Public Health England

Protecting and improving the nation's health

National End of Life Care Intelligence Network

Palliative Care Clinical Data Set (SCCI2036)

Consultation on proposed individual-level data collection from specialist palliative care

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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The Intelligence Networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National Cardiovascular Intelligence Network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

National Mental Health, Dementia and Neurology Intelligence Network

The National Mental Health Intelligence Networks (NMHDNIN) brings together the distinct National Mental Health Intelligence Network, the Dementia Intelligence Network and the Neurology Intelligence Network under a single programme. The Networks work in partnership with key stakeholder organisations. The Networks seeks to put information and intelligence into the hands of decision makers to improve mental health and wellbeing, support the reduction of risk and improve the lives of people living with dementia and improve neurology services.

Contents

1. Introduction

Public Health England (PHE) and NHS England, together with partner organisations, are exploring the potential to develop a new national data collection from hospices and specialist palliative care services.

Consultation is a key component of the work underway to develop this individual-level data collection. To date, there have been two key phases:

- capturing feedback from stakeholders and experts
- national online survey

An exploratory consultation event with key stakeholders was held in October 2013, followed by extensive consultation with experts in end of life care, specialist palliative care and data collections and a series of regional roadshow events.

This consultation informed the draft data set that was then consulted on nationally through an online survey. The survey ran throughout March 2015. This report describes the consultation plan and presents the results from the national online survey.

Further work is planned this year for consultation with patients, carers and the public to find out their views on the collection and use of this data.

2.   Consultation plan

Throughout March 2015, the Health and Social Care Information Centre ran an online consultation entitled *'Specialist Palliative Care: Proposed Data Collection'*. This contributed to the consultation plan as described below.

Communication plan stages:

Consultation with stakeholders and experts in end of life care, specialist palliative care and data collections

⬇

Draft data set developed

⬇

Online consultation March 2015

⬇

PHE to analyse/summarise results

⬇

Submission to SCCI for approval

⬇

Further consultation with the patient and public

⬇

PHE to review results/amend

⬇

Submission to SCCI for approval

⬇

Publish full report and disseminate to implementers and users

3. Results

We received 163 responses to the online consultation, of those that responded to questions:

Health or social care professionals	71
Specialist palliative care provider service managers	41
Specialist palliative care provider service data team	7
Specialist palliative care commissioners	3
Palliative/end of life care researchers	15
Policy makers	3
IT systems providers	1
Patients/carers/member of the public	5
Individual professionals	16
Professional body	1

The following section provides a summary of the online consultation.

For full details of the free text responses (Q.11, Q.12, Q.16 of the consultation), and response from the national team, please see Appendix 2.

4. Survey Questions

Question 1: Do you think a new national individual-level data collection from specialist palliative care services will improve care for individuals and their families/carers?

Responses

Yes	123	(75%)
No	8	(5%)
Unsure	27	(17%)
Not Answered	5	(3%)
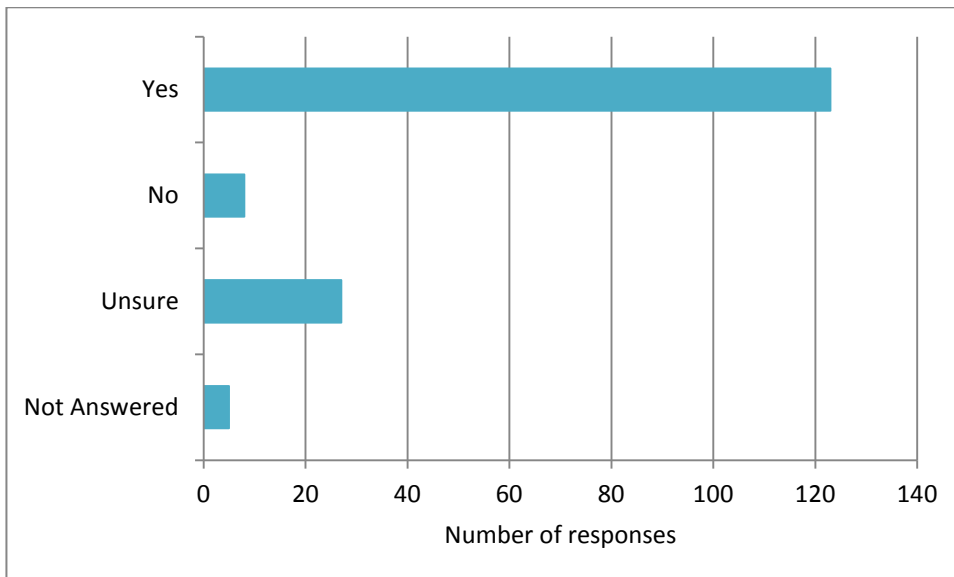
Question 2: Do you think that a new national individual-level data collection from specialist palliative care services will drive service improvement and better use of resources?

Responses

Yes	123	(75%)
No	6	(4%)
Unsure	29	(18%)
Not Answered	5	(3%)
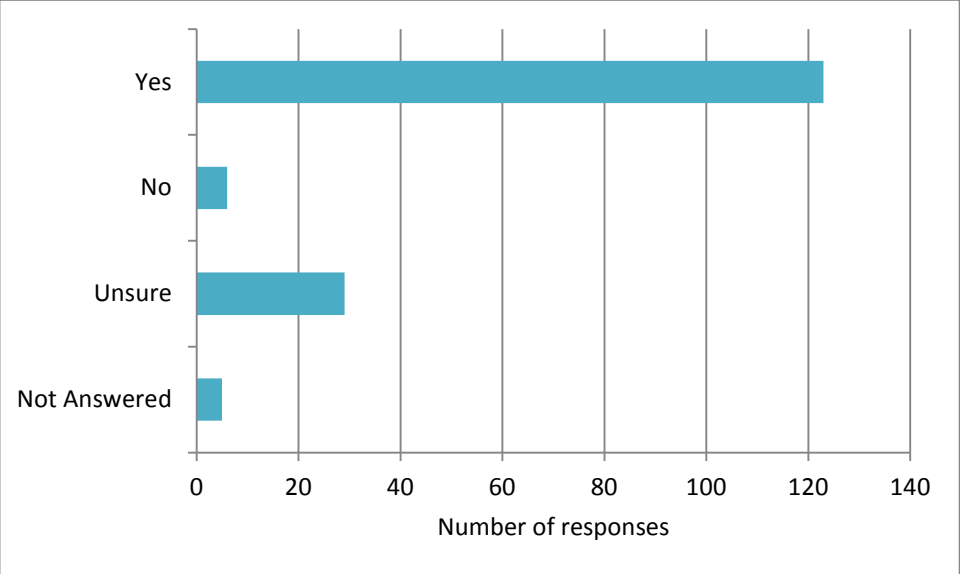
Question 3: Do you think that the proposed data items include the right information to support clinical care?

Responses

Yes	92	(56%)
No	23	(14%)
Unsure	45	(28%)
Not Answered	3	(2%)
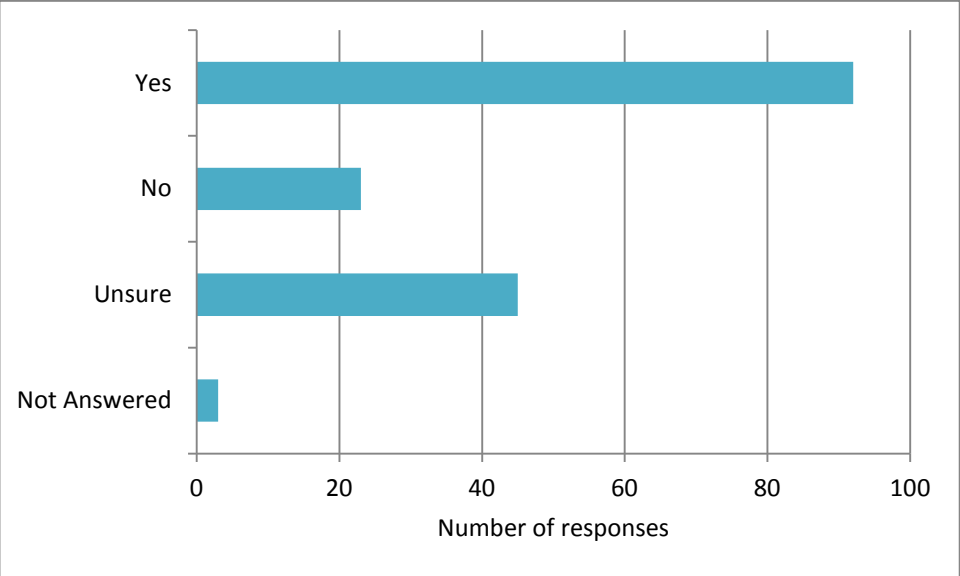
Question 4: Do you think that the proposed clinical outcomes have the potential to improve care?

Responses

Yes	84	(52%)
No	15	(9%)
Unsure	62	(38%)
Not Answered	2	(1%)
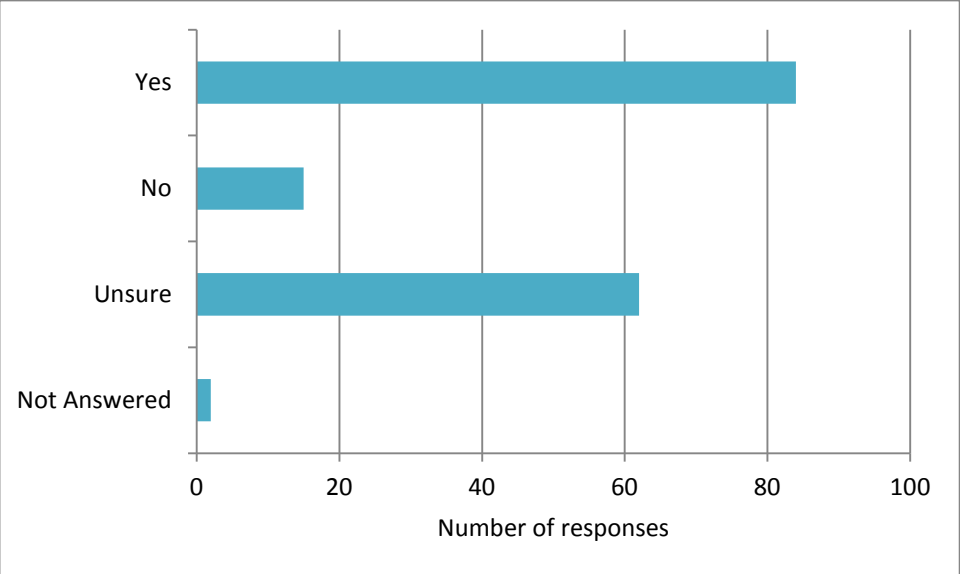
Question 5: Is the number of data items included in the data set?

Responses

Too Many	43	(26%)
Too Few	10	(6%)
About Right	106	(65%)
Not Answered	4	(3%)
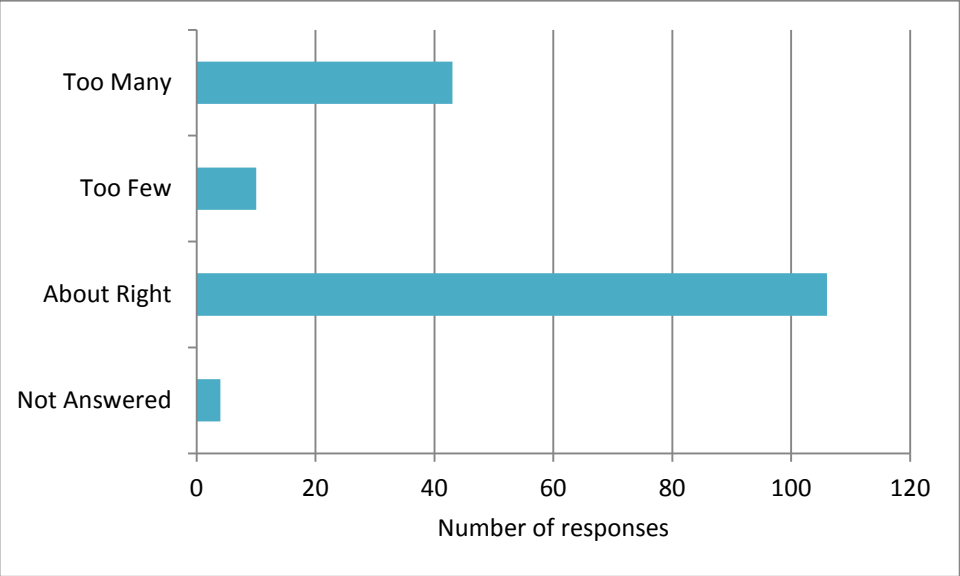
Question 6: Are there any data items that you think should not be included?

There were 60 responses to this question.

Summary of consultation comments

- overall agreement with the scale of the data collection
- too many data fields or too repetitive
- not the right data items or not likely to benefit
- confirmed data items needed and/or benefits
- not enough data items
- outcomes need to be psychometrically robust
- suggestions for what is needed to achieve
- need for automated population of data fields
- suggestions for specific data items

Please refer to Appendix 2 for a full listing of comments and the national team's response.

Question 7: Are there any additional data items that you recommend as essential?

There were 62 responses to this question.

Summary of consultation comments

Additional data items to include by category:

Demographics - age/age group; sexuality along with gender; literacy; learning disability; language; living circumstance; full postcode.

Care setting - further categories, allow more than one selection, clear definitions.

Care details - length of stay/visit; type of visit; date of visit/stay; timing of discharge and death; type of care; frequency/intensity of care; more information about a patient's care plan and treatment preferences.

Diagnosis – additional categories specified for non-malignant diseases especially for neurological conditions; include general frailty, include co-morbidities.

Advanced care planning.

Patient preferences – preferred place of care, more than 1 option preferred place of death, barriers to achieving.

Reason for referral – extend list of options, clarity on whose perspective.

Carers needs – capture additional information, including carer's needs assessment, clarity on when information is captured.

Physical components – nausea/vomiting; fatigue.

Other indices – overall QoL; economic burden; other indicator for functional status; activities of daily living; patient experience measures.

Service information – extending the 'views of care'; availability of services; individual service KPIs; reasons for admission; telephone activity; level of social care input.

Psychological well-being – separate emotional, psychological and spiritual; more on anxiety, depression/other mental health issues.

Support – people/human interaction close to time of death; bereavement support.

Resources – funding arrangements; resource use and cost effectiveness; number of hospital admission avoidance.

Children's needs – specific items for children's palliative care.

Decision making process –advanced care planning and shared decision making.

Personal goals – person's goals or self-defined outcomes.

Life history/hobbies and activities – coping strategies need to be recorded.

Full IPOS collection.

Method of data collection – need to be able to record on paper and electronic.

Complexity of cases – clarification on how to assess/capture.

Please refer to Appendix 2 for a full listing of comments and the national team's response.

All suggestions that have not been addressed by the current plans will be considered, alongside feedback from the pilot testing being carried out in 2015/16, for future addition to the data set.

Question 8: Do clinicians in your organisation currently capture clinical outcomes for individual patients?

Responses

Yes	88	(54%)
No	35	(21%)
Unsure	16	(10%)
Not Applicable	22	(14%)
Not Answered	2	(1%)
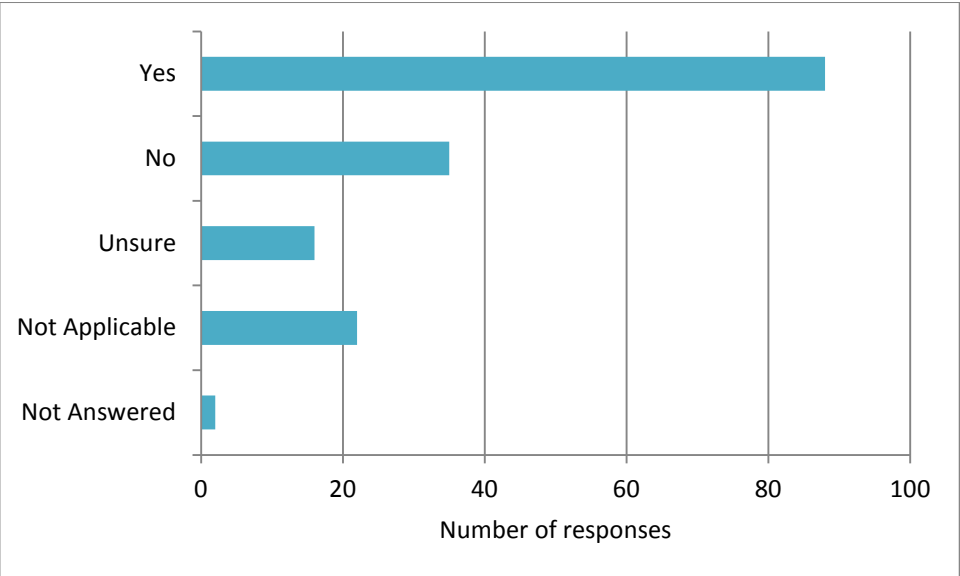
Of the 88 respondents who replied 'Yes' to clinicians currently capturing clinical outcomes for individual patients:

Responses

Electronic records   61   (69%)

Paper records   27   (31%)
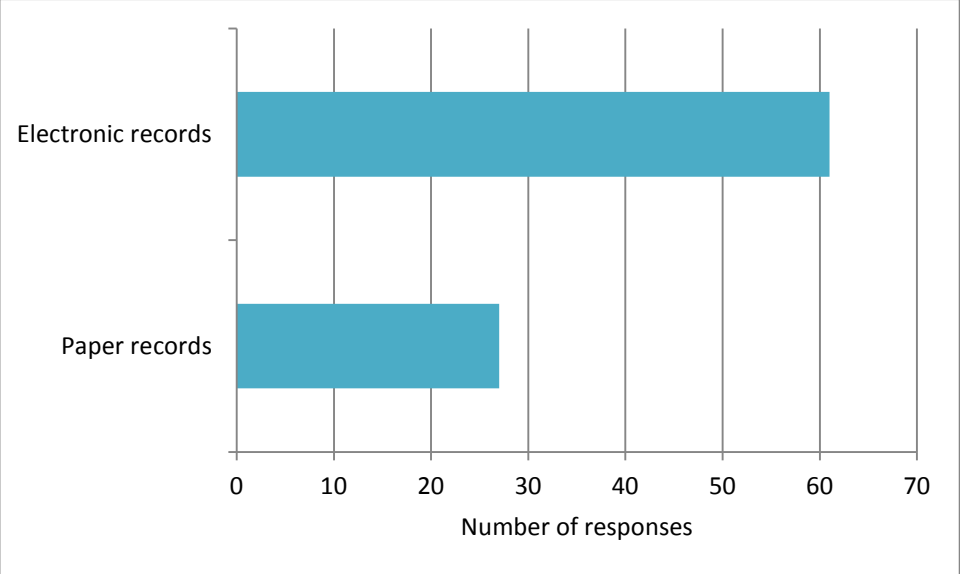
Question 9: If you are a provider service, do you currently have IT system capacity to collect and report individual-level data?

Responses

Yes	77	(47%)
No	32	(20%)
Unsure	19	(12%)
Not Applicable	30	(18%)
Not Answered	5	(3%)
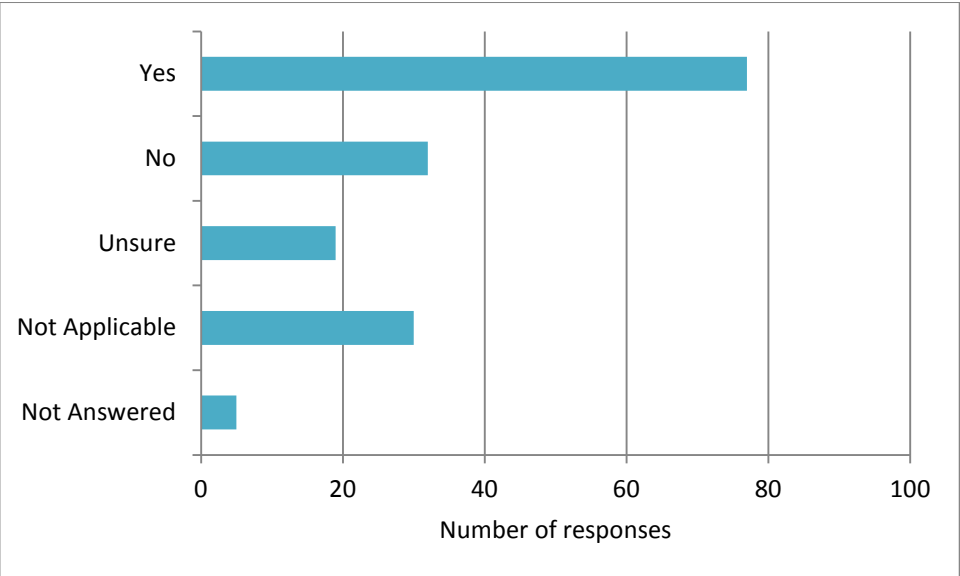
Question 10: If you are a provider service, do you expect the data collection to support you with performance reporting eg to commissioners, CQC?

Responses

Yes	104	(64%)
No	5	(3%)
Unsure	13	(8%)
Not Applicable	34	(21%)
Not Answered	7	(4%)

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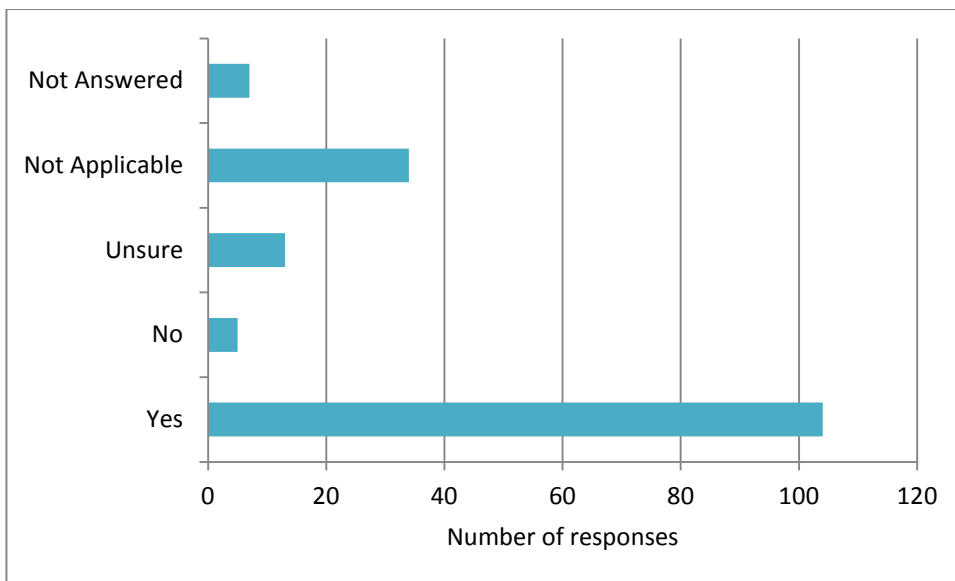
Question 11: Do you have any other comments regarding this consultation or the proposed data collection?

There were 92 responses to this question.

Summary of consultation comments

1.   Data and collection processes

Concerns:

- resources and capacity for collecting/inputting data

- duplication of data entry and how to utilise existing data

- extensive data to address only few areas of concern

- electronic systems need to be simple, easy to use and support effective data collection

- difficulty assessing 'phase of illness'

- collected data should be linked with other data sources

- challenge for small hospices if data collection is mandatory

- consent procedure and secondary use of data should be clarified

- clarity on what will be done with the data

- data security

- need to plan for extension for children and young adults

Benefits:
- provides evidence for better services

- good data is critical for service improvement and improving access

- individual-level data is important

- understanding proportion of people using palliative care services will lead to better planned services

- opportunity for hospices to share their experiences

- important for benchmarking

- important step in moving to collection of new data

- outcome data is critical – Palliative Care Outcomes Scale (POS) should be used

2.   Support Required:

- IT support and resources needed eg templates

- IT systems should avoid replication and allow uploading of existing information

- existing IT systems/capacity needs to be assessed

- admin/secretarial support needed so that it does not impact on patient contact time

- patients should be provided with information about data collection

- needs to be compatible with systems that hospices are using

3.   Data Items:

- need for consistency in interpretation/assessment of data items including 'phase of illness' and performance status evaluation

- frequency of data collection relating to 'phase of illness' is concerning

- socio-economic measures are also needed

- postcode should be fully captured to ensure analysis on deprivation

- items do not adequately reflect holistic hospice and palliative care

- need to be able to include additional locally relevant questions

- clarity required for the terms; palliative care and end of life care

4.   Training Requirements:

- clinicians will require training in the importance and value of data collection

- need for piloting of data collection and its procedures

5.   Other issues:

- as focus is data collection from specialist services, integration of services vision is neglected and not reflected in this study

- focus on data is not empowering or changing

- data capture is adult focused

- default is dissent not consent

- non-malignant group is hardest to reach and biggest group

Please refer to Appendix 2 for a full listing of comments and the national team's response.

5. Conclusion

The findings from the national online consultation reflect feedback from previous consultation events with key stakeholders and the regional engagement events. There is clear support for a new national data collection from specialist palliative care.

Public Health England is very grateful to those who responded to the survey. The feedback has identified areas where better clarity is required and was used to improve the definitions and guidance developed to support pilot sites. Suggestions for additional content will be considered alongside the findings and recommendations from the pilot sites testing data collection in 2015/16, and will inform the final data set. Feedback will also be used to identify the support required for implementation of a national data collection.

Additional consultation with the public and people with personal experience of end of life care will be carried out during summer 2015 and will supplement the findings in this report.

This consultation report was submitted to the Standardisation Committee for Care Information and, together with the results of the data collection testing, will inform decisions on a national data collection from specialist palliative care provider services.

Appendix 1: Survey

Proposed individual-level data collection from specialist palliative care.

National Consultation

Public Health England and NHS England, together with our partners, are exploring the potential to develop a new national data collection from hospices and specialist palliative care services. Following consultation with stakeholders and experts in end of life care, specialist palliative care and data collections, we have developed a draft data set for further consultation and testing.

Further information including the plans, the work carried out to date and the proposed data items is available here.

Public Health England would be very grateful if you will review this information and let us have your feedback by completing the following questions. Thank you in advance for your time.

The survey will close on Thursday 26 March 2015

Survey questions

1. Do you think a new national individual level data collection from specialist palliative care services will improve care for individuals and their families/carers?

   □ Yes
   □ No
   □ Not sure

2. Do you think that a new national individual data collection from specialist palliative care services will drive service improvement and better use of resources?

   □ Yes
   □ No
   □ Not sure

3. Do you think that the proposed data items include the right information to support clinical care?

   □ Yes
   □ No
   □ Not sure

4. Do you think that the proposed clinical outcomes have the potential to improve care?

   □ Yes

☐ No
☐ Not sure

5. Is the number of data items included in the data set:?

☐ Too many
☐ Too few
☐ About right

6. Are there any data items that you think should not be included?
☐ No- they are all important and should be included
☐ Yes- I think you should not include: (please add details- free text)

7. Are there any additional data items that you recommend as essential?
☐ No
☐ Yes (please provide details- free text)

8. Do clinicians in your organisation currently capture clinical outcomes for individual patients?
☐ Yes
☐ No
☐ Not sure
☐ Not applicable

9. If you are a provider service, do you currently have IT system capacity to collect and report individual level data?
☐ Yes
☐ No
☐ Not sure
☐ Not applicable

10. If you are a provider service, do you expect the data collection will support you with performance reporting, eg to commissioners, CQC ?
☐ Yes
☐ No
☐ Not sure
☐ Not applicable

11. Do you have any other comments regarding this consultation or the proposed data collection?
☐ No
☐ Yes (please provide details- free text)

12. Name
13. e-mail address
14. Organisation and job title

15.   Are you responding as:
(select one option)

☐   Health or social care professional,
☐   Specialist palliative care provider service manager
☐   Specialist palliative care provider service data team
☐   Specialist palliative care commissioner
☐   Palliative/end of life care researcher
☐   Policy maker
☐   IT systems provider
☐   Patient/family member
☐   Member of the public

Thank you very much for completing this survey. Your help is much appreciated.

Appendix 2: National online survey – full summary of free text responses

Q6. Are there any data items that you think should not be included?

General comments:
Too many data fields or too repetitive:

	Consultation comments	National team response
1.	There are too many ID fields. I do not understand the numerous ID codes, which seem repetitive.	The ID fields are required to enable matching of records for separate spells of care, across provider services, with other care records.
2.	Far too much detail: concerns that considerable investment will be needed including new data collection software and the recruitment of staff to undertake.	Pilots will test the burden, usefulness and feasibility of national roll-out.
3.	A bit repetitive with the National Council for Palliative Care minimum data set.	The new data collection captures individual level data compared to aggregated data in the MDS. This provides potential for additional analysis and data linkages.
4.	A lot of work to complete.	Pilots will test the burden, usefulness and feasibility of national roll-out.
5.	It is a lot to record.	A/A

Not the right items or not likely to benefit:

	Consultation comments	National team response
1.	Some of the data items, particularly the outcome measures, are not appropriate for children.	Aim to extend to children in the future when validated outcome measures are available.
2.	Straying into symptom and care quality outcomes by proxy assessments that are fraught with interpretative complexity.	Will be tested by pilots.
3.	Section 3: we are not convinced yet as a team that these items will improve the quality of care or treatment for individual patients being cared for at the time of data collection.	Will be tested by pilots.

Data items needed and/or benefits:

	Consultation comments	National team response
1.	The need and ability to capture this information is understood.	For information.
2.	I agree that all included are necessary but in practice it may prove difficult to achieve full compliance, particularly in small providers or areas that do not have good clinical or admin support to enter data.	Will be tested by pilots.
3.	We think that the items are valid.	For information.
4.	There may well be benefits for future patients in terms of using the data for developing clinical practice/service development.	For information.

Not enough data items:

	Consultation comments	National team response
1.	The proposed data collection is fairly limited in its ability to measure outcomes rather than process.	Planning to start with small data set and to test. The data set may be extended over time.

Importance of outcomes being psychometrically robust:

	Consultation comments	National team response
1.	For the outcomes data - I would recommend the use of nationally as well as internationally validated tools specific to palliative care or general. My expertise lies in psychometrics so I would really like to underline the importance of using validated tools rather than joining up items in a new way without testing first how this new configuration might do to its utility or measurement properties.	The proposed outcomes are from validated tools.

What is needed to achieve?

	Consultation comments	National team response
1.	IT will need additional support and resource to amend current data base.	Will be tested by pilots.
2.	The phased data collection element will involve a significant workload for a relatively low impact on actual patient care.	Will be tested by pilots.
3.	There is a question regarding the practicality of capturing with the patient and carer through each phase change.	Will be tested by pilots.
4.	Small providers or areas [will need] good clinical or admin support to enter data.	Will be tested by pilots.

Need for automatic population of data fields:

	Consultation comments	National team response
1.	Certain data items need to be automatically populated: 11 GP practice, 12 care setting, 15 agency code, 20 location at spell start, 34 phase ID, 35 spell ID, 36 phase data collection date, 38 date of phase change.	National team will work with IT systems providers to consider automated population of data items where possible.
2.	Needs to be populated from electronic records and all web or IT based, not paper.	The intention that the data set is part of an electronic patient record.
3.	It is a lot to record so the important thing is to ensure that the data can be captured as efficiently as possible.	For information.

Other concerns:

	Consultation comments	National team response
1.	Some [data items] are subjective regarding pain/anxiety/info needs etc.	Will be tested by pilots.
2.	As there is no money available in CCG's how can this improve care?	Expectation that improved data supports best use of resources.
3.	From my experience, not all end of life patients go through specialist palliative care services.	Agree. The data set will provide more information about those that are referred to and receive specialist palliative care.
4.	Confusion around preferred place of care as opposed to preferred place of death, carer informal carer etc.	The proposed data set includes preferred place of death. Action: to ensure that there are clear definitions for carers.

Specific comments:

No	Data items to exclude	Consultation comments, why?	National team response
1-6	Personal identifiers/ patient identifiable data	Surely against the Data Protection Act. Need to reduce. People won't be happy to consent to share this information. NHS number and ethnicity are already being collected and might be repetitive.	The identifiers are NHS number and an alternative of initials/DoB/Post code where this is not available. Explicit consent for sharing of data will be required for the pilot. The pilot will inform the consent model for national roll-out.
8-10	Reason for referral Reason for referral 2 Reason for referral 3	It is always 'specialist assessment advice and management' when referring to a specialist service. Otherwise it suggests the referring agency is able to do the specialist assessment. More important to know who made the referral. Sometimes very inconsistent, so introducing some consistency is reasonable. There does need to be clarification of 'who' defines the reason, as we know referrers and SPC teams often differ.	Expert Reference Group have confirmed that the reason for referral is specified by the referrer. This will be clarified in the guidance.

11	GP practice	GP is known – this will require some 'look up' to ensure practice code is allocated.	Options for completion of this field will be considered with IT systems providers.
13&14	Ready for service date and spell start date	Seem to be repetitive of referral date.	'Ready to start' date refers to when patient is able to be seen – this accommodates the practice some have of alerting community palliative care teams of a forthcoming referral prior to actual hospital discharge, for instance. Piloting will confirm whether this is feasible and useful to collect.
16-18	Client reference Client ID Spell ID	Client reference and client ID appear to be the same? Client reference: N/A to acute trust. Client ID & spell ID: not needed.	The ID fields are required to enable matching of records for separate spells of care, across provider services, with other care records.
19	Consent	It is not usually obtained for use of patient data in audit or service evaluation. If consent is obtained for other secondary uses then that secondary use needs to be specified for each consent - a global consent for secondary use is not helpful. Query raised about consent needed for secondary data sharing. Practically how will this be implemented in the clinical setting? Staff need to know the procedure what happens and what to fill in when patient does not give consent or is incapacitated. At the moment that is not clear and needs to be clarified. Time could be a consideration for the process of obtaining consent.	Explicit consent for sharing of data will be required for the pilot. The pilot will inform the consent model for national roll-out.

11	GP practice	GP is known – this will require some 'look up' to ensure practice code is allocated.	Options for completion of this field will be considered with IT systems providers.
20&27	Location at spell start postcode	Both should be included in section 1, patient identifiable data, as this can identify an individual, especially if the person lives alone. The BMA recommend these data fields be moved to section 1.	Expert Reference Group feel that it is valuable to capture this information is captured for each spell as patients may move location.
21	Living conditions	Suggest either we just ask about whether the patient lives alone or provide more options for the descriptors for living conditions.	Proposal is to capture whether person lives alone.
22	Preference for place of death	Usually contingent on the circumstances therefore collecting a single preference gives a false picture. Is tricky – evidence that 20% will change their minds over time. Many people are unwilling to discuss and may not be appropriate at early stage of illness. Difficult to capture accurately without a whole systems approach (if they are discharged with FastTrack funding we know we are discharging to their identified PPD but what happens if they are then admitted elsewhere if there is a change in circumstance?).	Expert Reference Group has considered the comments and decision made that the following options from national information standard SCCI1580 (palliative care co-ordination:core content) are added to this data item: Preferred place of death: patient unable to express preference Preferred place of death: discussion not appropriate Preferred place of death: patient undecided Additional guidance will be provided to support completion of this data item and regular review of people's preferences.
23	Personalised care plan	This is a process measure and without further information it is probably useless, as	Expert Reference Group has considered the comments. It acknowledged that all patients should have personalised care plan and collection of the

11	GP practice	GP is known – this will require some 'look up' to ensure practice code is allocated.	Options for completion of this field will be considered with IT systems providers.
		tick-box exercise. Surely all will be yes if they have had a specialist palliative care assessment. This is palliative practice and will be ticked as having been done in every case.	data item may be found not to be useful but the piloting will confirm and inform final decision. Additional guidance will be provided for the pilot sites.
22&23	Preference for place of death Personalised care plan	Both to be moved to Section three, all of which will be completed by a clinician. Section one and two are likely to be completed by administrative staff.	Expert Reference Group has considered the comments and confirmed that the clinician needs to complete these fields. Supporting guidance will reflect this requirement.
26	Secondary EoLC Diagnosis (2)	Option 2 is very complex and capable of misinterpretation.	Expert Reference Group has considered the comments and recommends that secondary diagnosis is include in the evaluation of the pilot testing. In the future, linkages with Hospital Episode Statistics (HES) could provide this information.
27	Postcode	Maybe LSOA so that analysts could do LA, district or ward breakdowns. Why a full postcode and not just the first half of it.	Full post code is required: • as identifier • to enable analysis of socio-economic status and equality
28	Disability	Not needed in such depth practically. May not be known to healthcare professionals. Needs definition – what constitutes a disability? Is it patient defined? How will disability information be collected? Would the patient themselves report this?	A definition is included for disability Expert Reference Group has considered the comments. The feasibility and usefulness of disability will be tested through there pilots and will inform whether this data item is included in the final data set.

11	GP practice	GP is known – this will require some 'look up' to ensure practice code is allocated.	Options for completion of this field will be considered with IT systems providers.
29	Case mix	Not really sure what this is. When I read it I wondered if it was intended to capture performance status, but I see you have Australian Modified Karnofsky Score later on so I was then even more puzzled.	This is a weighting that will be used to adjust the analysis based on specific data items.
34-36	Phase ID Spell ID Phase data collection date	Technical description. Baffling.	Will review and update as required.
37	Phase of illness	Disputed internally as being helpful - open to 'game playing' for various reasons. Too complicated especially change in phase rater comparability and consistency. Often difficult to establish other than retrospectively. Is the implication of this section that the form will be changed repeatedly?	Will be tested by pilots.
39	Functional status	Could be confusing, especially to practitioners who are not familiar with the AKPS- is the question 'are they functioning at their usual level' (potentially this could include their 'normal' long-term vegetative condition) or is this 'are they competent'?	This has been tested in the palliative care funding pilots and is included in the EPaCCS data set. The pilot sites will test the feasibility and usefulness of collection of this data item.
40-45	Symptom assessment section and patient experience	Very complicated to capture robustly via electronic system. Items on symptom control are difficult to	Will be tested by pilots. Clarification of the timing of data collection will be

11	GP practice	GP is known – this will require some 'look up' to ensure practice code is allocated.	Options for completion of this field will be considered with IT systems providers.
		interpret when involvement is in an advisory role eg, how to interpret improvement in pain control following surgery/lancing of an abscess in hospital/a spell of IV antibiotics in hospital, but patient also under hospital palliative care team?	provided to the pilots.
		Need to clarify if these are the problems identified on first assessment. If throughout care period these symptoms may resolve how can this be identified?	
42	Feeling 'at peace' question	Why is it seen as an outcome we wish to achieve, some patients do not want to go gently into the night!	Will be tested by pilots.
		Not sure what is meant - need further definition?	'At peace' is part of IPOS- a validated tool.
		Explanation of why 'nausea' substituted by 'at peace' would be helpful. Has the item 'at peace' been piloted around the country, in a way that is representative of differing regions? Is there evidence that routinely asking this question has proved of benefit to patients? I would struggle to ask this of a patient in extremis, at the beginning of an unstable phase.	
44	Information needs	To be recorded at each phase change may be difficult in an acute trust.	Will be tested by pilots.
45.47	Views on care Carer views on care	Will not be valid if collected as part of the clinical assessment or in a patient	Will be tested by pilots.

11	GP practice	GP is known – this will require some 'look up' to ensure practice code is allocated.	Options for completion of this field will be considered with IT systems providers.
		identifiable way due to reticence to criticise directly those giving them care. Also if collected in line with the other assessments the frequency would be burdensome. If collected should be by anonymised method at the end of each spell of care. Same for carer view on care.	
		To be recorded at each phase change may be difficult in an acute trust. The answer could relate to any level of care across the acute environment rather than palliative specific. These are also not included in the Australian Palliative Care Outcomes Collaboration assessment, and carer/family needs are recorded separately. Perhaps these could be identified better in a more informal manner as part of routine practice as appropriate, or through an independent survey.	
34-47	Including: Functional status / AKPS Phase Pain Breathlessness At peace Anxiety/distress Information needs Views on care	A direct quotation: '34-47 will not be helpful in my view. Having worked as a palliative care registrar and palliative medicine consultant in Adelaide, South Australia from 2006 to 2014, I saw the implementation of PCOC and move towards activity based funding in palliative care. It appears that the NHS is aiming to use this model. I do not believe this is a good model. A model like this seems purpose built for people that are interested in data collection and statistics. Almost every clinician, nurse and doctor, on	Will be tested by pilots.

11	GP practice	GP is known – this will require some 'look up' to ensure practice code is allocated.	Options for completion of this field will be considered with IT systems providers.
	Assessor of items Carer views on care	the ground that I worked with felt incredibly frustrated by this model. It impeded our day to day work significantly. It altered the way we were forced to conduct ourselves clinically. No longer were we driven by the patient's agenda, instead we were driven by the data collector's agenda. Consultations with the patient suffered as a result. Patients found it frustrating being asked this check-list of questions frequently. Doctors found it frustrating have to justify to managers about why patients in phase 1 or phase 3 were still in the hospice/inpatient units. Community nurses found it frustrating about having to justify why their patient was in phase 2 for a whole week. Inpatient nurses found it frustrating having to record this information daily. My advice is this will have a negative impact on patient care and staff morale and I would avoid it if possible.'	

Q7. Are there any additional data items that you recommend as essential?

Comments

Category	Additional items to include	Reasons	National team response
Demographics	Age/age group	Rather than date of birth.	Age will be calculated from DoB.
	Sexuality along with gender		To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.

Category	Additional items to include	Reasons	National team response
	Literacy		To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Learning disability	It's important to record dyslexia, where IQ may be high, but reading/writing problematic and may produce barriers.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set
	Language (need for interpreter)		Agree that this should be considered as part of the clinical data set for local use but not thought to be required as part of the national data set at this time. Will consider alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Living circumstances - the data item asks if the person lives alone (y/n), but does not give a complete picture of their circumstances. Expanding this data item to collect information about the person's support network, and to use this to identify extra support which may be needed for the patient and also for their family and friends.	What if people live in a place not normally regarded as a home, eg hostel, homeless. A person may live alone but have a good support network. Therefore, to identify support needs.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Full postcode	To ensure that population level census data can be obtained for	Full post code will be collected.

Category	Additional items to include	Reasons	National team response
		important determinants of health such as socio-economic status. Only using the first part of the postcode will not be sufficient.	
Care setting	Further subdivision of in-patient and community.	In-patient can be specialist IP or acute hospital or community hospital or hospice. Need to define community care setting - in terms of its relation with specialist palliative care and the input that is provided by the voluntary services. Community could mean patient's home, care home, GP surgery.	Inpatient setting definition: A patient receives care in a designated specialist palliative care setting or from a designated specialist palliative care team which includes at least one overnight stay. Community setting definition: A service provided by professional members of a specialist palliative care service to patients in their place of residence. Outpatient setting definition: A patient having an individual day time appointment with a specific member of a multi-professional palliative care team, within a healthcare facility. This includes day care.
	Include day services		
	Allow for more than one preference in answer options.		Only one care setting per spell is allowed.
	Define different care settings more clearly.	For example, would a person being cared for in an inpatient bed in a hospice be classified as 'inpatient' or 'community'? Is a patient in a care	To ensure that guidance clearly defines the care settings.

Category	Additional items to include	Reasons	National team response
		home bed an 'inpatient' or a 'community' patient'? Is a patient attending, for example, a breathlessness workshop at a hospice, a 'community' patient or an 'outpatient'?	
Care details	Length of stay, length of visit, type of visit, date of visit/stay.		Proposal is to start with a core data set and then to assess the need for additional data item.
	Timing of discharge and death	If discharge from hospital (other than to usual place of residence) in the last 2 to 3 days of life is a marker of poor care - it certainly leads to a lot of distress.	The data set should provide information on the patterns of care especially if linked to other data sets eg hospital data (HES).
	Type of care	More information should be collected on the type of care provided.	Proposal is to start with a core data set and then to assess the need for additional data item.
	Frequency and intensity of care	The current outcomes do not necessarily capture how frequently healthcare staff are required to attend a patient. A patient with a low performance status may be stable but this only because of the intensity and frequency of healthcare professional input for example.	Proposal is to start with a core data set and then to assess the need for additional data item. Specialist palliative care providers may collect this information and be able to analyse locally.
	Scope to gather more specific information about a patient's care plan and the methods that have been used to record their treatment wishes.		Proposal is to start with a core data set and then to assess the need for additional data item.

EPaCCS holds information about |

Category	Additional items to include	Reasons	National team response
			people's wishes and preferences.
Diagnosis	Primary and secondary diagnosis	Consider coding for conditions such as metastatic spinal cord compression (MSCC) and hypercalcaemia. Include ICD-10 disease codes for secondary disease C77-C79, inclusive. Secondary disease may contribute most to the symptom burden and deterioration of the patient.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Specify the different non-malignant diseases, especially for neurological conditions.	Eg chronic respiratory disease (COPD), pulmonary fibrosis, bronchiectasis, MS?	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Include general frailty in the list .		To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	To include co-morbidities		Looking to replace secondary diagnoses with co-morbidities.
Advanced care planning	ADRT and LPA	Has the patient formally recorded their care preferences via an advance decision to refuse treatment (ADRT)? Has the patient appointed a lasting power of attorney for health and	EPaCCS aims to support co-ordination of care and holds this information.

Category	Additional items to include	Reasons	National team response
		welfare? Beneficial to know how and where this info has been recorded so relevant healthcare professionals can access.	
Patient Preferences	Preferred place of death – achieved/not achieved What else to capture?	Need to capture if this is patient's or a best interest decision involving family for those who lack capacity. Also need to clarify whether this has been assessed and a professional judgement made not to have this discussion at this time/patient not engaging in discussions, to differentiate from just not trying. It is important not to facilitate poor and insensitive communication.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Barriers to achieving preferred place of death	Could be relevant to achieving patient centred outcomes/integrated working, eg availability of services.	Proposal is to start with a core data set and then to assess the need for additional data item.
	According to whom? Patient, family, health care prof?		To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Preferred place of care may be different from preferred place of death.	It is essential to capture, but to ask on every start of spell in order to achieve patients' preferences considering his circumstances.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.

Category	Additional items to include	Reasons	National team response
	Allow option for more than one preferred place of death.		This had been included in preliminary consultation with key stakeholders and steering group decision made that we test adequacy of one option in the pilot.
	Is 'preferred place of death' the most appropriate measure?	Home may not be an option or hospice may not be an option due to bed availability.	To be tested by pilots.
Referral	List of options for reason for referral (no. 8-10) should include: For end of life care support (or referred for last days of life care) Advance care planning Hospice assessment Patient choice Reason for referral from whose perspective? Staff or service users?	The inclusion of an option for 'symptom control' does not adequately reflect this. Need to capture 'brink of death' referrals as there is increasing evidence of the value of earlier intervention. The two perspectives may not correlate and service user's perspective should be paramount. Differentiate between patients' reported problems and staff's identified problems.	'Care in last days of life' has been added to the reasons for referral.
	Length of time of response by professional		Proposal is to start with a core data set and then to assess the need for additional data items.
	Fatigue to be added in specifically as an option under data item no. 8: Reason for Referral.	A common symptom for many other conditions.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
Carers needs	Financial/benefits needs		Proposal is to start with a core data set

Category	Additional items to include	Reasons	National team response
			and then to assess the need for additional data items.
	Advanced care directives		This is included in the EPaCCS data set.
	Performance status and self-management/enablement		Proposal is to start with a core data set and then to assess the need for additional data items.
	Primary carer (eg sibling, partner, offspring, neighbour, friend, whatever)		ERG to comment. We may need to add more guidance on the carer?
	Should also be registered as part of beneficiaries?	Many hospices register carers on their system, but this causes confusion.	As above.
	Link to ONS VOICES survey	The views of relatives and carers are important and it is not clear how these will be collected. Carers needs directly influence patient needs but have not been mentioned.	There will be potential to link the data with the national survey of the bereaved (VOICES) data to understand how the bereaved views align with the outcomes data.
	Assess at beginning and end of spell of care (most useful)	'Carers' will not always be available at the time of the clinical assessment – so there will be huge logistical challenges to completing the data set at each phase change.	Will be tested by the pilots.
	Measures of carer well-being (psychological well-being – depression), burden or experience.		Proposal is to start with a core data set and then to assess the need for additional data items.

Category	Additional items to include	Reasons	National team response
	A question about whether carers needs have been assessed.	This is crucial and is not currently happening in a systematic way.	This is expected to be held in the local clinical record but it is not intended to be part of the national data set at this time.
Physical components	Nausea and vomiting	Common symptoms.	Proposal is to start with a core data set and then to assess the need for additional data items.
	Fatigue: to record this at each phase change	Common symptoms.	Proposal is to start with a core data set and then to assess the need for additional data items.
Other indices	Overall QoL	Economists seem to have some good scores that are easy to complete. could be proxy/carer filled a really short one such as EQ-5D.	This was considered by the expert reference group but 'Views on Care' felt to be a better option.
	Indices from health economics	To measure economic burden.	Proposal is to start with a core data set and then to assess the need for additional data items.
	Functional status - palliative prognostic index, instead of Karnofsky.	More robust prognostic indicator than Karnofsky score. PPI is more robust	Karnofsky is a validated tool and we wanted to align with EPaCCS and the palliative care currency pilots which both use Karnofsky.
	Activities of daily living (ADL)		This may be included in the local clinical record but not included as part of the national data set at this time. Proposal is to start with a core data set and then to assess the need for additional data items.
	Patient experience measures	Need to go beyond preferred place of death as marker because patient	Plan to incorporate national patient experience measures once they have

Category	Additional items to include	Reasons	National team response
		decisions may change along the way.	been agreed.
	More outcome measures?	Different services might want to include more outcome measures as time and implementation progresses. This would need to be an option for those.	Proposal is to start with a core data set and then to assess the need for additional data items.
Service information	Extending the 'views on care' item (no.45)	It is essential for quality improvement. A single item is easy to use but cannot pinpoint what the service is doing well and where it is lacking.	Proposal is to start with a core data set and then to assess the need for additional data items.
	Availability of services	Concerned that this will not adequately capture differences in availability of other services/social deprivation.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Individual service KPIs		Suggest that these can be included in local data but only national indicators included in the national data set.
	Reasons for admission	Carer breakdown or carer support may be a reason.	The data set includes reasons for referral. To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Telephone activity	These can lead to significant clinical outcomes, important to recognise.	Telephone interventions are included as long as there is a minimum of one face to face intervention. This is included in the definitions.
	Level of social care input	Level of social care input ie	To be considered alongside the findings

Category	Additional items to include	Reasons	National team response
		low/medium/high could be relevant to show the role of social care alongside specialist palliative care at the EoL, provide a comparison to patients not receiving social care and also relevant for integrated working and considering new funding models.	from the pilot evaluation to inform decisions on the final data set.
Psychological well-being	Separate emotional, psychological and spiritual	Support to these needs is provided by different professionals.	The data set includes assessment of anxiety/distress.
	More on anxiety and depression and other mental health issues at early stages of data.	It's good you're asking patients and carers themselves later on, but healthcare professional assessment looks thin on this.	Proposal is to start with a core data set and then to assess the need for additional data items.
Support	People/human interaction close to time of death	Did the individual have enough positive human interaction near their time of death?	Proposal is to start with a core data set and then to assess the need for additional data items.
	Bereavement support	These can lead to significant clinical outcomes, important to recognise.	Proposal is to start with a core data set and then to assess the need for additional data items.
Resources	Funding arrangements for care before and after spell	Social care funding or continuing healthcare funding which could be relevant in considering new funding models.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Resource use and cost effectiveness	How to include telephone activity and bereavement support. There is, and rightly should be, an increasing number of telephone interventions and support to other professionals	Telephone interventions are included as long as there is a minimum of one face to face intervention.

Category	Additional items to include	Reasons	National team response
		which can lead to just as significant clinical outcomes. These are important to recognise.	Bereavement support is not included in the data set for piloting. To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
	Number of hospital admission avoidance.	To see how specialist palliative care input has helped.	There is potential for linking data with HES data which would enable comparison of different models of care and the impact on hospital use.
Children's needs	Specific items for children palliative care.	Need to be defined separately. A further consultation process with the children's palliative care sector is required to do this robustly.	Plan to extend to children's services in the future.
Decision making process	Patients' experiences of advanced care planning and shared decision making (patient autonomy and control). Data item 44 (Information Needs) should be supplemented by an additional question to ask whether the person has been involved in decision making about their care.	A question about being in control about decisions or making decisions about their future care. It would be interested to compare those were all the boxes were ticked appropriately but scored poorly on this question.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.
Personal goals	A person's goals or self-defined outcomes.	Reflects further on how to ensure that the data set reflects the holistic and goal-focussed nature of hospice and palliative care.	To be considered alongside the findings from the pilot evaluation to inform decisions on the final data set.

Category	Additional items to include	Reasons	National team response
Life history & hobbies /activities		Coping strategies need to be recorded (eg, type of music they prefer, whether they like touch).	This can be included in the clinical record but is not required for national analysis of the data.
Validated measures	Full IPOS	Covers relevant symptoms and patient experience. Useful in priority setting during clinical assessment.	Proposal is to start with a core data set and then to assess the need for additional data items.
	Palliative care outcomes scale (POS)	Although five items are comprehensive, they are not validated in this group as such and use of a whole scale (and POS is brief and succinct) would be more desirable. Its use helps service improvement and comparing services on a national level, clinical care and may help guide it more specifically to the individual's need and not forgetting about issues other than physical symptoms!	As well as the existing extensive body of evidence on all the items from the POS family of measures, the Cicely Saunders Institute team have recently completed an extensive validation study of IPOS in the palliative care population; this will be published shortly. For the complete IPOS measure, there is good evidence of validity, reliability, and importantly, responsiveness to change, in this population. This includes evidence on inter-rater reliability (staff-staff, and patient-staff). There has not been a formal validation of IPOS-5 as yet, because these items are only recently selected for national use, however, the Cicely Saunders Institute team considers that each item individually has sufficiently robust psychometric properties to support clinical use.
	Deeply concerned that the proposed narrow range of outcome measures, mainly	By selecting and prioritising a few outcomes from IPOS over all others, there is a danger that what needs to	We aim to assess the impact of data collection of outcomes as part of the pilot testing.

Category	Additional items to include	Reasons	National team response
	focussing on biomedical outcomes, is a reductionist approach that may not truly reflect the impact of palliative services.	be measured then drives practice.	
Method of data collection		In item 13 below, need to be able to record paper and electronic.	Data can be recorded on paper and then transferred electronically when appropriate.
Complexity of cases	It is difficult to know how to capture this.	Concerned that this will not capture all the supportive care/complex case management that underpins specialist palliative care by reducing to different components.	We plan to use the case mix factor that has been tested by the Palliative Care Funding pilots and the C-Change project.

Q11. Do you have any other comments regarding this consultation or the proposed data collection?

1. Data and collection processes

Concerns

	Consultation comments	National team response
1	Redundancy and having to complete two data sets should be avoided.	Aiming to develop a single data set that supports clinical care and that provides data required for funding system.
2	Time for collecting and inputting data is concerning.	The burden of data collection will be assessed by the pilots.
3	Capacity of services for collecting data should be assessed.	This has been included in the consultation and we plan to support those who do not have adequate capacity- through provision of a web-based data collection tool.
4	Stored/existing data should be utilised.	The data is collected from the clinical record and therefore, existing data is utilised.
5	Resources should be allocated for data collection and entry/implementation – 'charitable income cannot be spent on data collection'.	It is expected that the data collection will support clinical care of the individual patient and also support service improvements. This will be tested through the pilots.
6	Extensive data to address only few areas of concern, justification should be made for the detail of data to be recorded.	The burden, value and feasibility of data collection will be tested through the pilots.
7	Missing data should be minimized by simplifying data collection, prevent response skipping and should be electronic.	Working with IT systems providers to support completion of data items.
8	Difficulty of consent procedure.	Explicit consent will be required for the pilots but the pilots will also gather information to support

		Consultation comments	National team response
			decisions on consent model for a national data collection.
9		Difficulty of assessing phase of illness – it should be clear of how often this should be done.	Assessment of phase of illness is required daily or whenever person is seen in the community/outpatient settings.
10		The wording of the items should be short, simplified and color coded to ease their collection.	For information.
11		Consultations on collection of data on children and young adults should start.	We plan to extend data collection for children's services in the future.
12		What would be done with the data should be made clear.	For information.
13		Collected data should be linked with other data sources such as ONS, VOICES survey and Systematic Anti-Cancer Therapies Database.	There is the potential to link the data with other individual-level data collections.
14		Data collection needs to be piloted.	The data collection will be tested by pilot sites during 2015/16.
15		If data collection is made mandatory, patient care and staff morale would suffer in small hospices.	The burden, benefits and feasibility of data collection will be tested by the pilot sites.
16		Consent procedure and also secondary use of data should be clarified and data security addressed.	This will be addressed.

Benefits

	Consultation comments	National team response
1	Provide evidence for better services.	For information.
2	Good data is critical for service improvement and access.	For information.
3	Individual level data is important.	For information.
4	Understanding the proportion of people using palliative care services will	For information.

	Consultation comments	National team response
	lead to better planned services.	
5	This is an opportunity for hospices to share their experiences.	For information.
6	Important for benchmarking.	For information.
7	Important step in moving to collection of new data.	For information.
8	Outcome data is critical – POS should be used.	For information.

2. Support

	Consultation comments	National team response
1	IT support and resources needed to prepare a template of data collection, integration of the template into existing or non-existing systems, utilize the existing data and produce reports.	For information.
2	IT systems to avoid replication and allow for transport of existing information.	For information.
3	Existing IT systems/capacity need to be assessed.	Consultation has explored IT capacity in the sector.
4	Administrative and secretarial support is needed so as not to reduce face-to-face time with patients.	For information. Burden of data collection will be assessed through the pilots.
5	Patients should be provided with information about data collection.	For information. Plan to develop a template for a patient information leaflet.
6	Systems that hospices are using might not be compatible with sharing of information with others.	A web-based data collection tool will be available to sites that do not have IT capacity for data collection

3. Items

		Consultation comments	National team response
1		Variability in interpretation and assessment of 'phase of illness' and performance status evaluation should be addressed.	Definitions and guidance will be provided to ensure consistency.
2		Frequency of data collection relating to phase of illness is concerning.	This will be tested through the testing of data collection and inform the burden assessment and feasibility.
3		Socio-economic measures are also needed.	Socio-economic status can be assessed through the post-code.
4		Postcode should fully be captured to ensure analysis on deprivation could be carried out	Full post code will be collected.
5		Terminology should be consistent (patients or clients?) (spell of care or episode of care?).	Data set will be reviewed to ensure consistency.
6		Items do not reflect holistic hospice and palliative care – it only focuses on activity and outcomes but should address: physical, psychological, emotional needs and goals – at peace question is not sufficient.	Plan is to start with small data set and to test. It may be extended over time.
7		Additional locally relevant questions should be included.	Local providers can identify additional data to be held in the clinical record. Specific local data is not required for national data collection.
8		Terms such as palliative care and end of life care should not be used interchangeably.	Data set will be reviewed to ensure consistency.

4. Training

	Consultation comments	National team response
1	Clinicians should be trained in the importance of collecting the data.	For information. Training needs will be assessed as part of the pilot.
2	Need for piloting of data collection and its procedures.	Data collection will be tested through pilot sites during 2015/16.

5. Other issues

	Consultation comments	National team response
1	As the focus is data collection from specialist services, integration of services vision is neglected and not reflected in this study.	Linkages with other data sets will enable a better understanding of how care is delivered across different services and sectors.
2	Focus in on data not empowering or changing.	The vision is that improved data will drive service improvement and support commissioning.
3	Data capture is adult focused.	We plan to extend to children's services in the future.
4	Default is dissent not consent.	Explicit consent for data sharing is required for the pilot.
5	Non-malignant group is the hardest to reach and the biggest group.	The data collection will allow analysis of referral patterns and service provision for cancer and non-cancer groups.