



Professional
Record
Standards
Body

**Better records
for better care**

DIGITAL SOCIAL CARE INFORMATION:

Survey Results and Analysis v 1.0

**About Me, Care Homes View and Local
Authority Information**

OCTOBER 2020

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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1 Introduction

This is an appendix to the final report for the digital social care information project.

The online surveys were one part of the overall consultation approach in the development of the standards, after the detailed work on specific topic areas and national survey on the 5 areas of focus. We split the five topic areas over two surveys, and 820 people responded across the surveys. Feedback from the consultations prior to the survey's (webinars and a national survey) aided the design. The surveys were aimed at frontline care professionals, people who use services and their carers and systems suppliers.

The surveys were shared widely, to our advisory board representatives, key contacts, newsletter subscribers, those who attending our topic specific webinars and the NHS Digital [pathfinders](#) and their networks. The surveys were featured in a number of publications, on professional platforms such as Ryver and with other groups including the Care Provider Alliance representing up to 2 million working in domiciliary care and care homes, system suppliers and patient groups such as the Patient Information Forum representing 300+ charities.

This report focuses on the results of 'survey 1' which ran from 22nd June – 24th July 2020 and includes the results and analysis of the survey. The findings from the survey are described further in the final report.

In total 477 people participated in survey 1 (this includes those who responded to the easy read version of the survey which focused on About me information).

2 Respondents

The initial survey questions related to respondents. In this section, the following quantitative data relating to respondents is shown:

- Q1: The first question identified whether respondents were answering the survey on behalf of themselves (n = 381, 94.54 %) or supporting someone else to complete it (n = 22, 5.46 %).
- Q2: The second question identified the respondents who worked in health or social care (n = 336, 83.33%) or did not (n = 67, 16.66 %).
- Q3: The third question identified the 403 respondents' roles and the settings in which they work, which is shown in table 1 below.
- Q4: The fourth question identified, from the 336 respondents who work in health and social care services, the area in which they work most regularly; which is shown in table 2 below.
- Q5: The fifth question identified, from the 336 respondents who work in health and social care services, the setting in which they work most regularly (See table 3 below).

Participants	Percentage (n)
Secondary care doctors	1.74 % (7)
Nurse	4.22 % (17)
NHS administration and management	5.46 % (22)
Service users and informal carers	10.42 % (42)
Care assistant / support worker / team leader	4.96 % (20)
Care home management	15.14 % (61)
Social services administration / management	6.45 % (26)
Allied Health Professionals	9.43 % (38)
Social worker	6.95 % (28)
GP	2.23 % (9)
Health or social care IT systems supplier	4.47 % (18)
Midwife	0.25 % (1)
Other	20.84 % (84)
Healthcare assistant	0.50 % (2)
Volunteer	3.23 % (13)
Pharmacist	1.99 % (8)
Directors of social care	1.74 % (7)

Table 1: Roles of survey respondents

What area do you work in?	Percentage (n)
Care of older people	27.98 % (94)
Other	26.19 % (88)
General medical services	2.98 % (10)
Frailty	0.60 % (2)
Community services	8.93 % (30)
Learning disabilities	14.58 % (49)
Long term conditions	2.38 % (8)
End of life	1.49 % (5)
Dementia	1.79 % (6)
Emergency Care	1.19 % (4)
Mental Health	5.95 % (20)
Acute care	1.79 % (6)
Physical disabilities	2.68 % (9)
Adult's nursing	0.30 % (1)
Other nursing (including children's nurse)	0.30% (1)
Rehabilitation	0.89 % (3)

(Specific areas identified in the 'Other' category included: Digital and Information Systems, Adult Social Care, Community Pharmacy, Information and Systems for Adult Care, Quality Team in CCG, Addiction, Education, Cancer care, Advice Services, Midwifery, Frailty, Dementia, Emergency Care, Long Term Conditions, Care of the Elderly, Reablement Occupational Therapy, Telephone Triage, Home Visiting Service, Domestic violence/abuse Research, Learning disabilities. ASD (Autistic Spectrum Disorder) , PD (Personality Disorder), Mental Health Complex Needs, Commissioning, Healthwatch, Local Councillor and Chair of Health Scrutiny Committee, Health Informatician, Neonatal Care, Paediatrics, Hospital discharge and flow, PPG (Patient Participation Group)).

Table 2: Area worked in by professional respondents

What setting do you work in?	Percentage (n)
Acute hospital	5.36 % (18)
Other	16.07 % (54)
Local authority	23.21 % (78)
Community care	13.39 % (45)
CCG, national NHS or social care body	5.65 % (19)
Primary care	5.36 % (18)
Care home with nursing	5.06 % (17)
Care home without nursing	14.29 % (48)
In a person's home	4.76 % (16)
Specialist centre	2.08 % (7)
Urgent and emergency care	1.79 % (6)
Ambulance	0.00 % (0)
111	0.30 % (1)
Assisted living	1.49 % (5)
Mental health / learning disability hospital	0.30 % (1)
Hospice	0.89 % (3)

Table 3: Setting worked in by professional respondents

3 Question Analysis

Each question is shown in the following section together with quantitative statistics and key themes that emerged from qualitative analysis of the comments (where provided) and (where appropriate) where / how the comment was addressed in the Standard, Implementation Guidance, or Clinical Safety Case.

3.1 Questions relating to the Care homes view (answered by care home staff only)

3.1.1 Q6: Please indicate how important it is for you to be able to access the information below when caring for or supporting a resident?

Section	Percentage (n)
Professional contacts	97.96 % (48)
Personal contacts	95.92 % (47)
About me	85.41 % (41)
GP details	91.84 % (45)
Individual requirements	97.96 % (48)
Reasonable adjustments	87.50 % (42)
Impairments	93.88 % (46)
Mental capacity assessment (Legal information)	93.88 % (46)
Lasting power of attorney (Legal information)	81.64 % (40)
Deprivation of liberty safeguards (Legal information)	87.76 % (43)
Mental health act or equivalent status (legal information)	87.76 % (43)
Organ and tissue donation (legal information)	65.31 % (32)
Safeguarding	95.91 % (47)
Care and support plan	97.91 % (47)
Contingency plans	95.92 % (47)
Additional support plans	97.87 % (46)
Referral information	83.34 % (40)
Contact with professionals	91.49 % (43)
Admission details	91.67 % (44)
Discharge details	91.67 % (44)
Future appointments	85.42 % (41)

Alerts	89.58 % (43)
Risks	97.92 % (47)
Medications and medical devices	95.83 % (46)
Allergies and adverse reactions	91.67 % (44)
End of life care	97.92 % (47)
Investigations required	85.42 % (41)
Investigations results	87.50 % (42)
Examination findings	85.42 % (41)
Assessments	91.67 % (44)
Documents	93.75 % (45)

Table 4: Percentage of respondents (Care home staff only) who responded either ‘Important’ or ‘Very important’ to Question 6

Key Theme:

- In order to “provide the highest standards of care” it is “extremely important”/ “important” / “essential” for the care home to have access to as much information about the resident as possible, in order to provide a “safe” and “holistic” approach to care. Variants of this point of view were very well supported by care home managers / nominated individuals responsible for services in care homes. Key quote: “As the registered manager it is important to have oversight of all matters relating the needs of the individual to be able to plan and provide appropriate care”.

3.1.2 Q7: Is there any other information that would help you when caring for or supporting a resident?

- A majority of respondents (68.09 %, n = 32) recorded ‘No’.
- Approximately one third of respondents recorded ‘Yes’ (29.79 %, n = 14)

Key suggestions:

The suggestions given in response to question 7 were already contained within the care homes view or were appropriate for inclusion in existing sections. Suggestions included are below with the corresponding section in the Care homes view in parentheses:

- Activity Plan / National Activity Providers Association Activities (Care and support plan – Actions and activities), Interests (About Me), Hobbies (About Me), Likes and dislikes (About Me), Personal Preferences for Care (About Me, Care and support plan, End of Life), Resident Background History / Personal History / Life History (About Me), Individual and Person Centred Needs (Individual requirements, About Me, Care and Support Plan), Funding line (Care and support plan – Care funding source), DNACPR Orders (End of Life - Cardio-pulmonary resuscitation (CPR) decisions), IMCAs (Independent Mental Capacity Advocate)

(Professional Contacts), Sensory Assessments (Assessments), Psychology Reports (Documents).

3.1.3 Q8: What would be the benefits to you of having access to this information?

Key Themes:

- Suggested benefits included: “Effective working”, “Plan[ing] work”, “Better care”, “Confident clients”, “Timely” / “Appropriate” / “High standard of...person-centred care” plans / “activity planning”, “Improved professional relationships with residents”, “true holistic care”, “continuity of care”.
- Key quote (Nursing home setting): “We frequently are not included in blood results etc which is frustrating when we are looking after the person. We also do not get info from the hospital in a timely manner and this could potentially avoid those mishaps”.
- Key quote (Residential home setting): “...often key information is sent direct to GPs and not then disseminated to the care home meaning vital information is not included in their [the resident’s] care plan”.

3.1.4 Q9: Do you have any concerns about who has access to this information in a care home?

- A majority of respondents (72.82 %, n = 35) recorded ‘No’.
- Approximately one quarter of respondents recorded ‘Yes’ (27.08 %, n = 13)

Key concerns:

- Need to know basis: Information within the care home “would only be shared on a need to know basis”. This theme was supported by a wide variety of care home workers and was emphasised by care home managers / nominated individuals and allied health professionals.
- Security: Information within the care home should be “secure” – “All information [needs to be stored] either on a secure computer or locked away”.
- Role-based access: There was a significant belief that this should be achieved via appropriate role-based access control (RBAC) mechanisms. It was clear from the comments that there was a high expectation that this should only be done by the care home manager / nominated individual responsible for services:
- Key quotes (RBAC): “Info should be supplied to management to decipher who to provide info to within the care home”; “As only the registered manager (me) and those authorised by me would have access, I do not have concerns [about who has access to this information]”; “Permissions should be held with senior staff. Some entries may cause conflict therefore roles with extensive professionalism must be maintained”.
- Appropriate training: “People accessing info should have training about data protection that is relevant to their role and the setting” – See Core Information Standard (CIS) Clinical Safety Case (Hazard 15: ‘Consent for information sharing section may cause confusion’; Hazard 16: ‘Sex data item may cause accidental disclosure of gender reassignment without consent’; Hazard 19: ‘Risk of sharing confidential information inappropriately’); “[Staff] need to [be given] the relevant knowledge to understand [information in the record]” – See CIS Clinical Safety Case (Hazard 21: ‘Competent patient or their carer unable to understand information recorded in sections’).

3.2 Questions relating to the Care homes view (answered by health and social care professionals)

3.2.1 Q10: Please tell us who you think should see the following information:

	Registered practitioners only	All care home staff	Don't know
Risks	6.86%	92.00%	1.14%
Medications and medical devices	18.13%	79.67%	2.20%
Allergies and adverse reactions	2.72%	95.65%	1.63%
End of life care	12.57%	86.34%	1.09%
Investigations required	62.50%	35.33%	2.17%
Investigations results	61.96%	35.33%	2.72%
Examination findings	59.24%	38.59%	2.17%
Assessments	31.52%	64.67%	3.80%
Documents	36.61%	57.38%	6.01%

Table 5: Percentage (%) of respondents (care home staff and health professionals) who believe that a given section should be seen either by 'All care home staff' or 'Registered practitioners only'.

This question relates to the role-based access proposal for the care homes view that suggested the sections in table 5 above should only be seen by 'registered practitioners'.

It is clear from the data in table 5 that the RBAC proposal was strongly rejected by respondents for the following sections: Risks (92.00 % against), Medications and medical devices (79.67 % against), Allergies and adverse reactions (95.65% against), End of life care (86.34 % against). The RBAC proposal was also rejected by a slight majority for Assessments (64.67 % against) and Documents (57.38 % against). The RBAC proposal was supported by a slight majority for only three sections: Investigations required (62.50 % for), Investigations results (61.96 % for), and Examination findings (59.24 % for).

Key quote: "There is Information taken from examinations, assessments and investigations which would benefit [both] the resident and staff".

Overall the RBAC preproposal was not supported for implementation. For supporting evidence and further discussion, see sections 3.1.4 - 3.2.3 of this document and the Care homes view (of shared health and care records) guidance product. We have identified significant safety issues with filtering the CIS record that must be addressed during implementation - see CIS Clinical Safety Case (Hazard

33: 'Inappropriate role-based access (RBAC) implementation'; Hazard 34: 'The care home view of the CIS record does not include some important information').

3.2.2 Q11: Is there any other information that would help care home staff care for or support a resident?

- A majority of respondents (56.49 %, n = 103) recorded 'No'.
- A minority of respondents recorded 'Yes' (41.76 %, n = 76)

Key suggestions:

- The majority of suggestions given in response to question 11 were already contained within the care homes view or were appropriate for inclusion in existing sections. Suggestions included are below with the corresponding section in the Standard in parentheses:
- Coordinate My Care Plans (Additional support plans), Shared Care Plans (Additional support plans), DNACPR (End of Life - Cardio-pulmonary resuscitation (CPR) decisions), Person Centred Plans (Additional support plans), Individual Preferences (About Me, Care and support plan), Support Plans (Additional support plans), Communication issues (Individual requirements - Reasonable adjustments), Preferences (About me; End of life care), Covid Status (Investigation results), Interests (About me), Hobbies (About me), Family Networks and Carers or Other Significant Persons (Personal contacts, Professional contacts), Personal history (Care and support plan – Needs, concerns or health problems), Opportunities for Stimulation / Social Inclusion (About me), Life History (About me), Decision and Time Specific Elements of Mental Capacity Assessment (Legal information – Mental capacity assessment – Date), What [they like] to be Called (Person demographics – Person preferred name), Important Routines (About me – How and when to support me), Cultural or Religious Beliefs (Person demographics – Religion, About Me – What is most important to me), Treatment Escalation Plan (Contingency plans), ReSPECT (Recommended Summary Plan for Emergency Care Treatment) (Contingency plans), Ongoing Safeguarding Concerns (Safeguarding, Alerts), Health and Care Professionals Engaged with the Resident (Professional Contacts), How I Like to be Supported (About me – How and when to support me), Communication Needs (Individual requirements – reasonable adjustments, About me), Advanced Care Plan (End of life care), Some Diagnoses (Problem list, Admission details, Discharge details, Contacts with professionals etc), Next of Kin Details (Personal contacts), GP Information (GP practice), Occupational Therapy or Physio[therapy] Assessments (Assessments), Lasting Power of Attorney (Legal information), Discharge Information (Discharge details), Allergies (Allergies and adverse reactions), Risks (Risks), End of Life Plan (End of life care), Health Passport (About me), "Reason why a device is being used i.e. urinary catheter" (Medications and medical devices – Medical devices entry – Comments), "How they like to give feedback, raise concerns or make complaints" (About me – How I communicate and how to communicate with me).

Other suggestions that are not part of the Care homes view included:

1. “Explicit Consent [for sharing certain data]” – Consent for sharing data is a required field in the PRSB Core Information Standard under legal information only. See Clinical Safety Case Hazard 15: ‘Consent for information sharing section may cause confusion’; Hazard 16: ‘Sex data item may cause accidental disclosure of gender reassignment without consent ‘; Hazard 19: ‘Risk of sharing confidential information inappropriately’).
 2. “Whether medicines have been ordered and when to expect them” – Meta data relating to the ordering of medications is not a part of the standard. See CIS Clinical Safety Case (Hazard 9: ‘Medication section: Differences in system representation of medication and workflows around medication’).
 3. Finances – Specific entry for details about a person’s finances are not included as part of the standard.
- Key quote: “It is essential that information relating to Lasting Power of Attorney, Advance Decisions and DNACPR is accessible to all care home staff. It is currently under Legal Information and End of Life Care and this cross reference is helpful. If the person has any other documentation, such as ReSPECT or TEP that should be included too”.
 - Key quote: “We need a picture of the whole person not just a description of their ailments, tests and problems”.

3.2.3 Q12: What would the benefits be for care home staff of having access to this information?

General themes relating to benefits of access:

- “Improved care”, “safer care”, “joined up care”, “care tailored to individual”, “holistic picture of the patient”, “improved out of hours care”, “person centred care”, “help to achieve their [the resident’s] goals”, “[useful in] emergency situations”, “greater communication and coordination”, “reduce duplication of referrals”, “shared understanding of the resident’s needs”, “reduction in unnecessary admission to hospital”, “Increase [staff] confidence, knowledge and understanding”.
- Key Quote: “Person-centred support rather than just provision of essential care”.

Key comments on specific sections of the standard:

- Medications and medical devices: “Whilst not all care home staff need to know the medications a person is taking there may be instances where all care staff need to know about and how to use medical devices”.
- End of life care: “In the absence of a central and easily accessible register for Advance Decisions and DNACPR orders, it is vital that everyone involved in the care of an individual is aware of their treatment preferences so that care will be in line with preferences as required by the Mental Capacity Act 2005. Experience from the Compassion in Dying information line demonstrates that patients and families can feel distressed when care home staff and other professionals are unaware of written and legally binding care plans”; “Advanced decisions avoid unnecessary admissions then deaths in hospital”.
- Risks – “awareness would allow staff to support people in the most effective way and reduce possible harm to the staff member”

- Allergies – “[There is a] clear need for staff to be aware of possible allergies. If only authorised staff have access/knowledge, then other staff may not know how to recognise an adverse reaction without that person present”.
- Investigation and examination results – “[Care home] staff caring for people need to be aware of the most up to date medical information in order to be able to identify any health concerns when they are supporting [a resident]. Care home staff supporting on a day-to-day basis are more likely to be able to pick up on health issues/changes and need to be aware of any relevant details”.

3.2.4 Q13: Do you have any concerns about who has access to this information in a care home?

- A majority of respondents (61.02 %, n = 108) recorded ‘No’.
- A minority of respondents recorded ‘Yes’ (38.98 %, n = 69)

Key quotes:

- Information sharing: “Staff would need to be aware that there may be some information that the person themselves does not know yet, e.g. test results”. See CIS Clinical Safety Case (Hazard 20: ‘Patient sees information that they were not aware existed and might be sensitive’).
- RBAC: “Care homes (especially without nursing) do not always have registered professionals onsite so a senior carer, or carer may need to see all information. However, as there is no professional register of care workers there is no professional accountability. Care home staff often cover many roles: from the manager stepping in to cook dinner and the laundry or domestic staff covering care shifts when required. Depending on what role someone is working at that time would depend on what level of access they would need. this would be in line with Caldicot guidance”; “Access should be maintained via role based access systems and the flexibility in place to allow staff members access as required/authorised”; “[Information access] needs to be on a need to know basis for care staff but management should be aware of any potential issues and advise staff as necessary”.

3.3 Questions relating to the Care homes view (answered by individuals using services, or by health or social care staff on their behalf, or informal carers or volunteers)

3.3.1 Q14: Looking at the list above is this everything you, as a resident or carer (family, friends, etc) would expect care home staff to be able to see in a health and care record?

- A majority of respondents (67.86 %, n = 19) recorded ‘Yes’.
- A minority of respondents recorded ‘No’ (32.14 %, n = 9)

Key quotes:

- “A carer's insight and input is invaluable and can be a valuable resource to the Care Home”.
- “This is info essential to 'best care' -whether in family home or a professional care or nursing home. Some info is sensitive therefore adherence to data protection and confidentiality essential”.
- “Most important is About me information so they know how to care and support the resident”.

3.3.2 Q15: Is there any other information that would help care home staff when caring for you or someone close to you?

- The quantitative results for this question were equivocal.
- An equal number of respondents recorded 'Yes' (48.15 %, n = 13) and recorded 'No' (48.15 %, n = 13).

Key quotes (corresponding section in the Care homes view in parentheses):

- "That my partner is also disabled and has access needs" (About me)
- "Information of your former employment and interests including hobbies" (About me, Social Context)
- "Contact preferences in an emergency e.g. daughter/husband" (About Me – People who are important to me, Personal contacts)
- "What activities they like to be supported to do. When and how they like to eat. How independent the person is to live their life". (About me)

3.3.3 Q16: What would the benefits be to staff in a care home having access to this information? Please explain

Key quotes:

- "To have the most comprehensive and up to date picture of me as a person – a holistic view".
- "In case of emergency they would know what to do, from this info they could plan my care better".
- "Not having to repeat the same information again and again".
- "They would be able to ensure that my living environment provided me with the opportunities to remain as independent as possible and this would have a positive impact on my mental and emotional wellbeing".

3.3.4 Q17: Do you have any concerns about any staff in a care home having access to this information?

- The quantitative results for this question were equivocal.
- A slight majority of respondents (53.85 %, n = 14) recorded 'No'.
- A slight minority of respondents recorded 'Yes' (46.15 %, n = 12)

Key quotes:

- "[No]...so long as confidentiality is respected".
- "There are always concerns regarding access to information and its appropriate use".

3.4 Questions relating to the About me standard (answered by staff working in health and social care)

Questions 24 to 29 and the 'easy read' questions referred respondents to the following proposal for the About me standard:

3.4.1 About me proposal

What is most important to me - this should include any essential information that any professional in health and social care should know about the you in any situation, including emergencies. It could also include other information such as this could include meaningful activities, values, goals, ethnicity, culture, religion, pets.

People who are important to me - details of who is important to you and why (e.g. family members, carers, friends etc.) and could include people you do not want to be contacted about you and why.

How I communicate and how to communicate with me - how you communicate normally and when you are in pain or distress. Any communication aids you use, for example a hearing aid. How you indicate choices. How you would like others to communicate and engage with you.

Please do and please don't - things you want someone supporting you to do and what they must not do.

My wellness - what you are able to do and how you feel on a typical day, things that might make you unwell, signs that might indicate you are becoming unwell and what you are able to do and feel on a bad day.

How and when to support me - how and when you want someone caring for you to support you, including in an emergency situation and in important routines or situations (such as personal care routines). Support with making choices, understanding dangers/risks, memory, managing emotions and behaviours.

Also worth knowing About me - this could include things you like e.g. particular foods, places, a football team and things you like to talk about, your dislikes and any care preferences.

3.4.2 Q18: Looking at the sections above, is there any other information that a person could provide about themselves that would help when caring for or supporting them?

- A majority of respondents (67.07 %, n = 110) recorded 'No'.
- A minority of respondents recorded 'Yes' (32.32 %, n = 53)
- Key quote (history of the individual / "life story"): "Details of their background - Especially but not exclusively for people with dementia, the ability to talk to them about important people and events from their past life provides a better quality of care".
- Key theme ("care preferences including end of life): "How I liked to be addressed" (*NB*: this element is found in the PRSB CIS under person demographics); "preferences around health provision..."
- Key theme (my behaviour and routines): "How I look when angry or frightened, triggers, sensory sensitivities and needs"; "Emotional support, especially around challenging behaviour"; "Previous routines both day to day and socially that the individual would like to be supported to maintain"
- Key theme (empowerment): "I am able to.... Information about the tasks that people can do themselves e.g. I am able to brush my own teeth, pour my own drink...etc. This will enable care home staff to understand a person's abilities and empower the person to be as independent as possible".

3.4.3 Q19: Looking at the sections above, do you think they would help you to find the relevant information to provide better care?

Quantitative data for question 19 is shown in table 6 below:

Scale	%
Very Easy	27%
Easy	48%
Neutral	22%
Difficult	1%
Very Difficult	2%

Table 6: Percentage (%) of respondents stating how easy it would be to find the relevant information if the About me was structured as set out in the survey (see section 3.4.1 of this document).

Qualitative analysis and quotes:

The respondents scoring it as **difficult or very difficult** to find the relevant information stated:

- “There’s potentially too much information in About me. Some sections can be combined (e.g. what and who are important - Please do/don’t and how/when to support, How I communicate and My wellness). A more concisely formatted About me will promote higher engagement from the people reading it”. See CIS Clinical Safety Case (Hazard 6: ‘User cannot find the data they need’).
- “It provides a list of information that is not understood in relation to the actual situation the person finds themselves in. It’s like having lots of ideas without connection. Yes, it would help having the information but as a resource to understand that person at that particular time”. See CIS Clinical Safety Case (Hazard 8: ‘The context of the information is lost’; Hazard 21: ‘Competent patient or their carer unable to understand information recorded in sections’).

Respondents scoring it as **easy or very easy** to find the relevant information stated:

- “Obviously it will depend on how the information is laid out” (The format of the graphical user interface for displaying the standard is out of scope)
- “I like that this has only a few sections with guidance and examples for each - easy to read at a glance, lots of info can be provided”
- “Good to have headings, so long as not too many”. See CIS Clinical Safety Case (Hazard 6: ‘User cannot find the data they need’).
- “This profile is essential and should be easily accessible. It allows me to understand the key personal information about an individual”.
- “The information could be recorded in a way that tells a story about the individual and is easily navigated”
- “Knowing more about a person is going to make it easier to provide care (e.g. during periods of agitation) ...”

Respondents scoring it as **neutral** said that:

- “In theory, yes. However, that will require every carer to spend substantial time and pay attention to detail whilst reading and remembering each person's information. The reality is that many staff will be unable or unwilling to do that”. See CIS Clinical Safety Case (Hazard 24: ‘Failure to adopt record standard’).
- “Please do and please do not feels like a difficult section that could be covered in the others”.
- “The information would have to be easy to access, in a busy workplace with slow IT systems and already multiple passwords to remember its often easier and quicker to ask the person directly rather than fight through more systems. I can see instances when the option to access this information would be helpful”
- “It depends how the information is recorded as to whether it is possible to identify the relevant facts. These could get lost if there is a lot of narrative provided”.
- “The biggest danger with the separation of data will be the repetition across the record, and whether the information is usable at the point it is required”. See for example, CIS Clinical Safety Case (Hazard 10: ‘Allergies not present or correct in the CIS’).
- “A key challenge is presenting information so that the screen is not too busy, yet one can drill down into the detail if required. This is a design issue which needs focused input from a wide variety of users”. (The format of the graphical user interface for displaying the standard is an implementation issue that is out of scope)

3.4.4 Q20: Would it be helpful if this information was presented as **MUST KNOW** or **WORTH KNOWING**?

- A majority of respondents (90.36 %, n = 150) recorded ‘Yes’.
- A minority of respondents recorded ‘No’ (9.04 %, n = 15)

Of the 165 respondents 90.36 % said that the information should be presented as “must know” or “worth knowing”. However, from some of the comments provided it is clear that this question has been interpreted differently by different respondents. Some have answered the “Must a professional have access to this information” question rather than whether the information should be categorised into subcategories:

1. You must know this information About me and
2. It is also worth you knowing this information About me.

Respondents answering that it **should not be** presented separately said:

- “All the info in About me is important otherwise the individual wouldn't mention it - don't see the need in categorising”.
- “Staff should be trained and understand that the information presented is relevant to the presentation and maintenance of wellbeing for the person”.
- “Risk of only reading the **MUST KNOW**”.
- “That judgement may change and may be different in different circumstances”

Respondents answering that it **should** be presented separately said:

- “I would suggest careful balance of what is must or worth knowing so as to not relegate worth knowing as not important, whilst providing a snapshot for short assessment or interventions (say locum duty doctor on a night shift at end of life may need a certain snapshot)”.
- “Possibly. That could allow those with limited time to focus on the essentials for safe delivery of care - but it could encourage others to focus only on the 'MUST KNOW' and deliver sub-optimal care as a result”.
- “Will help it to be read more easily by professionals. Bullet pointed. Word limits for each section to avoid autobiographical writing”.
- “In an emergency situation - it might be easier/ helpful just to go to the must know section”
- “The person should be known as a whole, and not as their illness/disability/impairment. This information is worth knowing to be able to care for the person better”.
- “Yes because this gives you a good insight into what that person is like and make the work person centred and how best to support that person”

3.4.5 Q21: Would it be helpful if this information was presented in multi-media files e.g. short video clips and pictures?

Quantitative data for question 21 is shown in table 7 below:

Element	Number (n)	% answering Yes
What is most important to me	162	67%
People who are important to me	164	79%
How to communicate with me	164	78%
Please do and please don't	161	70%
My wellness	161	66%
How and when to support me	163	71%
Also worth knowing about me	163	68%

Table 7: Percentage (%) of respondents stating that it would be helpful if the information set out in the About me proposal (Section 3.4.1 of this document) was presented in multi-media files e.g. short video clips and pictures.

Qualitative analysis and quotes:

From the comments it is clear that respondents believe some of the sections suit video clips more than others and that this may be person and context dependent:

- “Size of files, time taken and likelihood of them being opened, requirement of office time/space and software to play videos - this is not practical”. Allied health professional

- “Different people communicate differently and process information differently. My personal preference would be written but for others video, pictures or sounds is much more effective to both produce and receive information”. Worker in adult services
- “[It may be] inaccessible in most hospital situations” Hospital nurse
- “A short video clip will not only convey the information needed but will also send nonverbal information across since the viewer will note the individual's baseline mood and manner of communication”.
- “Staff are unlikely to view multimedia files. It is easier to scan through a written document to find the information relevant to a situation”. Care home manager
- “Takes too long to watch. For [a] GP we need to talk about very [concise] information. [A] picture might work but I am worried about ability to change things [and the] IT working. [It] will add layer of complexity”. General practitioner
- “Not sure people would have the time to watch video, but pictures would be good. Or multimedia and text”. IT worker

3.4.6 Q22: Would there be potential barriers to accessing this information as multi-media files e.g. short video clips and pictures?

Key themes / suggestions included:

- Time burden: “Time - as can be time consuming ploughing through a number of video clips to find one crucial piece of information” ; “...sometimes the information just needs to be scanned”.
- Technical issues: “May be technical issues with formats and they may go out of date”. See CIS Clinical Safety Case (Hazard 35: ‘Multimedia attachments’).
- Confidentiality and data protection: “May be overheard/seen by unauthorised persons. See CIS Clinical Safety Case (Hazard 19: ‘Risk of sharing confidential information inappropriately’).
- Digital maturity and systems capability: “Having appropriate equipment to view files in video format is an issue”; Systems capability development and download/bandwidth issues and any virus risks with media.

Key quote: “The care workforce is tech-poor as a sector currently. However, as more providers move to digital platforms and mobile devices, this barrier will be reduced”.

3.4.7 Q23: Do you have any concerns about the inclusion of this information in a health and care record?

Question 23 refers to the About me proposal in section 3.4.1 of this document.

- A significant majority of respondents (80.00 %, n = 132) recorded ‘No’.
- A minority of respondents recorded ‘Yes’ (20.00 %, n = 33)

Key themes:

- “Confidentiality and privacy”, “need to know basis”, “Consent”, “Keeping this information current”, “Who can access it and how” (See CIS Clinical Safety Case (Hazard 33: ‘Inappropriate role-based access (RBAC) implementation’),
- Key quote:” If a person gives consent to share the important information about themselves, all agencies involved in supporting that person should be able to access the information. Including ED (emergency departments), GP's, Social Workers and Care Homes”. - Allied health professional
- Key quote: “I don't see any potential harm in authorised staff having this knowledge. If it was accessible to untrustworthy people, I would be concerned that this information could be used to gain a vulnerable person’s trust and put them at potential risk of trusting an abuser i.e. knowing their favourite team/foods/likes/dislikes/family members names etc”. - Care home manager (nominated individual)
- Key quote: “It’s basic [information] and essential to avoid discrimination and even abuse”.
- Key quote: “There is a duplication/contradiction issue with some info being within About me and some info being elsewhere e.g. diagnoses within a diagnoses field but within this section as well, what if one field isn't populated or one of them becomes out of date, but not other etc?”. See for example, CIS Clinical Safety Case (Hazard 10: ‘Allergies not present or correct in the CIS’).

3.5 Questions relating to the About me standard (answered by people who use services and informal carers)

3.5.1 Q24: Do the categories contain the types of things you want a nurse or doctor caring for you in hospital to know about you in an emergency?

- A majority of respondents (70.83 %, n = 17) recorded ‘Yes’.
- A minority of respondents recorded ‘No’ (20.83 %, n = 5)

Key quotes:

- “I feel that autistic sensory sensitivity such as light, sound or smells should be a separate recorded category. The need for someone to be seen in a quiet, darkened room away from beeps and bright overhead lights or be provided with visual (blind) or deaf sign language translator or aids is really important for a doctor or staff to know before any examination takes place”. – Informal carer
- “Any allergies. Any antibiotics that the person might be allergic to. Carer needs to be consulted”. See CIS Clinical Safety Case (Hazard 10: ‘Allergies not present or correct in the CIS’).
- “Consider a list of people (e.g. family) and things that I do not want to visit me or take part in my care. Things I do not like including Church, 'popular' music and TV”.
- “Beware of information overload. Many aspects of a person's character and personality will take time to learn and understand. Good communication, whenever possible should be encouraged and depend on a level of trust between patient/person and carer”.

- “They should have as much information as possible and know when my vital signs are normal for me”.
- “It contains key information that might affect my presentation that I might not be able to give”.
- “Hearing impairment, false teeth and other personal details are often overlooked. Personal views on treatment or care should be known”.
- “It gives a picture of who I am and particularly important my communication needs”.
- “How my independence and care needs alter drastically when I'm not in my home environment (e.g., is not adapted to enable me to manage my needs independently)”.

3.5.2 Q25: Thinking about when you receive care and/or support that isn't an emergency, would these categories (they do not all have to be completed if not relevant to you) let you share the most important types of things you want someone caring or supporting you to know?

- A majority of respondents (86.96 %, n = 20) recorded 'Yes'.
- A minority of respondents recorded 'No' (13.04 %, n = 3)

Comments:

- “My partner's needs as a Disabled person”.
- “All relevant information can fit into these categories”.
- “Should always be built on with ongoing care and personalised as agreed between resident and carer, peoples' needs change and should be addressed regularly to ensure daily (non-emergency) care is person centred and accounts for changes in needs”.
- “...also include things/people I do not want to be part of my care - e.g. untrustworthy family members”.

3.5.3 Q26: Should the information in each category be separated into information that a professional MUST KNOW about a person and information that is WORTH KNOWING about a person?

- A majority of respondents (66.67 %, n = 16) recorded 'Yes'.
- A minority of respondents recorded 'No' (25.00 %, n = 6)

Comments:

- “This could contain a lot of information which is useful but not vital, the vital information should be first and clear”.
- “In an emergency there is a need to act swiftly. This demands a shorted dataset concentrated on what is absolutely needed at that time/in that situation”.
- “I think the professional should know as much as possible. What seems important to one professional may not be to another, and vice-versa”.

3.5.4 Q27: Do you have any concerns about sharing this information with people responsible for your care?

- A significant majority of respondents (54.27 %, n = 13) recorded 'No'.
- A minority of respondents recorded 'Yes' (45.83 %, n = 11)

Comments:

- "Who has access to it - making sure that strict access measures are in place".
- "Sometimes, too much information can be as bad as too little - some information needs to be given in stages over time not all at once to avoid overload on the part of the care staff".
- "I want to be able to control the information so would worry about it be electronic and so easily forwarded to anyone. It contains a lot of personal info that not everyone needs to know".
- "Lack of confidentiality and information being used against the resident". See CIS Clinical Safety Case (Hazard 19: 'Risk of sharing confidential information inappropriately').

3.5.5 Q28: Do you think it would be helpful for this information to be shared as short video clips and/or pictures?

- A majority of respondents (50.00 %, n = 12) recorded 'Yes'.
- A minority of respondents recorded 'No' (33.33 %, n = 6)
- (NB: Some respondents recorded a comment but did not respond yes or no)

Comments:

- "Video or pictures carry much more impact".
- "Limits accessibility".
- "It might be useful in care homes to see who their patient used to be or still is, if they cannot speak or communicate".
- "Only key things like positioning or how I need my food chopped up".
- "I regularly use Maketon pictures to help communicate needs where necessary. Video is helpful as it can be pre-recorded. However, there are concerns about accessibility platforms and media used - not everyone has an iPhone".
- "Visuals help support workers fully understand care needs (e.g. video on good wheelchair postural management)".
- "Pictures would be useful but not video clips as they are too easy to skim through".

3.5.6 Q29: What would the benefits be of sharing the information as short video clips and/or pictures?

Comments:

- "A very useful communication tool. People learn things in different ways, therefore use different means of communicating important information".
- "Only if learning difficulty or communication difficulties".

- “Tone and style come across and the clip could better illustrate the problem in some instances e.g. ability to walk or stand, than words might”.
- “Pictures could ensure everyone does it the same way each time and might be easier than words”.
- “... Who would make the video and what information would it contain AND it might prevent clinicians reading notes which contain important information”.
- “People who prefer visual communication. Gives a more personal account”.
- “Pre-recording information when a [person being cared for] is calm and understanding of what is being asked can be a great deal of help if they are unable to process information under stress. Also, it can help provide a "baseline" response the care staff can compare to the current situation to help further assess the condition of the [person being cared for]. It can also be more accessible when people have sensory disabilities and provide a "short cut" when no translator or aids are available”.
- “For those with language difficulties (e.g. pictures rather than talk) and/or cognition or attention difficulties”.
- “Clearer instructions (e.g. how to use aids), better understanding of how someone communicates”.

3.5.7 Easy read survey

Quantitative data for the easy read survey is shown in table 8 below:

Question	Number of respondents	Yes	No	Not sure
Q1: Are the 7 things in the list the most important things that doctors and nurses should know about you in an emergency?	65	72%	14%	14%
Q2: Would having a list like this help you get the right support from your carers and support workers?	52	73%	19%	8%
Q3: Should there be 2 lists, the first for really important information and the second for other information?	51	55%	16%	29%
Q4: Are you worried about sharing your information with the NHS and people who support you?	50	16%	74%	10%
Q5: Would it be ok to share your information using pictures and short videos?	48	50%	35%	15%

Table 8: Quantitative output from easy read survey

Question 6 of the easy read survey provided qualitative responses.

Q6: What would be good about sharing your information using pictures and video clips?

Comments:

- “Would lead to a much better understanding of me the person and how I cope”.
- “You can see the person”.
- “It’s accessible and can provide more information quickly the reading reports”.
- It’s only any good if people watch them.
- “Pictures and video clips can communicate something clearer and more easily than text. Visual images are more memorable than text”.
- “Easy to understand for everyone and very informative”.
- “People will be able to 'see' me more clearly and pics and videos can help capture things that are not so easy to show with words alone”.

3.6 Questions relating to the Local authority information standard

3.6.1 Q30: Tell us how important it is for a member of a health and care team to have access to this information from the Local Authority?

Section	Percentage (n)
Professional contacts	88.56 % (147)
Personal contacts	85.03 % (142)
Services and care	90.96 % (151)
Deprivation of Liberty Safeguards (legal information)	92.17 % (153)
Mental Health Act or equivalent status (legal information)	92.73 % (153)
Mental Capacity Assessment (legal information)	90.42 % (151)
Safeguarding	93.97 % (156)
Referral information	81.33 % (135)
Assessments	86.82 % (145)
Alerts	90.30 % (149)
Primary support reason	87.20 % (143)
Equipment	87.81 % (144)

Table 9: Percentage (%) of respondents who responded either ‘Important’ or ‘Very important.’

Key comments:

- Safeguarding: “Incorrect inferences about safeguarding if they are shared without the detail are possible. And the detail may be sensitive. The content of assessments may be sensitive and not appropriate to share routinely, but the fact of an assessment and subsequent outcomes is very helpful”; “Extreme caution needed [regarding] safeguarding due to the sensitivity of the data that may be contained”.
- Avoiding unnecessary assessment and repetition: “By knowing what assessments etc have already taken place and their outcomes we can avoid reassessing or requesting unnecessary repeat assessments”; “All of the above should be shared between local authority, health and care team for reasons of making the care pathway efficient and effective and ensuring an individual does not have to repeat the same information over and over again”.
- Key quote: “Information above (see table 9) is essential to fully understand a person’s individual circumstances and allow person-centred care to be provided. Provision of specified information will enable efficiencies in the system regarding access to data and reduce time spent finding out information that is not always currently easy to access or widely available”.

3.6.2 Q31: Is there any other information that a Local Authority could provide about a person that would help when caring for or supporting them?

- A significant majority of respondents (64.24 %, n = 106) recorded ‘No’.
- A minority of respondents recorded ‘Yes’ (33.94 %, n = 56)

Key suggestions:

- Finances and care packages: “[We] have residents who have been concerned about whether their money would “run out”. I would also like more transparency in the decisions made when a resident [is moved] from privately funded to local authority funding. My local authority will (and have) relocated residents in order to save £5 per week. This is all the more frustrating as I would have liked the option to reduce our fees to the same level to avoid the relocation of residents who view this as their home” – Care home manager; “Financial details and who is providing the different support packages, with contacts”; “LAs [Local authorities] may be able to provide details financial vulnerabilities, the residents choices and capacity regarding financial independence and any possible financial support in place that should be notified of certain changes in personal circumstances”: “Financial status [CHC/S117/Self funder etc.]”. *NB:* Financial assessments and funding relationships between the local authority and other organisations are out of scope.
- Lasting power of attorney: “LPA [Lasting power of attorney] details”..
- Equipment: “Information regarding equipment and who is responsible”. – Care home manager; “Recommendations made for adaptations to the property / existing adaptations”. See implementation guidance.
- “Current worker, NOK [next of kin], carers”: “Carer information”.

- “As a local authority employee, what health teams are involved and what their action plans are so that the person can be joint worked”.
- “A main, named contact”.
- “Previous support. It would be helpful to know if someone had had previous support as this can often be linked to an individual’s preferences around care”.
- “Housing status - are they awaiting rehousing? Are they awaiting major adaptations to their property?”
- Personal history: “Any relevant historic information about the person which would be useful to current or future care”.
- Safeguarding: “Important that if there are any ongoing safeguarding concerns that Health or Care professionals refer to LA for details to ensure that are not acting in a way to put the person in an unacceptable situation”.

Quotes from individuals receiving care:

- “What are the things that are important to a person which might not be seen as important to a professional for example being supported to keep pets”.
- “How to access person’s home”.
- “General history of involvement or not. Whether any other agencies the local authority knows about have been involved [with the person]”.
- “People responsible for the care of others often break confidentiality and share this information when they shouldn’t in the form of gossip”.

Quotes from IT services:

Key quote: “It would be beneficial if there could be agreed (or at least recommended) ValueSets for the different types of some of these information types, e.g. - Alerts: including a type for Safeguarding - Referrals: GP, Community Health, Mental Health, Hospital Discharge etc. - Assessments: Social Care and Support Assessment, Occupational therapy, Joint SC and OT, etc”.

3.6.3 Q32: What would the benefits be of having access to this information that can be shared as part of a health and care record?

Key suggestions:

- Key quote: “Staff will be able to see what interventions and services are in place, and the contact details of the person/ team to contact for further information. If a care package needed re-starting from hospital the ward staff can contact the provider directly”.
- Finances: “Responsibility of the LA [local authority] or other body to pay fair and accurate fees”. – Care home manager. *NB*: Financial assessments and funding relationships between the local authority and other organisations are out of scope/
- Holistic care: “Holistic picture of the service user to inform care and support”; “Health and care staff are able to see the full picture for a person and know who to contact should a concern

arise. They will also be able to see how they fit into the 'jigsaw'; "Rounder knowledge of the person"; "Personalised and informed care".

- Other benefits: "Improved care, less duplication, joined up services"; "Transferring information eases the burden on care/nursing staff in finding significant information at a later date"; "Save time and resources"; "Historical information will be available that is not currently included when a new service user is admitted".

3.6.4 Q33: Do you have any concerns about adding this information from the local authority into a person's health and care record?

Key concerns:

- Data quality: "Yes - it is not always up-to-date and is frequently irrelevant to the person's current circumstances". See CIS Clinical Safety Case (Hazard 5: 'Poor quality data'; Hazard 12: 'Care plans are not up to date')
- Data protection: "Misuse of information"; "Need to be data protected checked"; "Yes, a social care assessment is often a very detailed assessment written with the service user and can contain sensitive information they may not want many to access"; Data protection/GDPR standards need to be maintained within each organisation"; "The records cannot contain information concerning other family members or others [third parties]". See CIS Clinical Safety Case (Hazard 15: 'Consent for information sharing section may cause confusion'; Hazard 16: 'Sex data item may cause accidental disclosure of gender reassignment without consent'; Hazard 19: 'Risk of sharing confidential information inappropriately').
- Safeguarding: "in relation to safeguarding issues, the information would only be shared on a need to know basis"; "Only the fact that there is an ongoing Safeguarding concern needs to be shared not the actual details as this could undermine any ongoing investigations. Health and Care staff should refer to LA (local authority) if any ongoing Section 42 enquiries". See CIS Clinical Safety Case (Hazard 19: 'Risk of sharing confidential information inappropriately'; Hazard 33: 'Inappropriate role-based access (RBAC) implementation').

3.6.5 Q34: Is there any other information about equipment that is needed? A detailed view of equipment provided to a person is shown below (repeated for each item of equipment):

NB: It is recognised from the survey and webinars conducted that many of the suggestions requested by respondents in this section are not generally recorded by the local authority and therefore cannot be included in the standard (See equipment and adaptations section in implementation guidance). Details relating to equipment may be obtainable from assisted living services the contact details of which, can be stored in local or shared care records.

Key quote: "Often detailed data about the type of equipment isn't recorded in a structured way by social care, so may be hard to share". – Local authority

Suggestions relating to equipment:

- Safety concerns: “Keysafe information carries risk - especially if the access code is accidentally shared”. – Local authority
- Equipment records, review and maintenance: “If the equipment should be reviewed or services, and if so for when and by whom”. (NB: for small equipment under the purview of the local authority (as opposed to assisted living services or other commissioned service) items such as ordering details, implementation date, 6 weeks review and annual review can be usefully recorded under ‘Comment’ if they are recorded – See implementation guidance); “The date it [the equipment] was reviewed”.; “Who is maintaining the equipment”.; “Name of the organisation responsible for maintaining the equipment and, in the case of technology, the call centre that manages any alerts”.; “Maintenance requirements”.; “If other equipment was discussed and not felt appropriate as often referrals come in for things that have already been explored. This will also help with assessments/putting referrals in if we know it has already been done/explored”.; “Who to contact if any issues with equipment”.; “Who is paying for it? Whether it is transferable when it is moved. Who does it belong to and who is responsible for collecting it once no longer required”.; “How the equipment is used - by individual or other as safety network”.; “Details of how to service the equipment and equipment manual. Training of how to use the equipment to all staffs”.; “Equipment that was unsuitable e.g. bariatric bed unsuitable as bedroom too small”.; “Equipment ID number should the equipment need to be returned to the supplier”.; “Date of next inspection particularly for hoists, slings, electrical equipment”.; “Who to contact in case of breakdown, whether it was privately purchased or provided under DFG/grant and who is responsible for maintenance”.; “Whether it enabled independent use or safely assisted use”.; “Adaptations- major and minor also needed- not just equipment”.; “Contact information on manufacture repairs or who to contact for key safe codes/numbers etc”.; “Keysafe number - obviously care needed with this security information - height for frames/sticks”. (NB: Where to obtain the key safe number could be appropriately recorded under – Equipment – Comment, without entering the number itself into the record); “The date [a person was] trained on an adaptation”.; “Serial number, contact details for anyone responsible for it, service intervals and records. If a piece of equipment fails it is important to be able to act quickly to rectify this”.; “Warranty period and date of last assessment to ensure equipment is safe to use and fit for purpose”.