Professional Record Standards Body

Better records for better care

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Mental health inpatient discharge summary standard

Implementation Guidance

V3.2

September 2021

1 Introduction

The Professional Record Standards Body (PRSB) provides professional and patient endorsed and evidence based clinical record standards. These provide the basis for technical (FHIR) specifications produced to enable industry to implement technical solutions. This document provides guidance to support the implementation of the urgent transfer from care home to hospital information standard.

It provides general guidance as well as guidance for each specific part of the standard. PRSB has carried out a clinical safety review in accordance with DCB0129, which is detailed in the clinical safety case and accompanying Core Information Standard hazard log. This guidance should be used in conjunction with section 2.4 Risk Mitigation.

This report provides consolidated implementation guidance, for the following standard:

- Mental health discharge summary v3.0 (2021)

2 Purpose

This document is intended to provide guidance to those implementing the PRSB clinical record standards. It contains information relevant to both industry and clinical practice. The intended audience is broad, encompassing all involved in the design, development and implementation of IT solutions which are deploying the standards, including those developing learning resources.

The guidance was derived from consultation during the development of the individual standards. It is therefore not able to provide definitive guidance and it is anticipated that it will be refined in response to findings and feedback during actual implementation of the standards

4 Mental Health Inpatient Summary - Section-Specific Guidance

4.1 Patient demographics

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

3.3.1 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.

3.3.2 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.

3.3.3 To improve the accuracy of the organ and tissue donation element systems should link directly to the organ donation register where possible.

4.2 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

3.3.4 'GP practice identifier' does not need to be a displayed field. It is intended to be used to provide the GP practice details via lookup from national registers.

3.3.5 Many people will not offer a named GP. Only the 'GP practice details' element would need to be completed in these situations

3.3.6 A patient may be registered with more than one GP practice. Normally patients are registered with one practice, but may be treated as a temporary registration (e.g. whilst on holiday) by another practice. The registered GP practice can be obtained from the PDS. Suppliers should enable more than one GP practice to be recorded to accommodate temporary registration. Communications will go to the GP surgery that the patient is permanently registered with. However, sometimes a GP who is serving a patient on a temporary basis may also need to access the transfer of care communication. In this instance, both GP practices should be recorded.

3.3.7 If a patient is not registered with a GP practice, then the GP practice record entry should appear with the text "No known GP practice".

4.3 Referral details

4.3.1 Referral details should be copied forward from the referral or transfer of care where possible.

4.3.2 Coded text 'self-referral' should be used where the patient is not referred or transferred from a health/care organisation. Where 'self-referral' is recorded the referrer data items should be left blank.

4.4 Problem List

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

4.4.1 'Problems' may also be 'diagnoses' or 'issues', depending on the context in which they are recorded. 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.

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

4.4.3 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.

4.4.4 Unconfirmed or excluded diagnoses should not be coded 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.

4.4.5 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.

4.4.6 In some situations, a diagnosis may need to be qualified by a number of attributes to give further detail e.g. grade; severity; distribution; behaviour; laterality etc. SNOMED CT codes are available for this purpose.

4.4.7 The discharge summary should inform the GP of the main problem(s) / diagnoses that were important during the admission including any new diagnosis that came to light during the admission.

4.4.8 The 'Problem on discharge' element should be used to record the main problem or diagnosis on discharge, which may differ from the reason for admission. Where no code is available the free text field should be used.

4.4.9 When a diagnosis has not yet been made, the most granular clinical concept with the highest level of certainty should be recorded. 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.).

4.4.10 Co-morbidities' should be recorded 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.

4.4.11 Unconfirmed or excluded diagnoses or problems should not be recorded in structured coded fields, but may be listed 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 recorded in the problem list field. The differential diagnoses should only be recorded in free text in the comments field, and not in a coded field until confirmed with confidence.

4.5 Procedures and Therapies

4.5.1 All procedures undertaken should be included in the e-discharge summary, including:

- diagnostic as well as therapeutic procedures and therapies
- medical as well as psychological procedures and therapies (e.g. cognitive behaviour therapy; follow-up interventions as a result of physical health checks)
- procedures carried out on different days during the hospital stay.
- complementary or alternative procedures and therapies

4.5.2 Outcomes or results of procedures should be recorded in the 'comments' field, as well as a comment to clarify such as statement that information is partial or incomplete

4.5.3 The discharge summary should include the operation which 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) rather than the planned procedure (e.g. consent to treatment).

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

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

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

4.5.7 Clinical coders use discharge summaries for coding hospital episodes. All those deemed to be clinically important for future care should be listed. Thus venesection would not usually merit noting, unless undertaken as a therapeutic procedure for polycythaemia.

4.5.8 Whilst hospitals use OPCS codes for procedures, these cannot be used by GP practices, so should not be included in discharge summaries.

4.6 Participation in research

This section should be used to flag participation in clinical trials or other research initiatives. When a patient is enrolled on a drug trial/ intervention, the GP receives detailed information from the research sponsor. To avoid duplication the discharge summary need contain the following information only:

- Drug/intervention name
- Trial name (and URL if possible)
- Whether the patient is currently involved in a trial.

4.7 Individual requirements

4.5.9 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’.

4.5.10 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.

4.5.11

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

4.8 Risks

4.8.1 The Risks section could potentially contain sensitive information. Therefore sufficient role based access controls should be in place to ensure this information is only shared with those care professionals where there is a need to do so.

4.8.2 There may be situations where it not advisable to share information in this section with the person to whom it relates. Appropriate policies and technical solutions need to be in place for these situations.

4.8.3 All information needs to be reviewed on a regular basis, but it is particularly important for this type of information, given its sensitive nature. There must be mechanisms in place to validate the information in this section and for it to be reviewed regularly.

4.8.4 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.

4.9 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.

Non-technical guidance for medication information has been developed by the PRSB in collaboration with NHS Digital and NHS England and should be referred to alongside the guidance below. See https://theprsb.org/projects-2/digitalmedicationinformation/

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.

Preparing the Medications and medical devices summary at the sending end

- It is very important that a full and accurate summary record of medications (both prescribed and non-prescribed) is contained within the discharge summary. This should include:
- Any medications that were current at the time of admission and which the hospital wants the patient to continue following discharge
- Any changes made to medication that was current at the time of admission – such as changes of dosage
- Any medications that were current at the time of admission which were discontinued either during the admission or at the time of discharge
- Any new medications added since admission and which should be continued following discharge
- The reasons for any of the above (i.e. changes, discontinuations or additions of medication)

4.9.2 Ideally the above information should be generated semi-automatically from a hospital e-prescribing system such that drug names will be automatically represented by dm+d codes and also as far as possible the appropriate fields for route, dosage amount and dosage timing etc. will be completed. It is however recognised that, at least initially, much of this information will need to be entered manually. Please see section below which outlines the differences between dose based and product based prescribing and which provides guidance as to how the various fields available should be used in each case.

4.9.3 Whilst medical devices that are prescribable in primary care are generally well represented in dm+d, there are other kinds of devices used in hospital care. While these may well be codified in SNOMED CT or in some other proprietary coding scheme they will generally not be prescribable in primary care. The following rules apply ONLY for a hospital system which uses dm+d. When entering information about medications and devices into the discharge summary the following rules should be applied:

- Any medication item or medical device that can be dm+d coded (both prescribed and non-prescribed) should be entered as a ‘medication item’ entry. Changes and reasons for change can be also handled here.
- Where any admission medication has been discontinued this should be entered using the ‘medication discontinued’ entry
- Where a medical device has no dm+d code then this should be represented as text using the ‘medical devices’ record entry.

4.9.4 Where recording dose duration directions, 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.

Communicating medication changes

4.9.5 Any alteration to a medication that might require a change to the GP prescription should be communicated to the GP with the status ‘amended’. Amended generally

means changes in VTM and, where relevant, dose. Changes in form or strength should also be communicated where clinically relevant.

4.9.6 Changes should be recorded in a structured way where possible. Changes in medication can be structured where the medication history was recorded electronically and the system can automatically recognise changes. For clinical safety, an automatic assessment of change would have to compare the exact medication statement(s) on admission and discharge for all drugs with the same VTM (erring on the side of marking a medication as a change if unsure). To match up corresponding medications between two lists for automatic reconciliation would be using the underlying VTM. Then the algorithm could compare the individual prescriptions and determine if there are any changes (this may include change from single to multiple statements for the same VTM and vice versa). The OPENeP system has a user interface to do this (http://www.marand.com/thinkmeds/).

4.9.7 Hospitals are required to use the Summary Care Record (SCR) for admission medication history, but for hospitals without electronic medication records reconciliation would need to be a manual process.

4.9.8 If the admission is short (e.g. surgical daycase) and detailed medicines reconciliation hasn't taken place, on-going medications that the patient is already taking may be omitted from the discharge summary. In this case, the discharge summary should make it clear that any medications listed may not be the only medications that the patient takes. In practice this is often done with a statement of 'no changes to patient's regular or pre-admission medication'.

Communicating quantity of medications

4.9.9 The discharge summary provides a statement of the medication the patient should be taking following discharge. Often it also functions as a prescription/request for those drugs, and some or all of them may be dispensed/supplied by the hospital pharmacy based on how much the patient already has.

4.9.10 Quantity may be expressed as the duration, eg number of days, or the number of items, eg tablets, inhalers etc supplied. The days prescribed/supplied should be recorded as a numeric value under the element 'dose directions duration'. The quantity should be recorded as a textual value eg 30 tablets, 2 inhalers, etc. under medication quantity Whether the quantity is that prescribed or dispensed should also be recorded in the discharge summary.

Handling the medicines and medical devices summary at the receiving end

4.9.11 Guidelines for safe on screen display of medication items should be followed in design for display of medication in e-discharge summaries. The NPSA guidance can be accessed via the NPSA website.

4.9.12 Recipients of e-discharge summaries should be aware that the medications and medical devices summary is generated by the hospital from the information that they have at their disposal around the time of discharge. Despite best intentions this information may neither be complete nor accurate.

4.9.13 Where the hospital systems use dm+d, those items which are prescribable in primary care will be represented in dm+d. Those which are not prescribable in primary care will need to be recorded as textual items.

Medicines Reconciliation

4.9.14 This section primarily applies to the GP receiving system. When a patient is discharged from hospital to GP care any change in medication generally involves a handover of responsibility for prescribing from hospital clinician to GP.

4.9.15 The discharge summary should inform the GP of medications that have been continued, changed, discontinued or added since the time of admission along with reasons for these changes. The responsible GP prescriber will therefore need to review the patient's GP medication record, which is likely still to represent the medications that were current at the time of admission, and to reconcile this with medication recommendations in the discharge summary. It will therefore be helpful to enable the receiving GP prescriber easily to compare the intended list of discharge medications listed in the discharge summary with the patient's recorded current medication. Any changes that may as a result be made to the patient's current medication should be subject to the usual prescribing decision support / alerts as for any other addition / change / discontinuation of medication that prevails when any change is made to the GP medication record.

4.9.16 In the short term this will require reading each individual discharge medication and then making any appropriate changes to the GP patient medication record manually. In time, as hospital systems become able to transmit dm+d coded medications it may become possible for suppliers to utilise these codes to assist the GP in finding the appropriate medicinal product that needs to be added / changed / discontinued. Longer term, the expectation is that in many cases it will be possible to utilise both the dm+d code and also a structured statement of dosage to compute the most likely equivalent GP prescription and to present this to the GP prescriber.

4.9.17 For the avoidance of doubt, changes to the GP medication record resulting from hospital discharge summary MUST always require the authorisation of the responsible GP prescriber.

Dose based compared with Product based prescribing

4.9.18 In UK General Practice systems "product based prescribing" is used, so called because medicinal products are prescribed. An example of this is:

"Furosemide 40 mg tablets, take 2 at 8am"

4.9.19 In contrast Hospital systems often use "dose based prescribing" which is not dependent on using any particular product but starts with a drug name and then links this to a dose amount and a dose frequency. The same example as above but expressed as dose based prescription would be:
"Furosemide 80mg oral at 8 am".

4.9.20 It can be seen that in product based prescribing the size of the tablet / capsule / inhalation / etc. is usually explicitly stated as part of the product name and that typically the route of administration is implicit. In contrast, dose based prescribing starts with the drug name and then typically explicitly builds a dose string out of dose amount, route, and dose timing. Both of these prescribing patterns are therefore supported in the Medication item entry of the Discharge summary Medications and medical devices information model.

4.9.21 It is recommended that the fields in the Medication item entry should be used as follows.

For Product based prescribing:

- Medication name: Enter the medicinal product (e.g. “Furosemide 40 mg tablets”). In dm+d terms this would be either Actual Medicinal Product (AMP) or Virtual Medicinal Product (VMP)
- Dose directions description: Enter the remaining dose direction (e.g. “take 2 at 8 am”). Information about route may also be included in this same text string but is generally omitted

For Dose based prescribing:

- Medication name: Enter the drug name (e.g. “Furosemide”). In dm+d terms this would be Virtual Therapeutic Moiety (VTM)
- Form: Optional (e.g. “capsules”, “tablets”, “liquid” etc.)
- Route: Optional (e.g. “oral”, “intraocular”,” intramuscular” etc.)
- Dose amount: A plain text description of dose amount (e.g. “80 mg”)
- Dose timing: A plain text description of medication dose frequency (e.g. “once daily”, “at 8 am”)
- Site and method are other optional fields that may be used

Plans for future structured dose syntax

4.9.22 The intended direction of travel is to move towards a future:

- where all health care prescribing systems express drug names using dm+d coding both for product based and for dose based prescribing and
- where all health care prescribing systems can also generate a parsable dose directions string that will incorporate all of the remaining information beyond the drug name that is essential to express an unambiguous prescription.

4.9.23 Through a combination of using dm+d and also parsing of these structured dose strings it should then be possible to convert a dose based prescription to a semantically equivalent product based prescription and vice versa. Depending on the structured dose syntax solution eventually adopted it is anticipated that upwards from 80% of all prescriptions could be automatically converted between dose based and product based expressions of prescriptions. Components are already included in the Medications and medical devices information model to support structured dose syntax and its processing.

4.10 Allergies and adverse reactions

4.10.1 A full record should be provided of:

- allergies that the patient tells the hospital about
- allergic and adverse reactions related to their admission.

4.10.2 If relevant investigations and observations have been carried out and no allergies or adverse reactions identified then this section should appear in the discharge summary with the text **“No known allergies or adverse reactions”**. If no information is available about allergies or adverse reactions (but allergies or adverse

reactions may have been identified), then this section should appear in the discharge summary with the text **"Information not available"**.

4.10.3 Guidance on good practice recording of allergies and adverse reactions is provided by NICE (https://www.nice.org.uk/guidance/CG183/chapter/1-Recommendations). This relates to end systems rather than the discharge summary, but is included here as its use should improve quality of the information communicated by the hospital.

4.10.4 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.

4.10.5 Adverse reactions other than allergies are mapped to intolerances when communicating them outside the Trust so that the information can be carried within FHIR messages.

4.10.6 Information about probability of recurrence may be included under allergy text section if this was identified by clinician. There is no longer a separate element for this information. This decision was reached by suppliers and clinicians during FHIR profile mapping.

4.11 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.

4.11.1 Only important or relevant results should be included, ie those thatthe clinician wants to communicate. This is to reduce the risk of overload of irrelevant information.

4.11.2 This can be a difficult decision to make and so consideration should be given to ways that a clinician could be helped in this task.

4.11.3 It is important to record why test have been done and where relevant, who is going to follow up (i.e. GP or hospital). Follow up should be recorded in the plan and requested actions section.

4.11.4 Investigations carried out where results are not yet available should be recorded in this section.

4.12 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 (LPA), Advance Decision to Refuse Treatment (ADRT), Mental Capacity Assessments (MCAs) and Mental Health Act (MHA) status.

The documentation may be available centrally as part of shared care records or held locally as part of the persons health and care records.

NB: Advance statement element is found in the End of life care section.

4.12.1 Systems should allow copies of legal documentation to be attached to the record

where it would be necessary to see copies of the original documents.

4.12.2 Mental capacity assessment

- Mental capacity needs to be assessed at each moment where treatment decisions need to be made. Hence there should be provisions for more than one MCA to be recorded.
  - Mental Capacity Act 2005 (England and Wales)
  - Adults with Incapacity Act 2000 (Scotland)
  - Mental Capacity Act 2016 (Northern Ireland).
- If there is a need to communicate the outcome of a mental capacity assessment it is important to record to which specific decision it relates.

4.12.3 Lasting power of attorney (LPA) should include details of one or more people who have been given power by the person when they had capacity to make decisions about their health and welfare should they lose capacity to make those decisions. To be valid, an LPA must have been registered with the Court of Protection. If life-sustaining treatment is being considered the LPA document must state specifically that the attorney has been given power to consent to or refuse life-sustaining treatment.

4.12.4 A clinician should satisfy themselves that the **Advance Decision to Refuse Treatment (ADRT)** is valid and that the circumstances that they are dealing with are those envisaged when the person made the ADRT. A valid and applicable ADRT is legally binding. The record should include the location of the legal document.

4.13 Formulation

4.13.1 If a current Formulation is recorded it should be included in the communication. 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. It is recorded in free text.

4.13.2 Subheadings within this free text field may be used when recording a person's formulation. One common example is known as the '5 P's' ('Presentation, predisposing factors, precipitating factors, perpetuating factors, protective factors'). Others include the '5 W's' (Who, What, Where, When, Why, How), and the SBAR (Situation-Background-Assessment-Recommendation) model. The system must not limit or constrain the free text in this field.

4.14 Plan and requested actions

4.14.1 This is the treatment plan, following discharge, for the treating teams and clinicians and any actions requested. The plan should make clear who is expected to take responsibility for actions following the encounter, eg 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.

4.14.2 NICE guidance about involving carers in the discharge planning process should be followed (1.5.29 to 1.5.31 of NG [27] and Quality Standard [136] quality statement 5).

4.14.3 Shared decision making principles should apply to the development of the plan and where the patient's opinions differ, this should be recorded under the section 'Patients concerns, expectations and wishes'.

4.14.4 The plan could be presented in various ways in the system to prompt complete information to be recorded eg table, best practice prompts, etc.

4.14 Information and advice given

4.14.1 In some instances health care professionals may want to communicate to the GP specific information and advice which was given to the patient. It is important that this is concise and is only information which it is pertinent for the GP to be aware of.

4.14.2 Where patients are provided with literature (e.g. pamphlets) there is no need to provide details of the information contained in the literature e.g simply state that the patient was provided with a pamphlet.

4.14.3 The default is that patients (or their designated carer or guardian where applicable) should get a copy of the discharge summary. Where this is not possible an explanation should be provided in the clinical summary.

4.15 Distribution list

4.15.1 This should be a list of people that the discharge summary is being sent to, as the patient and GP need to know where it is being sent.

4.15.2 Where local systems are capable of doing so, they may use this information to trigger the message to be sent.

4.15.3 Consideration should be given to sending copy discharge summaries to recipients by secure email where they are unable to receive a structured message, e.g. care homes, community pharmacies. The PRSB has provided guidance on use of secure email.

4.15.4 Who exactly should receive a copy of a discharge summary will be situation and service specific and should be agreed in a trading agreement with each participating organisation, e.g. whether the copy goes to generic mailbox or to an individual.

4.16 Person completing record

4.16.1 This should be the individual responsible for the completion of the discharge summary in the hospital. Others may have contributed to the discharge summary and a record will be maintained in the hospital system.

4.17 About Me

This section supports the sharing of information that the individual thinks is important to share with people caring for and supporting them. This should include information about what matters to the person (their needs, preferences, concerns and wishes). The About me section should be prominently displayed in a shared care record as it is important information about the person relevant to all care and support providers. It is an optional section in the mental health discharge summary standard.

A carer or clinical staff member should quickly review the About Me section before meeting and supporting the individual. 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 information in

the About me section and things like Advance Directives and preferences and wishes expressed in other care plans such as end of life plans. Likewise reference to any other legal documentation e.g. lasting power of attorney in the About Me should be checked against the electronic record.

Professionals using the information in the About Me section should be reminded that the information is entered by the individual from their perspective and therefore any clinical information contained in the About Me e.g. their allergies or their conditions could be compared with other information in the electronic record.

If there are discrepancies between the About Me information and the information in the electronic record, following discussion between the clinician and individual to reconcile the differences, both the individual and the clinician should (where appropriate) amend their records to align them.

As the About Me section allows for free text and multimedia information it is recommended the individual (or the person supporting them to write the information) is prompted to consider:

- that the most important information comes first in any sub-category
- avoiding adding too much information as important information may be buried within text making it difficult for the professionals to easily digest the information and use it to personalise care
- when multimedia is effective and ensure that videos are kept short
- that they do not need to put information about themselves in every element (sub-category of the About Me section) only where they feel they have information they want to share

The elements (sub-categories) enable the individual to record whatever is most important to them and therefore are broad and few in number. Local implementers could decide to structure the information within the sub-categories further but it is not mandatory.

To help individuals to structure their information within the sub-categories a set of possible prompt questions have been included with this guidance. They will not apply to all individuals and if implementers are designing a user interface for a particular population cohort they may wish to use a sub-set of the questions and consult guidance from relevant bodies (for example the National Autistic Society, Alzheimer's Society, Dementia UK and Macmillan etc.) and tailor prompt questions accordingly.

The About Me information should sit alongside clinical and social care information entered by professionals in the shared care record such as medications and allergies. This would enable professionals to cross-check information given in the About Me section with other information in the record.

4.17.1 What it is:

- a section within the core information standard and transfer of care standards which is designed for sharing information that the person (or somebody acting on their behalf) considers important to share about themselves with others caring for or supporting them for the purposes of direct care, to enable the best, personalised care and support to be provided
- aimed at capturing an individual's needs, preferences and wishes for how they receive care and support in a person-centred approach. It could also include information on the

individual's strengths to provide a basis for building upon personal and community assets to enable self-care where possible
- aimed at capturing holistic information about the individual (not just what people caring for and supporting the individual need to know when someone is unwell (or in an emergency) but what they are able to do and enjoy on a typical day)
- divided into sub-categories of information to help individuals to determine what information to share and to help those providing care and support to the individual to easily locate the information they need
- designed to be generic and apply to everyone, from those who have complex care and support needs to those who rarely require care and/or support. This could include, for example, older people, people with mental health conditions, people with learning disabilities, people with physical impairments and people with long-term conditions etc.

4.17.2 What it is not:

It is not:
- intended to be used for determining an individual's right to access social care or health services
- a person-held record, therefore, does not include any information recorded by professionals in an electronic patient record such as medications, problems, examination findings and investigation results. In a shared care record the About Me (information from the person themselves) would sit alongside clinical and social care information recorded by professionals about the person
- a care or support plan. Individuals may have an end of life care plan, plans for management of specific conditions or situations (e.g. an asthma management plan or a behaviour support plan) and these would sit alongside the About Me information in a shared care record
- a go-to section for legal information such as Deprivation of Liberty Safeguards, Lasting Power of Attorney, Nearest relative or Next of Kin
- a prescriptive definition of what must be included. The About Me section enables an individual to reflect their unique position. They can include whatever information they choose in an About Me section and they can choose not to share any information at all
- a definition of who should be able to see the information in the About Me section for an individual (local implementers will need to determine this based on the legal framework and NHS England's Information Governance Framework and Role-Based Access Control framework)
- a definition of how the information in the About Me section should be presented to professionals. What is presented and how much information (history) and how it is viewed and accessed should be defined locally
- a definition of a form or system for capturing information in the About Me section from an individual
- a definition of how and where individuals can record information in the About Me section, how it is captured and displayed in clinical systems and shared records, how it is kept up-to-date and how multiple versions of information in the About Me section are managed (e.g. About Me records originating in different settings)

4.17.3 What is most important to me

Element	Description
What is most important to me	A description of what is most important to you **Emergency Information**

	Include any essential information that any professional in health and social care should know about you in any situation, including emergencies. **Other Information** This could include: • Values • Spirituality and religion • Ethnicity • Culture • Pets • Goals and aspirations • Meaningful activities including leisure activities, visiting places, sport and exercise, listening to music, employment, education, volunteering

Prompt questions:

1. What does someone caring for, or supporting you, need to know about you in an emergency?

Consider including any important preferences, needs and wishes that indicate how you need to be cared for and supported in an emergency such the need to avoid any disturbing stimuli e.g. noise, visual, smell, taste or touch etc. for example by being seen in a quiet or darkened room, the need for visual aids, the need for a translator or the need for vegan appropriate medications etc. Consider including any food allergies or risk of choking.

Consider referencing other documents in which you have already recorded any needs, wishes and preferences such as an Advance Decision, a lasting power of attorney, a communication or hospital passport or an end of life plan.

2. What's most important to you?

This is just as important as emergency information.

Think about your core values, spiritual beliefs, culture, ethnicity and religion as they relate to your care.

Think about what makes you happy, for example meaningful activities you enjoy, pets, objects, computer games, exercise sport, places you like to visit, education or spending time with family and friends. There may be a specific stimulating sensory item or activity you enjoy.

3. What are your aspirations and goals for the future?

4.17.4 People who are important to me

Element	Description
People who are important to me	Details of who is important to you and why. They could be family members, carers, friends, members of staff etc. Include how you want the people important to you to be engaged and involved in your care and support in both emergency and normal situations. Include how you stay connected to the people important to you. Who should not be contacted or consulted about your care and support and why, if you wish to say.

Prompt questions:

4. Who are the important people in your life and why?

Think about family, friends, staff in the care home and people who support you at home or in the community or at a club.

5. Who should be contacted in an emergency and why?

6. Who do you want to be consulted on, and involved in, your care and support in an emergency and in normal situations?

7. Is there anyone that should not be contacted or consulted about your care and support and why (if you wish to say)?

4.17.5 How I communicate and how to communicate with me

Element	Description
How I communicate and how to communicate with me	A description of how you communicate normally including any communication aids you use, for example a hearing aid. Include your preferred language of communication, if your first language is not English. Include how you would communicate when you are in pain or distress. Include how you communicate choices. Include how you give feedback or raise a concern. Include how you like to receive information.

	Describe how you would like others to engage and communicate with you, including how you would like to be addressed.

Prompt questions:

8. What do people caring for you and supporting you need to know about how you communicate and how they should communicate with you?

Consider:

- the language you prefer to communicate in
- whether you communicate by, for example, signing, symbols, pecs, gestural or body language
- how you like to be addressed
- whether you use a communication aid (high or low tech) (If so, who provides maintenance and technical support?)
- whether people speaking to you need to speak slowly and clearly

9. How do you let people know you are in pain, anxious or in distress? For example, do you communicate it verbally, facially or through body language?

10. How do you make choices? When offered a verbal choice do you always make an informed choice, or do you need those supporting you to explain choices in detail?

11. How do you indicate yes and no?

12. How do you give feedback or raise a concern?

13. What support would help you understand what is happening and what treatment you might need in hospital?

14. When is a good and bad time to have important conversations with you?

4.17.6 My wellness

Element	Description
My wellness	A description covering what you are able to do, how you engage with others and how you feel on a typical day through to on a day when you are unwell or really unwell. ▪ Include any causes that might result in you becoming unwell and strategies for avoiding or addressing the causes. For example, not drinking enough water could cause constipation.

	▪ Include any signs that indicate you might be becoming unwell. ▪ On a bad day describe what is different about what you are able to do, how you engage with others and how you feel. ▪ Include how your everyday life is affected by any medical conditions, e.g., dementia or symptoms, e.g., itchiness, cough or pain, and how you manage those conditions. ▪ Include past health issues or experiences that need to be considered ▪ Include your wellbeing and lifestyle goals and aspirations

Prompt questions:

15. What shows the good things in your life and who you are as a person?

Think about photos, videos, letters from people you value, Facebook pages, Twitter or Instagram accounts.

16. What are you able to do and how do you feel on a typical day?

17. How do any conditions or symptoms you live with affect you and how do you manage them?

18. Do you have any long-term pain, if so, how do you manage it?

19. Do you have past events or health issues that affect you, if so, how do you manage them?

20. What triggers or vulnerabilities can cause you to become unwell, how do you avoid or address them?

21. What might indicate that you are becoming unwell, how do you manage it?

22. What are you able to do and how do you feel on a bad day, how do you want to be supported?

23. What helps and hinders you to be well?

4.17.7 Please do and please don't

Element	Description
Please do and please don't	A description of things you want someone supporting you to do or not to do. For example, this might include: • Talk to me not to my carer • Remind me to take my medication • Encourage me to wash my hands regularly • Explain to me what is happening and why • Respond to my communication A description of things you do not want someone supporting for you to do. For example, this might include: • Discussing or asking questions about certain topics • Making assumptions about something • Providing support when it is not wanted • Talking to you in a certain way.

Prompt questions:

24. What are the really important things that you want someone to do when caring for or supporting you?

25. What are the really important things that you don't want someone to do when caring for or supporting you?

4.17.8 How and when to support me

Element	Description
How and when to support me	A description of how and when you want someone caring for you to support you. This could include support needs in an emergency situation (for example taking blood) This could include support you need to maintain important routines or to carry out particular activities, for example: ▪ Personal care routines ▪ Eating and drinking ▪ Bedtime routines ▪ Taking medications ▪ Moving and transitioning

	This could also include support needed with: ▪ wearing glasses, hearing aids or false teeth etc. ▪ making informed choices or understanding dangers and risks. ▪ managing your emotions, moods and behaviours. ▪ memory or confusion. Include how your support needs change in different environments. Include any triggers that might result in you needing further support and strategies for avoiding or addressing the triggers. Include how you want the support to be provided.

Prompt questions:

26. What do people caring for and supporting you in an emergency need to know about how and when to support you?

27. What are your important routines? What are you able to do for yourself, what do you need support with and how do you want to be supported?

Think about:

- your morning, bedtime and personal care routines
- dressing and undressing
- using the toilet
- having a shower or bath
- brushing your teeth

Think about eating and drinking:

- Do you use any special bowls (e.g. lipped plate), cutlery (e.g. weighted spoon) or cups?
- How do you like your food presented (e.g. chopped up or liquified etc.)?
- How do you like to be supported to eat (e.g. verbal prompts or physical help)?
- What do you like to drink and eat?
- How do you like to be supported in making food and drink choices?
- How do you like to be supported in preparing food?

Think about sleeping:

- Do you sleep well at night?
- What helps you to have a good night's sleep (e.g. warm milk before bed, leaving lights on, music)?
- If you have disturbed sleep how do you like to be supported?

Think about taking medication:

- How do you like to take your medication (e.g. liquid or tablet form, mixed up with a drink or food etc.)?
- What helps you to take your medication? (e.g. verbal encouragement)

Think about your mobility:

- Do you use any walking aids (e.g. splints, frames, wheelchair)?
- How do you like to be supported to move around?
- Think about what you can do for yourself and how do you like to be supported when transferring? e.g. from a wheelchair to bed
- Can you use public transport independently? If not, how do you like to be supported?

Think about memory and thoughts:

- What helps you remember things (e.g. use of diaries, apps or photographs etc.)?
- If you are confused what helps you and how do you like to be supported?

Think about your emotions, moods and behaviours:

- What do you find difficult or upsetting, how do you behave?
- How do you like to be supported to manage your emotions, moods and behaviours?

Think about work, college and/or leisure activities:

- How do you like to be supported in these activities?

28. What works well and what doesn't work for you when someone is supporting you?

29. What triggers could result in you needing further support and strategies for avoiding or addressing the triggers?

30. How do your support needs change in different environments?

4.17.9 Also worth knowing about me

Element	Description
Also worth knowing about me	A description of what is also worth knowing about you for people caring or supporting you. This could include a short history of your life (where you have worked, where you lived, important events in your life, important people in your past life). This could include a short profile of your current life: ▪ your work and/or study ▪ your aspirations ▪ your skills ▪ your networks

	▪ things you like e.g. particular foods, places, a football team and things you like to talk about. ▪ things you dislike This could also include any care and support preferences that have not been included elsewhere.

Prompt questions:

31. Provide a short summary of your past life.

Think about:

- where you worked, what jobs you have had
- where you lived
- important people in your life
- important events in your life

32. Provide a short profile of your current life.

Think about:

- where you work, your job or college
- your strengths and skills
- your networks
- exercise

33. What do you like to do?

Think about people you like to see, places you like to visit, activities you enjoy doing and your favourite tv programmes etc.

34. What are your food preferences or requirements?

35. What do you like to talk about?

36. What do you not like?

Think about environments you do not like to be in, food, places, things you do not like to do and things you do not like to talk about.

4.18 Care and Support Plan

4.18.1 It should be possible to restrict access to the care and support plan in most cases based on the individual's consent preferences. However, a data controller may choose to release all or part of the record for legitimate reasons, for example when a person using services is unable to give consent.

4.14.4 It should be possible to add attachments or hyperlinks in care and support plans to

provide guidance, learning materials, explanatory notes, etc. The date/time of the hyperlink/addition should be included.

4.18.2 It should be possible to add comments to the plan and to sections in the plan, for example. to identify progress towards a goal (which should have a formal mechanism associated for capturing information). It should also be possible to comment on actions undertaken or suggest changes to actions. Note that adding comments to a plan is not the same as having a dialogue with others involved in the care and support planning process. Separate functionality, e.g. secure messaging would be required for this.

Care and Support Plan > Strengths

4.18.3 Definition: Any strengths and assets the person has (i.e. things a person is good at or enjoys doing) relating to their goals and hopes about their health and well-being For example, 'able to participate in leisure activities' such as a sport in order to improve health and wellbeing by losing weight.

Care and Support Plan > Needs, Concerns or Problems

4.18.4 **Needs** are defined as health or care deficits identified by the person with their carer(s) or professionals and are the motivations/indications for healthcare activities. Examples of needs could be (e.g.) 'to dress myself'; 'to better understand what my various medications are for'; 'to reduce pain in my knees'.

4.18.5 **Concerns** are gathered information to support continuity of care for a person. Concerns can include biological, psychological or social concerns. They may include things the person or carer is concerned about. For example, a person's concern may be 'the quality of social housing'; a professional's concern could be 'high blood pressure'

4.18.6 **Problems** are defined as: A condition that needs addressing and is important for every professional to know about when seeing a person. Problems may include diagnoses (e.g. COPD; diabetes), symptoms (e.g. joint pain; breathlessness), disabilities (e.g. sensory impairments; amputations), health, social and behavioural issues. Problems recorded here may link to the problem list held in a shared care record or GP system for a person using services.

4.18.7 **Goals and hopes** are defined as: The overall goals, hopes, aims or targets that the person has. Including anything that the person wants to achieve that relates to their future health and wellbeing. Each goal may include a description of why it is important to the person. Goals may also be ranked in order of importance or priority to the person. For example, 'weight loss'; smoking cessation'; 'reducing alcohol intake'; 'increased sleep'. 'Goals' tends to be historically a more medically-used term, whereas 'hopes' is used more widely in social care settings.

4.18.8 It should be possible to include tables (e.g. weekly schedule), diagrams or images (e.g. to illustrate how a person has made progress towards a goal) as well as video and audio clips (i.e. as a communication tool for individuals with complex accessibility requirements).

4.18.9 It should be possible to prioritise goals, indicating the importance of each goal to the person (e.g. a scale 1 to 10).

4.18.10 Each action may also have an associated additional indicator showing how confident the person is to carry it out (e.g. a scale from 1 to 10).

4.18.11 The care and support plan should be structured in a way that supports digital information exchange, with separate sections for strengths, needs and problems which can be linked to specific goals.

4.18.12 Of particular importance is the link between needs in a care plan and related goals. Each goal must link to specific needs, as well as any actions associated with it. Goals may also have related outcomes.

4.18.13 The sections associated with goals and actions that are the focus of specific care professionals should be interoperable with the care plan that professional uses for their day to day work.

4.18.14 Updates to the care and support plan section may include:

- Add, edit or archive strengths, needs, concerns or problems. If a strength/need/concern becomes more or less important, then goals may need to be changed, as will associated actions.
- Add, edit or archive goals. When a goal is archived it should be possible to also archive the actions associated with it. If the actions are still valid it should be possible to attach them to another goal.
- Add, edit or archive actions. Once an action has been completed (i.e. status updated to indicate it has been completed), it should be possible to archive it from the care and support plan. It should be removed from the current active view of the plan, but available to view in previous versions of the plan.
- Recording outcomes related to goals. Once a goal has been achieved, it should be possible to archive it from the care and support plan, so that it is removed from the view of the current plan, but available to view in previous versions of the care and support plan.
-

Care and Support Plan > Agreed with person or legitimate representative

4.18.15 Agreement of the plan with the person (or representative) should be recorded. If agreement cannot be obtained the reason for this should be documented.

4.18.16 Where a person has been unable to agree, due to, for example, lacking mental capacity, actions should be undertaken to maximise capacity and the plan should demonstrate how a person's rights will be promoted. If a person is unable to consent, a mental capacity assessment should be attempted, and if there is no legal representative a best interest decision made.

Care and Support Plan > Care Funding Source

4.18.17 In health and social care there may be different sources of funding (e.g. personal budget/personal health budgets) to meet the aims and goals of the person. The 'Care Funding Source' section should only detail the source of the funding so as to support easy resolution where a question about funding arises. The information should not include the details of the funding, which will be held in separate documents.

Care and Support Plan > Date this plan was last updated

4.18.18 This information should be automatically retrievable from the system.

4.19 Contingency/safety plans

4.19.1 Contingency/safety plans are known by other terms depending on care setting. In mental health for example, 'safety plans' is a commonly understood term while medically these are more commonly known as 'Contingency plans'. Please see section 5 for a list of alternative terms.

4.19.2 Not everyone who has a care and support plan will need a contingency/safety (also known as crisis/emergency/escalation/advance/anticipatory) plan. See the Glossary (section 5) which includes alternative names for care planning concepts in the standard.

4.19.3 This plan is 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.

4.19.4 There may be a number of different contingency/safety plans to manage different aspects of health and wellbeing, e.g. diabetes, respiratory, mental health, substance misuse, etc. The plan may cover different scenarios, e.g. mild disruption/issues, through to more severe.

4.19.5 It must be possible to create a contingency/safety plan at any time when the individual and those providing care and support identify a need for such a plan.

4.19.6 Contingency/safety plans must be subject to or as a result of an assessment.

4.19.7 Contingency/safety plans may include end of life care planning elements. These only form part of an initial conversation and a full end of life care plan should be included separately as an end of life care document.

4.19.8 The 'Coping Strategies' element should include details of all coping strategies used in free text. Any tools used to carry out the coping strategy should be included here.

4.19.9 Coping strategies may need to be regularly updated as it may depend on the stage of recovery the person is at.

4.20 Additional support plans

4.20.1 It must be possible to hold additional support plans, which may be linked to the care and support plan where the individual or care professional decides that the information should be available to others. Examples of additional supporting plans: asthma plan, mental health plan, tissue viability plan, nutrition plan, falls prevention plan, hospital or other service transfer of care plan, etc.

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

4.20.3 Additional support plans should be available for others to view, but will only be created, updated and ended by the service creating the plan. These may be made available on the National record Locator Service (NRL) in PDF format.

4.20.4 When an additional support plan is updated a new version of the plan may be linked to the care and support plan, again at the discretion of the individual or care professional.

4.20.5 Educational and health care plans are produced for people with neurodevelopmental conditions and apply up to the age of 25. However, they transition into adult services earlier so it is important to note that this plan may exist at the same time as a care and

support plan.

4.20.6 Any reference to documents related to additional support plans should be recorded under the element ‘Care and Support Plan’ > ‘Other care planning documents’.