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PALLIATIVE CARE AND END OF LIFE INFORMATION STANDARD

SURVEY RESULTS AND ANALYSIS

August 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 whoprovide 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 Directorateworking group report in 2012.

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Revision History

Version	Date	Summary of Changes
1.0	2/9/2021	Publication version

Reviewers

This document was reviewed by the following people:

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This document was approved by the following:

Name	Date	Version
Project Board		
PRSB Assurance Committee		

1 Introduction

This report is an appendix to the final report for the Palliative and End of Life Caer Information Standard.

This online survey was one part of the overall consultation approach in the development of the Palliative and End of Life Care Information Standard and came after detailed work on specific topic areas and national consultation on the standard. The survey was sent to key stakeholders for completion in July 2021. Feedback from the consultation prior to the survey (webinars, citizen's focus group and a national workshop) was used in the design of the survey.

The survey was aimed at care professionals including palliative and end of life specialists, people who use services and their carers; clinical leaders; voluntary providers and digital, information, policy experts and other key stakeholders. This report includes the results and analysis of the survey. The findings from the surveywere used to inform the development of information standard. In total 450 individuals participated in the survey.

The survey concentrates on specific areas to help update and enhance Electronic Palliative Care Co-ordination Systems (EPaCCS) standard, published in September 2015 by Public Health England (Information Standard (SCCI1580))

Respondents completed a series of questions on what information they felt was important to include in the information standard. Questions were included on people with palliative and end of life care needs and recording information on the following areas were explored:

- Whether people live in communal living arrangements, i.e. care homes
- Peoples cultural, spiritual and religious beliefs
- Information on carers
- Care planning including personalized care and support planning
- Preferences on place of care and place of death
- Ensuring the standard clearly records who is involved in decision making
- Ensuring the standard clearly records what actions professionals need to take
- Requesting any additional information not included in the standard
- Highlighting if the standard includes information that may not be necessary
- Recording people's choice on place of death and if they were wishes were met
- Clarification on terminology and scope of the standard

2 Who responded to the survey?

The first six questions of the survey identified respondents, their roles and the settings in which they work.

- *Question 1*

  Are you answering this survey on behalf of yourself or supporting someone else to answer it?

  96% of people (433) completed the survey for themselves while 4% completed the survey on behalf of someone else (17).

- *Question 2*

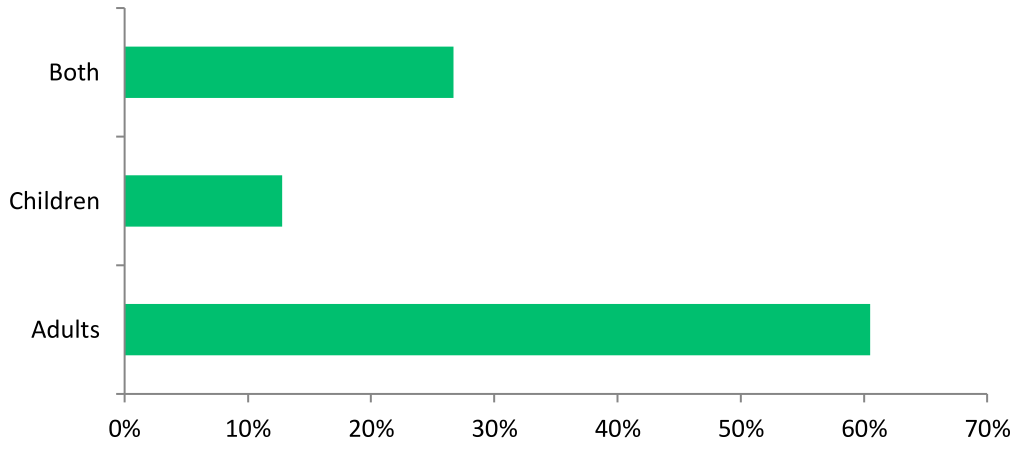
  Do you work in health or social care?

  86% of people (385) completing the survey worked in health and social care, while 14% (65) identified as service users or informal carers.

- *Question 3*

  Do you work with adults or children?

  367 people completed this question with 60% of responders (222) stating they worked with adults, 13% (47) with children and 27% (98) with both. 83 people did not complete this question.



- *Question 4*
  What is your role?

  The largest groups who completed this question were palliative care specialists, nurses and service users accounting for 55% of respondents. General practitioners, NHS administration/management, social workers and carers made up the next highest responder groups (20%). However, people who responded came from a wide range of backgrounds.

Answer Choices	Responses	
Individual using services	14%	60
Informal carer	2%	8
Volunteer	1%	4
Director of social care	0%	0
Care assistant/ support worker/ team leader	1%	5
Care home management	1%	4
Social worker	4%	17
Social care administration/ management	1%	4
Pharmacist	0%	2
Nurse	19%	83
General practitioner	6%	28
Secondary care doctor	5%	20
Geriatrician	1%	3
Palliative care /End of Life specialist	22%	94
Paediatrician in palliative/end of life care	1%	6
Healthcare assistant	0%	1
Chaplain	1%	3
Religious support	0%	0
NHS administration/ management	8%	33
HSC IT systems suppliers/Digital Experts	4%	18
Allied health professional	8%	34
Community Workers	1%	5
	Answered	**432**
	Skipped	**18**

- *Question 5*
  What area/s do you work in?

  Of those working in NHS and Social Care over half worked in end-of-life care, over a third in hospice care and over a quarter in care of the elderly, community services and long-term conditions. Other areas included frailty services, physical disabilities, learning disabilities, general medical services, acute care, dementia Some responders worked across more than one area.

Answer Choices	Responses	
Care of older people	25%	93
Frailty	22%	81
Learning disabilities	17%	62
Physical disabilities	16%	58
End of Life	55%	203
Hospice care	34%	126
Rehabilitation	7%	27
Dementia	18%	65
Emergency Care	12%	45
Mental Health	11%	39
Long term conditions	29%	107
General medical services	17%	62
Acute care	18%	65
Community services	28%	102
Adult's nursing	10%	37
Children's nursing/care	12%	45
Neurodevelopmental disorders	6%	23
Research/Education	8%	28
Digital & Information	2%	9
Commissioning	1%	5
Palliative Care	2%	7
Uncategorised	2%	7
	Answered	**367**
	Skipped	**83**

- *Question 6*

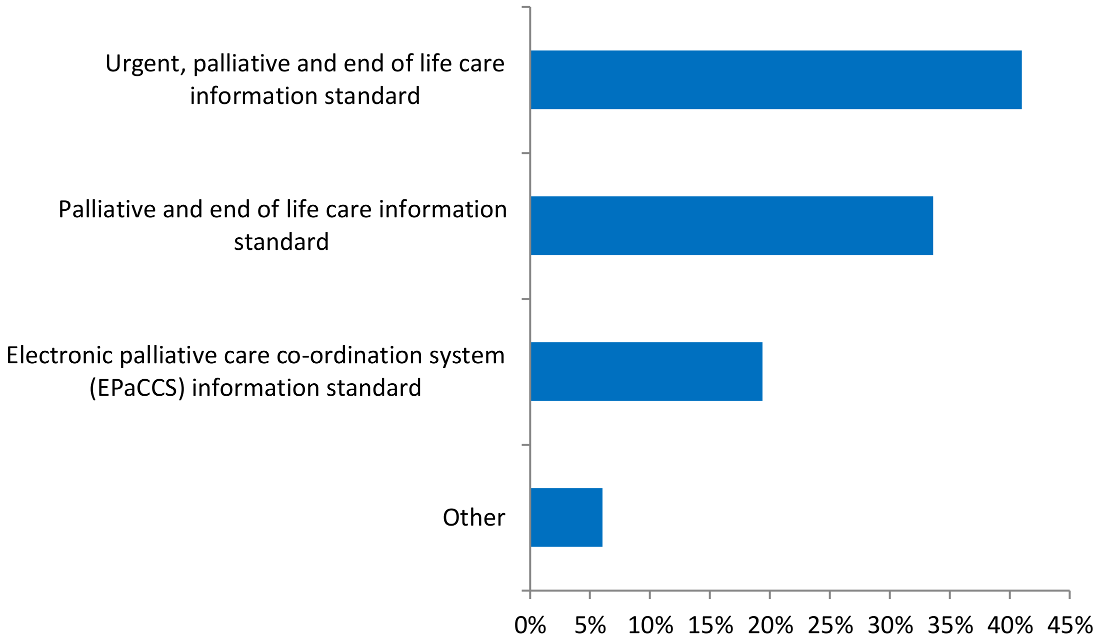
Where do you work?

Of those working in NHS and Social Care over a third worked in hospice care, 30% in community care and a quarter in acute hospital care. However, people worked in a wide range of settings including care homes, their own homes, primary care, ambulance services, local authorities, commissioning and NHS governing bodies, urgent and emergency care services.

Answer Choices	Responses	
Acute hospital	25%	92
Ambulance	2%	8
Assisted living	1%	2
Care home with nursing	2%	9
Care home without nursing	3%	10
Community care	30%	109
CCG, national NHS or social care body	11%	42
Hospice	33%	120
In a person's home	9%	34
Local authority	3%	11
Mental health/ learning disability services	2%	8
Nursing home	4%	13
Primary care	11%	39
Specialist centre	2%	8
Urgent and emergency care	4%	13
National Body inc Charities	4%	16
Educational establishment	1%	4
Private Company	1%	4
Uncategorised	1%	5
	Answered	**367**
	Skipped	**83**

3 What should we name the information standard?

Question 7
"The information standard aims to support care in urgent and emergency situations, and for people with palliative and end of life care needs. The previous version of the standard was called the 'Palliative care co-ordination: core content' standard. What should the updated standard be named?"



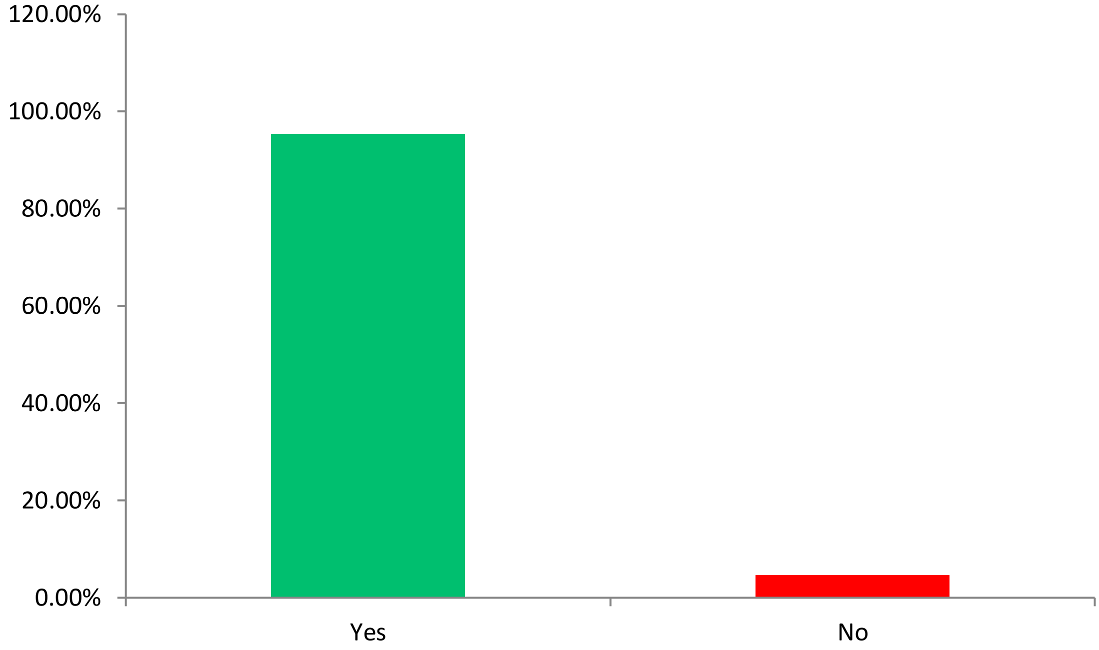
Answer Choices	Responses	
Urgent, palliative and end of life care information standard	41%	150
Palliative and end of life care information standard	34%	123
Electronic palliative care co-ordination system (EPaCCS) information standard	19%	71
Other	6%	22
	Answered	**366**
	Skipped	**84**

22 respondents selected the 'Other' option and provided alternative names for the standard, 12 of which excluded the term 'urgent' and 10 of which excluded the term 'end of life'.

Filtering for service users and carers and reanalysing the data produced the following results:
47% oped for "Urgent, palliative and end of life care information standard".
21% opted for "Palliative and end of life care information standard".
33% opted for "Electronic palliative care co-ordination system (EPaCCS) information standard".

4 Should the standard record whether a person lives in a communal setting?

Question 8
Should the standard include whether a person lives in a communal setting e.g a care home or other shared living accommodation or at a private home address?



Answer Choices	Responses	
Yes	95%	349
No	5%	17
Comment		55
	Answered	**366**
	Skipped	**84**

97% of service users and informal carers answered ‘Yes’ to this question.

53% of people who left comments (55 respondents) felt data on communal settings was valuable and would ensure equity and quality of care. 35% said it would help ensure end of life support mechanisms are in place for particular locations. Service users’ comments aligned with these key themes.

Some selected comments include:

“this allows data collection to look at outcomes for the care home population who have been traditionally underserved by advance care planning”

“This was part of the previous EPaCCs, although this is not core information that is essential to management and can be gained from other part of the patient record”

“this clearly identifies the individual's homely environment”

“It is helpful to know the person's circumstances and the baseline level of support available (e.g. whether they have waking night support). It is concerning, though, that sometimes people in care homes get less specialist palliative care input due to the expectation that e.g. a care home will offer this. Staff may or may not be trained to a sufficient level, staff shortages”

5 What information should be included on a person’s religion?

Question 9
What information should we include about a person’s religion? e.g., contact details of religious leader, place of worship, a free text box for additional information?

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data to include	**Number (% of responders)**	**Rationale**
Religious details including religious leader and place of worship	134 (41%)	Many respondents felt data about religious practices/preferences were important including initially asking people if they wish to record this information and who to contact at the end of life
Free text box	122 (37%)	Many replies supported the use of free text for this question in order to support open dialogue and not be prescriptive on possible replies
Contact details of religious leader/place of worship	115 (35%)	Some felt contact details of religious and spiritual leaders and places of worship including telephone numbers were important to record
Spiritual wishes	63 (20%)	Some emphasized the inclusion of ‘spiritual’ or ‘other wishes’ as not everyone is religious
Should include anything that is important to the person and they want to include	39 (12%)	Others emphasised the need to include anything the person may want to include about their spiritual wishes at end of life
Death wishes/rites	25 (8%)	Some suggested the subjects wishes around death and funeral preferences should be included
Not mandatory	21 (7%)	Some did not want this data to be mandatory and only be included if the person wanted it recorded
Caution on how used	3 (1%)	A few people advised caution on how the data is used.

325 people responded to this question.

The preferences of service users and informal carers followed the same pattern as all respondents with religious details (38%), contact details (38%) and the inclusion of free text box (33%) and “Anything that is important to the person” (13%) the most popular suggestions.

Some selected comments include:

“Under social, emotional and spiritual needs - information about My wishes - things that are important to me including any religious or spiritual support”

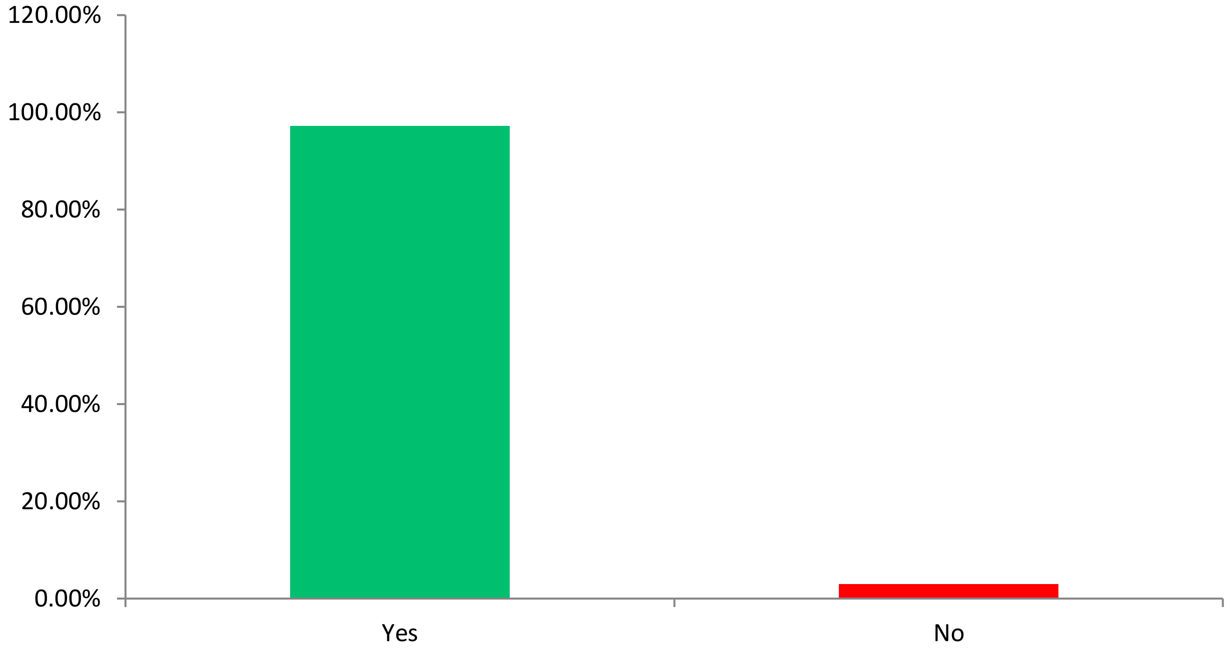
“Whether the person is practicing their religion. • Any religious beliefs or practices that might affect how care is delivered. • Individual Spiritual needs • Details of any belief about the end of life and the process of death. • What should happen to the body after death”

“We should report anything that is important to the person and maybe that should be the question. "what is important to you" what would you want us to know?”

“I am not sure this is needed in the end of life standard particularly as i would have though relevant information around this would be in the 'about me' standard”

6 Does having a personal care and support plan enhance advanced care planning?

Question 10
Do you think that having a personalised care and support plan, that includes information about cultural? and spiritual wishes, will help to inform a person's advance care plan?



Answer Choices		Responses	
Yes		97%	301
No		3%	9
Comment			88
	Answered		**310**
	Skipped		**140**

91% service users and informal carers agreed that having a personal care and support plan enhanced advanced care planning.

Of the 88 people who left comments on this question 24 % were definite that personal care plans enhance advanced care planning with a further 47% citing that religious and spiritual issues should be included in care planning while 21% felt it would improve the holistic care of the people at end of life. Some responders cautioned the collection of too much information especially through tick boxes. Service users' comments aligned with these key themes.

Some selected comments include:

"It is important for the individual to be able to record their own wishes and for health staff to understand these."

"If they have cultural and/or spiritual wishes/requirements that they want incorporated into their care."

"A personalised care plan provides detailed information to help understand the individual's cultural and spiritual needs and those of their family".

"On retrospective death audits I have undertaken, patient's with a shared ACP has the most positive outcome"

"yes, as long as it is open enough for people to express preferences, choices, cultural requirements and indeed to state they do not wish to disclose details".

7 Is there any information on holistic care not included in personal care and support plans?

Question 11

"Is there any information about a person's holistic palliative or end of life care needs that isn't included in the personalised care and support plan?"

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data to include	**Number (% of responders)**	**Rationale**
No further data is required	80 (39%)	Many respondents felt that the standard didn't need any further information added
Not sure or don't know	18 (9%)	Some felt they could not think of anything else to add or are not sure what extras were needed
Anything that is important to the patient	39 (19%)	Some respondents felt a free text box could be added asking the patient to add any information that was important to them
Wishes on death and funeral	16(8%)	Some felt that preferred places of care and death, religious requirements, information on organ donation, funeral wishes could be added
Person's background and environment	20 (10%)	Some suggested that understanding more about the patient's background, family structures, pets, befrienders, nutrition preferences, biography would be helpful
Holistic and escalation planning	12 (7%)	Some wanted to ensure that plans are holistic and included or linked to escalation plans
Respect	7 (4%)	Some wanted to ensure this information linked to or included the Respect form
Miscellaneous	7 (4%)	Some wanted to add information on diagnosis, equipment, mental capacity
Caution	24(12%)	Some expressed concerns that the information was only as good as how it was completed and there needed to be instructions and training on completing the information. Also, terminology used should be in plain English.

205 people responded to this question in the survey.

52% of service users and informal carers felt no further data on holistic care was required in the personal care and support plans. 16% were not sure about what else could be added while 16% expressed concerns that the information standard was completed correctly by the appropriate professionals.

Some selected comments include:

“ I think that very much depends on the skill level of the person completing the plan and the time that they are given to complete it”

“The personalised care and support plan does not cover content. Allergies are not currently covered. For somebody that is unable to express their needs, this is very important.”

“I think it is fairly comprehensive. If too much info it will make it unwieldy to use for both patients and health care professionals. However I do wonder if there should be something to indicate if a safeguarding has been raised in recent past, or person is considered vulnerable or lacks mental capacity?”

“the personalised care and support plan should be holistic and include physical, psychological, social, spiritual and information/insight needs”

“I'd suggest asking if there is anything they'd like to say, maybe something not asked and may be important to them. Maybe reduce the total words, too, simplify things.”

“The current epaccs data set doesn’t effectively differentiate between frailty and palliative care. The differences and overlap is poorly understood”

8 What further information should the standard contain on care plan decision making?

Question 12
“It is crucial to involve the individual (and their carer if they wish) in end-of-life care decisions and agree a personalised care plan, to ensure that they remain in control. This is fundamental to keeping an individual’s dignity at a time when they are likely to be feeling at their most vulnerable. A person may choose not to be involved in care decisions or they may lack capacity to make care decisions. When an individual or their carer has been involved in care planning decisions, we make a note of who the plan was agreed with
Person- Name-Role Is there anything else we should record?”

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data to include	Number (% of responders)	Rationale
Contact Details	52 (21%)	Most wanted contact details including phone number of those involved in care planning decisions to be added
All those of importance in decision making need to be recorded here	42 (17%)	Many want to record who else is involved in the subject’s care and maybe not be present or was present but not part of decision making or needs to be informed of decisions or is excluded from the decision process for some reason
Date and Time	37 (15%)	Some felt it was important to note the date and time of decisions
Relationship to patient	29 (12%)	Other felt the relationship of those involved to the subject was important to capture
No	33 (13%)	Some people felt that it was not necessary to collect further information
Review date and version control	33 (13%)	Some felt as plans may change over time so it was important to record the review date and the versions of changing plans

Legal Power of Attorney	25 (10%)	Some people felt it was important to note if there was a power of attorney for health and who had it and how it could be located
Comment Box	10 (4%)	Some people felt that a comment box could be added here for other relevant information.

247 people responded to this question.

22% of service users and informal carers felt that all those of importance in the decision-making need to recorded.
18% of service users and informal carers felt that recording the dates and times of all decisions were important to know.
7% felt contact details were important and 8% felt review date and version control were important.
11% wanted to ensure legal power of attorney was recorded.
10% wanted a comment box to capture any other information that was not specifically included.
21% felt it was not necessary to collect any further information.

Some selected comments include:

“The date when the decision was made and the date when it must be reviewed by as circumstances and views change”

“What has been discussed and what hasn't. Just a tick box - discussed with patient - must be on the form. That then emphasises the need to talk. My Dad's care plan was never discussed with him nor with myself, his carer. I just read it after the community nurse left it in a box. It wasn't the document that it should have been, potentially because of time constraints and the sheer volume of care that each individual nurse was having to deliver (pre-pandemic), however, the failure to focus on the holistic role of the document in ensuring a 'good' death meant that opportunities to make this happen were missed.”

“Worth considering other individuals close to the patient who may not have been able to participate in the decision, e.g. are there other children who were not present, yet who the patient considers as being close enough that they should be consulted about the decisions made. Similarly who are the people who should be informed of the plan and decisions made?”

“If the patient chooses not to discuss their end of life care and any specific wishes they have relevant to their choices. Many patients choose to die in denial needs to be recognised”.

“Name of a person if they have lasting power of attorney for health decisions or court of protection”

“For children it is almost always parents. Hence their name, contact numbers addresses will be helpful. Parental responsibility. Not necessary that a father has that. In very rare cases the responsibility might be with the Social care if parents are not on scene and child is with foster carer.”

9 What information should be recorded on the carer’s needs

Question 13
What information about the carer’s needs should be included here?

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data to include	**Number (% of responders)**	**Rationale**
Support required	95 (40%)	Many respondents felt that this part of the standard should capture if the carer requires further support including respite care and if they are aware of the support available and have access to this support
Carer’s capacity	72 (30%)	Some raised the need to understand the carers capacity to cope especially elderly carers and highlighted the need for a full carer’s needs assessment
Impact of caring on the carer	42 (17.5%)	Some wanted to record If caring had a particular impact on the carer including mental and emotional impact
Communication details	72 (30%)	Some wanted to capture contact details of all carers, best time and method of communication and relationships or dynamic among more than one carer
Carers relationship to the subject	12 (5%)	Some felt it was important to capture the relationship of the carer to the person they care for
Record elsewhere	4 (2.5%)	A minority felt the carers needs should recorded elsewhere .

240 people responded to this question.

36% of service users and informal carers felt it was important to capture the carer’s capacity to cope.
22% said information should include the support required and available to the carer.
18% said the impact of caring on the carer should be included.
28% felt communication and contact details were important including how to communicate, telephone numbers and best times to reach the carer.

Some selected comments include:

“How and when they want to be contacted. Anything they want recorded about where they need support in their caring role, covering such matters as back up and respite and who else will step into the caring role if they are unable to continue (that is if there is anyone)”

“Social care details if relevant, eg if carer is a spouse/partner in sheltered housing. Any health issues that might be relevant (eg mental health)”

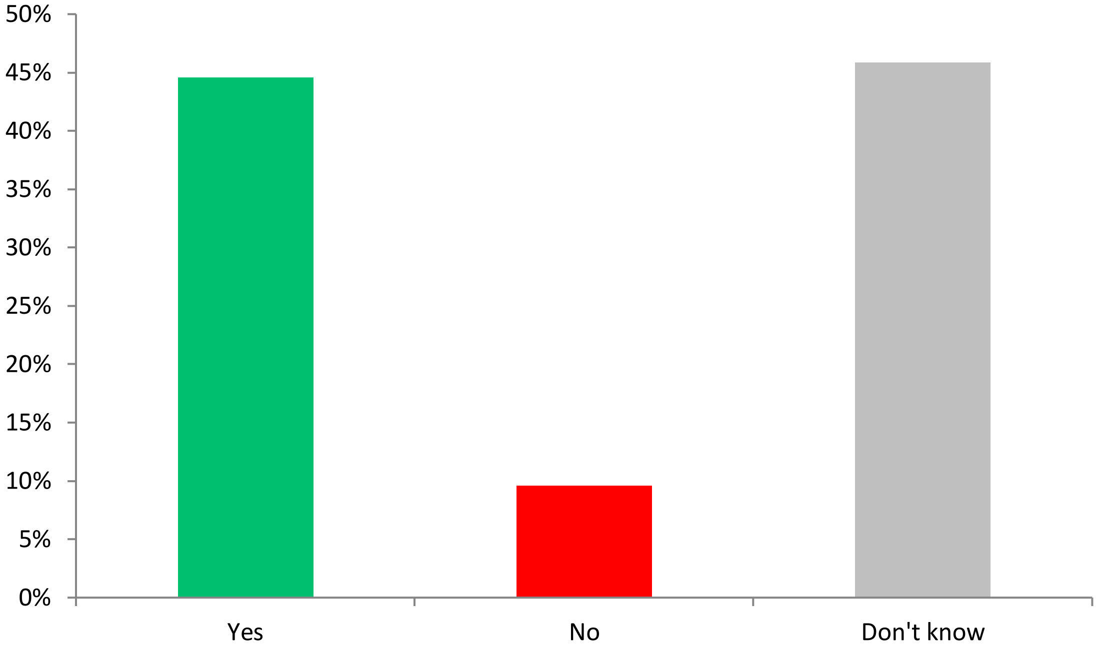
“Ensure that they have access to a full carers assessment”

“Anything relevant to their ability to provide care which they consent to being recorded
link to carers needs assessment eg CSNAT free text box for comments code to say carers needs assessed
only those relevant to the care plan and with consent of carer”

“What aspects of care they are involved in, relationship to the patient, support available and support offered.”

10 Should Child CRP data be added to the standard?

Question 14
When recording cardio-pulmonary resuscitation (CPR), some areas include an option for recording modified child CPR. Should this be added as standard?

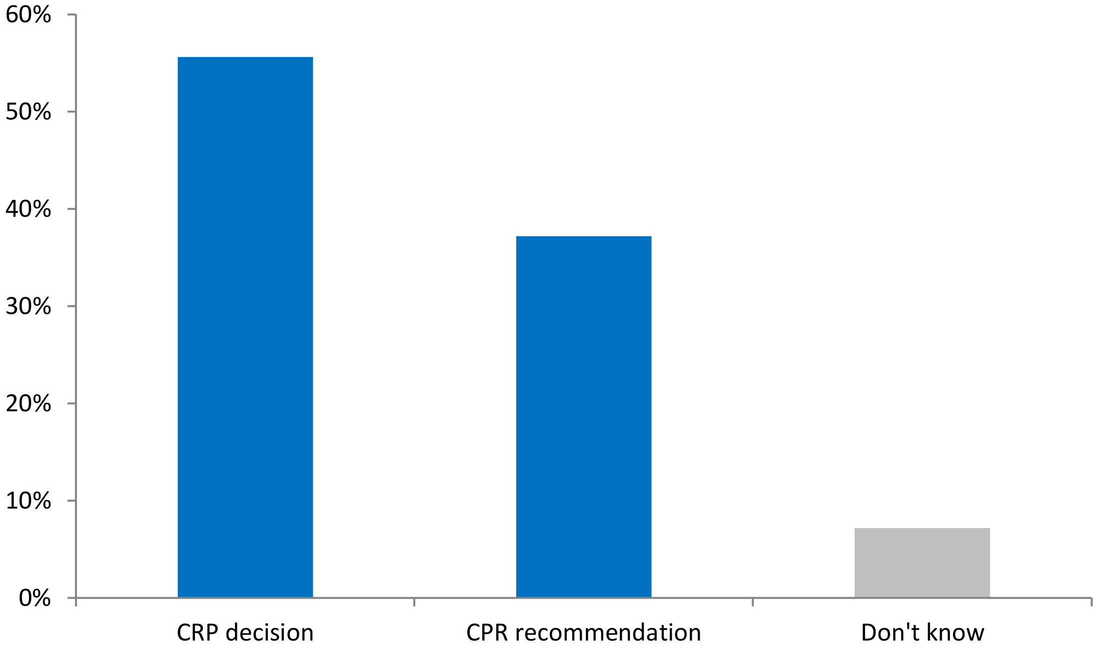


Answer Choices	Responses	
Yes	45%	135
No	10%	29
Don't know	46%	139
	Answered	**303**
	Skipped	**147**

Among service users and carers only:
42% replied ‘Yes’.
18% replied No.
40% replied ‘Don’t know”.

11 CPR recommendation or CPR decision?

Question 15
When we talk about CPR instructions, some areas use the term 'CPR decision' and other areas use 'CPR recommendation'. Which term do you think is most appropriate?



Answer Choices	Responses	
CRP decision	56%	163
CPR recommendation	37%	109
Don't know	7%	21
Comment		119
	Answered	**293**
	Skipped	**157**

Among service users and carers only
62% opted for "CPR decision"
34% opted for "CPR recommendation"
4% opted for "Don't Know "

Some selected comments include:

"Decision feels more instructive implying a conversation has been had and decision made. Recommendation feels open and what if that meant families/ carers could interpret that to mean something else."

"Recommendation suggests that health staff have discretion to act differently, if so it becomes necessary to set out what the issues for decision are."

"Decision is reasonable as professionals reading it in future should appreciate any decision is time-specific and subject to change/review. Recommendation seems less 'decisive' and perhaps too 'burdensome' to the emergency responder - faced with a cardiac arrest and only a recommendation, then who decides whether to start CPR...?"

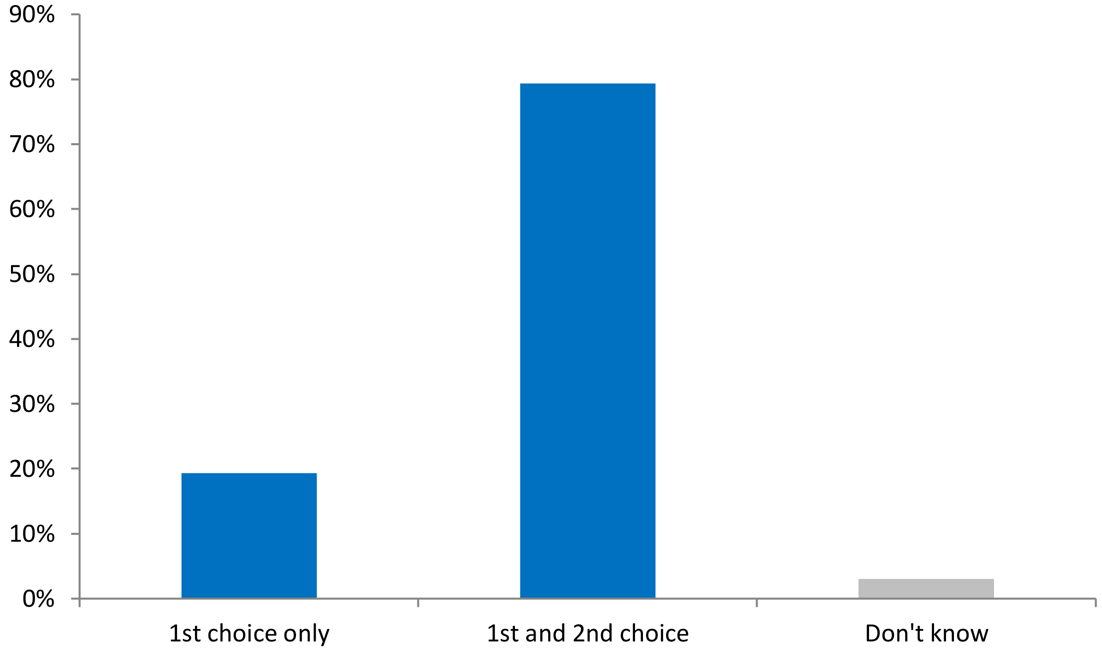
“Whatever term is used should reflect any autonomous decision made by that individual whilst acknowledging any clinician needs to evaluate the situation (especially if there is an emergency) and reach her/his own conclusion at that time taking into account any previously documented wishes, their findings along with any additional information provided by relatives or carers.”

“Other terminology also used eg Allow Natural Death”

“if recommendation then person and their carer needs to understand their wishes may be overridden and why”

12 Preferred place of death

Question 16
Preferred place of death’ records the place the person would prefer to die or where someone representing them prefers. Should the standard include two choices for ‘Preferred place of death’ or just the person’s 1st choice?



Answer Choices	Responses	
1st choice only	19%	57
1st and 2nd choice	79%	234
Don't know	3%	9
Comment		119
	Answered	**295**
	Skipped	**155**

Among service users and carers only:
27% opted for “1st choice only”.
70% opted for “1st and 2nd choice”.
3% opted for “Don’t Know”.

119 respondents left comments on this question:

40% felt that the subject’s first option was not always available and this information was helpful to ensure the person and their family had choice. (31% of service users and carers raised this issue.)
21% felt the wording of this information and the offer of two choices was helpful.
26% expressed caution that it may not always be possible to met a person expectation and the way the information was collected was key to ensure family members did not feel guilty if they cannot cope. (31% of service users and carers raised this issue.)
15% wanted to include a free text box to capture further information and help open communication on the issue as they felt that is more nuanced than simply two choices. ((17% of service users and carers raised this issue.)
8% felt it was important that a person’s wishes are met and 7% felt there was a requirement for more hospice care.

Some selected comments include:

“it should say 'home' or 'not at home'”

“This is quite general, e.g. 'in hospital' or 'at home'. More than one choice doesn't seem necessary. It is very important for staff to find out this preference sensitively and not ask blunt questions like 'where do you want to die'!”

“1st and 2nd choice ‘gives greater likelihood that their wishes are fulfilled”

“ the plan should state the prefered place 'if possible”

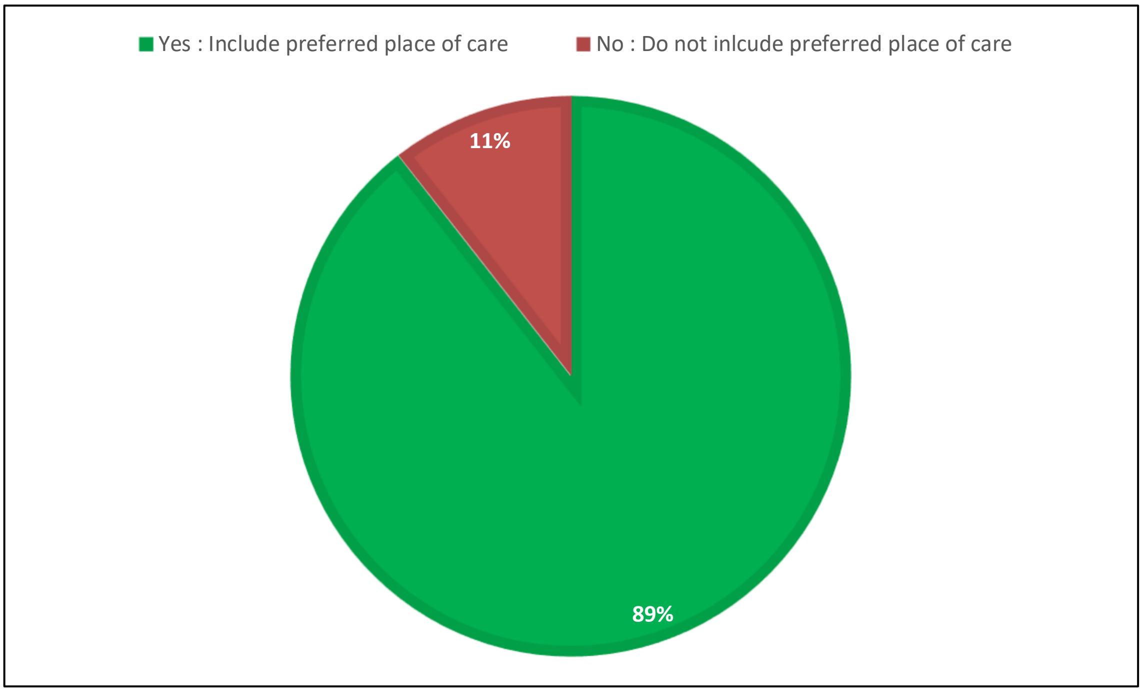
“This is not always possible, for example someone may ask to die at a hospice but the hospice has no beds. So alternatives may be helpful for the next of kin when grieving so as not to feel like they failed the individual”

“My husbands preferred place of death was home but we couldn’t keep on top of his symptoms at home so second choice was Hospice - this was all happening Out of Hours so records need to be visible for all”

13 Preferred place of care

Question 17

'Preferred place of care' is the place where the person most wishes to receive care or where someone representing them prefers. This may be subject to change and depend on the clinical need of the individual, and not all areas of the UK record this information. Should this be included in the standard?

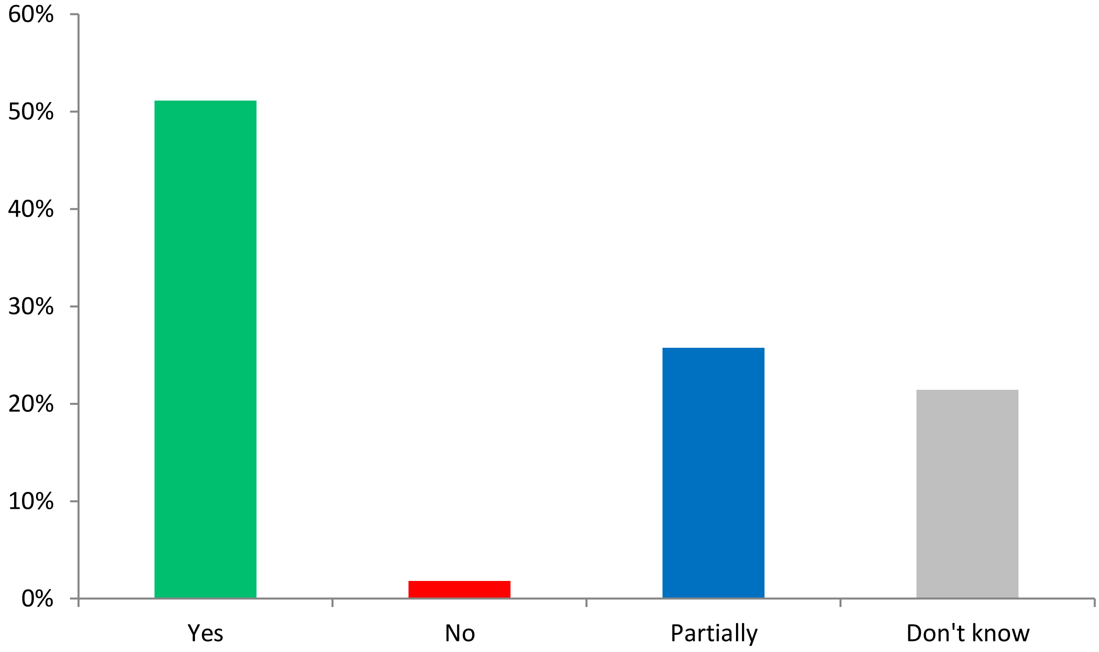


303 people responded to this question.

97% of service users and carers felt 'preferred place of care' should be included in the standard:

14 Does the standard contain the correct information to ensure a person’s care needs is met?

Question 18
From the view of the person receiving care does this standard contain the right information to allow their care needs to be met?



Answer Choices	Responses	
Yes	51%	143
No	2%	5
Partially	26%	72
Don't know	21%	60
Please explain your answer		98
	Answered	**280**
	Skipped	**170**

Among service users and carers only:
41% opted for “Yes”.
4% opted for “No”.
26% opted for “Partially”.
29% opted for “Don’t Know”.

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data to include	**Number (% of responders)**	**Rationale**
Dependent on detail and completion	41 (42%)	Many felt the standard covered what was required but wanted to point out that how the data are collected, ensuring all details are captured thoroughly and the data are reviewed and amended as required are key
Person centered	26 (27%)	Some felt it was paramount that the wishes of the dying person and discussions with them and their family were paramount. It should be a holistic approach
Advance Planning	13 (13%)	Some felt planning was key including advance care planning and contingency planning and should be highlighted and reviewed as required
Missing Items	9 (9%)	Some cited missing information including recording the mental capacity of the person, who was involved in discussions around their care, and their 'best interests'. Also safeguarding, use of digital apps, escalation issues and what the person was like before becoming ill were suggested
Religious, Spiritual and Death wishes	8 (8%)	Some felt this data was very important including preferred place of care and preferred place of death.
Medical Information	2 (2%)	A few people felt the standard should capture the more complex clinical needs of the person
What are the persons options	2(2%)	A few felt there was a need to inform the person as to what services were available to them
Pilot the Standard	2(2%)	A few people mentioned the need to pilot the standard to ensure it captures the required data adequately
Carer	1 (1%)	More information on the carer and their relationship with the person.

98 people provided comments on this question.

46% of service users and carers felt that while the standard captured the right data to meet the patient's needs but much depended on how the information was completed and how accurate it was.

31% of service users and carers wanted to ensure religious and spiritual issues were included, the ReSPECT form conversation was included and the terminology used on the form was clear and unambiguous.

Some selected comments include:

"Emergency/ crisis prevention needs to include all the Holistic needs of the patient and family"

"Sometimes the patient isn't fully involved, a GP or other think they know what's best"

"It would be helpful to include more information about the person as an individual and what activities, contacts or surroundings are important to them."

"Records persons wishes of care planning and medical information and contact details for people involved in their care and who to contact in the care of persons deterioration"

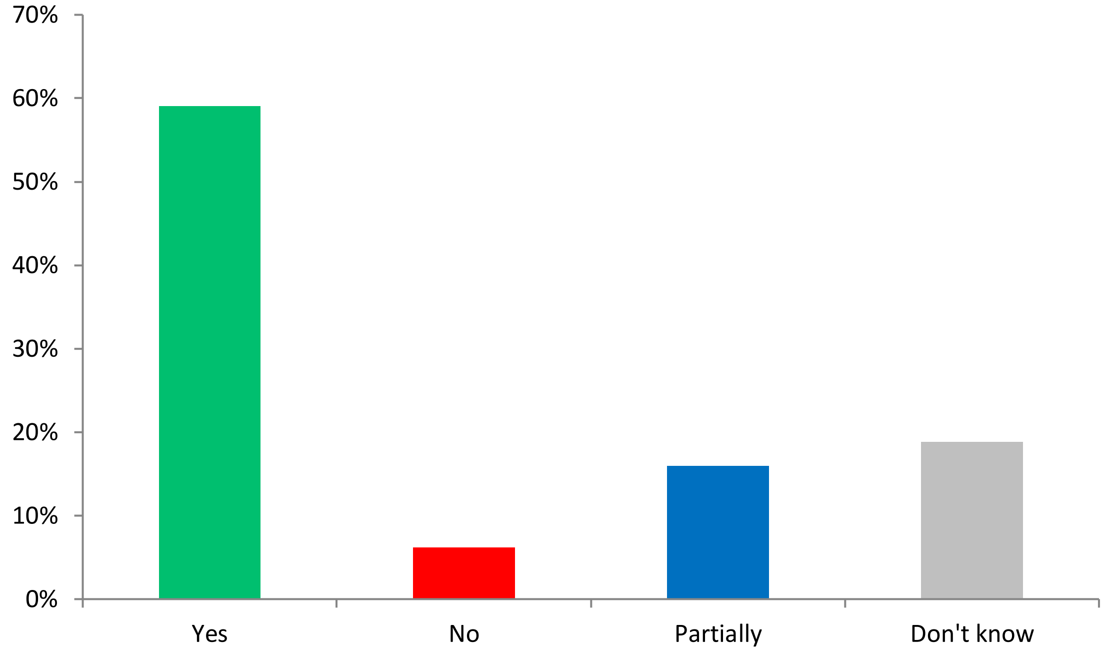
“As long as supporting documents such as About Me and care and support plans are fully completed”

“In my opinion the key aspects are to discuss ceilings of care and preferred places of care and death. These are all covered well.it would be helpful to ask "what is a good death?" to allow the patient to express their fears and concerns about dying.”

15 Is the information in the standard clear as to who was involved and what decisions were made?

Question 19

Will it be clear from the information that the person, their carers and family or representatives have been involved and have agreed with all the major decisions made to date?



Answer Choices	Responses	
Yes	59%	163
No	6%	17
Partially	16%	44
Don't know	19%	52
Please explain your answer		86
	Answered	**276**
	Skipped	**174**

Among service users and carers only:
58% opted for “Yes”.
8% opted for “No”.
15% opted for “Partially”.
19% opted for “Don’t Know”.

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data to include	**Number (% of responders)**	**Rationale**
Dependent on detail and completion	37 (43%)	Many felt how thoroughly and correctly the details are captured is key and how the data are reviewed and amended over time
Communication	29 (34%)	Some felt that communication with the family and carer was key but also how the information in the standard was available to all professionals involved in the persons care
Documentation	25 (29%)	Some felt that the family and person wishes need to be documented in the standard and their level of involvement in decision making explicitly recorded. Some were not sure if these fields were included
More Detail	19 (22%)	Some felt there need to be detailed section to capture all involved in decision making
Not clear	14 (16%)	Some felt it was not clear from the standard where this information would be captured and by who
Advanced care planning	5 (6%)	A few felt this should be part of advance care planning.

86 people provided comments on this question.

58% of service users and carers felt much depended on the how the standard was completed and wanted to ensure patient and carer agreement were explicitly sought and included throughout the completion process. 50% felt there should be good communication with person and the family on all parts of the standard information collection and on agreements reached.

Some selected comments include:

“The standard as far as I can see does not include a space where the carers/named family member is asked to agree/ask questions/state what they do not understand”

“My Dad's care plan existed, it was never discussed, so it was completely a 'tick box exercise' with no value placed on the purpose of the document, which was to talk through decisions and plan for death.”

“Will depend on the requirement for detailed free-text information about the explanations given to the person and their carers and the discussions and reasons that underpinned the ‘agreed’ plan.”

“Patient conversations about ACP and escalation plans should be prevalent. So they don't have to cover the same ground every time they speak to a professional. Although there should be a check-in about that information as their ideas on ACP or escalation may have changed.”

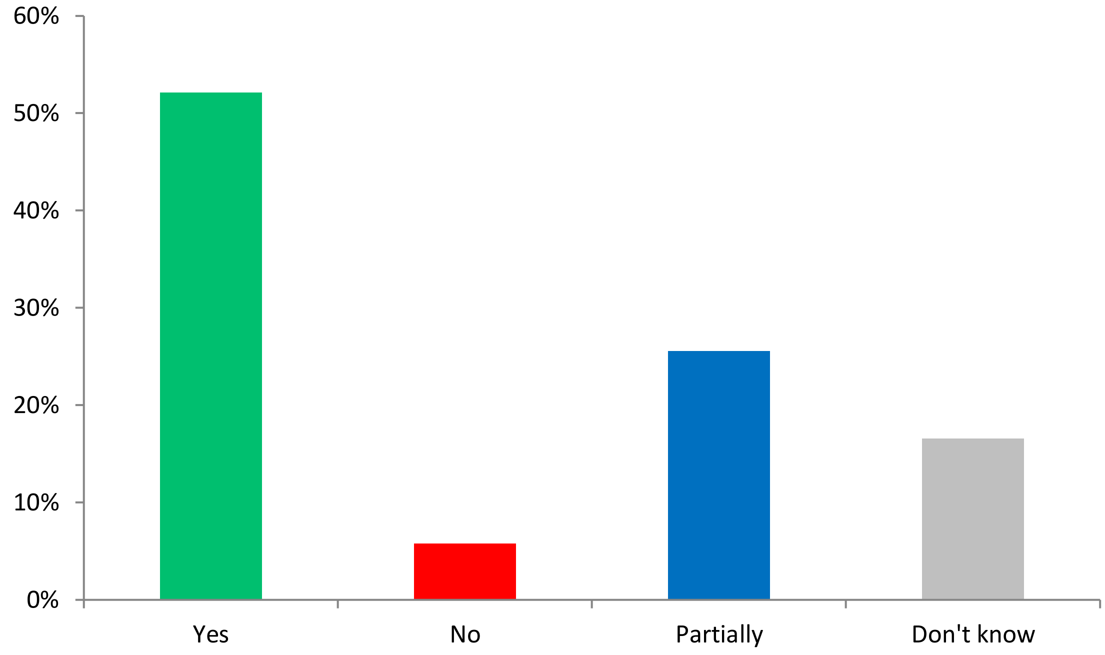
“ It is long and detailed. My concern is that there is reference to many different types of care plan and this is incredibly confusing to understand what information to place in the different sections. But i am not sure there is a place to record specific information related to the wishes and preferences at the end of life - an advance care plan”

“sometimes the patient isn't fully involved, a GP or other think they know what's best”

16 Is it clear from the information standard what actions are needed and who will do them?

Question 20

Will it be clear from the information what actions are needed from the health and care staff and who is being asked to do them?



Answer Choices	Responses	
Yes	52%	145
No	6%	16
Partially	26%	71
Don't know	17%	46
Please explain your answer		95
	Answered	**278**
	Skipped	**172**

The main themes identified from the qualitative analysis of those who left comments:

Feedback on data to include	**Number (% of responders)**	**Rationale**
Completion and ownership	34 (26%)	Many respondents felt that how the information was collected and who was responsible for completion were important in order to clarify actions
Details	26 (27%)	Some felt the information details need to be explicit and comprehensive and allowances made for how information can change over time
Planning	19 (20%)	Some felt that alignment or inclusion of advance

		planning was key to success
Documentation and terminology	14 (15%)	Some felt the documentation and terminology used while collecting the information was important and should be clear and unambiguous
Structure & Layout	7(7%)	Some felt that the layout of the ‘forms’ collecting the information and the structure of how the information was collected was also important.

95 people provided comments on this question.

The responses from service users and carers followed the same themes as in the table above.

Some selected comments include:

“It should be clear but again the tool is only as good as the person using it . Therefore the standard needs to include something which requires the health and care staff to understand the document and what their roles and responsibilities are within it”

“as long as all this information is added”

“Unable to see any clear information about this. It is crucial that a standard of this nature is easy to access, simple to understand and doesn’t involve patients, carers or professionals in frustrating trawls through numerous pages of jargon when trying to understand the purpose and required content of the records”

“It might be helpful to have a section specifically stating who is responsible for what, and any roles or actions outstanding / not yet allocated.”

“It will depend on the information provided by the person completing the care plan”

“If it is completed with empathy. And the person completing the form really listens.”

17 Is there any information missing that should be added?

Question 21
Is there any information missing that should be added? If so, please state what is missing and why it should be included.

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data to include	**Number (% responders)**	**Rationale**
No information missing	63 (42%)	Many respondents felt the standard was comprehensive and no information was missing
What matters to the person and their love ones	15(10%)	Some responded felt that what mattered to the patient (religion, spiritual, pets, wishes) and their carer/family was very important to complete
Care planning	10(7%)	Some wanted to ensure detailed care planning including advance care plans and escalation plans were included
Preferences of care around death	9(6%)	Some respondents wanted to ensure that preferences including religious, spiritual, place of death and specific death wishes were included
Detail of the data	10(7%)	Some felt the data needed to be completed correctly with proper coding and free text where appropriate
Review Date	7(5%)	Some wanted to ensure a review data was included for plans and decisions
Contact Details	7(5%)	Some wanted to include contact details of carers, family and other significant people
Extra Clinical Information	7(5%)	Others mentioned access to information of the specific clinical needs of the person including any specific conditions or medical history or treatment
Legal Power of Attorney	4(3%)	Others wanted to ensure access to the subject's legal power of attorney for health
Carer	4(3%)	Some wanted to ensure data on the carer(s) was included
Individual responses	7(5%)	Some individuals wanted the following included: social care data, safeguarding information, do not resuscitate directives, pets.

150 people responded to this question.

The comments of service users and carers followed the same themes as in the table above.

Some selected comments include:

Actions following death, not just leading to

An emphasis on discussed with patient and carer, plus the need to review, as needs change.

I think it is good to keep the document as clear and simple as possible. The only way it will become clear "what is missing" is to use it for a set period of time, review, evaluate and readjust where necessary. Adding more information at this stage would in my view complicate matters

Anticipatory care planning discussions - dignity respect and person centered care at the right time by the right people in the right place

What the person’s preferences are for the lead up to death ie do they want visitors, or to be left with close family / carers only. Would they prefer if a particular environment can be created ie playing favourite music.

clearer care plans section - who is involved, when last reviewed, what decisions have been made versus general discussions. Opening out issues to different problems - Contingency plans for different issues. What are the priorities?

18 Is there any information that is not needed?

Question 22
Is there any information that is not needed? If so, please state what should be removed and why

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data Item to include	**Number (% responders)**	**Rationale**
No	82(68%)	Many respondents felt all the data presented in the standard was required
No Sure	20(17%)	A further group were not sure what was not needed and did not expand further
Caution on data collection and data quality	12(10%)	Some responders expressed concerns that the information is collected and coded correctly. That terminology is correct and there is useful documentation and version control
Ensure data item	2(2%)	A few want to ensure information on religion and death preferences is included.
Uncoded	6(5%)	

120 people responded to this question.

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55% of service users and carers felt there was no data that was not needed with 20% unsure.
A further 20% wanted to ensure the terminology used was clear and in ‘plain English’.

Some selected comments include:

“ remove jargon and substitute with plain English.”

“Not sure . I think greater clarity about what is meant by "professional contacts" may help narrow down what is an what is not needed”

“Difficult to say - when designing a generic form one doesn't want to miss anything but sections should be optional”

“not that i recognise. This issue is more around those who read it and their interpretation”

“Not sure what you mean by After Death can that be a bit more explicit ?? Is that bereavement support because I think that should be mentioned.”

“I think that that sections are all sections listed are appropriate for recording a persons care plan”

19 Are there any further comments?

Question 23
Is there anything else on which you would like to comment?

The main themes identified from the qualitative analysis of this question are as follows:

Feedback on data Item to include	Number (% responders)	Rationale
No further comments	68 (60%)	Most respondents had no further comments
Care planning	11(10%)	Some felt the inclusion or alignment of care planning was important
Concerns	8(7%)	Some respondents raised concerns and wanted to ensure data quality, data sharing, training and documentation were key to implementation of the standard
Review Date	6(5%)	Some respondents wanted to ensure review information was included in the standard
Sharing information	5(4%)	Some raised concerns that the information can be shared among all involved in the care of the person including carers, medical staff and social care staff
Who is responsible	3(2.6%)	A few raised concerns about who was responsible for ensuring the data is collected
Children & Young People	3(2.6%)	Some raised the need for specific information for children and young people
RESPECT	2(1.8%)	Other wanted to highlight the need for the standard to include the Respect form
End of Life care	2(1.8%)	Some wanted to raise the need for better end of life care
User friendly	2(1.8%)	Some wanted to highlight that the data collection needs to be user friendly
Prognosis	2(1.8%)	Two people raised the issue of knowing the persons prognosis would help in organizing their place of care and preferred place of death

114 people responded to this question.

42% of service users and carers who left comments felt they had no more to add while some individuals mentioned the importance of care planning, a review date and ensuring clarity about who was responsible for ensuring all the information was collected .

Some selected comments include:

“ to tell a patient how long they have left to live, please ask them or their family if they or the patient would wish to know this information. My mum wasn't asked this and she was in deep shock when the consultant just said 12 weeks, as a matter of fact. When I asked my mum she said she'd rather not have known this. The consultants' can become 'sanitised' to this and not see the patients as a person with feelings. Please ask the patient first!”

“Regular review and evaluation of the actual standard is essential and also regular dated review, evaluation and readjustment is needed for each area type of plan”

“I think you should have one for adults and one for children. …”

“Hospices may have good, personalised documents which have evolved over time to reflect good practice. Also, it is helpful to sensitively obtain information very early on in the person's care.”

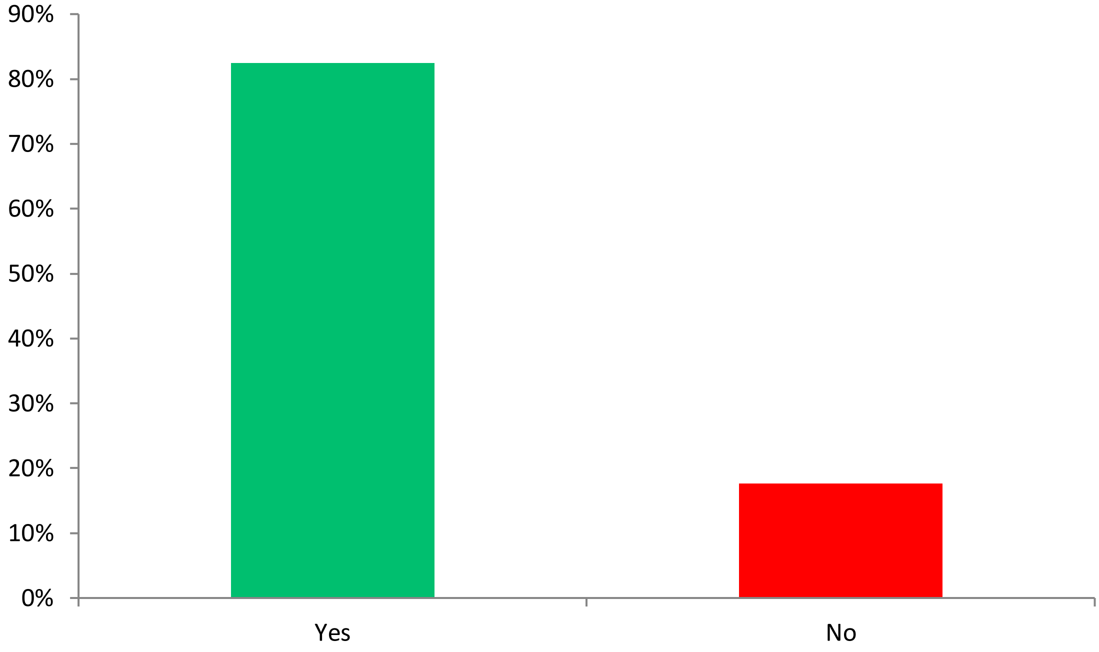
“For ease of clinical use; ACP, TEP and EPaCCS need to be separate documents as they will be required at different life stages for some people. e.g. everyone is recommended to have an ACP but may not need a EPaCCS for years or a TEP”

“This will need to be accessible to ALL health care staff who become involved with the patient - currently there are different recording systems for GP, Hospitals, Community services and social services - maybe need a key place where everyone knows they can access the plan, e.g. GP or patient held record?”

20 Should the standard record if preferred place of death was achieved

Question 24

Recording if the person died in their preferred place of death can help areas to improve the quality of their end of life care and End of Life services. We could record this as: ‘Preferred place of death achieved’ Do you think this is important information that should be included in the standard?



Answer Choices	Responses	
Yes	82%	206
No	18%	44
Comment		81
Answered		**250**
Skipped		**200**

81 respondents left comments on this question.

32% of which felt this was important to include this information because it improves audit data and thus improves quality of care and ensures the delivery of what matters to the patient. (38% of service users and informal carers agreed with this issue.)

30% felt the accuracy of the data was important especially as choice around place of death could change last minute for valid reasons and this was a subjective assessment. 20% felt that this data item was of little use. (12% of service users and informal carers also commented on this issue.)

22% felt there were more important measures to concentrate on such as quality of end-of-life care. (25% of service users and informal carers also commented on this issue.)

Some selected comments include:

“Patient choice of preferred place of death achieved?”

“Quantifying a 'good' death is a key metric for improvement”

“To document if preferred place of death requires someone to make that assessment. It is better to record the actual place of death, because then this assessment can be an automated process, reducing staff time to "close" a care plan/record.”

“Yes it should but PPOD is sometimes disproportionately applied as a surrogate marker for the quality of end of life care.”

“This is only helpful if the recording of PPD is accurate and menu options allow enough flexibility in the first place. Also need to allow for changes in PPD - even in final days a pt might decide it is better to remain in hospital rather than burden of transfer home which might have been recorded as their previous PPD. In such instances, which PPD are we judging whether achieved - they did not achieve their 1st stated PPD, yet achieved their final stated PPD.”

“Only relevant if ppod recorded and updated if changes along pt journey. Not a measure of quality as standalone. If you choose to have ppod 1 and 2….and they die in second choice have they still died in their ppod? Important to record when someone doesn’t achieve ppod and reasons why.”