Professional
Record
Standards
Body

Better records
for better care

ABOUT ME

Implementation Guidance v 1.4

APRIL 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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Revision History

Version	Date	Summary of Changes
1.0	21/10/20	Approved version for publication
1.1	27/01/21	Updated following feedback from the Royal College of Nursing
1.2	11/03/21	Updated following feedback from the Royal College of Nursing
1.3	19/04/21	Updated following feedback from NHSE/I Personalised Care Team
1.4	20/04/21	Updated to incorporate minor change to information model agreed with Personalised Care Team & Citizen Advisor

Approved by

This document was approved by the following:

Name	Date	Version
Project Board	30/09/20	0.5
Assurance Committee	07/10/20	0.5

Glossary of Terms

Term / Abbreviation	What it stands for
A&E	Accident and Emergency
CCG	Clinical Commissioning Groups
CIO	Chief Information Officer
CRO	Clinical Responsible Officer
DCB	Data Coordination Board
EPR	Electronic Patient Record
FHIR	Fast Healthcare Interoperability Resources
GP	General Practitioner
NHS	National Health Service
PRSB	Professional Record Standards Body
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms

Planned Review Data and Route for User Feedback

Planned Review Date and Route for User Feedback The next maintenance review of this document is planned for October 2023, subject to agreement with NHS Digital as the commissioning body. Please direct any comments or enquiries related to the project report and implementation of the standards to support@theprsb.org.

Contents

1 Introduction

1.1 Purpose of this document

This document provides guidance to support the implementation of the About Me section within the Core Information Standard or other standards that use it (e.g. the Digital Care and Support plan and Urgent Referral from Care Home to Hospital standard). The document is for people involved in developing, deploying and using systems that exchange information pertaining to health and care. It provides general guidance as well as guidance for each specific part of the About Me section.

PRSB has carried out a clinical safety review in accordance with DCB0129, which is detailed in the Clinical Safety Case and accompanying Hazard log. This guidance should be used in conjunction with the hazard log and clinical safety case report. This is further discussed under section 2.4 Risk Mitigation.

This document should be read alongside the implementation guidance for standards in which the About Me section is being implemented e.g. the Core Information Standard.

1.2 Background

NHS Digital is delivering the Social Care Pathfinder programme; funding 16 local programmes to implement innovative technology and information solutions to improve sharing of information between social care and health care. The local programmes will deliver national outputs to wide-spread national adoption. The outputs include the development of new, or changes to existing, information standards and the Professional Record Standards Body has been commissioned to support this.

One of the areas identified as requiring potential changes that is used in existing standards (including the Core Information Standard (CIS) which is a standard for a shared care record and the Digital Care and Support Plan) was the About Me section.

This section is for individuals to be able to share important information about themselves with others who support or care for them to enable person-centred care and support. This may be different from the information that a professional may record about a person as it is what the individual wants to share and it will be what is important to them. It will only be shared with people who have a legitimate legal basis for accessing the information. It can include anything the individual wants to share including their needs, strengths, values, concerns, wishes and preferences.

In the Digital Care and Support Plan the About Me section was a single element, allowing free text and multimedia files, and there has been an on-going debate about whether adding more structure (adding the ability to capture different sub-categories of information) would enable relevant information to be more easily located by those that need to access it and help individuals to determine what information about themselves they should share.

The consultation on the About Me section has resulted in the addition of sub-categories (elements). The changes to the About Me section will be applied to the Core Information Standard as part of this work resulting in an uplift to the standard. It is also used in the new standards developed as part of this programme of work, urgent referral from care home to hospital and referral from hospital to Local Authority.

The Core Information Standard (including the About Me section), described in this document and related documents can be found on the PRSB website, informs the technical specifications to be commissioned by NHSX and deployed within local implementations to ensure the information defined by the standard can be shared digitally.

1.3 Implementation guidance development and updating process

This guidance was developed on the basis of extensive consultation described in the final project report. 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.

1.4 Audience – who is this document for?

This guidance is intended for anyone implementing or using the About Me section (within any of the PRSB standards that use the section). This will include project teams (including clinicians, other care professionals and people who use services) involved in building systems and system suppliers.

1.5 Definition and scope of the About Me section

The section defines a set of sub-categories of information that an individual can use to help them to determine what important information about their needs, values and wishes to share with people supporting and caring for them. It should also enable people accessing the information to more easily locate the key information they need.

This information can be shared either as part of a transfer of care (e.g. when a care home resident is transferred into hospital in an emergency) or as 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 local data sharing agreements. These are not addressed in this document.

1.5.1 **What it is:**

About Me 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.

1.5.2 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)

2 General guidance

This section describes general principles and rules covering the About Me section in its entirety.

The About Me section is a set of information sub-categories (elements) making up an About Me record. This section is included in a number of existing PRSB standards including the Core Information Standard. An individual can choose to record any information in some or all of the elements. Equally they can choose not to record any information at all.

It has been designed as a generic section, not for specific use cases. The expectation is that use cases will be prioritised locally and the ability to capture and share About Me information will be built into systems and processes aligned with these use cases.

The About Me section is a set of related elements with dependencies. The record entry within the section is used to indicate that elements are related to one another.

Each element, record entry and section will have a statement of cardinality, whether there can be zero, one or many entries. They also have a statement of conformance - whether the item is ‘Mandatory’, ‘Required’ or ‘Optional’. An explanation of the meaning of these terms appears in the table below (in section 2.1).

The About Me section is set to ‘Required’. This means if information exists in the About Me section in an individual’s health and care record, it must be shared. All the elements within the About Me section are also set to ‘Required’.

2.1 Structure of the PRSB standards explained

An information standard is organised into sections made up of several data (information) elements, with record entries and clusters (subsections) to support repeated sets of information and grouping of related items.

The set of rules and instructions governing the type of information expected within a section, cluster, record entry and element and how it is communicated is defined in the information model under the headings Description, Cardinality and Conformance.

The PRSB information model structure and rules are explained in Table 1 and the annotated example below.

Information Components	Model Description
Section	A section groups together all the information related to a specific topic e.g., 'Medications and medical devices' and 'Person Demographics'. It is the highest level to logically group data elements that may be independent or related. For example: - 'Legal information' includes a set of independent elements or information items, grouped in a logical section. - 'Medications and medical devices' include sets of related elements with dependencies between the elements.
Record entry	A record entry within a section is used where a set of information is repeated for a particular item, and there can be multiple items. For example, for each medication there is a set of information associated with that medication. Other examples are allergies or adverse reactions and procedures.
Cluster	This is a set of elements put together as a group and which relate to each other; e.g., medication course details cluster which is the set of elements describing the course of the medication.
Element	The data item. An element can appear in one or more sections e.g., name, date.
Information model rules and instructions	**Explanations**
Description	This is the description of the section, record entry, cluster or element. For an element, it describes the information that the element should contain in as plain English as possible.
Cardinality	Each section, record entry, cluster and element will have a statement of cardinality. This clarifies how many entries can be made i.e., zero, one or many entries. The number of records expected and allowed are displayed as: 0……* = zero to many record entries are allowed 0……1 = zero to one record entry is allowed

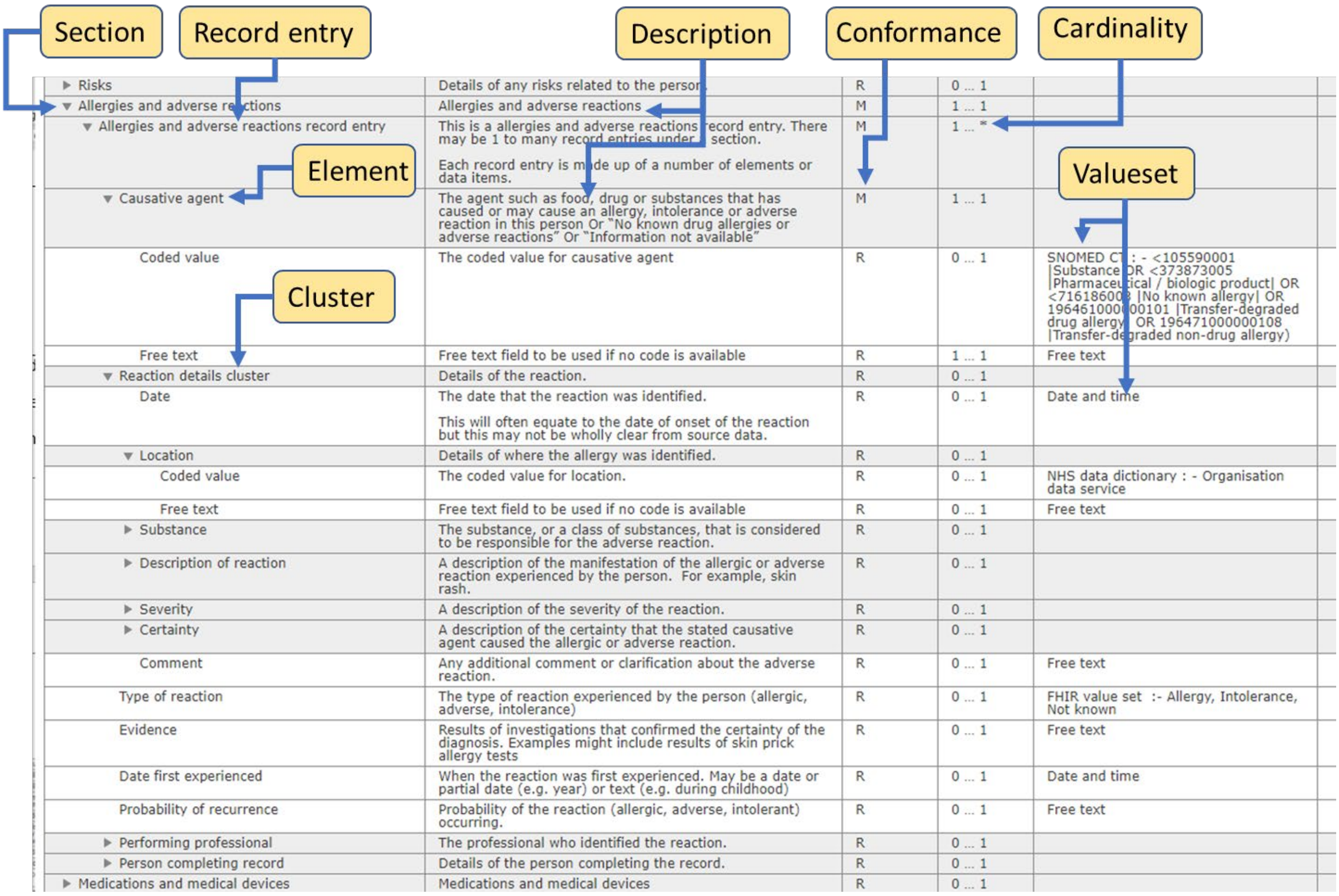
	1……1 = one record is expected 1……* = one to many records are expected For example, the ‘Medications and medical devices’ section may have zero to many medication item records in it and is displayed as 0…… *.
Conformance	Conformance defines what information is ‘mandatory’, ‘required’ or ‘optional’ and applies to sections, record entries, clusters and elements. The IT system must be developed to handle all the information elements that are defined in the Standard but not all the information is required for every individual record or information transfer. The following set of rules apply to enable implementers to cater for the end users (senders and receivers) requirements: • Mandatory – the information must be included • Required – if it exists, the information must be included • Optional – a local decision is made as to whether the information is included These rules apply at all levels and give the flexibility to allow local clinical or professional decisions on some information that is included, while being clear on what is important information to include. For example, a person subject to a referral may have many assessments, but not all of these will be relevant to the referral. The conformance can be used to allow just relevant assessments to be included. Assessment Section – Required – i.e. its important information you must include if you have it. Record entry level – Optional – allows a local decision on what assessments are included, so only relevant ones are included based on clinical or professional needs. Assessment elements – Conformance set on the normal basis of which elements for an assessment are mandatory, required or optional. **NB:** It is permitted to upgrade a conformance rule but not to down grade one. For instance, a section that is classed as optional in the standard can be upgraded to required or mandatory in local implementations. However, one that is classed mandatory or required cannot be downgraded to required or optional.

Valuesets	Valuesets describe precisely how the information is recorded in the system and communicated between systems. This is required for interoperability (for information to flow between one IT system and another). The information can be text, multi-media or in a coded format. If coded it can be constrained to SNOMED CT and specific SNOMED CT reference sets, NHS Data Dictionary values or other code sets.

Table 1: PRSB information standard data structure

In the annotated example shown below for Allergies:

- The Core Information Standard has a section for 'Allergies and adverse reactions', it's conformance is 'mandatory' and the cardinality is '1 only' (or 1...1) i.e., there must be just one allergies section
- It has a record entry to allow for multiple allergies, which is also 'mandatory' but with a cardinality of 1 to many (or 1...*). The record entry contains a set of elements, i.e., the set of information for each allergy and there must be at least 1 record entry.
- The record entry also includes a cluster (reaction details cluster), which groups the reaction details together.
- Each element has a description, conformance, cardinality and valueset. e.g., Causative agent, which is mandatory with a cardinality of 1 only (or 1…1) and a valueset with two options, coded value with a constrained set of SNOMED codes (including an option for "No known allergy") or free text if coded values are not available. Other elements are required in this example. i.e., the set of information for each allergy or adverse reaction must have a causative agent, and where available should have the other information such as reaction details, substance, severity etc.



▶ Risks	Details of any risks related to the person	R	0 ... 1	
▼ Allergies and adverse reactions	Allergies and adverse reactions	M	1 ... 1	
▼ Allergies and adverse reactions record entry	This is a allergies and adverse reactions record entry. There may be 1 to many record entries under [illegible] section. Each record entry is made up of a number of elements or data items.	M	1 ... *	
▼ Causative agent	The agent such as food, drug or substances that has caused or may cause an allergy, intolerance or adverse reaction in this person Or "No known drug allergies or adverse reactions" Or "Information not available"	M	1 ... 1	
Coded value	The coded value for causative agent	R	0 ... 1	SNOMED CT : - <105590001 |Substance OR <373873005 |Pharmaceutical / biologic product| OR <71618600[illegible] |No known allergy| OR 196461000[illegible]00101 |Transfer-degraded drug allergy OR 196471000000108 |Transfer-degraded non-drug allergy)
Free text	Free text field to be used if no code is available	R	1 ... 1	Free text
▼ Reaction details cluster	Details of the reaction.	R	0 ... 1	
Date	The date that the reaction was identified. This will often equate to the date of onset of the reaction but this may not be wholly clear from source data.	R	0 ... 1	Date and time
▼ Location	Details of where the allergy was identified.	R	0 ... 1	
Coded value	The coded value for location.	R	0 ... 1	NHS data dictionary : - Organisation data service
Free text	Free text field to be used if no code is available	R	0 ... 1	Free text
▶ Substance	The substance, or a class of substances, that is considered to be responsible for the adverse reaction.	R	0 ... 1	
▶ Description of reaction	A description of the manifestation of the allergic or adverse reaction experienced by the person. For example, skin rash.	R	0 ... 1	
▶ Severity	A description of the severity of the reaction.	R	0 ... 1	
▶ Certainty	A description of the certainty that the stated causative agent caused the allergic or adverse reaction.	R	0 ... 1	
Comment	Any additional comment or clarification about the adverse reaction.	R	0 ... 1	Free text
Type of reaction	The type of reaction experienced by the person (allergic, adverse, intolerance)	R	0 ... 1	FHIR value set :- Allergy, Intolerance, Not known
Evidence	Results of investigations that confirmed the certainty of the diagnosis. Examples might include results of skin prick allergy tests	R	0 ... 1	Free text
Date first experienced	When the reaction was first experienced. May be a date or partial date (e.g. year) or text (e.g. during childhood)	R	0 ... 1	Date and time
Probability of recurrence	Probability of the reaction (allergic, adverse, intolerant) occurring.	R	0 ... 1	Free text
▶ Performing professional	The professional who identified the reaction.	R	0 ... 1	
▶ Person completing record	Details of the person completing the record.	R	0 ... 1	
▶ Medications and medical devices	Medications and medical devices	R	0 ... 1	

2.2 How we expect the About Me section to be used

The expectation is that this information would be written or recorded by an individual (or someone supporting them) in an electronic record for that individual. How the information is recorded and added to the electronic record is for local determination.

The information in the About Me section should be prominent and one of the first sections viewed in a health and care record as it includes important information about the person relevant to all care and support providers. Ideally this information is also available in a multimedia format e.g., video, particularly when a person has difficulties expressing themselves.

The information in the About Me section should sit alongside other information entered by health and social care professionals such as medications and allergies to enable the information to be cross-checked.

Local implementations will need to define how and where the information is displayed.

It should be possible for the individual to update the information as it changes or when they need to record new information. A record of the changes that were made and when they were made should be captured.

It is recommended that About Me information is reviewed and updated at key transition points for example for children and young people with Education, Health and Care (EHC) plans when transitioning from primary to secondary school, moving onto college and whenever their home circumstances change (for example moving into supported living or residential care). The transition process from children's social care to adult's social care is also a recommended time for reviewing and updating About Me information. For adults, it should be reviewed and updated at planned reviews or when requested by the individual.

It is the intention that everyone should be able to record About Me information however local implementers may want to identify population groups for which the ability to record and share this type of information would deliver most benefit and start with those groups for example children and young people accessing children and adolescent mental health services (CAMHS), children and young people with an EHC plan, older people in care homes, people living with long term conditions and individuals receiving support from children's and adult's social care.

The information in the About Me section is intended to be used to support direct care and not to assess an individual's right to receive care or support.

2.3 Dependencies

The implementation of the About Me section is dependent on the following:

- 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)
- 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 About Me section by an individual (or person supporting them)

2.4 Risk Mitigation

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

2.5 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.

2.6 Context and provenance of the information

It is important that the professional is confident that the information in the About Me section 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 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.

Consideration should also be given to how information in the About Me section is updated by the individual. There is a risk that it can get out-of-date and not updated, particularly if it involves multimedia files. When one element (sub-category) within the About Me section is updated, the user should be prompted to check that information in the other elements (sub-categories) are up-to-date.

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.

2.7 Time stamp and audit trail

Each About Me 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.

2.8 History

It should be possible to store a history of applied changes and access previous versions of this information after any changes are made.

2.9 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 About Me section and compared with, where possible, information held elsewhere in the person's electronic record.

2.10 Accessibility

Attention must be paid in the design of user interface for recording and viewing the About Me 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.

3 Section specific guidance

3.1 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 could include information about 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. 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.

3.2 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 as 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?

3.3 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)?

3.4 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?

3.5 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, and 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?

3.6 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:

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

25. 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 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 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?

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

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

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

3.7 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:

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

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

3.8 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 PRSB support

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

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