

## SCCI2210 De-Identification Data Items

### Consultation – Summary Document

*This document provides the background, reasons and purpose for the proposed information standard. In addition it reproduces the text and questions, with answer options, used for this consultation. The online consultation is available on the NHS Digital consultation platform - <https://nhs-digital.citizenspace.com/scci/didi> - please use this to submit your responses. Should you have problems with accessing this platform, please email [scci@nhs.net](mailto:scci@nhs.net)*

#### 1.0 Overview

The Standardisation Committee for Care Information (SCCI) has received a request for a new information standard which will lay the foundations for in-scope patient-level data sets to be anonymised in accordance with the latest guidance. As part of the development and assurance process, this consultation seeks feedback on the proposal.

The request is being assessed on a two-stage basis, with the Requirements Stage being considered at the SCCI meeting in November 2016 and the Full Technical Regulation being considered at the SCCI meeting in February 2017. This consultation runs from 11 November 2016 to 9 December 2016.

Consultation feedback will be included in the submission to SCCI for its meeting in February 2017.

#### 2.0 Consultation Objectives

This consultation has been designed to support the following objectives:

- To test stakeholder's understanding of the requirement and the reasons for it
- To seek opinions from stakeholders on whether the requirement will deliver the intended outcomes
- To seek feedback on specific technical elements of the proposed standard
- To assess the impact of implementing the proposed standard and specifically whether current data provider collection and extraction systems will need to be modified
- To seek feedback on the proposed implementation strategy
- To seek views on how implementation should be supported.

#### 3.0 Requirement

This proposed information standard will ensure that the main commissioning data sets (CDS) and other specified national patient-level data sets that flow from providers to NHS Digital, and that are used for commissioning purposes within the NHS, contain a consistent set of data items for the following purposes:

1. Enabling NHS Digital to create a consistent commissioning pseudonym for an individual patient in data set records pertaining to that patient. This will be delivered by the patient NHS Number for most records, but will use additional identifiers where the NHS Number is not accurate or available.
2. Enabling NHS Digital to disseminate specific data within patient-level data flows to commissioning data recipients to support invoice validation.
3. Enabling NHS Digital to create derivations based on date of birth and postcode of usual address. For example, to calculate the patient's age at the time of the activity.
4. Supplying NHS Digital with derivations based on patient date of birth and postcode of usual address for those patients records where identifiers have been withheld by the provider for legal or other reasons.

Under the Data Protection Act 1998, principle 4, the NHS is also required to have accurate and up-to-date information which is crucial to any anonymisation process. Without proper verification of patient details there is a danger of introducing perpetual error into the health and social care system.

Data sets in scope of this specification fulfil the following criteria:

- Current or future nationally-defined and at patient-level
- Mandated (or will be) by an information standard
- Used to support NHS commissioning purposes and activities
- Flow from providers to NHS Digital for processing

Until these criteria have been ratified, data sets subject to this standard are currently being regarded as:

- **In-scope:** data set meets all 4 requirement criteria (namely it has an information standard, is patient-level, processed by NHS Digital and used for commissioning purposes)
- **Potentially in-scope:** data set is an information standard and at patient-level, but is not currently directly-processed by NHS Digital or its commissioning purpose is uncertain

Termed *De-Identification Data Items* (DIDI), the suite of data items has been selected from fields that exist within the majority of national patient-level data sets and are all currently described in the NHS Data Model and Dictionary. The DIDI are described in the table below which also provides a rationale for each field's inclusion:

**Table 1: List of De-Identification Data Items**

<b>Data Item Name (with links to NHS Data Model and Dictionary reference)</b>	<b>Validation Rules and Requirement for Data</b>	<b>Rationale</b>
<a href="#">NHS Number</a>	Must be a valid NHS Number. May be blank if record is sensitive or NHS number is unavailable	Used as a unique patient identifier. Also a potential part of the data linkage within and between different data sets
<a href="#">NHS Number Status Indicator Code</a>	Permitted national code in the national format	Highlights the status of the NHS number
<a href="#">Patient Name</a>	Only submitted when NHS Number is blank and the record is not sensitive, in line with existing CDS sensitive records guidance	Used to support patient-matching algorithms and identification of unique individuals
<a href="#">Patient Usual Address</a>	Only submit where NHS Number is blank and the record is not sensitive, in line with existing CDS guidance	Used as a potential part of the data linkage within and between different data sets
<a href="#">Postcode of Usual Address</a>	Must be a current live postcode following NHS Postcode Directory (NHSPD) / Organisation Data Service (ODS) data definitions. However, may be blank / default if record is sensitive	Used to derive location based data items (e.g. Lower Super Output Area and organisation code (residence responsibility), e.g. a Clinical Commissioning Group (CCG). Used as a potential part of the data linkage within and between different data sets
<a href="#">Withheld Identity Reason</a>	Permitted national code in the national format	Explains whether the data items relating to the identity are missing or have been withheld
<a href="#">Local Patient Identifier</a>	Must conform to published data standards for each data flow	Used as alternative patient identifier, in addition to NHS number. Required to

Data Item Name (with links to NHS Data Model and Dictionary reference)	Validation Rules and Requirement for Data	Rationale
		support specific stated commissioning activities. Used in conjunction with Organisation Code (Local Patient Identifier) to support patient-matching algorithms and also to facilitate communication between providers and commissioners about individual patients, without the commissioner needing to know the identity of the patient
<a href="#">Organisation Code (Local Patient Identifier)</a> or <a href="#">Organisation Identifier (Local Patient Identifier)*</a>	Must be a current live organisation in the national Organisation Data Service tables	Used in combination with Organisation Code (Code of Provider) to establish a unique reference for an individual
<a href="#">Organisation Code (Code of Provider)</a> or <a href="#">Organisation Identifier (Code of Provider)*</a>	Must be a current live organisation in the national Organisation Data Service tables	Shows the provider for the activity and also be a potential part of the data linkage within and between different data sets
<a href="#">Activity Date</a>	Must be in the national format of CCYY-MM-DD	Used as a generic term to represent the instantiation of a data set specific date, such as the A&E arrival date or episode start date. Enables date-based derivations to be applied and differential date rules to be applied. Also used to support data linkage between different data sets. Implementation guidance will state which specific data set

Data Item Name (with links to NHS Data Model and Dictionary reference)	Validation Rules and Requirement for Data	Rationale
		field will be mapped to this item for each in-scope national data set.
<a href="#">Age at Activity Date</a>	Only submit where Person Birth Date is blank and the record is not sensitive, in line with existing CDS guidance. Must be the same value derived by subtracting the Person Birth Date (if not blank for sensitive reasons) from the Activity Date	Used to represent the difference between the Activity Date, such as the A&E arrival date and the patient's date of birth (for example Age at CDS Activity Date). Enables age to flow for sensitive records
<a href="#">Person Birth Date</a>	Must be in the national format of CCYY-MM-DD. However, may be blank if record is sensitive	Used in combination with other date fields (e.g. activity date) to derive age. Also a potential part of the data linkage within and between different data sets
<a href="#">Person Stated Gender Code</a>	Permitted national code in the national format	Will enable analyses to explore potential health inequalities. Also a potential part of the data linkage within and between different data sets
<a href="#">Person Phenotypic Sex</a>	Permitted national code in the national format	Will enable analyses to explore potential health inequalities. Also a potential part of the data linkage within and between different data sets, for use in the Maternity Services Data Set only
<a href="#">General Medical Practice Code (Patient Registration)*</a>	Must be a current live organisation in the national Organisation Data Service tables	Used to derive commissioner and General Medical Practice-based analyses
<a href="#">Organisation Code (Code of Commissioner)</a> or <a href="#">Organisation Identifier (Code of Commissioner)*</a>	Must be a current live organisation in the national Organisation Data Service tables	Shows the commissioner for the activity. Enables commissioner identity data to flow for sensitive records where defining

Data Item Name (with links to NHS Data Model and Dictionary reference)	Validation Rules and Requirement for Data	Rationale
		data items may be withheld by the submitting organisation and central derivation is not possible
<a href="#">Organisation Code (Residence Responsibility)</a> or <a href="#">Organisation Identifier (Residence Responsibility)</a> *	Must be a current live organisation in the national Organisation Data Service tables	Shows the residence responsibility for the activity and also be a potential part of the data linkage within and between different data sets

\* In accordance with [SCCI0090 Amd 24/2015](#), Organisation Code is being replaced by Organisation Identifier on a rolling basis in all data sets from August 2016.

In line with existing CDS guidance, data providers must only include Patient Name and Patient Usual Address in their submissions if the NHS Number is blank because it is either unavailable or has failed local verification. Where NHS Number has been suppressed because the record is sensitive, Patient Name and Patient Usual Address must not be submitted.

NHS Number, Patient Name, Patient Usual Address, Postcode of Usual Address, Person Birth Date and Local Patient Identifier must not be submitted if the record is sensitive, in line [with existing guidance](#). It is noted that this guidance is currently being reviewed and a new information standard may be produced in due course. Work is currently underway to understand the impact of this proposal and ensure that the DIDI requirement is properly aligned.

For flat national data set submissions such as CDS, all of the De-Identification Data Items will be included within each transaction record in each CDS message in an interchange. For modular national data set submissions, such as the Mental Health Services Data Set (MHSDS), the submission of the De-Identification Data Items will depend on the specified and published table and table record inclusion rules for the data set. Specific information on how this will work in practice will be included within the detailed implementation guidance.

#### 4.0 Background and Reason for the Requirement

This requirement is aligned to National Information Board (NIB) Domain H (Data Outcomes for Research and Oversight) and is designed to ensure that innovative uses of data for commissioning activities can be properly maintained and supported when the various information governance (IG) controls for commissioning data flows, supported by NHS Digital's Data Services Platform (DSP), becomes operational.

The Health and Social Care Act 2012 and other legislation require commissioners to assess the value, quality and effectiveness of the services they commission. The

provision of anonymised patient-level data will support commissioners in meeting this obligation. The current temporary measures, implemented through the approved applications under Regulations enabled by section 251 of the NHS Act 2006 (usually referred to as Section 251) allow commissioners to use either an NHS Number or a date of birth or a postcode in certain circumstances. These arrangements are due to expire at the end of March 2017.

After this date the main identifiers in national patient-level data sets: NHS Number, Date of Birth, Date of Death and Postcode of Usual Address, will need to be transformed by NHS Digital into a consistent pseudonym and age-related and postcode-related derivations respectively within the data sets that it disseminates to legitimate recipients for commissioning purposes. Other provider-specific created identifiers, such as Local Patient Identifiers and Event Identifiers, will be included in data disseminations unless they are withheld for sensitive reasons. Identifiers are used to identify unique individuals within a health care provider and are also required for specific commissioning purposes. These derivations and other controls will support commissioners in meeting their legal obligation to use the minimum amount of data necessary in order to continue to perform their statutory duties whilst still maintaining patient privacy. Work has already commenced within NHS Digital's Data Services for Commissioning Regional Offices (DSCROs) to implement this capability on a regional basis before 1 April 2017, with the Data Services Platform providing a national capability during 2017/18.

The new pseudonym will be used to link records across and between data sets, to support the new Models of Care and integration agendas introduced by the Five Year Forward View and related policy documents. Multiple derivations based on Date of Birth and Postcode will support age-related and geographical analysis.

Most commissioning activities can be undertaken in the absence of patient confidential data, but it is important that consistent patient, activity and status identifiers are present in all commissioning data flows in order to mitigate the risk that:

- Patient objections will not be observed.
- Pseudonyms are not allocated consistently or assigned multiple times.
- Records are not accurately anonymised and linked appropriately across data sets.

This risk exists because:

- Around 1 in 20 events has insufficient data completeness or is missing an NHS number.
- Around 1 in 100 events has the potential for a different pseudonym to be wrongly assigned the same person.

These figures are sourced from the Secondary Uses Service Extract Mart (SEM) Accident and Emergency (A&E) data set for the financial year 2014 to 2015. It is a relatively mature data set, indicating that less-established data sets may hold greater data quality challenges. Analysis of SEM A&E data also suggests that approximately 10% of records may benefit from further matching and around 6% of NHS Number errors may be resolved by DIDI implementation.

Analysis has shown that the impact of not receiving a consistent pseudonym disproportionately affects patients from lower income demographics, people from

ethnic minorities and other disadvantaged groups. This impact may skew commissioning data analyses and any commissioning decisions based on these with a consequent risk that these patients may not receive the healthcare services that they need.

In the majority of cases the new pseudonym will be based on the supplied validated NHS Number and it is important that providers continue to trace their data using PDS and supply validated NHS Number data at high levels of completeness. Where an NHS Number has been submitted, then providers do not need to submit Patient Name and Patient Usual Address (but do need to submit all of the other DIDI fields).

However, the reasons listed above describe situations where an NHS Number will not be immediately present (if at all) in data flows to the DSP. In these situations the DIDI will be used within DSP to support as part of secondary PDS-tracing and further patient matching algorithms which will be carried out centrally on submitted data to ensure that unique individuals can be identified consistently and so receive the same pseudonym. This will reduce the incidence of false and non-matches when using linked data sets to support commissioning analysis and help mitigate the risk described above.

## 5.0 Expected Benefits

Improvements in commissioning data will enable a number of compliance, service delivery and efficiency benefits to the NHS:

- **Improved Compliance with Legal Requirements for Anonymisation:** implementation of common standards for identifiable information will allow easier application of information governance requirements and ensure that systems to anonymise and distribute data to the correct commissioner can be implemented effectively with minimal risk to patients.
- **Improved Compliance with Patient Objections:** through maximising the accuracy of unique patient identification, the DIDI will enable the effective identification of patients registering a Type 2 Objection to prevent their personal identifiable data leaving NHS Digital, both in terms of a recorded objection or the withdrawal of an objection.
- **Improved Commissioning Decisions for All Patient Groups:** common and coherent identifiers will ensure that certain patients in certain groups, particularly health inequality and protected characteristic groups where patient data quality is inherently poor, can be consistently identified and linked. Commissioners will consequently be better informed and able to make better decisions about the services that patients need.
- **Improved Ability to Support Integrated Care and Patient-Centric Analysis:** with consistent and robust patient identifiers supporting data quality improvements and improved linkage, commissioners will be in a much better position to undertake the detailed linkages required to track data across providers and pathways as will be required to realise the benefits of integrated care, as set out in the Five Year Forward View (FYFV).

The implementation of DIDI will also decrease the risk of patients not benefitting from the provision of appropriate care packages, particularly as

they journey between services and settings under the care of multiple healthcare professionals.

- **Improved Use and Validation of NHS Number and Other Identifiers:** linkage of NHS data relies heavily on the accuracy and completeness of the NHS Number, which was introduced to be the general, unique patient identifier for all patients in the NHS. This proposal therefore supports the NHS Number data standard and recommendations to flow data for tracing where the NHS Number is available.
- **Improved Efficiency and Interoperability of Data Collection, Transmission and Analysis:** the DIDI will help to standardise the collection of identifiers in mandated national flows, which supports the NHS' commitment to reduce inefficiencies and burden in data collection. They will also enhance interoperability between systems and enable data sets from various sources to be linked effectively.

## 6.0 Proposed Implementation Strategy and Timescales

The De-Identification Data Items will be an information standard applied across Health and / or Adult Social Care to support a general business need, and consequently there is a need to define at a high level how they should be implemented, when this should start ('commencement date') and when this must be completed to the required conformance criteria ('completion date').

Three categories of national data sets are in-scope for implementation:

1. Existing nationally-defined data sets, mandated by an information standard, flowing to and processed by NHS Digital, and disseminated to recipients for NHS commissioning purposes.
2. Proposed new data sets currently within the SCCI Development process for new information standards, collections or extractions.
3. Any future data set proposals not currently within the SCCI Development process and submitted as an idea to SCCI after the DIDI information standard commencement date.

All new data set proposals under category three above will have to include the final agreed list of DIDI in the data set's requirements specification for any idea submitted to SCCI after the commencement date. The SCCI secretariat will also make sure that idea submitters are aware of the impending information standard for DIDI, before the DIDI information standard is published, so that idea submitters can take account of it in their data set proposal.

Consultation has already commenced with Senior Responsible Owners (SROs) (or their representatives) for data flows in category two above and will continue for all other data sets currently within the SCCI development process. This consultation will assess the level of DIDI compliance within the proposed data set's actual or planned requirements specification and agree a realistic and feasible commencement date for the DIDI information standard which will give the SRO time to ensure that the proposed new data set's requirements specification includes all of the DIDI before the Full technical Regulation is approved by SCCI. Current discussions suggest that the DIDI information standard commencement date will be no earlier than 1 October 2017.

Consultation has already commenced with the relevant Information Asset Owners (IAOs) for all of the in-scope nationally-defined data sets listed in the [Appendix](#). These discussions will be used to help define a realistic and achievable completion date for the relevant national data set to include all of the DIDI in line with the data sets' maintenance strategy. Each IAO must provide resource as part of the maintenance cycle of the data set to comply with the fundamental standard. Current discussions suggest that the DIDI information standard completion date will be no earlier than 31 March 2019. This is in line with the timescales within the current DSP release roadmap.

The inclusion and completeness of DIDI in any locally-defined flows of patient-level data submitted by providers to NHS Digital's DSP for commissioning purposes will be managed by the data landing capabilities within the DSP. They will also be subject to the relevant terms and conditions laid out in the Information Schedule of the NHS England Standard Contract agreed between a provider and a commissioner. Commissioners will be supported to use the powers of the Standard Contract to encourage providers to include DIDI in locally-defined commissioning patient-level data flows.

## 7.0 Other Information

Areas: All areas

Audience: Any healthcare data processors and controllers who create, submit, receive, process and consume national patient-level data sets data, NHS system suppliers, NHS Commissioning Organisations (Clinical Commissioning Groups, NHS England Commissioning Teams with Regional Geography offices), analytical teams within NHS England, other analytical teams outside NHS England who analyse national patient-level data sets.

Interests: Use of national data sets data to support commissioning activities, national data set generation, submission and receipt, national patient-level data processing, aggregation and analysis, using linked patient-level data sets to support secondary uses.

## 8.0 Questions

### 8.1 About You

- If you are happy to be contacted in connection with this consultation so we can follow-up your response, or if you would like us to notify you when the outcome of this consultation is available, please provide your email address below: [email address box].
- Is this a co-ordinated response on behalf of a specific organisation or group? [Yes/No]; If Yes, please specify the organisation's name: [Text Box]
- Is this response on behalf of an SRO or group responsible for a national patient-level data set? [Yes/No]; if Yes, please specify the data set [Text Box]
- Please choose the description that best describes the type of organisation you work for:
  - NHS provider (please specify)
    - i. Acute
    - ii. Mental Health

- iii. Community
    - iv. Mixed Mental Health / Community
    - v. Mixed Acute / Community
  - Independent sector provider
  - General Practice
  - Other Primary Care Provider
  - NHS England Commissioning Team (select all that apply)
    - i. Specialised Services
    - ii. Armed Forces Health
    - iii. Health and Justice
    - iv. Secondary Dental
    - v. Public Health
  - NHS England (Other)
  - Clinical Commissioning Group
  - Commissioning Support Unit
  - Other form of Commissioning Support Organisation
  - Public Health England
  - Health Education England (HEE)
  - HEE local education and training board
  - NHS Digital
  - Local Authority
  - University
  - Other research organisation
  - Charity
  - Department of Health
  - NHS System Supplier (Please specify which system type below:
    - i. Electronic Patient Record / Patient Administration System
    - ii. Departmental Clinical System
    - iii. NHS Contract Management / Monitoring System
    - iv. Generic Business Intelligence System
    - v. Other
  - Private individual
  - Other [Text Box]
- Please select the area that best describes your role:
    - Clinical
    - Information Management (inc. data analysis)
    - Information Technology / Services
    - General Management
    - Administrative
    - Research
    - Campaigning
    - Member of the public
    - Other [Text Box]

## 8.2 Proposed Changes

- Are the four [Purposes](#) for the De-Identification Data Items clear and easy to understand? [Yes/No]; If No, please specify why this is the case and what further detail should be provided to improve the clarity of the requirement: [Text Box]

- Is the [Scope](#) of the requirement clear and easy to understand? [Yes/No]; If No, please specify why this is the case and what further detail should be provided to improve the clarity of the requirement: [Text Box]
- Are the [background information and reasons](#) for the requirement clear and easy to understand? [Yes/No]; If No, please specify why this is the case and what further detail should be provided to improve clarity: [Text Box]
- Do you think any of the data sets [identified as being in-scope](#) of the requirement should be excluded from the list? [Yes/No]; If Yes, please identify which data sets should be excluded and specify why: [Text Box]
- Please review the data sets [identified as being potentially in-scope](#) of the requirement and determine whether you think each should be included or excluded from the list? [Table]

Data set potentially in-scope	Should be included in-scope	Should be excluded from scope
Cataract Data Set		
Diabetes Audit Data Set		
Diabetic Retinopathy Screening Data Set		
National Drug Treatment Monitoring System Data Set		
Neonatal Data Set		
Radiotherapy Data Set		
Renal Data Set		
Systemic Anti-Cancer Therapy Data Set		
Trauma Audit and Research Network Notification Data Set		

- Are there any other national data sets which should be added to the scope of the requirement over and above those specified in the previous questions? [Yes/No]; If Yes, please identify which data sets should be included and specify why: [Text Box]
- Do you think any of the De-Identification Data Items' [fields](#) are unnecessary for the stated purposes and should be excluded from the requirements specification? [Yes/No]; If Yes, please identify which data items should be excluded and specify why: [Text Box]
- Do you think that there are any additional *new* data items, not currently specified within the NHS Data Model and Dictionary, that could support the objectives of this requirement and which should be added to the list of De-Identification Data Items? [Yes/No]; If Yes, please identify which new data items could be added and specify why in the text box below: [Text Box 1 – new field name]; [Text Box 2 – reason for new field]; [Text Box 3 – reason for new field]

### 8.3 Implementation Issues

- *Data Providers Only*: Using the table below estimate the approximate size of the impact on your organisation of including the full suite of De-Identification

Data Items in the national patient-level data sets that you currently submit (whether these are IN SCOPE or POTENTIALLY IN SCOPE):

National Data Set	Impact Area					Justification for Impact
	Business Process	Data Collection System	Data Extraction System	Data Processing System	Data Transmission System	
<b>Impact Measure</b>	Total extra hours human resource required to change and operate revised business processes to submit the data set	System upgrade and running costs	System upgrade and running costs	System upgrade and running costs	System upgrade and running costs	
Assuring Transformation						
Cataract Data Set						
Children and Young People's Health Services Data Set						
Commissioning Data Sets (CDS)						
Critical Care Minimum Data Set						
Diabetes Audit Data Set						
Diabetic Retinopathy Screening Data Set						
Diagnostic Imaging Dataset						
Improving Access to Psychological Therapies Data Set						
Maternity Services Data Set						
Mental Health Services Data Set						
National Cancer Waiting Times Monitoring Data Set						
National Childhood Measurement						

National Data Set	Impact Area					Justification for Impact
	Business Process	Data Collection System	Data Extraction System	Data Processing System	Data Transmission System	
Central Return						
National Drug Treatment Monitoring System Data Set						
Neonatal Critical Care Minimum Data Set						
Neonatal Data Set						
Paediatric Critical Care Minimum Data Set						
Radiotherapy Data Set						
Renal Data Set						
Sexual and Reproductive Health Activity Data Set						
Systemic Anti-Cancer Therapy Data Set						
Trauma Audit and Research Network Notification Data Set						

- *Data Providers Only:* Will modifications to systems and processes to implement De-Identification Data Items also facilitate their inclusion in locally-defined patient-level commissioning data? [Yes/No]; If No, please specify why: [Text Box]
- *Data Providers Only:* Once agreed, will it be reasonable to include NHS Number Status Indicator Code in all data sets in-scope? [Yes/No]; If No, please identify which data sets would be problematic and specify why: [Text Box]
- *All Stakeholders:* Do you agree with the proposed implementation strategy? [Yes/No]; If No, please specify why: [Text Box]
- *All Stakeholders:* Is the suggested information standard commencement date of 1 October 2017 realistic? [Yes/No]; If No, please specify why: [Text Box]
- *All Stakeholders:* Is the suggested information standard completion date of 31 March 2019 realistic? [Yes/No]; If No, please specify why: [Text Box]
- *All Stakeholders:* Can you think of any barriers to the implementation of this De-Identification Data Items standard? [Yes/No]; If Yes, please specify: [Text Box]

- *All Stakeholders except Data Providers*: Do you have any views regarding the impact on providers of implementing De-Identification Data Items in national patient-level data sets that they currently submit? [Yes/No]; If Yes, please specify: [Text Box]

#### **8.4 Information Governance Considerations**

The proposed De-Identification Data Items information standard requires the collection and flow of personal confidential data. On that basis please could you also answer the questions below:

- How would you best describe your level of Information Governance expertise? [No Knowledge/Limited Knowledge/Reasonable Knowledge/Good Knowledge/Expert Knowledge]
- Do you think that there are any significant new privacy risks associated with the proposed standard? [Yes/No] If Yes please identify any mitigating security measures: [Text Box]
- Could the aims of the proposed standard be achieved without the collection and flow of personal confidential information? [Yes/No]. If Yes please elaborate: [Text Box]
- Could the aims of the standard be achieved without the sharing of personal confidential information with NHS Digital? [Yes/No]. If Yes please elaborate: [Text Box]
- Are the proposals regarding collection and flow of personal confidential information proportionate to the expected benefits? [Yes/No]. If No please elaborate: [Text Box]
- Will the proposal result in you collecting more personal data than you do currently? [Yes/No]. If Yes please elaborate: [Text Box]

#### **8.5 Final Comments**

- Please provide any further comments or suggestions you have about the proposed information standard in the text box below: [Text Box]

## Appendix – National Data Sets

### Data sets in-scope

Data set fulfils all requirement criteria: it is an information standard, is patient-level, processed by NHS Digital and used for commissioning purposes.

Number	Title	Information Standard	Patient-Level	Processed by NHS Digital	Used for Commissioning
SCCI2007	Assuring Transformation	✓	✓	✓	✓
ISB 0146	Childhood Measurement Central Return	✓	✓	✓	✓
SCCI1069	Children and Young People's Health Services Data Set	✓	✓	✓	✓
ISB 0092	Commissioning Data Sets (CDS)	✓	✓	✓	✓
ISB 0153	Critical Care Minimum Data Set	✓	✓	✓	✓
SCCI1577	Diagnostic Imaging Dataset	✓	✓	✓	✓
ISB 1520	Improving Access to Psychological Therapies Data Set	✓	✓	✓	✓
ISB 1513	Maternity Services Data Set	✓	✓	✓	✓
SCCI0011	Mental Health Services Data Set	✓	✓	✓	✓
SCCI0147	National Cancer Waiting Times Monitoring Data Set	✓	✓	✓	✓
SCCI0075	Neonatal Critical Care Minimum Data Set (SUS elements only)	✓	✓	✓	✓
SCCI0076	Paediatric Critical Care Minimum Data Set (SUS elements only)	✓	✓	✓	✓
ISB 1518	Sexual and Reproductive Health Activity Data Set	✓	✓	✓	✓

### Data sets potentially in-scope

Data set is an information standard and at patient-level, but is not currently directly-processed by NHS Digital or its commissioning purpose is uncertain.

Number	Title	Information Standard	Patient-Level	Processed by NHS Digital	Used for Commissioning
ISB 0085	Cataract Data Set	✓	✓	✓	?
ISB 0110	Diabetes Audit Data Set	✓	✓	✓	?
ISB 0073	Diabetic Retinopathy Screening Data Set	✓	✓	✓	?
ISB 0107	National Drug Treatment Monitoring System Data Set	✓	✓	x	✓
ISB 1595	Neonatal Data Set (as part of the Neonatal Critical	✓	✓	x	✓

	Care Minimum Data Set)				
SCCI0111	Radiotherapy Data Set	✓	✓	x	✓
ISB 0066	Renal Data Set	✓	✓	x	✓
ISB 1533	Systemic Anti-Cancer Therapy Data Set	✓	✓	x	✓
ISB 1606	Trauma Audit and Research Network Notification Data Set	✓	✓	x	✓