CORE INFORMATION STANDARD

IMPLEMENTATION GUIDANCE

DECEMBER 2019

Acknowledgements

The Professional Record Standards Body
The independent Professional Record Standards Body (PRSB) was registered as a community interest company in May 2013 to oversee the further development and sustainability of professional record standards. Its stated purpose in its Articles of Association is: "to ensure that the requirements of those who provide and receive care can be fully expressed in the structure and content of health and social care records". Establishment of the PRSB was recommended in a Department of Health Information Directorate working group report in 2012.

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Revision History

Version	Date	Summary of Changes
1.0	10/07/2019	Publication version
1.1	25/10/2019	Updated sections: 2.1 purpose of document; 3.1.1 'sex' and 'gender' guidance; and 3.24 pregnancy status guidance
1.2	19/12/2019	Added new sections 2.2 Risk Mitigation: Updated sections 1.2. Purpose of document and section 3.1.1 Sex and gender

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Name	Date	Version
Project Board	26/06/19	0.1
PRSB Assurance Committee	11/07/19	0.3
Dr John Robinson, Clinical Safety Officer	19/12/2019	1.2

Glossary of Terms

Term / Abbreviation	What it stands for
A&E	Accident and Emergency
AoMRC	Academy of Medical Royal Colleges
CCG	Clinical Commissioning Groups
CCIO	Chief Clinical Information Officer
CDGRS	Clinical documentation and generic record standards
CIO	Chief Information Officer
CPAG	Clinical and Professional Advisory Group
CRO	Clinical Responsible Officer

CSP	Care and support plan. Used interchangeably with DCSP
DCB	Data Coordination Board
DCSP	Digital care and support plan. Used interchangeably with CSP
EHR	Electronic Health Record
EPR	Electronic Patient Record
ETTF	Estates and Technology Transformation Fund
FHIR	Fast Healthcare Interoperability Resources
GP	General Practitioner
GPSoC	GP System of Choice
HCPG	Health and Care Professionals Group
HIG	RCGP Health Informatics Group
HIU	Health Informatics Unit (Royal College of Physicians)
HL7	Health Level 7

HLP	Healthy London Partnership
HSSF	Health and Systems Support Framework
ICR	Integrated care record. Used interchangeably with IDCR
IDCR	Integrated digital care record. Used interchangeably with ICR
LDR	Local Digital Roadmap
LHCR	Local Health and Care Record
Metadata	A set of data that describes and gives information about other data
NIB	National Information Board
NHS	National Health Service

NHSCC	NHS Clinical Commissioners
NHSD	NHS Digital
NWL	North West London
NWL CCGs	North West London Collaboration of Clinical Commissioning Groups
PID	Project Initiation Document
PRSB	Professional Record Standards Body
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCOT	Royal College of Occupational Therapists
RCP	Royal College of Physicians
SCR	Summary Care Record
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms
SOCITM	The Society for Information Technology Management
STP	Sustainability and Transformation Plan
ToC	Transfer of Care
WSIC	Whole Systems Integrated Care

Contents

1   Introduction

1.1   Background

NHS England commissioned the Professional Record Standards Body to define what information should be shared between organisations and geographies, professionals and people using services to support health and social care. It is intended that this standard will be used across the UK.

The core information standard, described in this document and related documents that can be found on the PRSB website, informs the technical specifications to be commissioned by NHS England and deployed within local implementations to ensure the information defined by the standard can be shared digitally.

1.2 Purpose of this document

This document provides guidance to support the implementation of the core information standard for people involved in developing, deploying and using systems which exchange information pertaining to health and care. The document provides general guidance as well as guidance for each specific part of the standard.

The guidance was developed on the basis of extensive consultation described in the final project report. However, the guidance will be refined and updated regularly as it is anticipated that there will be further findings and feedback as the standard is actually implemented.

PRSB has carried out a clinical safety review in accordance with DCB0129, which is detailed in the Clinical Safety Case (Core Information Standard Clinical Safety Case Report v1.1) and accompanying Hazard log v1.1. This guidance should be used in conjunction with the CIS hazard log and CIS clinical safety case report. This is further discussed under section 2.2. Risk Mitigation.

1.3 Audience – who is this document for?

This guidance is intended for anyone implementing the core information standard. This will include project teams (including clinicians, other care professionals and people who use services) involved in building systems that will use the core information standard and system suppliers.

1.4 The Core Information Standard

The standard defines a set of information that can potentially be shared between systems in different sites and settings, with professionals and people using services. What information is accessed will differ depending on who is accessing it, for what reason and the wishes of the person the information is about. Access will be based on the national Information Governance Framework being developed by NHS England in parallel with this work.

The core information standard itself is based on the PRSB's "Standards for the Clinical Structure and Content of Health and Care Records" (PRSB, 2018) which can be found here.

1.4.1 What it is

The core information standard is:

- a core set of information relevant for direct care (across a variety of settings).

- a set of information that could potentially be shared with professionals depending on their role and circumstances.

- a definition of the information professionals and people who use services have told us they want to see in a shared record.

- an information set that is readily translatable across clinical settings e.g. mental health to accident and emergency; acute care to social care etc.

- a blueprint for local implementations to use to draw from for their own local sources depending on local requirements. Local implementers may add to the core information.

- a thoroughly researched and validated definition of the core information standard tested with citizens, patients, carers and health and social care professionals.

1.4.2 What it's not

- a definition of an exhaustive clinical or care record / history.

- a definitive set of information about the person's current status - no clinical record is ever this and clinical information needs to be understood by the professional reading it as such.

- a prescriptive definition of what must be included – this will be determined ultimately by local projects and specific use cases.

- a logical or physical data model. A logical data model will be developed by NHS Digital. FHIR profiles to support interoperability of the data between systems will be commissioned by NHS England.

- a definition of what information professionals should be able to see or change (which will be set out in NHS England's Information Governance Framework and Role Based Access Control work).

- a definition of how information should be presented to professionals (what is presented and how much information (history) and how it is viewed/accessed), which should be defined locally.

- a definition of a shared care record.

- a definition of how the content should be sourced, updated, de-duplicated and normalised i.e. the source data and its processing.

- additions or adjustments needed to successfully implement locally which must be defined in local projects.

It is recognised that full interoperability of systems is still some way off in most clinical environments and so what is likely at least at first is a data 'pull' from source systems without direct write back into those systems (see clinical safety case).

1.4.3 The approach to the development of the core information standard

The approach to the development of the core information standard is set out in the Final Report which can be found here.

2 General guidance

The standard can be seen as a broad set of "flexible" components (or sections), a sub-set of which will be relevant in different situations for different use cases. It has been designed as a generic standard, not for specific use cases. The expectation is that local health and care localities will prioritise their local use cases and build local interoperability informed by the core information standard.

The sections in the standard differ in terms of how the elements they contain relate to one another. Some, for example 'legal information', are sets of independent 'elements' or data

items, grouped under logical headings. Other sections, for example 'medications and medical devices', are sets of related elements with dependencies. A 'record entry' within a section is used to indicate that elements are related to one another. Some sections may also include clusters, which are groups of elements within a section that relate to one another. Clusters are similar to a record entry but occur within a single record entry and may repeat for a record entry.

Each element, cluster, record entry and section will have a statement of cardinality, whether there can be zero, one or many entries. They also have a statement of conformance - whether the item is 'Mandatory', 'Required' or 'Optional'. An explanation of the meaning of these terms appears in the table below.

Since different components will be populated by different care settings a minimal number of sections and clusters have been defined as 'Mandatory'. The mandatory sections are Person demographics and GP practice. This is the minimum amount of information required for a record about a person to exist. Many other sections are set to 'Required'. However, some of the elements within a 'Required' section may be 'Mandatory'. For example, if a record of a medication is shared, 'Medication name' is 'Mandatory' and must be shared.

The information model includes the following information:

Information Model	Description
Element	A data item within a section. An element can appear in one or many sections.
Cluster	This is a sub-section. It is a group of elements that are within a section which make up a record entry, for example, 'medication change summary cluster' is within the medication item entry and it is made up of the following elements: Status, Indication, Date of latest change, Description of amendment, Total dose daily quantity. There can be multiple cluster record entries within a single record for a section.
Record entry	A single record which will be made up of one or more elements (e.g. a medication item entry).
Section	This is the equivalent of a main heading in the PRSB standards, e.g. 'allergies and adverse reactions' and
	'procedures'. It is a logical grouping of elements that may be independent or related.
Description	A description of the information content of the element, cluster, record entry or section.
Cardinality	The number of records in a set. For example, the 'medications and medical devices' section may have zero to many medication item records in it.

Conformance	The conformance (applies to sections, record entries, clusters and elements) • Mandatory – the information must be shared • Required – if it exists, the information must be shared • Optional – a local decision as to whether the information is shared.
Value sets	Can be text or coded. If coded, can be constrained to SNOMED CT (could be constrained to specific SNOMED CT refsets) or NHS Data Dictionary values.

Table 1 – the core information standard data structure

2.1   How we expect the core information standard to be used

What is defined is a set of information which should be common to most systems and would be an amalgamation of records drawn from different settings. The expectation is that this information would be read only, at least initially. It sets out what information should be shared between organisations and geographies and could be used to populated shared care records. Local implementations will need to define different 'views' in their shared care record of the information for different professionals (and other users, including people who use services) and local use cases based on the information governance framework which will be published by NHS England in due course. These views should define what information is needed by a professional (or person) in particular circumstances. How the information is presented to professionals and citizens in a shared care record will be dependent on the local systems in place but it should be presented in such a way as to provide maximum benefit for different users (in different roles) in each given use case.

2.2   Risk Mitigation

We recommend system suppliers and health organisations apply further mitigations when incorporating the CIS in a local care record, by addressing the risks that have been flagged in the accompanying clinical safety case report and hazard log in order to reduce the risk scores to 2, or better than human transcription alone when carrying out clinical risk assessments and developing safety cases with respect to DCB0129 and DCB0160.

2.3   Information Governance

Sound principles of information governance and respecting the privacy of people and their information is paramount. NHS England is developing a national Information Governance framework which needs to be considered alongside the core information standard when planning implementation.

2.4   Context of the information

Key to the proper reading and comprehension of shared information is some understanding of the *context* in which the data were originally recorded. It is vital for clinical use of the data that all contextual information must be maintained and should not be lost on exchange or import of information. So, for example, where a diagnosis was made during an A&E attendance, the diagnosis should be linked to that A&E attendance.

The core information standard does not define all possible linkages between different components of information e.g. the diagnosis and the attendance. This will be defined in the logical data model, FHIR profiles and in the local shared care records.

However, following consultation and safety case review we arrived at the following key contextual data which need to be shared:

1. '**Performing Professional**' which has various attributes, name, role, specialty, organisation of the professional that, for example, performed the procedure or administered the vaccination etc. It might be that the actual professional is not known however the organisation and specialty are known and should therefore be included as contextual information.

2. '**Person completing record**' - which is the person that actually recorded the information and again has various attributes name, role, speciality and organisation and the date that the record was completed.

3. **Location** - the place in which the activity took place e.g. a procedure was performed.

4. **Date** - the date on which the activity took place e.g. then date the procedure was performed. In some cases, this would be start and end dates e.g. of child protection plans.

Note that although both 'Performing professional' and 'Person completing record' contain the element 'Speciality' it is recognised that this only applies to some professionals so only needs to be included where relevant.

The principle applied in the information model is that where it is important (from a professional perspective) to know who undertook the activity and who recorded the activity, 'Performing professional' and 'Person completing record' will be included in the model. For every item of information shared it is important that an audit trail is recorded (even if not explicitly stated in the information model). This is set out below.

2.5   Time stamp and audit trail

Each record entry will need to be time stamped from the source system with date and time recorded and the identity of the person making the record. This needs to be viewable in the records themselves where appropriate and via a full audit trail which may be viewable by the end user to enhance transparency.

2.6   History

The core information standard does define the requirements for history to be shared. It would be expected that relevant history of the information would be made available within a shared care record as it would provide important contextual information. Local areas would be expected to define the requirements for history.

2.7   Data Quality

Data quality and accuracy of coded data entry should be managed in local 'source' systems that will feed the shared core information.

2.8   Links to other records and documents

The person may have multiple detailed records or documents held on local systems, e.g. there may be a mental health record for a person at a particular trust or there may be other shared care records such as a maternity record or a healthy child record. The National Record Locator Service will, in due course, hold the links to the person's records that reside

in multiple different systems. The core information standard does not define all these possible links. It is expected that the local areas will define the requirements for accessing other records or documents, where applicable and provide access through the shared care record for authorised professionals.

2.9   Use of terms

The term 'role' has been consistently used rather than 'designation' throughout the standard to apply to the role the professional had in a particular activity. Role is the term used in the NHS data dictionary. We have used the term 'organisational role' to mean the role the professional has in the organisation they work for.

Some clusters such as referrer details have elements for one or more of specialty, team, service and department. This is to allow for all situations across health and care where different terms are required. Where possible specialty and service should be used and coded as detailed in the value set for the element.

2.10 Coding

The *Personalised Health and Care 2020 framework for action* (https://www.gov.uk/government/publications/personalised-health-and-care-2020) recommends the use of SNOMED CT and the dictionary of medicines and devices (dm+d). Local decisions need to be made about when these codes are to be used, depending on local system functionality and plans. The ambition is for SNOMED CT and dm+d to be the only clinical coding schemes in use in the NHS by 2020.

2.11 Accessibility

Attention must be paid in the design of user interface for viewing the core information complying with the NHS England Accessible Information Standard (https://www.england.nhs.uk/ourwork/accessibleinfo/). This sets out the rules for accessible patient information in patient literature and clinical systems.

2.12 Other dependencies

The implementation of the core information standard is dependent on the following:

• The national Information Governance Framework with nationally agreed role-based access controls and legitimate relationships being developed by NHS England.
• The logical data model and technical messaging standards FHIR profiles (to support the transfer of information between local health and care systems).

3   Section specific guidance

3.1   Person demographics

This section contains the person's demographic and contact details including key identifiers e.g. name, date of birth, NHS number, address etc.

NHS number (or equivalent, e.g. CHI number in Scotland), is likely to be the primary identifier however existing national guidance should be followed, including how to handle patients without an NHS number, for example, overseas visitors.

The PDS (Personal Demographics Service) should be used as the source of this information.The mandatory information in this section is person's name, date of birth and address. There can be multiple addresses associated with a person including temporary and correspondence addresses.

This section also includes communication preferences. These are stored on the PDS. This should include any language preferences where available. Note that the Individual requirements section includes specific elements for accessible information requirements to support communication.

It is recognised that some of the elements in this section are currently shared in a more granular way than currently defined in this information model. PRSB intends to address this in a later release of the information model.

3.1.1 Sex and Gender

Sex and gender data items may cause accidental disclosure of gender reassignment without consent. This is because both fields are included in the demographic model. Having both may show a difference and therefore disclose gender reassignment without consent. It is unlawful to disclose, without consent, a person's gender reassignment with or without a gender reassignment certificate

(ISB-000362 - ISB Standards Guidance – Sex, Gender and Transgender - Data Capture (2016)

https://data.gov.uk/education-standards/sites/default/files/ISB-Standards-Guidance-SexGender-and-Transgender-Data-Capture-v1-3.pdf).

This risk can be mitigated by appropriate implementation in a shared care record; refer to the CIS clinical safety case report and hazard log. One option is to leave out the "Sex" field but the implications and potential risks of that will need to be considered. The alternative is to ensure the design of the Shared Care Record, including its Information Governance model, reduces this risk to an acceptable level as described in the clinical safety case and hazard log.

3.2 GP practice

This section contains details of the GP practice where the person is registered. This information would be sourced from PDS. This will include the GP practice identifier code. In situations where a person is not registered with a GP practice, the GP practice identifier would contain the appropriate code to indicate this.

This section would also need to accommodate details for temporary GP where the patient is registered away from their usual place of residence.

3.3 Alerts

This section allows for the sharing of alerts. It is unlikely that all alerts generated for a person would be shared as part of the core information standard as some alerts are dynamically generated in local systems, for example within decision support systems.

The alerts that are shared as part of the core information standard should be determined locally. They might, for example, include the presence of a medical implant or MRSA diagnosis, the fact that the person has a dangerous dog or that a person requires reasonable adjustments.

It is important that alerts are managed and removed when they are no longer relevant – e.g. "the dangerous dog" alert if the dog is no longer present.

The alerts displayed to users viewing the core information may vary by use case and user's role.

3.4 Legal information

This section identifies where there is legal or formal documentation relating to the care of the person. This includes Lasting Power of Attorney, Deprivation of Liberty Safeguards, Advance Decision to Refuse Treatment, Mental Capacity Assessment and Mental Health Act status.

Mental capacity needs to be assessed at each instance where treatment decisions need to be made. Hence there should be provisions for more than one mental capacity assessment to be shared. If sharing the outcome of a mental capacity assessment it is important to record to which decision it relates.

The mental capacity assessment is based on one of the following Acts:

- Mental Capacity Act 2005 (England and Wales)
- Adults with Incapacity Act 2000 (Scotland) •   Mental Capacity Act 2016 (Northern Ireland).

Similarly, there can be more than one record of 'Mental health act status' (a record of a decision to detain the person diagnosed with a mental disorder under the Mental Health Act or equivalent. There can also be more than one record of consent relating to a child

Organ and tissue donation is also included in this section, but this is information that would be obtained directly from the national register.

Copies of the legal documents should be made available where possible as these may have a direct bearing on treatment.

3.5 Safeguarding

This section includes any concerns in relation to safeguarding and is applicable to children and adults. This section includes whether a child is looked after and indicates the presence of a Child Protection Plan or Unborn Child Protection Plan.

There may be situations where it is not advisable to share information in this section with the person to whom it relates, so local implementations may need to apply filters in these cases. Appropriate policies and technical solutions need to be in place for these situations.

Access must be controlled to this information as per SCCI1609: Child Protection - Information Sharing.

3.6 Individual requirements

This section allows for the sharing of any individual requirements the person may have, such as to support cognitive impairment or mobility issues. This may relate to special needs and would extend to include a record of reasonable adjustments which would be included in 'Other individual requirements'.

Specific disabilities would be included in the 'Problem list' section however the requirements to support the disabilities (e.g. needs wheelchair access, needs large print etc.) would be included in this section.

The accessible information requirements information would be the most recent requirement rather than a history of requirements.

3.7 Professional contacts

This section includes current and historic details of health and care professionals, teams or organisations involved in the care of the person. Third sector organisations can be included.

The name of the person's current care coordinator or key worker should be included here.

3.8 Personal contacts

This section includes the personal contacts (e.g. family, friends, relatives etc.). Comments should be used to share information such as if a particular contact should be called in an emergency etc.

3.9 Participation in research

This section should be used to flag participation in clinical trials or other research initiatives.

When a person is enrolled on a drug trial or intervention, the GP receives detailed information from the research sponsor, this section only requires the name of the trial / intervention and the identification code.

3.10 Referral details

This section includes a record of current and historic referrals. Referral details includes the service a person is being referred from. A service may not always be coded. If the service is known, and a code is available, it should be included otherwise the service should be described in free text.

3.11 Contacts with professionals

This section includes the details of the person's contacts with services, their encounters. This information may need to be filtered to only display what is relevant for a particular use case and professional's discipline. This includes outpatient appointments, home visits, hospital and outpatient attendances, out of hours GP visits, clinic appointments, social worker visits etc.

3.12 Admission details

This section includes all instances where a person is admitted to an inpatient setting and would include the relevant site code according to the Organisation Data Service (ODS) codes.

3.13 Discharge details

This section includes the summary details of the person's discharge, but not the actual discharge content which is shared in the relevant sections such as problem list or procedures. This should include all instances of discharge from a healthcare setting with

relevant ODS codes and readable names of the discharging wards or departments of organisations where available.

3.14 Future appointments

This section includes the details of any future appointments the person may have. This can include both health and care appointments for example a home visit from a domiciliary care worker.

The section includes both specialty and service. Specialty should be used where possible for secondary care appointments, but service can be used for example for social care where specialty doesn't apply.

3.15 Vaccinations

This section includes all vaccinations including routine vaccinations of children in accordance with the Public Health England Green Book, as well as any vaccines outside the schedule and those administered abroad.

Information about vaccines should be shared in line with nationally agreed naming and utilisation conventions.

The vaccine manufacturer should be derived from GS1 code.

Sequence number for a vaccination which is given in several separate doses should be shared using SNOMED CT.

If applicable, when sharing Indication for vaccinations given as part of the Green Book either free text or SNOMED CT can be used. Example SNOMED CT is 171279008| Immunisation due (finding).

This section allows for retrospective vaccinations as reported by the person or their guardian or carer, including those given abroad, with a flag to indicate if this is the case.

Vaccinations performed by a third party should include a date or partial date of when the vaccine was administered as well as location (which could include other countries). The attributes of performing professional would allow the organisation that administered the vaccine to be shared, if known. In addition, the 'Reported' flag should be set to 'Yes' to indicate that the information was reported to the professional by the person.

3.16 Problem list

This section allows for all relevant diagnoses, symptoms, conditions, problems and issues.

This would include disabilities, including learning disabilities, and conditions such as autism where they fall into the above categories i.e. are diagnosed, seen as a problem by the person or are considered a condition or similar. Behavioural factors which are not formal diagnoses but could be seen as a problem for the person would also appear under this section.

 'Onset date' should be included where available even if this is estimated in source systems.

When a diagnosis has not yet been made, the most granular clinical concept with the highest level of certainty should be displayed. This may be a problem, symptom, sign, or test result, and may evolve over time, as a conventional diagnosis is reached. For example, 'dyspepsia' may be the diagnosis when a patient first presents with indigestion,

upgraded to 'gastric ulcer' when this is found at endoscopy, and 'gastric cancer' when biopsies reveal this.

Unconfirmed or excluded diagnoses should not be include in structured coded

fields, but may be included in free text in the comments field. Thus, in the example above, gastric ulcer and gastric cancer may be in a list of differential diagnoses at presentation, but the symptom, dyspepsia, should be included in the diagnosis field. The differential diagnoses should only be included in free text in the comments field, and not in a coded diagnosis field until confirmed with confidence.

Co-morbidities' should be shown as separate diagnoses. For example, dementia may be recorded as a primary diagnosis by a psycho-geriatrician, but as a co- morbidity where a patient is admitted for a hip replacement. Local implementations will need to define what will be prioritised according to each use case.

In some situations a diagnosis may need to be qualified by a number of attributes to give further detail. A generic approach to these attributes (such as grade; severity; distribution; behaviour; laterality etc.) has not yet been agreed. Until this is achieved it is recommended that these features are included as free text comments.

3.17 Procedures

The section includes details of procedures performed. Which procedures are visible to viewers of the information should be based on what they need to see. Procedures vary significantly between primary and secondary care and therefore different types of procedures are more or less relevant in different use cases.

Procedures include diagnostic as well as therapeutic procedures and will need to be clearly defined as such in local implementations.

Outcomes or results of procedures should be included in comments.

The record should include what was actually carried out, not the planned procedure as this may have been changed. The detail should be taken from the record of the actual procedure (e.g. operating note).

The procedure, anatomical site and laterality should be SNOMED CT coded wherever possible, with free text as an option where this is not possible.

There are specific elements for complications relating to the procedure and anaesthetic issues

The anaesthesia issues included could be, for example, "short neck, difficult to intubate" and the actual intubation grade or adverse reactions.

3.18 Social context

This section includes information about the social setting in which the person lives, such as their household, occupational, and lifestyle factors. Social circumstances includes the person's social background, network and personal circumstances, e.g. housing, and should also include if the person is a carer. 'Smoking status' should be shared using SNOMED CT rather than yes or no.

3.19 Services and care

This section is a record of the services being provided (or that have previously been provided) to the person to support both health and social well-being. For example, it could include domiciliary care with help for washing and feeding. A start and end date for the services should also be provided where available so it is clear which services are currently being provided. The professional or organisation providing the service, along with contact details should be made available where possible (in the 'Performing professional' subsection).

3.20 Family history

This section includes information on conditions or illness in family relations relevant to the health or care of the person.

3.21 Investigation results

This section includes details of the investigation results. Systems should allow copies of reports, scans, images related to the investigation results to be shared with the record. It allows for results in either structured format (e.g. blood tests) or unstructured format (e.g. genetic test with the result as a report). One or other of these should be used for the result. Investigation results received from laboratories may be imported into this section.

3.22 Investigations requested

The section includes details of requested investigations as yet unfulfilled. This should include the reason and priority of the request.

Investigations that have concluded, and for which results are available, should be included in the investigation results section.

3.23 Examination findings

This section is a summary of key findings carried out as a result of an examination conducted by a healthcare professional.

Each record of an 'Examination finding' should include a named examination and associated findings, which may include both coded and narrative elements.

'Observations' includes a record of essential physiological measurements, e.g., heart rate, blood pressure, weight, height, temperature, pulse, respiratory rate, oxygen saturation.

For children, observations would also include weight, height/length and head circumference.

3.24 Pregnancy status

This is to share if someone is currently pregnant and the expected due date. This information should only be shared if someone is pregnant.

It seems unlikely that this information can be reliably imported from a single system and so, is likely, to be a calculated field. This is unique in this model and may be defined as a medical device, for which separate safety assessment and registration will be required. System manufacturers will need to consider this.

Any maternity management plans or birth plans related to the pregnancy would be shared in the section 'Additional Supporting Plans'.

Obstetric and gynaecological history, specifically any complications, would be shared in the problem list (history) for professionals that need and are authorised to access to the information.

If a person is pregnant there should be an electronic shared maternity record and if professionals need, and are authorised to access it, they should be able to link to the more detailed record. This would be through the national record locator service.

3.25 Assessments

This section includes details of a person's assessments allowing for unstructured, semistructured and structured outputs from the assessment. Some assessment outputs will be narrative and may come with their own particular sub-headings e.g. psychiatry (Presenting Problem, Personal/Family History, Mental State Examination etc.)

This section would also accommodate the results of any more structured assessment tools completed (e.g. screening tools/outcomes measures such as PHQ-9 or GAD-7). Numeric results of any assessments completed can also be included.

3.26 Formulation

This section includes the formulation. A formulation is an account, shared by a therapist and person, of the personal meaning and origins of a person's difficulties. This is viewed in the context of multiple factors including relationships, social circumstances and life events and will indicate the most helpful way forward.

3.27 Risks

Risks are likely to fall into the categories set out in the core information standard – Risk to self, risk to others, etc. However, there is also a category for other risks.

There should be mechanisms in place to validate the information in this section and for it to be reviewed regularly and if applicable ended, however the peculiarity of risk factors in mental health needs to be taken into consideration i.e. the most important factor in risk is history so information here should not be archived or filtered without careful consideration.

3.28 Allergies and adverse reactions

Guidance on good practice recording of allergies and adverse reactions is provided by NICE (https://www.nice.org.uk/guidance/CG183/chapter/1-Recommendations).

A record should be provided of all allergic and adverse reactions relevant to the person. Coded information on causative agents is important to healthcare professionals to enable safe prescribing of medications.

When an individual is diagnosed with an allergy related condition (e.g. anaphylactic shock or urticarial skin rash) this will be entered in addition into the diagnosis field in the healthcare system and will need to be cross referenced into the problem list and prominently displayed there.

Where there is a diagnostic code for an allergy recorded in the system, the system should trigger an allergy entry. There is a significant risk to patient safety if allergies are not explicitly and prominently displayed.

Adverse reactions need to be treated in a similar manner.

Information about probability of recurrence may be included in the allergy comments element if this has been identified.

3.29 Medications and medical devices

The medications section allows for using structured dose and timing information that is machine readable to facilitate the reading and transfer of medications information between systems and providers of care, through the structured dose direction cluster. Technical guidance for implementing the structured dose and timing in Fast Healthcare Interoperable Resource (FHIR) messaging is available from NHS Digital https://developer.nhs.uk/apis/dose-syntax-implementation/.

The free text Dose directions description is the form of dosage direction typically used in UK GP Systems.

Dose direction duration can be derived from the start and end dates if no other information is available.

When sharing Dose duration direction, the following examples are provided to clarify definitions for two of the coded text items which appear similar. In both cases, these directions are not an absolute instruction. They are:

- 'continue medication indefinitely' - ongoing treatment planned for example when starting daily aspirin or a statin. There will be circumstances where you would stop them such as a GI bleed.
- 'do not discontinue' refers to medication where suddenly stopping could be dangerous, for example the abrupt withdrawal of long-term steroids.

The medication change cluster and medications discontinued cluster both derive from discharge standards to ensure clarity of what medications had changed or been stopped in hospital. They are retained in the core information standard as they may still be useful to professionals in understanding previous medications.

The Medical devices element is for medical devices that cannot be prescribed and do not have representation in the NHS dictionary of medicines and medical devices (dm+d). Whilst medical devices that can be prescribed in primary care are generally well represented in dm+d, there are other kinds of devices used in hospital care which may not be so this section provides for this.

3.30 Plan and requested actions

This is the treatment plan for the treating team or clinician and any actions requested. This plan should make clear who is expected to take responsibility for actions following an encounter, for example the person receiving care or their carer; the GP or another heath care professional. For example, follow up renal function test to be arranged by the GP within two weeks of appointment.

Shared decision-making principles should apply to the development of the plan and where the person's opinions differ, this should be included under 'Agreed with the person or their legitimate person representative' which will include both the aspects of the plan the person (or their representative) agree with and the aspects they disagree with.

The section would allow for the recording of planned investigations, procedures and treatment for the person's identified conditions and priorities.

This is not a care plan it is a plan for specific actions to be carried out as a result of an encounter.

3.31 About Me

This section supports sharing of information that the person thinks it is important to share with professionals. This could include information about their needs, preferences, concerns and wishes. For example, it could include that a person has a pet that would need looking after were they to go into hospital.

'About me' should be prominently displayed in the record as it is important information about the person relevant to all care and support providers. This information may be available in multimedia formats e.g. jpeg, mp3 etc. These documents are likely to follow a variety of formats but should be transferred in their entirety.

Care will need to be taken in local implementations to differentiate between 'About me' and things like 'Advance Directives' and preferences and wishes expressed in other care plans such as end of life plans.

3.32 Care and support plan

It is anticipated that there will be a single care and support plan for a person. Linked to this there can be multiplate additional supporting plans (that may be for a specific condition e.g. dementia or asthma). There may also be multiple contingency plans.

See the detailed guidance in the Digital Care and Support Plan for further information https://theprsb.org/standards/dcsp/.

3.33 Contingency plans

This section includes contingency / crisis plans for those people who have specific and predictable risks associated with their health and wellbeing. It describes how disruptions to the care and support plan should be addressed.

A contingency plan sets out what should be done if the person's condition or other circumstances get worse.

Not everyone who has a care and support plan will need a contingency / crisis plan. It is, however, widely used in mental health.

Contingency plans may include end of life care planning elements. These may form part of an initial conversation but a full end of life care plan should also be included where appropriate as an additional supporting plan.

3.34 Additional supporting plans

This section includes additional supporting plans, which may be linked to the care and support plan. Examples of additional supporting plans include: The Asthma UK action plan, a mental health plan (for people that are supported by a Care Programme Approach package), tissue viability plans, nutrition plans, a falls prevention plan, an end of life care plan, a maternity management plan or a birth plan, a hospital or other service transfer of care plan etc.

The format of additional supporting plans will vary according to the type of plan. Some may be structured and coded, others may include diagrams or images.

Additional supporting plans should be available for others to view, but will only be created, updated and ended by the service creating the plan.

3.35 End of life care

This section contains information that would be expected in an end of life care plan that does not appear elsewhere in the core information standard. This is not a representation of an end of life care plan as it would be expected to include this information as well as information covered elsewhere in the standard. The information included in the standard is consistent with the end of life minimum dataset and SCCI1580. However, PRSB recognises that there is work to do to develop a nationally agreed information standard for an end of life care plan.

3.36 Documents

This section includes details for documents and images. It includes the metadata that is required for the document or image and a link to the actual document or image. When displayed in a record, documents and images should be organised logically in date order. Local implementations will need to determine the best logical groupings for use here.

A specific cluster is included for images as these are a special case where there is a document (e.g. a KOS document) with information about the image and often produced by the machine or imaging system, and a specific set of additional information (such as event code list and format code). Note that this document is separate from the investigation report which provides the results or interpretation of the imaging. For images the performing professional will be the person performing the imaging procedure rather than the author.

4 PRSB support

The PRSB support service is available for any help, enquiries or issues with the using or implementing the standards. Any feedback on the standard (including proposed changes) resulting from putting the standard into practice would also be welcome.

Contact is via support@theprsb.org or Tel: 02079227976