breach confidentiality."*[1]
- A further CAG request has been submitted for the Southend Pioneer site for Risk Stratification with the inclusion of Social Care Data.

*The s251 application covers SUS commissioning data sets approved under including NHS number, local hospital number, date of birth, postcode, gender and ethnicity, and to GP data including patient data, event data, referral data, prescriptions, conditions / diagnosis groups, health groups, interventions group, exclusions group, and practice data (practice ID and registered patient list)

[1] NHS England, Risk Stratification Assurance Statement, CAG 7-04(a)/2013 compliance for CCGs; **http://www.england.nhs.uk/wp-content/uploads/2014/02/rsa-state-02-141.pdf**

Effectively anonymised/aggregate output of the risk stratification process can be used for other commissioning purposes (E-J) either within the data processor if kept separate or by commissioners



PCD – Personal Confidential Data

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Any Questions?

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Section 251 Application

Darren Sugg

Integrated care team

Department of Health

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Department of Health

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Section 251 applications & the Confidentiality Advisory Group (CAG)

Darren Sugg DH/DCLG Integrated Care

What is a section 251 application?

Section 251

- Enables the Secretary of State for Health to set aside the common law duty of confidentiality to be so that confidential patient information can be transferred to an applicant without the discloser being in breach of the common law duty of confidentiality.
- In practice, this means that the person responsible for the information (the data controller) can, if they wish, disclose the information to the applicant without being in breach of the common law duty of confidentiality. They must still comply with all other relevant legal obligations (e.g. Data Protection Act 1998)

Section 251

- Must be for medical purposes:

> *"The activity must be a medical purpose as defined in s251 (12) of the NHS Act 2006. Medical purposes include medical research (that has received ethical approval by a research ethics committee) and* ***the management of health and social care services***"

Section 251 approval process

- The Secretary of State for Health receives independent advice from an independent body called the ‘Confidentiality Advisory Group’ (CAG)
- CAG has been supporting this function since 2013.
- The legal power has been in operation since 2002 and was widely debated in Parliament as the time.
- CAG advisory function was previously carried out by the National Information Governance Board’s Ethics & Confidentiality Committee (2009-2013); and the Patient Information Advisory Group (2001-2008)

Who are the CAG….?

Chaired by Dr Mark Taylor, academic specialising in Biotechnology, Law & Ethics

Members include GP's & hospital consultants (active and retired), Information Governance experts, lay members. Receive expert from Information Commissioners Office.

Remaining meeting dates 2014-15

- 24 July 2014 – bookings to be made no later than 5pm on Friday 27 June 2014
- **28 August 2014 – bookings to be made no later than 5pm on Friday 1 August 2014**
- 2 October 2014 – bookings to be made no later than 5pm on Friday 5 September 2014
- 6 November 2014 – bookings to be made no later than 5pm on Friday 10 October 2014
- 11 December 2014 – bookings to be made no later than 5pm on Friday 14 November 2014
- 15 January 2015 – bookings to be made no later than 5pm on Friday 12 December 2014
- 19 February 2015 – bookings to be made no later than 5pm on Friday 23 January 2015
- 26 March 2015 - bookings to be made no later than 5pm on Friday 27 February 2015

Background to current application

Southend-on-Sea – one of the 14 integration pioneers

Had problems sharing data for health and social care purposes

At the request of Minister of State, Norman Lamb, team of IG experts visited Southend in January…

Southend-on-Sea visit

Two days in Southend: intensive discussions with CCG and Local Authority to scope the problems and recommend solutions:

- Short-term solution: a 251 application
- Medium-term solution: new Regulation under S. 251

Workshop at end of February with all Pioneers

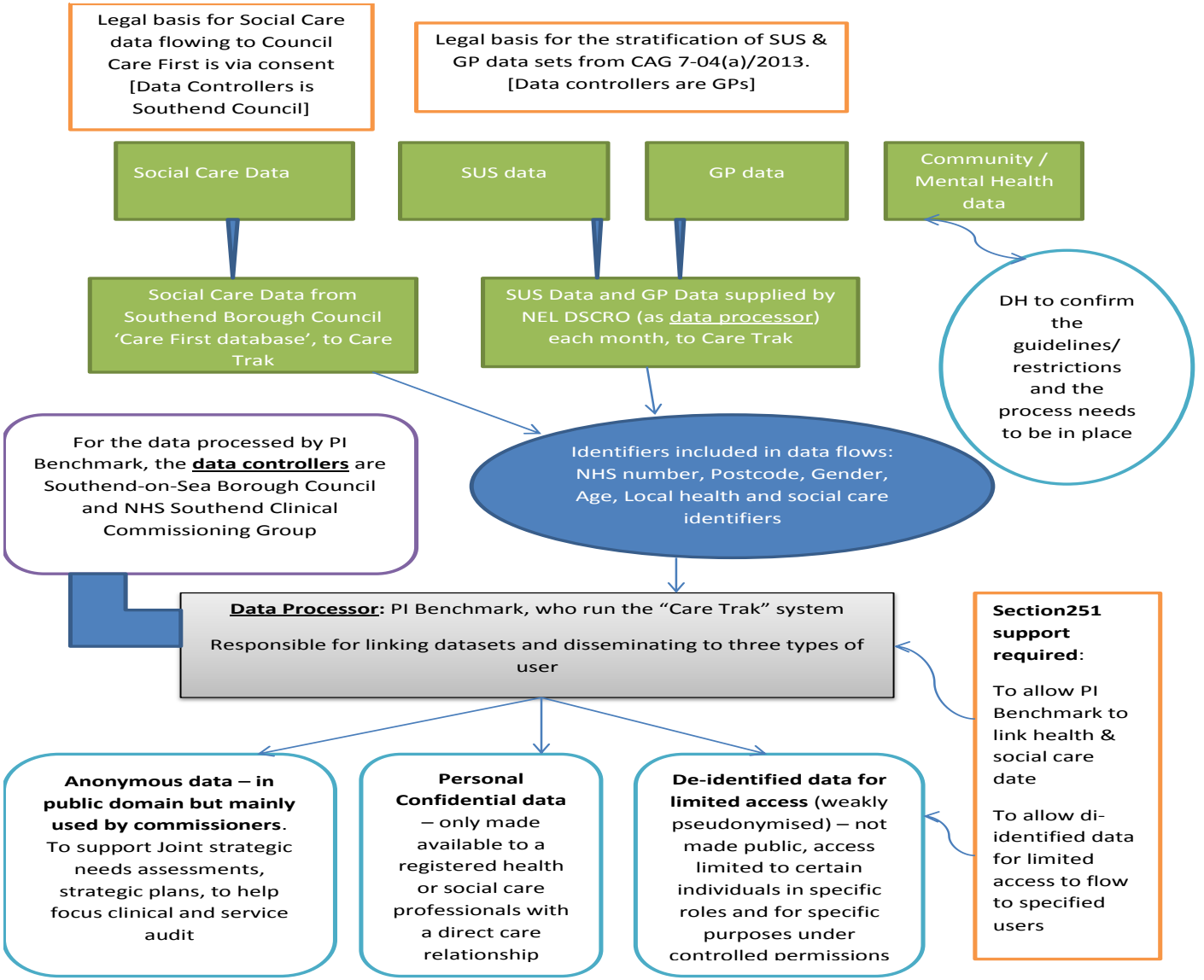
Initial plan: application for ALL pioneers

Application continued..

- Initial draft written and discussed with a sub-group of the CAG
- Advice that we would need separate applications for different programmes (Pioneers, Year of Care, PILS)
- By end of June – DH did not have enough information on all Pioneers to put in a single application, therefore an application was put in on behalf of Southend.
- Plan to put a single application for the remaining Pioneers on the 1st August for the late-August meeting. Additional information is being collected from Pioneers to help inform this
- The CAG meeting for Southend….is today!

Southend-on-Sea integrated care pioneers section 251 application

Diagram showing data sources, data flows, key identifiers and where s. 251 support is required.



What the application covers….

Section 1: Summary: why s. 251 support is being sought; list of confidential data being shared

Section 2: Justification of purpose & public interest

Section 3: Consent and practicable alternatives – why is consent not viable?

Section 4: Caldicott. Justification for using patient identifiable data. How application satisfies the requirements of the data protection act (including privacy notices, opt out procedures

Section 5: Measures to prevent disclosure of patient identifiable information. Includes assurance that 3rd party data processors met 'IGT Toolkit level 2'

“Justification of purpose” section

Examples of how stratified and linked health and care datasets will helping the development of integrated care and be of benefit to patients include:

- Identify high cost individuals whose care may need to be reviewed by the multidisciplinary team with whom they have a legitimate relationship
- Enabling analysts to investigate the data and come up with new commissioning innovations
- Enabling analysts to develop more accurate picture of how health and social care costs vary for people with different conditions, to develop more sophisticated tariff and pricing systems (for example, successful integration often means service A providing a service which saves service B money. Designing a system that identifies and attributes costs and benefits requires analysis of stratified and linked datasets.
- In summary, from a commissioning perspective, having linked health and social care data and analysis provides a more effective information base to enable service planning and joint commissioning decisions, including use of the better care fund and joint health and social care budgets.

Application Checklist

- Data flow diagram
- Copy of your organisation's Confidentiality Policy, including staff information leaflets and example(s) of confidentiality clauses in relevant staff contracts
- Copy of your organisation's Security Policy, covering physical and system security
- Copy of your organisation's Data Protection Notification including registered uses
- Examples of Patient Information Leaflets provided to the public

Any Questions?

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Proposed new regulations

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Head of Information Governance & Standards Policy

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Proposed New Regulations

New Regulations to cover:

- Accredited Safe Havens
- Controlling the disclosure of potentially identifiable data
- Access to data about vulnerable people in residential care

Consultation began on 24 June. Will run to 8 August.

- May be completed on line at: https://www.gov.uk/government/consultations/protecting-personal-health-and-care-data

Timeline

- Current consultation ends 8 August
- Final regulations need Political and Legal clearance by the end of August
- Parliamentary business processes need to be completed in September
- Regulations to be laid before Parliament in October for debate by both Houses (affirmative process)
- Regulations should come into force in December with first ASHs potentially in place by January
- Timetable is very tight with a lot of dependencies, not least implementation and accreditation processes need to be agreed and in place
- Those desiring ASH status need to start now!

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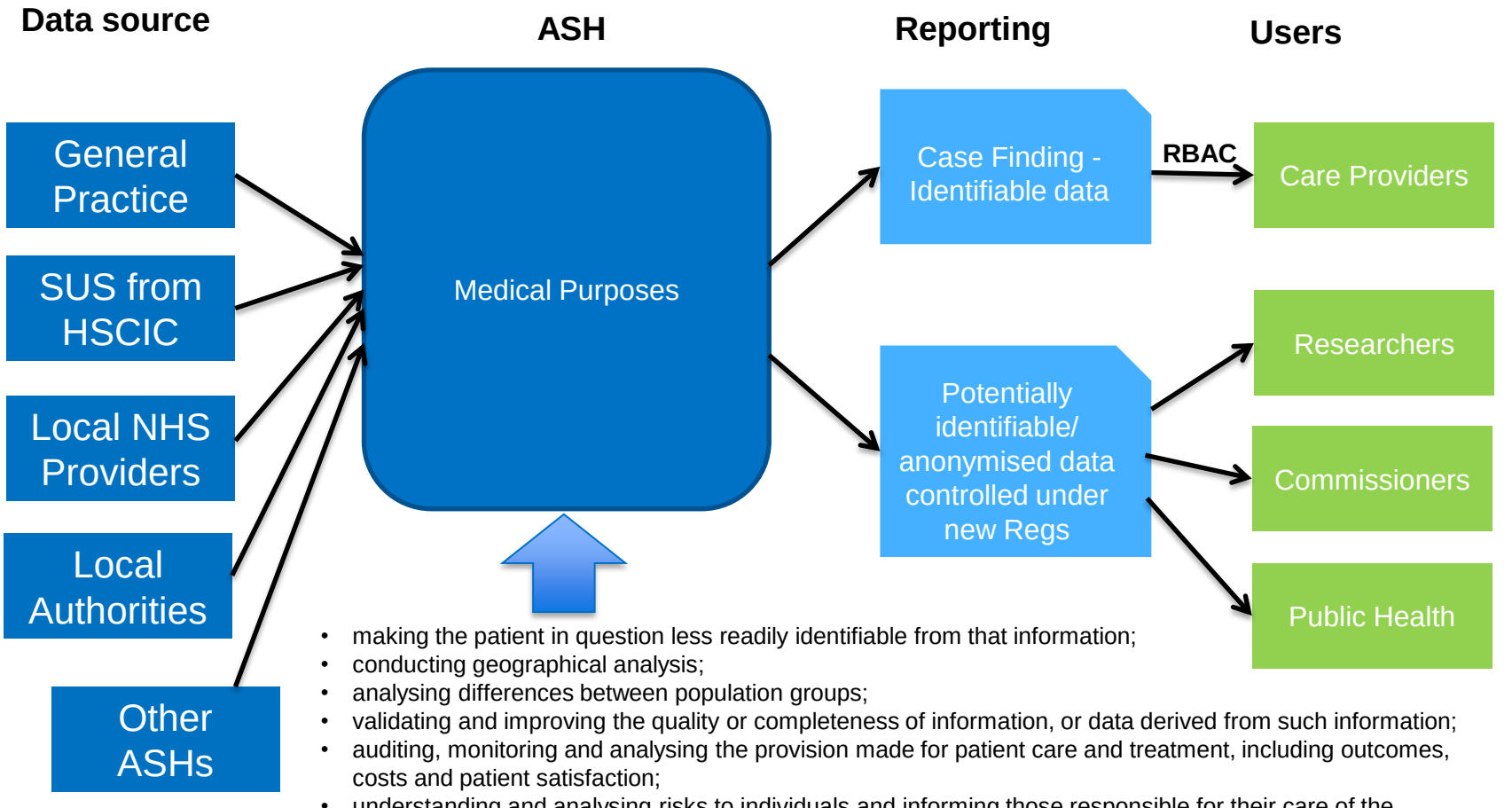
Proposed New Accredited Safe Havens



- making the patient in question less readily identifiable from that information;
- conducting geographical analysis;
- analysing differences between population groups;
- validating and improving the quality or completeness of information, or data derived from such information;
- auditing, monitoring and analysing the provision made for patient care and treatment, including outcomes, costs and patient satisfaction;
- understanding and analysing risks to individuals and informing those responsible for their care of the results of that analysis (risk stratification and predictive risk modelling);
- providing those responsible for providing care to an individual with information that might inform or support that care; and
- ensuring that the correct payment is made for care provided (invoice validation).

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Principles

- We need the minimum number of ASHs to deliver essential business requirements - Cost effectiveness and economies of scale are key considerations
- HSCIC will increase its ‘share of the market’ year on year
- NHS England will sponsor a number of intermediate/regional ASHs based around current DSCRO capabilities
- Additional ASHs will need either NHS England or DH sponsorship – robust justification
- Care communities need to define and agree requirements – NHS, Social Care, PH etc - no more than 1 local ASH / area
- We need to eliminate flaws in current systems and process that create dependencies on access to PID
- There will be annual reviews of ASHs to test whether they remain essential

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Next Steps and Close

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