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PERSONALISED CARE AND SUPPORT PLAN

DETAILED IMPLEMENTATION GUIDANCE

Final Draft v2.8

OCTOBER 2021

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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Professional Record Standards Body

7 - 14 Great Dover Street, London, SE1 4YR

www.theprsb.org

Community Interest Company No 8540834

Document Management

This Discovery Phase Report (DPR) is the deliverable that documents the evidence review, the first draft of the standard, the method utilised to validate the first draft, and the findings and recommendations for the design of the consultation phase. This work also facilitates refinement of initial estimates and plans for approval to proceed.

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Version	Date	Summary of Changes
1.1	16.12.20	Initial draft
1.2	05.02.21	Minor updates following update of the information model (to v1.2)
1.3	22.02.21	Updates to About Me and General Guidance sections following discussion with the NHSX Personalised Care Team
2.0	08.04.21	Minor updates to language used
2.1	01.07.21	Guidance rearranged under sections and elements; formatting changes
2.2	29.07.21	Sections reordered and detail added following terminology and clinical review; prior to submission to NHS Digital Data Standards and Assurance Service
2.3	03.08.21	Significant updates made following clinical and terminology review and consultation with PRSB clinical leads.
2,4	21.09.21	Further updates made as a result of discussions with the Data Alliance Partnership Board (DAPB) team.
2.5	22.09.21	Changes made to remove the term ‘safety’ from the Contingency Plans section and update wording.
2.6	27.09.21	Minor edits to the ‘Glossary of Care Planning terms’ section based on terminologist feedback
2.7	28.10.21	Minor addition to general guidance section following DAPB review
2.8	20.12.21	Formatting updates for web publication

Reviewers

This document must be reviewed by the following people:

Reviewer name	Title / Responsibility
Assurance Committee	PRSB Assurance Committee
Misha Imtiaz	NHS England/Improvement Digital Mental Health Team - SRO
Lorraine Foley	PRSB CEO
Martin Orton	PRSB, Director of Delivery & Development
Helene Feger	PRSB, Director of Strategy, Communications and Engagement
Project Board	Project Board

Glossary of terms

Term / Abbreviation	What it stands for
API	Application Program Interface
C4CC	Coalition for Collaborative Care
CCG	Clinical Commissioning Group
CIS	Core Information Standard
CMH	Community Mental Health
COPD	Chronic Obstructive Pulmonary Disease
CQC	Care Quality Commission
CSP	Care and Support Plan
DCSP	Digital Care and Support Plan
DPR	Discovery Phase Report
EHR	Electronic Health Record
EI	Early Implementer
EIP	Early intervention in Psychosis
FHIR	Fast Healthcare Interoperability Resources
FYFVMH	Five Year Forward View Mental Health
IAPT	Improving Access to Psychological Therapies
ICS	Integrated Care System
IDCR	Integrated Digital Care Record
IPS	Individual Placement and Support
ISCR	Integrated Shared Care Record
LHCR	Local Health Care Record
LTP	Long Term Plan
MDT	Multi-Disciplinary Team

Term / Abbreviation	What it stands for
MHSDS	Mental Health Services Data Set
NEL	North East London
NICE	National Institute for Clinical Excellence
NWL	North West London
PCN	Primary Care Network
PCSP	Personalised Care and Support Plan
PID	Project Initiation Document
PKB	Patients Know Best
PRSB	Professional Record Standards Body
SALT	Short and Long Term services
SMI	Serious Mental Illnesses
STP	Sustainability and Transformation Programme
VCSE	Voluntary, Community and Social Enterprise

Contents

1 Introduction

1.1 Purpose of this document

This document provides implementation guidance to inform those implementing the personalised care and support plan. This guidance was developed on the basis of extensive consultation described in the final project report (see https://theprsb.org/standards/personalisedcareandsupportplan/). However, it will be refined and updated regularly as it is anticipated that there will be further findings and feedback as the section is implemented in practice. The standard was developed alongside colleagues at NHS England (see https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/).

This document sets out the processes involved in creating and maintaining personalised care and support plans for adults. The information model for this standard has been updated iteratively since the first version in 2018 (previously entitled Digital Care and Support plan standard).

The most recent project to update the standard was carried out in 2021 alongside NHS England, focussing on the use case of adults in the community with severe and enduring mental illness to enhance the standard model and guidance. For more detail on that project please see Appendix A.

1.2 Audience – who is this document for?

This guidance is intended for anyone implementing or using the personalised care and support plan standard. This will include project teams (including clinicians, other care professionals people who use services) involved in building systems and system suppliers. The standard is for use across all care settings across the health and care system.

1.3 Scope

While in many cases a person's GP or carer will complete the personalised care and support plan, the standard is intended for use by all professions and care settings in the health (and social care) system. Once implemented, this should help care plans to be effectively shared between patients, carers and all the health and care professionals involved in that person's care.

1.4 How to use the Personalised Care and Support Plan standard

The documentation of the planning process is the personalised care and support plan. It is owned by the person and shared with others with appropriate consent. There should only be one active personalised care and support plan for a person using services. A person may have many plans throughout their lifetime, which should also be accessible. These should be developed starting with the About Me section, with the rest of the plan structured depending on the support or treatment the person is receiving. It is important to note that the personalised care and support plan must be used alongside information in a person's shared care record to be effective (see following section).

Supporting actions may be added by other professionals but should not override the care planning process and instead support the person the care and support plan is owned by. Care and support planning is a defined process which helps people set their own aims, and objectives. It helps to identify their strengths and assets, and the support that they need to achieve them.

The personalised care and support plan should demonstrate how the person's aims and goals will be met and who is responsible for delivery of the activities to reach them

A person may accumulate multiple **specialist care plans** as the complexity of their health needs increases with time.

These plans may help other people involved in a person's care to work in a co-ordinated way and may document detailed specialist input, however it is important to note the overall plan needs to be visible to any care provider with the appropriate permissions, to avoid unsafe or practices contrary to prior decisions made by the person using services or professionals caring for them.

Specialist care plans are often focused on a specific condition or need and may be developed in consultation with an individual by a professional, service or team. They do not necessarily form part of the personalised care and support plan (PCSP) but should be directed by it and may inform it.

Contingency plans (also known as anticipatory care plans – see section 5 for a list of synonyms) are for those people who have specific and predictable risks associated with their health and wellbeing. They will include foreseeable triggers, actions and people to contact should the person's health or other circumstances get worse. They address circumstances when the care and support plan is disrupted. They are not the same as the care and support plan but should be informed by it. They are distinct from and more specific than advance care plans, which typically may include more details around end of life including for example, CPR decisions. Future iterations of the standard may include advanced care planning information.

A record to support care coordination. Detailed care records may need to be shared between health and social care to support some individuals requiring multi-agency support. They are used to coordinate care and may include plans and schedules of care, and detailed care records.

An **End of Life Care Plan** will only be required when a person is in the later stages of illness and where there is an identified need for one. It includes information related to wishes and views about end of life care, including preferred place of care, as well as the individual's views about any interventions, treatments and whether or not cardiopulmonary resuscitation is appropriate or wanted.

A person may also appoint someone to be a lasting power of attorney for health and welfare to make decisions on their behalf should they lack capacity. This would be recorded in Legal Information section of the shared care record

The personalised care and support plan is a digital record which is intended to be used to support a person's care rather than individual service or specialist professional's needs. The record should be available across disciplines and different providers. It should support integrated communication and care packages so that referrals between different professionals can be mapped and any advice, recommendations or treatment plans can be supported by all those who see the individual.

The personalised care and support plan includes the person's priorities at the time and is a detailed record of the person's care needs. It should not be confused with the person's shared care record (also known as 'integrated digital care record'; defined by the PRSB core information standard) which will hold the demographic and other care delivery information (see section 1.6 below).

1.5 Personalised care and support plans and a person's shared health and care record

As people receive more of their health and care from a range of professionals working in the community and care becomes more integrated, the record of a person's health and care also needs to become more joined up. Shared care records provide that joined-up view of a person's health and care. Integrated Care Systems and Integrated Care Providers from Autumn 2021 will need to have shared care records in place for the people who live and use services in their area.

Professionals and patients consulted on within this project agreed that other information is essential to inform the care planning process from a person's shared care record (for example, legal information, assessments, and a record of medications and medical devices). PRSB has defined the key information for shared care records to support integrated care, which was commissioned by NHS England and NHS Improvement. The Core Information Standard forms the basis of shared care records and defines the information that may be shared depending on a person's needs, wishes and circumstances. Shared care records are being implemented nationally by Integrated Care Systems and Integrated Care Providers, which are joining up health and care locally. The Core Information Standard will ensure that information can be shared between IT systems so that a person's care information is available when and where it is needed.

The information in a shared care record typically includes medications, allergies, diagnoses (for example any follow up required as a result of the annual physical health check), tests and so on and it is available to health and care professionals on a 'need to know' basis only.

A person's care and support plan is part of their shared health & care record and contains any contingency plans, and any additional supporting care plans the person may have.

The shared health & care record, defined by the core information standard, includes information that may or may not be relevant to a care plan (see 'Related Standards' section below for more detail)

Relevant health & care information is essential for care planning, for example information around assessments and diagnoses: A care plan can't be created/updated without being aware of this information. This information may also be used for non-care planning purposes.

Information that is **unique/specific to care plans:** Creating a care plan creates this information, which includes goals, needs, activities and outcomes.

1.6 Related Standards

International standards are essential to be adopted where possible and extended where necessary for national and local requirements to extend or clarify them, whether for linguistic or more specific requirements identified in a relevant area. Proper implementation of this standard is dependent on the following related standards:

- the national and local Information Governance Frameworks which will determine information access and sharing controls and legitimate relationships between health and care provider organisations
- technical messaging standards e.g. FHIR profiles (to support the transfer of information between local health and care systems)
- SNOMED CT is mandated as a standardised terminology for health and social care - within the NHS as of April 2020. For more details, see DCB0034.
- local data sharing agreements between health and care provider organisations
- definition and implementation of local processes and technology for the creation and update of information in the care plan by an individual (or person supporting them).
- The Core information standard. Various core sections in a person's shared care record, defined by the Core information standard currently being implemented across the UK, are

deemed as being important contextual information needed for the care planning process and so should be accessible. Including (but not limited to) information under the following sections:

- Individual Requirements
- Legal Information
- Risks
- End of life care
- Social Context
- Diagnoses
- Problems List
- Medication and Medical Devices
- Investigation Results
- Allergies and Adverse Reactions
- Examination findings
- Procedures and Therapies
- Alerts
- Safeguarding
- Services and Care
- Pregnancy status
- Assessments > Structured Assessments (that are relevant to the use case)
- Plan and requested actions
- Documents

1.7 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 when planning implementation.

Consideration needs to be given to confidentiality where information is shared in multimedia files (as videos, audio or pictures) as viewing or listening to the files could result in confidentiality breaches if accessed in busy workplaces.

1.8 Context and provenance of the information

It is important that the recording professional is confident that the information being recorded is the latest version and a single source of the truth when using the information to make decisions about the care and support they provide. There is a risk that individuals could record information in (e.g.) the About Me section in different settings that are slightly different unless it is recorded and managed within a shared record. The latest version must be made available to professionals with a need to access it with an indication of when it was recorded or updated and by whom.

1.9 Time stamp and audit trail

Each record entry must be time stamped from the source system with date and time recorded and the identity of the person making or changing the record. This is in addition to recording whether the individual was able to record the information themselves or whether they needed support to write the information. 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.

1.10 Data Quality

Data quality and accuracy of information entered, particularly when it includes clinical information, should be considered by the professional when reviewing the information in the (eg) About Me section and compared with, where possible, information held elsewhere in the person's electronic record. Data quality and accuracy of coded data entry should be managed in local 'source' systems that will feed the shared core information.

Data quality should adhere to best practice and allow corrections of erroneous data conforming to GDPR principles and the Data Protection Act. The accuracy of record keeping, including correct use of terminology and completeness of records, is essential to maximise data quality.

1.11 SNOMED CT (Systematised Nomenclature of Medicine - Clinical Terms)

NHS Digital is using SNOMED CT coding where appropriate in this standard. Where this is not appropriate, national coding from the NHS Data Model and Dictionary has been used. The recording supplier system must be compliant with the SNOMED CT codes set out within the Personalised care and support plan information model. Compliancy is based on the scope of the standard SNOMED CT SCCI0034 (http://www.digital.nhs.uk/isce/publication/scci0034).

Further information on SNOMED CT, including mapping to and from other clinical terminologies, can be found in the SNOMED CT Editorial Guide (https://confluence.ihtsdotools.org/display/DOCEG/SNOMED+CT+Editorial+Guide).

1.12 Accessibility

Attention must be paid in the design of user interface for recording and viewing the personalised care and support plan 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, including choice of language, preferred communication method as well as technical enablers (e.g. W3C conformance).

1.13 Responsibility

The professional responsible for care coordination for a person is important, however the person facilitating the update of the care plan is responsible for the care plan. This is recorded under the elements 'person completing record'; 'responsibility for review' in the personalised care plan. This section may also link to 'Professional Contacts' section in a person's shared care record.

2 General Guidance: Using the Personalised Care and Support Plan standard

2.1.1 Personalised care and support planning is part of planned systematic care and support. It should be possible for a care and support plan to be created at any time, but once in place it will need to be subject to regular reviews as part of a planned process.

2.1.2 It should also be possible for a care professional from any care setting (primary, secondary, mental health, community, social care), as well as family/carers to support an person in creating a care and support plan.

2.1.3 Personalised care and support plans should be created in a collaborative way with the person using services. Note that this would not override a duty of care (e.g. end of life care and associated plans).

2.1.4 It should be possible for a personalised care and support plan to be recorded by an person and/or a health or care professional.

2.1.5 Where a care and support plan has been created, the person may wish to notify others of its existence. There are various ways in which this could be done (for example the National Record Locator (NRL) service could be used to make this available), and this functionality is out of scope of this standard.

2.1.6 The person and health and care professionals from any care setting who are involved in the person's care and support should be able to view a person's care and support plan online, subject to the person's consent.

2.1.7 It should be possible to have multiple ways to view the personalised care and support plan, by including or excluding particular details. This should depend on who is accessing the PCSP and the information that is most relevant to them, e.g. it may be more important for ambulance services to see the contingency plan over the care and support plan section. It should be possible to filter information by need/problem and by service.

2.1.8 It should be possible to view and update the personalised care and support plan in an integrated system in real time when there is an interaction/conversation with the person or when the person wants to update it.

2.1.9 The personalised care and support plan, once properly integrated in systems, will be reviewed as a whole at a regular, scheduled review meeting with the person or their legitimate representative

2.1.10 When a personalised care and support plan is updated in an integrated system it should be saved as a new version, but the previous versions must be retained as part of the person's care record. The person updating it should be identified and the date/time of the update.

2.1.11 The personalised care and support plan may be ended when, for example, the plan is no longer applicable, the person wants it to be ended or if the person is deceased.

2.1.12 In all of these cases the plan should be made dormant or inactive, i.e. no further updates can be made, but the care and support plan should be retained as part of the person's record.

2.1.13 When a care and support plan is ended, all those involved in the person's health and care should be notified.

2.1.14 SNOMED-CT should be used for clinical concepts as the agreed national standard.

3 Information Model Content

The personalised care and support plan sections and elements are as follows (please refer to the PCSP web page on the PRSB website for the full information model):

Section Name	Description
About Me	This is a record of the things that a person feels it is important to communicate about their needs, strengths, values, concerns and preferences to others providing support and care.
Care and Support Plan	This records the decisions reached during conversation between the individual and health and care professional about future plans and also records progress
Formulation	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.
Contingency Plans	These are the things to do and people to contact should an individual's health or other circumstances get worse.
Additional Supporting Plans	An embedded record of any additional care plans which the individual and/or care professional consider should be shared with others providing care and support.
Personal Contacts	The details of the individual's personal contacts.
Professional Contacts	The details of the person's professional contacts.
NB: Care and support plans and contingency plans are known by other terms depending on specialty and implementations – please see section 5 for a non-exhaustive example list of commonly used alternative terms to support local mapping to the structures defined for a core care and support plan.	

This guidance will include specific information around use of the 'About Me' section, which while it may 'sit' within a person's shared care record as opposed to within the personalised (digital) care and support plan, it has been identified as essential information in the care planning process.

4 Section specific guidance

4.1 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.

4.1.1 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.

4.1.2 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.

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

4.2 Person Demographics > Sex and Gender

4.2.1 The definitions used for sex and gender use the NHS data dictionary definitions to ensure interoperability with other systems. However, we recognise that the definitions used do not reflect today’s more inclusive society. We have provided feedback on this to NHS data dictionary team in NHS Digital who are actively addressing this area, and any updates to the NHS data dictionary will update our standards.

4.2.2 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

4.2.3 Section 22 of the Gender Reassignment Act 2004 makes it an offence to disclose the history of a transgender patient who has had formal gender reassignment under the Act, unless consent has been sought. The exemption of disclosure is for medical professionals involved in direct medical care, but not currently for administrative and non-medical staff. For the full Act, see https://www.legislation.gov.uk/ukpga/2004/7/contents.

4.2.4 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. A further mitigation on implementation could be to record self-expressed gender in the administrative area of systems, and record sex at birth in a separate clinical area, that can only be accessed by medical staff.

4.3 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

4.3.1 ‘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.

4.3.2 Many people will not offer a named GP. Only the ‘GP practice details’ section would need to be completed in these situations

4.3.3 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.

4.3.4 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".

4.4 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. 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 to avoid duplication of information and resulting errors/incidents.

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.

It is critical that the provenance of information is maintained wherever the information is rendered. 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. Note that (for example) clinical and lay language may be different yet this would not be a difference/discrepancy.

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
- that the information is concise and important information or context is not lost.
- when multimedia is effective and ensure that videos are kept as short as possible (without losing important information or context).
- 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
- that the information has been understood and where information has not been filled in, it is because they have nothing to add to that element

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.

4.4.1 **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). Note that differentiation between what the person is able to do and actually does is important. For example with regards to exercise, is their exercise limited by joint pain or shortness of breath?)

- 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.

4.4.2 What it is not:

It is not:

- intended to be used for determining an individual's right to access social care or health services (without accessing other information).
- 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 personalised care and 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 and with the person using services' consent where possible. Anyone accessing the record must have a legal basis for doing so.
- 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)

4.4.3 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?

4.4.4 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)?

4.4.5 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?

4.4.6 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?

4.4.7 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.

It is essential that Information here is grouped under the subheadings ‘Please do’ and ‘Please don’t’ when entering into the record.

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?

4.4.8 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?

4.4.9 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 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.

4.5 Formulation

4.5.1 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.

4.5.2 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.

4.6 Care and Support Plan Section

4.6.1 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.

4.6.2 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.

4.6.3 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

4.6.4 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

4.6.5 **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’.

4.6.6 **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’

4.6.7 **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.

4.6.8 **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.

4.6.9 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).

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

4.6.11 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).

4.6.12 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.

4.6.13 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.

4.6.14 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.

4.6.15 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

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

4.6.2 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

4.6.3 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

4.6.4 This information should be automatically retrievable from the system.

4.7 Contingency plans

4.7.1 Contingency plans are known by many other terms depending on care setting and local implementations. Please see section 5 for a non-exhaustive list of alternative terms for the sections of the personalised care and support plan.

4.7.2 Not everyone who has a care and support plan will need a contingency plan (also known as e.g. crisis / emergency / escalation plans – see Section 5 below).

4.7.3 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.

4.7.4 There may be a number of different contingency 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.

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

4.7.6 Contingency plans must be subject to or as a result of an assessment.

4.7.7 Contingency 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.

4.7.8 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.

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

4.8 Additional supporting plans

4.8.1 It must be possible to hold additional supporting 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.

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

4.8.3 Additional supporting 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.

4.8.4 When an additional supporting 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.

4.8.5 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.

5 Glossary of care planning terms

A review of existing care and support plans in previous work has identified many different names for each section of the care and support plan. A non-exhaustive example list of these is included in the table below, to support local mapping to the structures defined for a core care and support plan. Please note that these are not intended to describe all options for SNOMED CT concepts reflecting care plan types. Where specific require representations are required for care plan types, these can be requested at https://isd.hscic.gov.uk/rsp-snomed.

Section	Alternative names
About me	○ This is me ○ All about me ○ What is essential to know about me ○ Person's Views (in their words) ○ About me and my life ○ About me in the context of my life ○ About my care ○ About my health and wellbeing ○ My care record ○ My health ○ My preferences ○ My story / my life ○ Things in my best interest ○ Things you should know about me ○ What I like ○ What is important to me and my health ○ What matters to me ○ What you need to know about me
Care and Support Plan	○ Action Plan ○ Care and Personal Support Plan ○ Care Delivery Plan ○ Care, Support And Treatment Plan ○ Health and Social Care Management Plan ○ Health and Wellbeing Care And Support Plan ○ Individual Support Plan ○ My Goals and Plans ○ My Plan of Care And Support ○ My Recovery Plan ○ Recovery Plan ○ Rehabilitation Plan
Goals	○ Goals of care ○ Goals, aspirations or wishes ○ What I want to achieve ○ Desired outcome

Actions	○ Activities ○ Proposed care and support
Outcomes	○ Meeting goals set ○ My desired outcomes ○ Review ○ What that looks like
Contingency plans	○ Anticipatory care plan ○ Back-up plan ○ Contingency steps ○ Emergency action plan ○ Emergency plan ○ Future planning or decisions ○ If all else fails ○ If something goes wrong ○ Just in case ○ My crisis care plan ○ Plan of action ○ Plans for an emergency ○ Plans for unforeseen events ○ Step up plan ○ Urgent Action Plan ○ What should happen if things go wrong ○ What to do if things are not going well ○ What to do if things get suddenly worse ○ What to do in an emergency
Trigger factors	○ What might go wrong
What should happen	○ Suggested actions
Anticipatory medicines/ equipment	○ What I might need

6 Appendices

Appendix A – Community mental health project (2021): Background and context

The NHS Long Term Plan set out the most ambitious re-design of mental health services that has ever been undertaken. The combination of new funding and a complete transformation of the way care is organised and delivered aims to prevent mental health problems where possible and help people earlier so that they have better experiences and outcomes of care and improved life chances.

These plans span care for women with pregnancy and birth-related mental health problems through to care for older people. An important part of these plans is improving access to high quality mental and physical health care for the 370,000 adults in the United Kingdom with severe mental illnesses who live in the community. This includes giving people with specific needs greater choice and control over their care – such as dedicated services for adults with eating disorders or a 'personality disorder' diagnosis.

The NHS announced a transformation fund to support this ambition: in 2019/20 and 2020/21, 12 localities are to receive over £70 million of additional funds to test new models of integrated care and reduced four-week waiting times as part of the Clinically-led Review of NHS Access Standards.

Care planning is at the heart of these improvements and PRSB was asked by NHS England/Improvement's mental health team to test whether the Digital Care and Support Plan Standard, which PRSB published in 2018 (now called the personalised care and support plan), could be tested for use in community mental health care for people with severe and enduring mental health problems as an important use case. The Five Year Forward View Mental Health (FYFVMH) and Long Term Plan ambitions define Severe Mental Illnesses (SMI) as covering a range of needs and diagnoses, including but not limited to; psychosis, bipolar disorder, 'personality disorder' diagnosis, eating disorders, severe depression and mental health rehabilitation needs – some of which may be co-existing with other conditions such as frailty, cognitive impairment, neurodevelopmental conditions or substance use.

6.1 Scope of use

A care and support plan is relevant to anyone with a health condition requiring long-term ongoing personalised care and support.

It should be an integral part of an individual's integrated health and care record and include relevant information e.g. personal demographics, relevant contacts, etc. without the need of duplicating those in the content of the personalised care and support plan.

Other information from the individual's care record may be needed to inform and monitor the integrated care and support plan such as medications, allergies, test results etc. These have not been included in the care and support plan as they would be part of the wider record.

The information in the care plan forms part of a shared care record – therefore it could be seen by any authorised person caring for or supporting the individual (where there is a legal basis for accessing the information) which could, for example, be nurses or consultants in the A&E department and inpatient areas, the individual's GP, care home staff, allied health professionals, social workers, ambulance staff or home care staff. Who can access the information is determined by the legal framework governing the use of personal confidential data in health care and by national (e.g. National Record Locator service) and local data sharing agreements. These are not addressed in this document.

The scope of the Community Mental Health project undertaken in 2020/21 excluded the following (although these issues may be addressed in future):

- Clinical safety assessments are out of scope and covered by DCB0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems - NHS Digital and DCB0160: Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems - NHS Digital. In addition specific guidance on the use of SNOMED CT in health and social care is within SCCI0034: SNOMED CT - NHS Digital
- Standards for use case or condition specific care plan content e.g. diabetes or end of life care. These specialist plans would be recorded under the 'additional supporting plans' section of the information model.
- Care plans used by individual disciplines or services to manage specific aspects of care (e.g. hospital hip fracture care pathway or plan, district nursing wound management care plan).

- Financial assessments, personal budgets and allocation of resources.
- Care plans for children and young people.
- Development of (or changes to) supporting technical messages (FHIR profiles or APIs) where they do not already exist – this will be commissioned separately by NHS Digital as required and should include assurance through PRSB by clinical and professional informaticians as identified above.
- Support for piloting and implementation (this could be commissioned as a subsequent phase)
- Development of any additional supporting plan standards.