



Public Health  
England



# **National End of Life Care Intelligence Network**

## **Palliative care clinical data set**

### **Evaluation report**

V1.0/ December 2016

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Public Health England  
Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Tel: 020 7654 8000  
[www.gov.uk/phe](http://www.gov.uk/phe)  
Twitter: @PHE\_uk  
Facebook: [www.facebook.com/PublicHealthEngland](https://www.facebook.com/PublicHealthEngland)

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Prepared by: National End of Life Care Intelligence Network  
For queries relating to this document, please contact: [neolcin@phe.gov.uk](mailto:neolcin@phe.gov.uk)

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## 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.

# Contents

Foreword by the members of the Expert Reference Group	5
Executive summary	7
1. Background	10
2. Pilot organisation and governance	13
3. Consultations	14
3.1 Consultation with key stakeholders and clinical experts	14
3.2 Open consultation via an online survey	14
3.3 Consultation with patients and the public	15
4. IT capacity of sector	15
5. Pilot site selection	17
6. Description of Pilot Sites	20
7. Evaluation methodology	28
8. Evaluation – Performance against plan	29
8.1 Evaluation - Costs	33
8.2 Technical capability	34
9. Evaluation - Change requests	34
9.1 Evaluation - Clinical hazards	34
9.2 Mitigation or transfer of risk	36
10. Evaluation – Information governance	36
10.1 Data sharing agreement	36
10.2 Consent	37
10.3 Findings	38
11. Evaluation - Interviews	39
12. Data Set Revisions	44
13. Conclusions and key messages from evaluation	47
13.1 Conclusions	47
13.2 Key messages from evaluation	48
Appendix A – Consultation and feedback on data set	50
Appendix B – Focus Group response	53
Appendix C – System configuration and implementation costs	57
Appendix D – Palliative care clinical data set	61
Appendix E – Membership of the Palliative Care Steering Group and Expert Reference Group	68
Appendix F – Data submitted during pilot	71

# Foreword by the members of the Expert Reference Group

The government is committed to improving end of life care for dying people, and reducing variation and inequalities in the quality and access to care that people experience. If those objectives are to be achieved, better data and information needs to be collected and made available to commissioners, providers and members of the public. At the moment, there is no nationally recognised way of measuring the outcomes that specialist palliative care achieves for individual people.

This report tells the story of pilot work to collect data about outcomes achieved for individuals by specialist palliative care services. It contains the lessons learned within the project and makes recommendations for the future. We hope that it will be read closely by policy makers, commissioners and providers in particular, to inform and guide future activity.

Towards the end of the pilot, it became clear that funding could not be secured to establish the national collection that it originally had been hoped would follow the pilot. As members of the Expert Reference Group to the project, we would like to put on record our views about the pilot work in the hope that this will both encourage better informed and more engaged discussions between commissioners and providers at local level and support future deliberations by policy makers at national level. We believe that it is essential that work towards the collection of individual level outcomes for specialist palliative care is continued even if that cannot happen via a national collection for the time being.

We consider that the pilot project should be seen as successful. It achieved broad support from provider organisations and clinicians. It showed that it is possible to collect data about specialist palliative care that links quality to activity in a way that carries an acceptable reporting burden and enables both measurement of benefits to individual people and benchmarking between services. There was evidence that the data set could be used to improve quality. It supports integration of care and coordination between services. It provides a common language with which to harmonise data in the future.

Taken together, the work of this project and the linked work that has been done in relation to developing a palliative care currency provide a much stronger platform than has been available to date for the commissioning of specialist palliative care services. We hope that commissioners and providers will use this to support informed discussions about innovation and improvement and that commissioning of specialist

palliative care will become more proactive, going beyond the superficial procurement exercise that is often the current experience. There is an important caveat: the data set is reasonably comprehensive but does not include every aspect of specialist palliative care, for example the indirect support provided to other services. The publication **Specialist Level Palliative Care: Information for Commissioners** by NHS England in April 2016 provides further information and guidance about the wider role and contribution of specialist palliative care. All the more need, therefore, for proactive engagement and discussion between commissioners and providers about the ways in which specialist palliative care can support the needs of a local population and the priorities of the local health and care system.

We also hope that the learning from this work will be taken into account by national bodies in any future development of standardised data forms and collections so that specialist palliative care is incorporated into mainstream data collection.



Dr Sarah Cox  
Consultant in Palliative Medicine  
Chair, ERG for Palliative care clinical data set Project

## Executive summary

In this report we present a new data set for specialist palliative care (SPC) services and the processes which have underpinned its development. The report describes a process going back almost a decade to the National End of Life Care Strategy 2008 which outlined the developments required to achieve a continuous improvement in the provision of end of life care. It was apparent then that a lack of information about services and the people receiving those services had restricted progress in achieving care which provided choice, equity, equality and value for money. This lack of information also risked limiting progress in improving commissioning and in developing a funding solution. In 2011 the publication of the palliative care funding review began work which also required the collection of a data set at an individual patient level to support commissioning based on need. More recently the **Ambitions for Palliative Care: A national framework for local action 2015-2020** identifies 'evidence and information' as one of eight foundations that underpin all six ambitions.

The development of this data set is important because it is the first step in measuring the impact of SPC services. Up to this point providers, commissioners and most importantly users of SPC services have only been able to assess the quality of SPC services with satisfaction surveys or process measures such as achievement of preferred place of death. The introduction of outcome measures with this data set reflects a huge step forwards.

The data set also collects information which can demonstrate the case mix of an SPC service, and supports commissioners to fund on the basis of complexity and need for resources.

The vision was to present the data set with support for collection and reporting of data at a national level. The experience of the Australian Palliative Care Outcomes Collaborative (PCOC)<sup>1</sup> suggested that collection and reporting of outcome measures could result in demonstrable improvements in quality and consistency of care. During the pilots it became clear that funding for the proposed national collection would not be available. As a result objectives relating to establishing the technical specification and legal gateways for a national collection system have not been met.

However, a data set has been developed and found to be a feasible and acceptable way to collect information about patient outcomes and complexity data by clinical pilot sites in all settings of care. Most sites reported that the reception to the new data collection by local staff had been positive, and there also was very positive feedback from all pilots regarding the use of the tools Australian Karnofsky Performance Status (AKPS) (a measure of dependency) and Phase (a measure of need for SPC). There

was a consensus that these terms provided a useful common shorthand to describe patients. Four pilot sites reported that implementation of the data set had improved the working operations of the unit, and two reported that they felt the process had already improved patient care. We recommend the data set to all providers and commissioners as a valuable way of reporting SPC outcomes data, and to support commissioning.

The time taken for implementation varied from 0-11 months between pilot sites with most of the variance explained by time taken to configure IT systems for the extraction of data. However, even with IT systems in place, successful and timely implementation required support from clinical leaders. Both appear to be essential and it is recommended that both are addressed by providers seeking to implement the data collection. Providers should be aware that implementation may take up to a year, although this includes time taken to develop data sharing agreements and consent policies which would not be required without a national data collection. Estimated technical costs ranged between £0k-£55K and implementation costs varied from £3K-£100K. Costs were less for providers with experience of using outcomes measures and where IT systems were already in place, or could be adapted by internal staff.

Indirect care such as education, support and advice provided to other professionals is not collected with this data set. This forms an important part of the activity of SPC teams and requires significant resource. There is a risk that the data set could be mistakenly used as a measure of SPC service activity. This in turn could result in underfunding of the service. As a result, we recommend that commissioners do not use the data set as a measure of the entirety of the SPC team. Instead, they should refer to NHS England's [Specialist Level Palliative Care: Information for Commissioners](#), published in April 2016, for further information and guidance on this.

We hope that opportunities for a national data collection will become available in the future as this would allow continuous quality improvement through national benchmarking. Work has begun on the feasibility of a national Community Services Data Set for people of all ages which would allow nationally consistent and comparable information. If this goes ahead it could provide a suitable vehicle through which the palliative care data set could be embedded. If so, there will need to be a review of procedures such as for data sharing in those patients who are unable to consent.

Key messages from the evaluation of this pilot project are:

1. Providers should consider implementing the data set to measure outcomes and complexity, to improve clinical communication and streamline clinical processes and to benchmark their service. The core data set should be used to ensure standardisation, but local providers may wish to collect additional data items.



2. Providers would be able to use the data set to collaborate and share good practice in outcome measurement with other local teams and across local regions.
3. The data set should be used alongside the Palliative care clinical data set Guidance and definitions report.
4. The most important factor for implementation in the pilots was the engagement of clinical leaders in the project. This should be the first step to ensure successful implementation.
5. IT system readiness is the next most important factor in implementation and the cause of most delays. Providers will need to ensure that their IT system is able to collect and report on the data set prior to rolling it out.
6. Commissioners would be able to use the data set as a way of monitoring outcomes and case-mix of their SPC services and to benchmark those services, so they may wish to encourage the services they commission to implement this.
7. Commissioners should be aware that this data set does not collect data about indirect care delivered by Specialist palliative care teams and therefore cannot be used as a complete record of activity of the service.
8. The pilot exercise provided limited, but positive, evidence that the data set could enhance quality and consistency of care. Further validation of the data set as a tool to measure and assure care quality should be undertaken.

# 1. Background

Specialist palliative care (SPC) aims to provide physical, psychological, social and spiritual support to patients with cancer and non-malignant diseases and their families on the basis of need. SPC services are delivered through Acute Trusts, community teams and Hospices (NHS and Third Sector).

## Current knowledge and data about specialist palliative care

The richest source of information about SPC in England that is currently available is the annual collection of the **National Council of Palliative Care (NCPC) Minimum Data Set (MDS)** commissioned by Public Health England and Hospice UK. The MDS collects data from all SPC services including inpatient activity, day care, community care, hospital support, bereavement support, outpatients, staffing, diagnoses and services for young people. Data is submitted annually to NCPC by around 65% of providers and an **annual report** is produced from this data.

However, this activity data does not tell us about the impact of SPC services on the care that patients and carers receive. We know that at the end of life patients and those close to them do not always receive the best care. Reports such as the Neuberger review of the Liverpool Care Pathway and repeated Health Service Ombudsman reports of complaints about end of life care reveal how much there still is to do to improve the consistency and quality of care. The **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020** identifies 'evidence and information' as one of eight foundations that underpin all six ambitions.

The first objective of this data collection was therefore to develop a nationally agreed data set that could be used to monitor outcomes for SPC services. Elsewhere in the world, nationally agreed outcome measures are being used to drive up quality of care. One example is the Australian Palliative Care Outcomes Collaborative (PCOC)<sup>1</sup>.

The Palliative care outcome scale (POS) was developed in 1999 for use with people with advanced disease to improve outcome measurement by evaluating many essential outcomes which are important for those with advanced illness<sup>2</sup>. POS consisted of 10 items which assess physical symptoms, emotional, psychological and spiritual needs, and provision of information and support, resulting in individual item scores and overall total scores. Since first launched, POS has been tested and improved by researchers around the world. In recognition of the wide range of symptoms which people with advanced disease experience, a symptom module (POS-S), with 10 specific symptom-related concerns, was added in 2008<sup>3</sup>.

The Integrated palliative care outcome scale (IPOS) is the most up to date and refined version of the POS family of measures<sup>3</sup>. It is a brief measure which incorporates the best of POS and POS-S and has been extensively cognitively tested and validated. It shows excellent psychometric properties with good construct validity, criterion validity, inter-rater reliability and responsiveness to change in the population with advanced illness<sup>4,5</sup>. In particular, it has both patient and proxy (staff) versions, allowing for completion when someone is too ill to self-report. This occurs frequently in palliative care; about 65% of inpatients receiving palliative care are unable to complete patient-reported measures<sup>6</sup>. IPOS has good patient-staff, and staff-staff, inter-rater reliability<sup>5</sup>, making it one of the best and most robust measures available for assessing the main symptoms and concerns of importance to people with advanced illness. Full details of IPOS, its development and psychometric testing, plus the measure itself, are freely available at [www.pos-pal.org](http://www.pos-pal.org).

Although some services have already embedded the use of other scales (eg Palliative care assessment tool [PACA]) in their clinical practice, it was agreed that it would be necessary to encourage the use of one scale across the country if benchmarking were to be possible. We would like to acknowledge the generosity of these services which have worked hard to change their practice to align with others.

## A new data set to support a new funding system

The second objective was to collect data to support a new funding system for SPC services. This arose out of an independent [Palliative care funding review](#) which was commissioned in 2010 by the Secretary of State for Health. The aims of the review were:

- to create a fair and transparent funding system
- to deliver better outcomes for patients
- to provide better value for the NHS

The review recommended that this should be achieved by developing:

- an NHS palliative care tariff which is based on need
- a funding system which incentivises good outcomes for patients, irrespective of both time and setting
- the commissioning of integrated care packages which stimulate community services

A commitment to implementing the recommendations of the review was included in the [coalition agreement](#). To support this ambition, the NHS England Pricing Review Team undertook a [pilot between 2012 and 2014](#). The pilot sought to address the absence of robust cost, activity and outcome data within the sector.

Through the collection of detailed activity and cost data from pilot sites, NHS England defined 28 'currencies' which apportioned relative costs to patient care. The published currencies are based on elements of the patient record which were found to correlate with costs. These are:

- phase of illness
- diagnosis
- age
- setting
- functional status

In March 2015, the Health Select Committee published a **report** of its enquiry into end of life care. This included considering submissions describing the work being done on the development of this data set (p38). The report recommends 'the development of outcome measures for palliative care. These must be properly evaluated and funded in order to improve the quality of care for people at the end of life'.

### Origins of the data set pilot

During 2013/2014, Public Health England (PHE) organised and facilitated two professional engagement events to assess the feasibility of, and reaction of the field to developing a national collection of patient records that could measure the quality and effectiveness of care, it would enable an accurate quantification of the activity and would support the production of currency data.

Based on highly supportive feedback, and similarly supportive feedback from a **professional consultation**, work was undertaken by PHE and NHS England to scope out a draft standard and to develop a business case for it.

In September 2014, Public Health England and NHS England issued a **joint position statement**, which proposed a national collection of individual level data from specialist palliative care providers. The two organisations would be working together to explore the 'feasibility options and costs' of doing so. The purpose of the collection as a whole was stated as being to:

- improve care for individual patients and their families through reporting of patient centred outcomes
- inform patient choice and better support their preferences
- enable providers to streamline team working and better implement local, regional and national audit and quality improvement initiatives
- provide a more complete picture of palliative and end of life care provision nationally
- enable comparisons across services and benchmarking (with appropriate case mix adjustment)

- facilitate more effective commissioning of palliative care services and support new funding models
- demonstrate effectiveness and cost-effectiveness of care
- underpin and inform future research

A second **statement** was issued by PHE in September 2015 which advised the field that in order to assess the feasibility, options and costs of a national implementation and collection of a clinical data-set, and that NHS England would fund a pilot collection of a draft clinical data-set during 2015/2016, led by PHE.

## 2. Pilot organisation and governance

To initiate the project, a National Palliative care clinical data set steering group was set up, and was chaired by the National clinical director for end of life care, Professor Bee Wee. Membership of this group was drawn from interested statutory bodies (NHS England, PHE, Health and Social Care Information Centre [HSCIC] and Care Quality Commission [CQC]).

During 2015/2016, central administration and support were through a programme office, managed by PHE. Staffing for the piloting was:

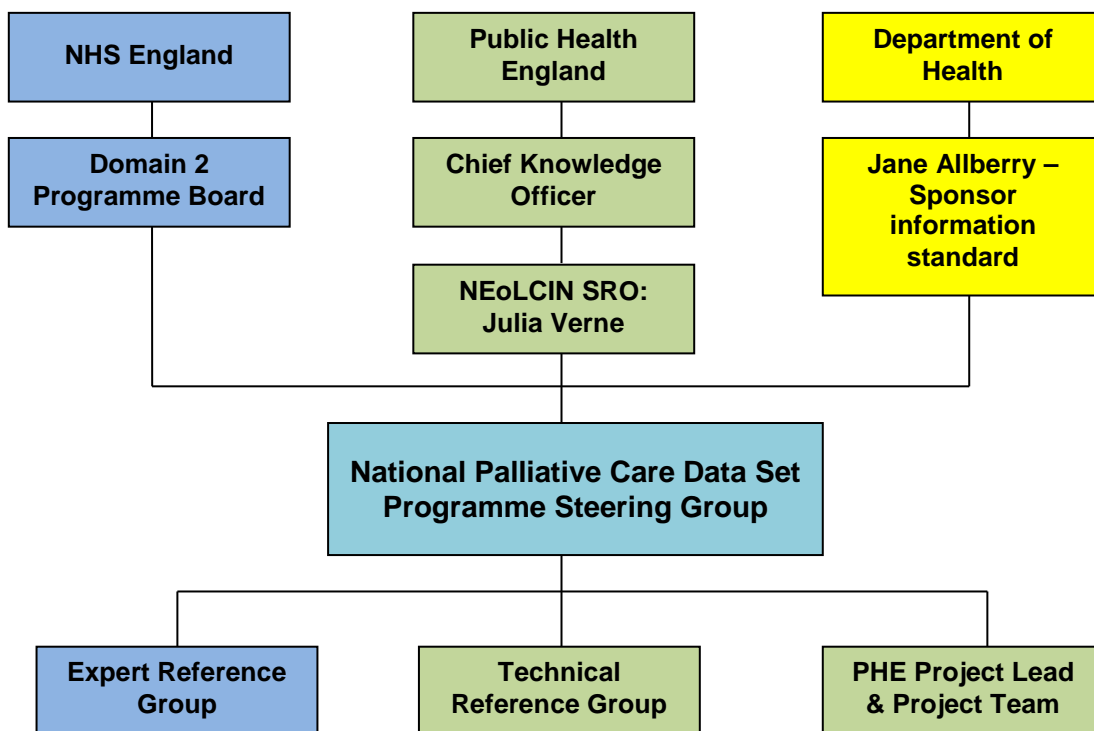
- programme manager, PHE (0.4 wte)
- project manager, PHE (1 wte)
- clinician (unfunded) and clinician (0.2 wte)
- NCPC data manager (0.3 wte)

The project was accountable to the Chief knowledge officer in Public Health England, to the Domain 2 programme board in NHS England and through the sponsor for the standard in the Department of Health.

The Expert Reference Group (ERG) membership included clinicians from the UK and abroad, representatives of national bodies, academics, and patient and carer representatives. The chair of the ERG, Dr Sarah Cox, was nominated by the Association for Palliative Medicine. The Technical Reference Group membership was drawn from representatives from the test sites. Both groups met at three month intervals during piloting.

Further sub-groups developing clinical guidance, reporting and to monitor clinical hazards were established during the course of the project, and met as required.

**Figure 1**



Monthly progress meetings to review the progress of the data set through the SCCI standards process were held with the HSCIC until November 2015.

## 3. Consultations

### 3.1 Consultation with key stakeholders and clinical experts

Prior to the pilot, PHE and NHS England undertook extensive regional, national and international consultation with clinical experts and other key stakeholders. This included a series of regional events, meetings with clinical experts, two stakeholder events in October 2013 and June 2014 and a targeted survey. More detailed information about the consultation undertaken in this stage is provided in Appendix A along with a summary of the results.

### 3.2 Open consultation via an online survey

In March 2015, the Health and Social Care Information Centre (HSCIC) ran an online consultation entitled ‘Specialist Palliative Care: Proposed Data Collection’. There were 163 responses to the 15 questions within the survey. The report is available on the

NEoLCIN website [Consultation on proposed individual level data collection from specialist palliative care.](#)

### 3.3 Consultation with patients and the public

The March 2015 HSCIC online survey was open to professionals and the public. However, only a small number of responses came from members of the public. In order to consult further with the public, including patients, carers and their relatives, PHE and NHS England ran focus groups to specifically gather views on the proposed data set and data collection process including their views on the value of the data collection, gaining consent, data sharing and the reporting of data to third parties in anonymised form.

The focus group was convened and facilitated by PHE's Public Involvement team. Recruitment to the focus group was through PHE's People's Panel, a randomly selected sample of approximately 1,500 members of the public, a proportion of whom have previously indicated a willingness to participate in focus groups. Additional recruits were sought through existing patient and carer groups established by the National Council for Palliative Care (NCPC) and Marie Curie. Detailed information can be found in Appendix B.

## 4. IT capacity of sector

From the outset of the planning for a Palliative care clinical data set, it was recognised that the poorly developed IT infrastructure in the sector would be a significant challenge. To gain a better understanding of these challenges, in November/December 2014 PHE commissioned NCPC to survey hospices about their use of IT. Key findings were:

- of the 518 known providers approached, responses were received back from 208 (42%)
- 28 (12%) respondents did not have local systems for recording clinical data
- two thirds (156) of respondents used one IT system to record patient records, 32 (14%) used two, 13 (6%) used three, and six (2%) used four
- 69/180 (38%) respondents said they did not have an annual maintenance contract with their IT supplier
- reported maintenance contract costs varied between £1000/pa and £100K/pa
- 37/101 (37%) of respondents said that existing maintenance contracts did not include data changes
- 33 of 184 respondents (18%) said they were planning to change their systems in the next 12 months

- 146/190 (77%) of services complete the NHS information governance toolkit, 22 (12%) reported that they complete another system, and 22 (12%) reported that they did not use an information governance framework
- 32/176 (18%) of services responding did not have an N3 connection, and 66/179 reported that they do not have PDS lookup for NHS numbers

The frequency of respondents using systems from different suppliers is shown in Table 1.

**Table 1 - Frequency of systems suppliers reported to the NCPC IT survey**

System Supplier	Number of systems reported	% of total
SystmOne	54	19
iCare	31	11
Other	31	11
Crosscare	26	9
Paper based	25	9
Excel/Access	22	8
Somerset Cancer Register	22	8
Infoflex	21	8
Casnisc	11	4
Palcare	7	3
Bespoke data-base	7	3
RiO	6	2
EMIS	6	2
Meditech	5	2
iSoft	3	1

### Interface with suppliers for pilot

PHE attempted to contact all system suppliers known to market clinical record systems to specialist palliative care providers in October 2014. This informed them about our intention to pilot the data set, and offered them a meeting to discuss the proposals. Suppliers who responded were Crosscare, iCare, Infoflex, EMIS and SystmOne. Suppliers that we were unable to initiate a dialogue with were Casinc, Palcare, RiO and Somerset cancer register.

Suppliers were sent initial drafts of the data set, and offered a face-to-face meeting. Two providers (Infoflex, EMIS) have worked or are planning work on developing standard templates and extracts for their products. Both SystmOne and EMIS introduced temporary codes in order to enable local recording of the data set.



Two software suppliers (Illy and Checkware), who do not currently have a presence in the sector, contacted PHE during piloting to obtain drafts of the data set to include in planned new products.

## 5. Pilot site selection

All known providers of specialist palliative care were contacted in January 2015 and organisations were invited to submit an expression of interest for participation in the pilot. Selection of pilots was then undertaken so as to ensure:

1. a mixture of service delivery models and organisations.
2. a variation in the familiarity with, and understanding of currency data.
3. a variation in the familiarity with, and understanding of IPOS outcome monitoring.
4. a representation of commercially available IT systems.
5. geographical spread across England.

Fifty two expressions of interest were received, and the following sites were selected in February 2015 by the steering committee to participate in the piloting.

**Table 2 – Pilot sites**

Service	Outcomes experience (1-low, 3-High)	IT Support (1-low, 3-High)	Type	System	Geography
Greenwich & Bexley Community Hospice	3	3	Voluntary	Infoflex	London
Newcastle upon Tyne Hospitals NHS Foundation Trust	3	3	NHS	SystmOne (community) Cerner (acute)	North of England
King's College Hospital	3	3	NHS	Teleologic	London Strategic Clinical Network
North London Hospice	3	3	Voluntary	I-Care	London
Marie Curie Hospice West Midlands	1	2	Voluntary	SystmOne	West Midlands with national body oversight
St Luke's Hospice, Plymouth	1	3	Voluntary	Crosscare	South West Strategic
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	3	1*	NHS	EPR – Graphnet	Wessex
Mid Yorkshire Hospitals Specialist palliative care team (SPCT)	1	3	NHS	SystmOne	Yorkshire and Humber
Rennie Grove Hospice Care	1	3	Voluntary	Infoflex	East of England

Addenbrooke's Hospital, Cambridge University Hospitals	3	2*	NHS	Epic	East of England
St Luke's Hospice, Sheffield	3	3	Voluntary	Infoflex	North of England

\*This is how we originally assessed applications for participation of the pilot, in practice several units (Forest Holme Hospice/Addenbrooke's Hospital) received better than anticipated support from their IT departments and would now have a higher rating of IT support.

Eleven sites were initially selected, and 10 of these agreed to participate following the initial site visit and briefing.

Mid Yorkshire Hospitals special palliative care team withdrew from piloting several weeks after initially agreeing to participate, as a result of the departure of the lead clinician from the trust.

As a result of post selection changes, there was some concern raised that no pilot site now used an EMIS system for clinical record keeping. A further pilot site (East Cheshire Hospice) formally joined the project in September 2015 in order to address this potential weakness.

## Pilot operations

Following site selection, discussions were held with each pilot site about their perceived readiness to implement the data set. A high-level overall draft plan was developed prior to the formal launch of the pilot (fig 2) at a workshop in May 2015.

**Figure 2**

Process	Exercise	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr
Consultation	Patient consultation	■	■	■	■								
Standard	SCCI requirement approval			■									
Standard	Develop clinical coding with DDS	■	■	■	■	■	■						
Standard	Review and amend clinical terms with HSCIC	■	■	■	■	■	■						
Standard	Submit revised data set for ISAS review							■	■	■			
Standard	SCCI full approval										■	■	■
Pilot	Site training event	■											
Pilot	Site level plans developed	■	■										
Pilot	Data collection and submission			■	■	■	■	■	■	■	■	■	■
Pilot	Checkpoint reviews with pilots					■			■			■	
Pilot	Revised data set produced								■				



9. data collected by clinicians
10. first monthly submission

During piloting, each site was asked to provide representation for:

- monthly half hour catch-up teleconference with all participants
- one day face to face checkpoint review workshops every three months

An issue log, change request log and hazard log were maintained through the course of the pilot.

## 6. Description of pilot sites

### Addenbrooke's Hospital, Cambridge University Hospitals

Addenbrooke's Hospital Specialist palliative care team is an advisory hospital support team with no allocated beds. Addenbrooke's Hospital is a tertiary referral University Teaching Hospital of over 1,000 beds, a Major Trauma centre, regional neurosurgical and transplant centre and cancer centre including Teenage and Young Adults. The Team consists of 2.5 WTE consultants, a clinical psychologist, Breathlessness Intervention Service and just over five WTE nurses seeing over 1,300 patients a year and also provides the trust's End of life care service. Patients range from the age of 17 to 104 and are referred from departments and wards trust wide. The team has been in place in the trust for over 20 years and is paid for in the trust baseline.

The electronic patient record used within Addenbrooke's Hospital is a bespoke system (using EPIC) built during 2014. During the build the IPOS and most palliative care assessments required for the data pilot were incorporated for use by the team and then adapted where necessary and supported by the hospitals IT staff. Before the pilot the clinical team had not been involved in palliative care currency data collection but collected activity data and were already trained and using IPOS. The team intends to continue to collect outcomes data to develop meaningful patient outcomes and continued service improvement.

### Forest Holme Hospice, Poole Hospital NHS Foundation Trust

Forest Holme Hospice, part of Poole Hospital NHS Foundation Trust, provides an integrated palliative care service for around 1,000 people living in Poole, Wimborne, Purbeck and surrounding areas (a population of 280,000) and supports the Dorset Cancer Centre, based at Poole Hospital, which serves the population of Dorset (around 750,000).

Forest Holme incorporates a community Specialist palliative care team, hospital palliative care team, inpatient ward, out-patient clinics, lymphoedema service, counselling, family support and bereavement counselling service. A generalist palliative care team, managed by Dorset University Healthcare Foundation, is also based at the Hospice.

The integrated palliative care service (PHFT) uses a shared palliative care record embedded in the PHFT electronic patient record (Graphnet EPR). The palliative care record is also shared by the specialist palliative care service at the Macmillan Unit, Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust to enhance continuity of care. The generalist palliative care team (DHUFT) uses SystmOne which is used by many GP practices locally. Documents or applications in the Trust EPR (Graphnet) are predominantly developed in-house by a supportive IT department. Staff at the unit had previously collected currency data for the Palliative care funding pilot. IPOS had not been collected at the hospice previously.

Funding for the services is approximately 70% NHS, 30% charitable. Some parts of the service are commissioned by the CCG (for example inpatient ward, out-patient clinics and lymphoedema - PHFT; generalist palliative care team - DHUFT). Other elements of the service are funded by Forest Holme Hospice Charity.

## East Cheshire Hospice

East Cheshire Hospice is a registered charity offering care and support for patients and carers dealing with life limiting illness. The Hospice provides Inpatient, Day, Outpatient and Counselling facilities for people who live in the communities across Eastern Cheshire and the High Peaks of Derbyshire.

The Hospice provides the following services:

- 15 Bed Inpatients unit open 24/7 7days per week
- 15 Place Day unit open Monday to Friday
- outpatient department
  - physiotherapy
  - complementary therapy
  - art therapy
  - lymphoedema therapy
  - occupational therapy
  - carers support groups including dementia
- counselling department
  - child bereavement
  - pre bereavement
  - post bereavement
  - spiritual support

The hospice uses EMIS Web clinical software as the electronic patient record to enable the Hospice to share clinical data with 22 GP surgeries, Local community nurses and Macmillan nurses. All IT is supported internally by the internal ICT department.

The hospice has not previously collected any currency data or IPOS.

The hospice currently has grants with signed service level agreements with two CCGs, Eastern Cheshire Clinical commissioning group and North Derbyshire Clinical commissioning group . This equates to 17% of all Hospice clinical running costs per annum.

## Greenwich & Bexley Community Hospice

Greenwich & Bexley Community Hospice is a registered charity and the leading provider of specialist palliative and end of life care to the London boroughs of Greenwich and Bexley. The hospice provides care for around 2,500 adults a year, with a range of life-limiting illnesses (cancer, dementia, heart failure, chronic respiratory disease, neurological conditions, frailty).

Specialist care is provided by a multidisciplinary team of over 80 healthcare professionals supported by support staff and more than 500 volunteers. Services provided include: management of pain and other distressing symptoms; respite; end of life care; rehabilitation support to promote independence; psychological and spiritual care; support with benefits and other issues; advance care planning support; befriending and drop-in services for carers and bereavement support.

Care is provided across a range of settings; a 19 bed inpatient unit, day hospice and outpatient clinics. Services are delivered at the main site in Abbey Wood, the Queen Elizabeth Hospital Woolwich, in the community, local prisons, people's own homes and care homes across the two boroughs.

The Hospice IT team provide first and second line support as well as operational and strategic management and information governance support.

The inpatient unit had some experience of using IPOS through recruiting patients to the IPOS Validation Study, however it was not in routine use.

Annual running costs are over £7m. Approximately 40% of funding is from NHS commissioners with the rest coming from charitable donations.

## Newcastle upon Tyne Hospitals NHS Foundation Trust

Newcastle upon Tyne Hospitals NHS Foundation Trust is a large tertiary teaching hospital which serves a population of over three million. The trust community services cover a population of 275,000 in the city of Newcastle upon Tyne.

Inpatient clinical services are based on two sites: the Royal Victoria Infirmary and the Freeman Hospital. The Royal Victoria Infirmary site is the acute admitting site with the Great North Trauma and Emergency Centre together with acute medical services, maternity services and the Great North Children's Hospital. The Freeman site is of a more elective nature with surgical services, cardiothoracic services, transplantation, and the Northern Centre for Cancer Care (NCCC).

Care is provided by four specialist palliative care service teams; Newcastle community team, Royal Victoria Infirmary (RVI) team, Northern Centre for Cancer Care (NCCC) team and Freeman Hospital (FRH) team. The four teams work independently for day to day clinical work, strategically the teams work as one joined up service. The team is interdisciplinary, including consultants in palliative medicine, Band 6 and seven nurse specialists, temporarily Macmillan funded AHPs, and Band 4 administrators. We also have support from the specialist palliative psychology service. The service sees approximately 2,700 new referrals a year.

The acute setting has Cerner Millennium as the patient electronic record. However, this does not extend yet to electronic patient notes and medical and SPCS notes are paper. In the community setting SystmOne Mobile is the electronic patient record in use by SPCS and DN service (since January 2016). At the outset of piloting, the service was not yet included in the configuration and roll-out plans for the trust wide Cerner system.

Prior to April 2015 pilot, the SPCS did not record AKPS or phase of illness but the service did have robust data collection which included the MDS and PROMs (PaCA). This data was collected on paper notes, inputted onto excel spreadsheets and data analysed and reported on by the SPCS leads without IT support. Prior to April 2015, the team did not use, nor were familiar with IPOS.

The service is currently commissioned by block funding top sliced from the trust's overall budget, with bespoke project funding for various Newcastle community based projects directly from the Newcastle CCG.

## St Luke's Hospice, Sheffield

St Luke's Hospice provides specialist palliative care to people in Sheffield. All medical and nursing care is planned and provided by a specialist team of consultants, specialist

registrars, doctors and nurses. The hospice provides care in three clinical settings: inpatient centre, Therapy and Rehabilitation Centre and for patients in the community.

The hospice offers a range of therapies, including occupational therapy, physiotherapy, social care, wellbeing services, spiritual care, as well as guidance on managing medicines. Some services are available to patients' carers, there is also a bereavement team. The inpatient centre has 20 beds, and provides care to around 400 patients a year. There are 17 community nurses and a Therapy and Rehabilitation Centre which provides care to around 1,600 patients in the community every year.

St Luke's use a system called Infoflex made by Chameleon Information Management Services Ltd (CIMS). This is hosted within Sheffield Teaching Hospitals and is used for all palliative care services in Sheffield. These services include the hospital support teams, outpatient services and the inpatient 'hospice' at the Sheffield Teaching Hospital as well as all the services within St Luke's Hospice. The data sent within the pilot however only relates to St Luke's hospice.

St Luke's was one of the original pilot sites in the palliative care funding review which commenced in 2013. The use of the phase of illness, Karnofsky scores and domain scores was already embedded into clinical practice at the outset of the pilot

St Luke's Hospice has good internal IT support, and was planning to introduce IPOS into the clinical record when selected for piloting.

Sheffield Clinical commissioning group funding accounts for 26% of the hospice's income. The balance of £6.1 million of the £8.7 million total income required is covered by fundraising and retail activities.

## Rennie Grove Hospice Care

Rennie Grove Hospice Care ('Rennie Grove') is a charity providing care and support for patients in North West Hertfordshire and Chilterns area of Buckinghamshire diagnosed with life-limiting illness. Through its hospice at home service and range of day services, Rennie Grove makes it possible for patients to choose how and where they want to be cared for towards the end of life. Support is also provided for families both during the illness and after bereavement. In 2015, Rennie Grove Hospice Care marked 30 years of caring for patients and families in Hertfordshire and Buckinghamshire.

The Hospice at Home ('H@H') service operates 24 hours a day every day of the year. Critical to provision of that service is the core business application holding all patient related information: 'Infoflex' is an SQL based application located on Rennie Grove premises. An in house team of 2.5 FTE staff provide day to day support and development of the application. Since the application was first introduced in 2011 it has



been used to record demographic and currency related information. This quantitative data enabled Rennie Grove to monitor activity and to complete the annual minimum data set.

In 2015, as a result of participating in the PHE Palliative care clinical data set pilot, Rennie Grove also started to capture qualitative data in the form of Phase of Illness, Australian Karnofsky Scale and the IPOS Outcome Assessments. From the start the project benefited from a pre-existing ambition within the organisation to introduce the IPOS assessments. The PHE pilot provided the added impetus to introduce the changes to clinical practice within a structured framework. Having completed the project and submitted three months' worth of data, Rennie Grove continues to record the outcome data, believing it significantly improves patient care.

In addition to the added depth of statistical data the PHE project has provided some interesting side benefits:

- it has forced the introduction of more consistent practices across the geographically spread teams
- it has provided a common language to use both internally and when working with healthcare professionals outside the organisation
- it has raised the organisation's awareness of the complexity of the concept of consent to share data in a positive way
- it has demonstrated the importance of cross department project teams to implement major projects

## King's College Hospital

The palliative care team at King's College Hospital NHS Foundation Trust (Denmark Hill site) is a hospital advisory team. It provides a specialist palliative care advisory service to the acute medical, surgical, orthopaedic, care of the elderly and tertiary (neurosciences, liver, renal, haematology etc) specialities across the >1,000 inpatient beds of the trust at Denmark Hill, plus outpatient support when needed. Patients remain under the care of their own medical team, and the input from the Palliative care team ranges from telephone advice and support to the medical team, to providing support with complex communication and decision-making, to detailed symptom review, psychological care, and social support for some patients and families with more extensive palliative care needs.

The team is referred over 1,400 people annually, with the duration of input by the Palliative care team of mean 11.2 days, median six days, with a range from 0-597 days (2015/6 data). The team uses two IT systems; the trust wide electronic patient record including electronic prescribing, and the palliative care-specific Teleologic patient content store (palliative care module), with some (limited) interoperability between systems. King's College London Palliative care team previously contributed to the

palliative care funding pilots and has routinely collected IPOS data on all patients since 2014. There is a local commissioning arrangement to support the work of the team; based on a fixed payment per person seen, regardless of complexity, team activity or length of stay. However, about 35% of those seen are not from local CCG areas; the tertiary work undertaken by the hospital ensure that a high proportion of the patients seen by the Palliative care team are from other, more distant CCGs across the south of England and nationally.

### St Luke's Hospice, Plymouth

St Luke's provide services across three clinical sites: Community, Acute Hospital and the hospice inpatient unit serving a catchment area covering Plymouth, South Hams, West Devon and East Cornwall, a population in excess of 450,000. Care is provided at the main hospice premise; patient's homes, care homes and at hospitals within the catchment area.

The electronic patient record system is Crosscare, hosted locally and has been in place since 2011. There is a dedicated clinical database manager responsible for maintaining and configuring Crosscare. All sites use Crosscare for clinical record keeping in dedicated templates as well as the ability to attached documentation to a patient record. Referral process and management of demographic information is controlled by the clinical administration teams based on information from the referrer and remote access to NHS records.

St Luke's had previously been collecting a form of dependence scores (RAG) across the three sites prior to the pilot, and had some limited experience of IPOS. Prior to the data set, we collected data relevant for NCPC MDS data collection on Crosscare.

Funding for community and inpatient care is from the NHS and commissioned through New Devon and Kernow CCGs. There is also an SLA in place with the local Acute Hospital Trust.

### North London Hospice

North London Hospice is a registered charity which has been caring for local people since 1984. The hospice works across three London boroughs: Barnet, Enfield and Haringey.

There is an 18 bedded inpatient unit in Finchley which provides specialist 24 hour care. Outpatient and therapies services operate from a site in Winchmore Hill. There is a specialist community palliative care service for each of the three boroughs.

Services are provided by a multi-professional team including doctors, nurses, social workers, psychological therapists, physiotherapists, spiritual carers and chaplains, complementary therapists and volunteers who provide general and enhanced support.

Services provided are hospice inpatient care, specialist community palliative care services, outpatient and therapies service, hospice at home and loss and transition service. Hospice staff work alongside other community health professionals to provide care for patients.

The Hospice uses an electronic patient database, iCare (provided by SMI Limited). The system is supported by the organisation's governance lead and an iCare user group of representatives from each service. In addition the organisation has appointed a data analyst to support the evaluation and use of clinical data.

The hospice had prior experience of collecting a number of the currency data requirements. Phase of illness, Karnofsky Performance Status and IPOS were introduced within the specialist community teams and outpatients service in December 2014.

The Hospice is commissioned by three London Boroughs (Barnet, Enfield and Haringey) to provide specialist palliative care services. The services are part funded by the commissioners.

### Marie Curie Hospice West Midlands

The hospice is one of nine Marie Curie hospices and the only hospice with an electronic patient record. The services provided by the hospice to four local CCGs are symptom control, terminal care and respite to all patients with a life limiting illness as well as support for their carers.

Provision includes a 24 bed inpatient unit, a community CNS team, day services and outpatient clinics for fatigue, anxiety and breathlessness, rehabilitation and Motor Neurone disease.

SystemOne had been in place within the hospice for three years prior to the pilot, supported by: Solihull Community Services (CSU) administration support.

The hospice had no prior experience of currencies or IPOS but had some limited prior use of POS.

## 7. Evaluation methodology

The goals of the pilot, and the evidence collected during piloting to demonstrate progress towards these is shown in Table 3.

At the outset of the pilot, it was thought probable that a national mandatory collection of the data set would be required to support the introduction of the palliative care currencies by April 2017. As this is no longer the case, a number of goals (indicated in **bold**) are no longer relevant, and were therefore not evaluated.

**Table 3: Evaluation against pilot goals**

<b>Goal</b>	<b>How assessed</b>
To review the contents of the pilot data set and amend as required.	Monthly pilot teleconferences. Quarterly checkpoint meetings. Issue log. Change request log. Feedback from consultation with patients, professionals and the public.
To assess the technical capacity of the field to implement the collection and submission of the data set, and to quantify the scope and costs of local support that would be required for roll-out.	Monthly pilot teleconference. Quarterly checkpoint meetings. Evaluation interview. Issue log. Pilot site cost estimates for implementation and ongoing maintenance. Site delivery against plan.
To assess the willingness of IT providers to support the collection and submission of the standard, including the identification of supplier costs that would be incurred for roll-out.	Contact suppliers to request data set support. Supplier costs incurred during piloting.
To assess the training requirements for clinical staff to be able to record and report the data within the standard, and to quantify the scope and costs of support that would be required for roll-out.	Evaluation of IPOS training (provided to all pilot sites on request). Support requirements during piloting. System related costs for pilots. Other costs (eg staffing). Evaluation interview.
<b>To assess the scope, function and cost of a central programme to support the introduction of the data set, including system development and support costs.</b>	Issue log. Site delivery against plan.

<b>Goal</b>	<b>How assessed</b>
To assess the ability to gain explicit consent, and to <b>seek a legal gateway for collection of identifiable patient records where this is not feasible.</b>	Local tally of number of patients who consented, refused consent and who were unable to consent. <b>Legal gateway approval by relevant body (eg s251 through Confidentiality Advisory Group)</b>
To assess and estimate the costs and timescales required to develop a data-collection robust enough to support the introduction of per-patient funding.	Initial site estimates for draft plans measured against actual time taken. Data quality of submissions.
To support the assessment of burden being undertaken by <b>Burden Advisory and Assessment Service (BAAS).</b>	<b>BAAS feedback to Standardised Committee for Care Information (SCCI).</b>

## 8. Evaluation: performance against plan

The time taken for pilot sites to achieve project milestones, and their initial estimates for these are shown below in the data tables 4a-d.

**Table 4a: Performance against plan – Information governance**

<b>Service</b>	<b>Data Sharing Agreement</b>			<b>Consent statement ready</b>		
	<b>Planned</b>	<b>Actual</b>	<b>Var</b>	<b>Planned</b>	<b>Actual</b>	<b>Var</b>
Greenwich & Bexley Community Hospice	1	3	2	2	3	1
Newcastle upon Tyne Hospitals NHS Foundation Trust		2		2	5	3
King's College Hospital	1	1	0		4	
North London Hospice	2	3	1	2	>11	>9
Marie Curie Hospice West Midlands	2	3	1	2	3	1
St Luke's Hospice, Plymouth	2	2	0	2	3	1
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	2.5	6	3.5	2.5	6	3.5
Rennie Grove Hospice Care	5	3	-2	2	3	1
Addenbrooke's Hospital, Cambridge University Hospitals	1	3	2	2	3	1
St Luke's Hospice, Sheffield	2	2	0	2	3	1
<b>Ave (months)</b>	<b>2.1</b>	<b>2.8</b>	<b>0.8</b>	<b>2.1</b>	<b>&gt;4.4</b>	<b>&gt;2.4</b>

All sites required between one and six months to approve a data sharing agreement. All sites were content to use the standard data sharing agreement used by PHE for this purpose. Initial estimates by sites of the time this would require were slightly underestimated (2.1 vs. 2.8 months).

Two sites, Forest Holme Hospice and North London Hospice were unable to provide a submission within the pilot time frame. In both cases, the time taken to gain organisational approval for a new consent model was identified as a main cause for the delay. North London Hospice obtained approval for the model but had difficulties around the consent process.

In general, the time required to get a consent statement ready for use was the most inaccurately estimated milestone.

**Table 4b: Performance against plan – Introduction of new data collection into clinical record keeping**

Service	Collecting prior to pilot			Currencies in clinical record			Outcomes in clinical record		
	Outcomes	IPOS	Currency	Planned	Actual	Var	Planned	Actual	Var
Greenwich & Bexley Community Hospice	Yes	No	Yes	3	5	2	3	6	3
Newcastle upon Tyne Hospitals NHS Foundation Trust	Yes	No	No	3	3	0	3	5	2
King's College Hospital	Yes	Yes	Yes	0	0	0	0	0	0
North London Hospice	Yes	No	No	5	4	-1	5	>11	>6
Marie Curie Hospice West Midlands	No	No	No	5	6	1	5	6	1
St Luke's Hospice, Plymouth	No	No	No	4	4	0	2	2	0
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	Yes	No	No	2.5	4	1.5	4	7	3
Rennie grove Hospice Care	No	No	Yes	4	4	0	4	4	0
Addenbrooke's Hospital, Cambridge University Hospitals	Yes	Yes	Yes	0	0	0	0	0	0
St Luke's Hospice, Sheffield	Yes	Yes	Yes	4	4	0	2	2	0
<b>Ave (months)</b>				<b>3.1</b>	<b>3.4</b>	<b>0.35</b>	<b>2.8</b>	<b>&gt;4.1</b>	<b>&gt;1.5</b>

In general, providers were able to accurately estimate how long it would take to introduce NHS England currency related items and outcomes related data items into their clinical record keeping. Feedback from providers suggested that where these were new, implementation was generally felt to be a very positive experience by staff, often improving and streamlining internal processes.

Time for implementation did not seem to be strongly correlated with prior use of currency data. It would instead seem to be more related to of the local timescale for technical implementation of the capacity to record the data on systems.

**Table 4c: Performance against plan – System readiness**

Service	System data capture ready		Data extract ready	
	Planned	Actual	Planned	Actual
Greenwich & Bexley Community Hospice	5	10	5	8
Newcastle upon Tyne Hospitals NHS Foundation Trust			3	6
King's College Hospital	0	0	0	0
North London Hospice		6		
Marie Curie Hospice West Midlands	5	6	5	7
St Luke's Hospice, Plymouth	3	4	3	3
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	6	11	2.5	
Rennie Grove Hospice Care			5	10
Addenbrooke's Hospital, Cambridge University Hospitals	0	0	0	0
St Luke's Hospice, Sheffield	3	4	4	4
<b>Average</b>	<b>3.1</b>	<b>5.1</b>	<b>3.1</b>	<b>4.7</b>

The capacity of pilot sites to configure and process the required data was highly variable. One site (King's College Hospital) already had systems configured to capture the required data. Another (Addenbrooke's Hospital, Cambridge University Hospitals) was able to include the technical specification as part of the departmental specification for a new clinical system being rolled out across the trust. This was completed within around two weeks of the specification being provided.

All pilot sites were able to configure the local system for the capture of the data set during the eleven month pilot with the exception of Newcastle upon Tyne Hospitals NHS Foundation Trust, where existing rollout plans for a trust-wide clinical system (Cerner) could not be changed to accommodate the pilot timescales. Data capture at Newcastle upon Tyne Hospitals NHS Foundation Trust was however successfully completed on spreadsheet extracts from hospital patient administration system and community system (SystemOne),

In general, estimates of the time required to configure systems for data capture were more accurate than the time taken to configure the extract.

**Table 4d: Performance against plan – Staff readiness**

Service	Training materials ready		Staff ready	
	Planned	Actual	Planned	Actual
Greenwich & Bexley Community Hospice	2	2	2.5	7.5
Newcastle upon Tyne Hospitals NHS Foundation Trust	4		2.5	3
King's College Hospital	0	0	2	7
North London Hospice				
Marie Curie Hospice West Midlands	5	6	6	7
St Luke's Hospice, Plymouth	1	4	2	2
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	1	3	2.5	7.5
Rennie Grove Hospice Care			2	1
Addenbrooke's Hospital, Cambridge University Hospitals	0	0	0	0
St Luke's Hospice, Sheffield	2	4	2	2
<b>Average</b>	<b>1.7</b>	<b>2.1</b>	<b>2.4</b>	<b>4.1</b>

Although the time taken to develop local training resources varied between sites, this was not reported to be an issue at any site, and variation appears to be more a function of the timing of the delivery of technical elements of the project, or local pressure to prioritise other work.

Initial estimates of the time required for clinical staff to be ready to supply clinical data to the local IT system were less accurate. There was no discernible pattern to the causes of this, with reasons including delays to technical configuration (Greenwich & Bexley Community Hospice), timetabling to accommodate other departmental priorities (King's College Hospital), a delay in getting IG clearance (North London Hospice) and cross organisation system integration work (Forest Holme Hospice).



**Table 4e: Performance against plan – Operations**

Service	Collection		First submission	
	Planned	Actual	Planned	Actual
Greenwich & Bexley Community Hospice	1	6	5	7
Newcastle upon Tyne NHS Foundation Trust	4	4.5	5	8
King's College Hospital	3	6	5	7
North London Hospice				
Marie Curie Hospice West Midlands	7	7	7	9
St Luke's Hospice, Plymouth	2	2	5	5
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	2.5		4	
Rennie Grove Hospice Care	2	4	6	7
Addenbrooke's Hospital, Cambridge University Hospitals	0	0	2.5	5
St Luke's Hospice, Sheffield	2	2	5	5
<b>Average</b>	<b>2.6</b>	<b>3.5</b>	<b>4.9</b>	<b>5.9</b>

Although pilots experienced a wide range of issues and unexpected delays during piloting, the overall impact of these on the time required to produce a first submission was more limited.

The exception to this was for the two sites that were unable to obtain the necessary IG clearances within the pilot time frame. These were for the introduction of a new consenting process (North London Hospice and Forest Holme Hospice).

## 8.1 Evaluation: costs

Pilot sites were asked to keep a record of capital costs, training costs and staff time spent on implementation by different professional groups (clerical/administrative/IT/managerial/other), and to break these costs down into the following activities:

- project management
- internal systems development
- external system development
- developing systems process
- data collection
- training

In practice, some pilots were unable to apportion staffing costs into these categories, and supplied a global figure for staff time on the pilot. However, for most pilots, it is

possible to estimate the costs of amending the technical capability of IT systems from the administrative and clinical costs.

## 8.2 Technical capability

The system configuration costs are all known costs associated with amending local IT systems, so that they can record and export the data set.

Estimated costs ranged between £0K-£55K. Two pilots (King's College Hospital, Addenbrooke's Hospital) had the systems configuration work done as part of an existing procurement or rollout with no additional costs incurred.

Where in-house developers were used, costs tended to be significantly higher. This can partly be explained by these providers extending the requirements beyond those specified for the pilot.

A breakdown of system configuration costs and implementation costs by each pilot sites is shown in Appendix C.

# 9. Evaluation: change requests

A draft data set and clinical guidance were defined at the outset of the project. During the project, issues raised by pilots with these drafts, and suggested resolutions were recorded, and maintained on a change request log. At the close of the pilot, the Expert Reference Group (ERG) and Steering Group Committee reviewed these, and recommended whether they should be accepted or rejected.

A summary of the data set revisions can be found in section 12 and the final data set is in Appendix D.

## 9.1 Evaluation: clinical hazards

During the project, a hazard assessment was carried out and a hazard log produced. Risks were assessed and mitigations identified and applied.

Eleven hazards were identified during development and piloting. Of these, four have been closed, six have transferred to implementers and users and one remains open. Hazards were transferred to implementers and users where they represent risks common to usual clinical practice.

### 9.1.1 Hazards related to the data set content

Six hazards were identified relate to the data set content.

<b>Hazard</b>	<b>Rating post mitigations</b>	<b>Status</b>
Patient or carer distress from questions in data collection	Low	Closed
Inaccurate data recorded	Moderate	Transferred to implementers and users
Incomplete data recorded	Moderate	Transferred to implementers and users
Data does not measure what it sets out to	Significant	Transferred to implementers and users
Data items incorrectly assessed and clinical care incorrectly directed as a result	Moderate	Transferred to implementers and users
Incomplete data set for reporting	Low	Closed

### 9.1.2 Hazards related to implementation

The remaining hazards relate to implementation of the data set in the diverse system and organisational contexts.

<b>Hazard</b>	<b>Rating post mitigations</b>	<b>Status</b>
Breach of confidence through sharing of patient data without consent from patient	Moderate	Closed
Data collection and recording takes time away from patient care	Moderate	Transferred to implementers and users
Data collection burdensome for patients	Low	Closed
IT failure results in loss of access to data	Low	Transferred to implementers and users
Funding reduced from inability to capture all SPC activity	Significant	Open

### 9.1.3 Open risks

This data set does not collect information about the indirect activities of SPC teams. This includes education, support and advice provided to other professionals who then provide direct patient care. This forms an important part of the activity of SPC teams and requires significant resource. There is a risk that this data set could be assumed to represent the entire activity of SPC teams and that they would be under funded as a result. This hazard has not been mitigated except through its identification and therefore remains open. But commissioners may be directed to NHS England's 'Specialist Level

Palliative Care: Information for Commissioners', published in April 2016, for further information and guidance about this.

## 9.2 Mitigation or transfer of risk

### 9.2.1 Closed hazards

There was no patient or carer distress reported by the pilots so this risk has been closed. Hazards related to data sharing or consent have also been closed as there is no plan for these activities. Pilots did not report that patients found the data collection burdensome.

### 9.2.2 Hazards transferred to implementers and users

Pilots did report that data collection removed staff from clinical care. However, the data set has also been positively evaluated in terms of its impact on service efficiency and potential to improve quality. Therefore this hazard has been transferred to implementers and users.

Inaccurate and incomplete data recording is a risk for all clinical records. The responsibility is for implementers and users to ensure complete and accurate data recording.

Failure of IT is a risk for all clinical services and should be addressed by implementers and users with robust policies to protect and secure data.

There is a risk that the data set does not measure what it sets out to. This hazard is transferred to implementers and users who remain responsible for the clinical interpretation of the data items.

## 10. Evaluation: information governance

The pilot sought to test the feasibility of agreeing with providers to obtain consent, for a national collection, and the degree to which support through a legal gateway (see below) would be required to support a national roll out.

### 10.1 Data sharing agreement

Although a data sharing agreement does not alter legal restrictions on access to identifiable patient data, they are common practice. Their function is to produce a clear,

agreed statement between parties, specifying what data is to be transferred, its purpose and the controls that will be put in place.

At the outset of the project, a data sharing agreement was drafted by PHE, and provided to pilot sites. As part of their initial planning, pilots were asked to estimate how long it would take to achieve agreement with the data owning organisation. The estimated delivery and actual delivery time (in months) for each site is shown in Table 5.

**Table 5: Months estimated, and taken to agree data sharing agreement.**

Site	Estimated	Actual	Variance
Addenbrooke's Hospital, Cambridge University Hospitals	1	3	2
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	1.5	5	4.5
Greenwich & Bexley Community Hospice	3	4	1
King's College Hospital	1	1	0
Marie Curie Hospice West Midlands	2	3	1
Newcastle upon Tyne NHS Foundation Trust		2	
North London Hospice	2	3	1
Rennie Grove Hospice Care	2	3	1
St Luke's Hospice, Plymouth	2	2	0
St Luke's Hospice, Sheffield	2	2	0
<b>Average (mean)</b>	<b>1.8</b>	<b>2.8</b>	<b>1.2</b>

## 10.2 Consent

In palliative care research cohorts between 40 to 50% of patients within specialist palliative care services do not have the capacity to provide consent for their identifiable data to be used for purposes other than direct care<sup>7 8</sup>. A national collection will therefore require an alternative legal gateway for these patients records to be included in submissions.

Section 254 of the Health and Social Care Act 2012 establishes powers for NHS England or the Secretary of State to direct the Health and Social Care Information Centre (HSCIC, now operating as NHS Digital) to establish and operate systems for the collection and analysis of specified information. When acting under directions HSCIC has a statutory basis to collect identifiable patient data for purposes specified in the directions, without consent. A legal basis for the collection of a national Palliative care clinical data set could therefore be established by NHS England issuing directions to HSCIC for this purpose.

Similar collections at PHE may also access powers under Section 251 of the same act. However, this is subject to those powers being granted by the Secretary of State, who must take regard of the recommendation of the Confidentiality Advisory Group (CAG).

Through testing and measuring the capacity of treatment providers to obtain consent from patients, the pilot aimed to provide quantitative and qualitative evidence to underpin the case for the granting of these powers to a full national collection.

Consequently, during piloting, only consented records could be returned to PHE, and providers were asked to keep a local record kept of the number individuals unable, and the number unwilling to provide consent.

A second mechanism for quantifying the proportion of patients that refuse consent is contained within the extract specification. This required that a fully anonymous empty record is added to each submission file for each patient that has refused consent.

Some pilot sites were concerned about the information governance around recording carer views within the patient record although many SPC services consider that recording carer needs is part of a usual patient assessment.

### 10.3 Findings

At the outset, most sites had not been previously requesting patient consent for record sharing. Feedback from these sites about introducing this were that they faced a number of challenges within their organisations in order to do so. These included;

1. Defining a process for asking consent (in writing, whether lasting power of attorney can consent) required time to clarify (Addenbrooke's Hospital, Cambridge University Hospitals, North London Hospice, Forest Holme Hospice). Several providers chose to develop a new IG policy, sometimes with a patient information leaflet (North London Hospice, Forest Holme).
2. It was a new process and not embedded with clinical teams (Addenbrooke's Hospital, Cambridge University Hospitals, Rennie Grove Hospice Care and King's College Hospital).
3. It was time consuming for clinicians to ask consent (King's College Hospital).
4. There was confusion about whether carer consent was required to record the carers views within the patient record.
5. Patients were thought to be too tired or ill to consent (Addenbrooke's).
6. Patients were thought to be overloaded with being in studies or trials and reluctant to consent to another pilot (Addenbrooke's Hospital, Cambridge University Hospitals).

Several sites reported initial staff resistance to the introduction of a consenting process, and that the implementation had been more difficult and lengthy than initially anticipated. As a consequence of this, only five pilot sites were able to report figures for the number of patients that refused or were unable to consent. Only one site was able to successfully implement the technical specification for dummy records to be added to the submission file where consent was refused. Four other sites reported figures for the last month in progress reports during the project.

A summary of the data returned to PHE by pilot sites is shown in Table 6.

**Table 6: Consent monitoring**

<b>Response</b>	<b>Number</b>	<b>%</b>
Yes	863	77
Refused	109	10
Unable to give due to lack of mental capacity	146	13

Summary data from St Luke's Plymouth, St Luke's Sheffield, Rennie Grove, Newcastle and Addenbrooke's Hospital.

The proportion of patients that were reported as unable to consent is lower than reported figures in the literature would suggest. This is thought likely to be as a consequence of selection bias by clinical staff in the early stages of the implementation of a consenting process.

The proportion of patients that refused consent (10%) is more surprising, and not consistent with the otherwise positive view of the work fed back from consultation with patients, carers and charities. The reasons for this warrant further investigation.

## 11. Evaluation: interviews

Towards the end of piloting, each pilot site agreed to participate in a structured feedback session of around one hour, which was recorded and documented. During the feedback sessions, all sites were asked the same questions about their experiences of the pilot, and their responses are summarised here.

### **Question 1: What changes have you had to make in order to collect the data?**

Seven pilots reported making changes to existing IT systems in order to participate in the piloting and a similar number reported making changes to clinical recording practices. Although all sites had to amend or adapt existing consenting arrangements, four sites reported that this required a substantially changed or new consent process.

'Changes include both changes in clinical practice on the ward and in various teams, trying to measure patients' needs using, IPOS, Karnofsky' Forest Holme Hospice, Poole Hospital

'Made changes to our electronic palliative care record to add views on care and IPOS' Greenwich & Bexley Community Hospice

'There were massive culture changes' St. Luke's Hospice, Sheffield

### **Question 2: What were the challenges of implementation?**

The most frequently mentioned challenge was the use of a patient consent model for the collection (seven sites). Most sites reported that there had been, and occasionally continued to be, staff resistance to its use. However, most sites also reported that this had been successfully integrated into clinical record keeping and occasionally reported that the process of seeking consent from patients had been helpful in enabling better communication with them about their wishes.

Six pilot sites reported that amending IT systems was a challenge and a similar number considered the timescales of the pilot to be over ambitious. Other challenges mentioned were initial staff resistance/lack of engagement, the use of IPOS as part of the clinical record, the construction and recording of patient data in 'spells' and ambiguity or inconsistency in definitions (three sites each).

'One of the challenges was staff training – getting them to think in a slightly different way' Rennie Grove Hospice Care

'The reporting system was not fit for purpose so we had to develop our own' Marie Curie Hospice West Midlands

'Consent proved quite challenging to get it through governance; North London Hospice

### **Question 3: What went well?**

Most sites reported that the reception to the new data collection by local staff had been positive, and there also was very positive feedback from all pilots regarding the use of Australian Karnofsky Performance Status (AKPS) and Phase. There was a consensus that these terms provided a useful common shorthand to describe patients. Four sites highlighted that implementation of the data set had improved the working operations of the unit, and two reported that they felt the process had improved patient care.

Three sites also reported that the administration and local management of the project had been positive.



'From a community team point of view we have embraced AKPS and phase of illness and that is actually helping support our patients' Greenwich & Bexley Community Hospice

'We used super users in each team who were experts and used them to answer queries at the first level' Newcastle upon Tyne Hospitals

'Actually seeing how the data collected directly affects patients and family/carers' St Luke's Hospice, Sheffield

**Question 4: What resources (eg staff new and existing/financial) were required to implement the data collection?**

Three providers reported spending in between £8-10K capital on system changes. Providers that used internal staff to make system changes reported higher costs.

Pilots generally reported that it was not possible to disaggregate the staff time spent on implementation from other duties. This was most true where providers had used the data set pilot as part of a wider service re-development. The reported staff time spent on implementation is therefore likely to be an overestimation of the input required to collect and report the patient data.

Sites that had some prior knowledge of palliative care currencies and IPOS required far fewer staffing resources (£0-3K) to implement the data collection than those that did not (£20K-100K). The reason for this is thought to be that external contractors were engaged to deliver only the specification provided by PHE for the collection and export of data. Internal development tended to be much more wide-ranging in scope, and supported wider changes in service delivery and care management.

'We needed a lot more IT time than we originally intending to have for the design changes' Greenwich & Bexley Community Hospice

'We had to build in a bit more time with the clinical teams in terms of training time' King's College Hospital

'We felt the benefits outweighed the costs as it was a focused piece of work' Rennie Grove Hospice Care

**Question 5: What support did you have for implementation and what do you think is needed?**

Most pilot sites (six) stated that the local management arrangements for the project work were an important support for the piloting. Four sites mentioned the support from

the National pilot administration (programme office at PHE) as having been important to them. Three sites reported informal peer support with other pilots. Other sources of support mentioned were the OACC team at KCH (two sites), and the NHS England pricing team (one).

Four sites reported that they would have benefited from better buy in to the piloting from local system support. However, all of these sites did manage to complete the pilot objectives within a year. One site reported that they would have benefited from better clinical buy in and were unable to complete the pilot targets. Three sites reported that they would have benefited from a more supportive approach from their IT suppliers.

'A project manager would have been good, admin support would have helped' Forest Holme Hospice, Poole Hospital

'The telephone conferences worked well because we certainly couldn't have left the building any more that we already did' East Cheshire Hospice

'We've got our consultants on board in terms of influencing and being lined up to what we're doing' North London Hospice

'The IT and the clinical support teams have been absolutely critical' St Luke's Hospice Sheffield

#### **Question 6: What aspects of your organisation do you think helped or hindered implementation?**

The most significant helpful aspect mentioned by pilots was the ownership of the project by local clinical leaders. In all cases where this was the case, the pilots managed to complete the objectives of the pilot for recording and submitting, including sites which did not have adequate IT support. Half of the pilots (five) reported that the local IT infrastructure and technical support was helpful, although one site which reported this, but did not have strong clinical leadership, was unable to complete data recording and submission. The two sites that mentioned IT infrastructure and support as a hindrance were however able to complete data recording and submission. Two multi-site providers mentioned that this had created additional complexity into the piloting.

Across sites in general, those where clinicians were already familiar with IPOS and the NHS England currencies were able to complete the project with far lower investment of capital or staff time than those which were unfamiliar. Although most organisations reported that staff had generally become more supportive over the course of the pilot, three responded that it had, at least initially been a hindrance.

'There are pros and cons of being one hospice in a national charity – if we were a standalone we would have our own IT support' Marie Curie Hospice West Midlands

'The fact that we are multi locality based, it wasn't a hindrance but it made rolling out a little more complex' Rennie Grove Hospice Care

'The IT development staff and IT staff talk to clinicians a lot about what works and what doesn't work and they mutually agree conclusions' King's College Hospital

### **Question 7: What impact (positive or negative) has the data collection had?**

Pilot sites were all very positive about the routine use of phase and AKPS scores for routine clinical record keeping. Key benefits, including shorter, more effective handovers and MDT meetings were reported very soon after collection had started.

There was also a general consensus that collecting IPOS data was helpful for enabling staff to better understand the priorities of patients, and clearly identify where these are, and are not being effectively addressed. Most sites reported they felt that this had a notable positive impact on their clinical effectiveness.

Some sites also reported that IPOS had been well received by patients, and that it helped them communicate more effectively with families and carers.

Most sites reported that the piloting had been difficult and burdensome, although there was a strong consensus that the benefits of doing justified this.

'Enhanced patient care, enhanced governance' St Luke's Hospice Sheffield

'It has allowed us to review the MDT, to review the way in which we work and the way in which we assess our patients' East Cheshire Hospice

'By describing patients in terms of their AKPS, phase and IPOS scores you very instantly get a picture of what they are like' Newcastle upon Tyne Hospitals Foundation Trust

### **Question 8: What advice would you give others implementing the data collection?**

There was a strong consensus that it is very important they should appreciate that implementation requires careful planning, and that the task should not be underestimated. Most suggested that units planning to implement the data-set would benefit from advice from peers who had already gone through the process.

Clinical leadership of the project was felt to be a key requirement for success, and that project teams should be multidisciplinary. Establishing early feedback of data to clinicians, and particularly the capacity of the data to illustrate the difference their care made to the patient was felt to be key in gaining support and enthusiasm from staff.

'Do need a project plan with realistic goals and timescales' North London Hospice

'Go for it and would strongly encourage other team to do it' Addenbrooke's Hospital, Cambridge University Hospitals

'Face to face teaching, not introducing it all at once but doing it step by step' Newcastle upon Tyne Hospitals Foundation Trust

### **Question 9: What in your view, would be the positive and/or negative impact of a national collection and reporting of the data?**

Responses from sites were almost universally concerning the potential positive impact a national collection would have. In particular, the ability to measure outcomes could provide a quantitative measure of quality. Other benefits mentioned included better commissioning, staff mobility (between units), and improved patient care.

'Just the ability to benchmark and measure your service with other similar organisations is also useful' Greenwich & Bexley Community Hospice

'The Australian experience is really relevant because they managed to improve significantly patient outcomes and the speed of symptom control by adopting this approach' Forest Holme Hospice, Poole Hospital

'A positive would be a standardised data collection where you can start to compare like with like' Marie Curie Hospice West Midlands

The one potential negative impact, mentioned by four sites, was that without comprehensive data capture and/or case mix adjustment, the data could be misleading.

## **12. Data set revisions**

The changes requested by participants over the course of the piloting, and the decision from the steering committee on which of these should be incorporated into a revised post pilot data set are listed. Table 7 contains the specific technical revisions that have been made to the revised data set.

**Table 7: Post pilot changes to data set**

Item(s)	Change Type	Notes
NHS NUMBER INDICATOR CODE	New item	Added to standardise data set and align with NHS Number information standard
Referral date Referral Reason	Data Model	To enable multiple entries from different referral sources
Referral Reason	Code	Add 'Respite Care'
Diagnosis	Data Model	To enable multiple entries over the course of a spell  All diagnosis recorded for the patient during the spell should be reported in data extractions used to calculate palliative care currencies
Preferred place of death	Data Model	To enable multiple entries over the course of a spell.  The last preferred place of death in a spell should be used to measure the proportion of patients who died at their preferred location.
Location at Spell Start	Data Item/Data Model/Codes	Replace with Usual Place of Residence, with codes <ul style="list-style-type: none"> <li>• patient's own home</li> <li>• other private residence</li> <li>• care home</li> </ul> Amend data model to permit multiple entries over the course of a spell.  The first Usual Place of Residence recorded during the spell should be used to calculate PCF currency for the patient.
Agency Code	Data Item	Replace with Organisation Data Service code <b>ODS code</b>
Living circumstance	Data Model	To enable multiple entries over the course of a spell.
Location	Data Model	To enable a change of treatment location during a spell.

Item(s)	Change Type	Notes
		The first location recorded during the spell should be used to calculate palliative care currency for the patient.
Functional Status	Data Model	To enable multiple entries over the course of a phase.  The first location recorded during the phase should be used to calculate palliative care currency for the patient.
Client Reference	Data Item	Dropped, as this item is no longer required as part of the design for a central collection.
Consent	Data Item	Dropped, as there are no data flows, or defined external uses for local clinical data which would enable this to be defined.
Living Circumstance	Data Item	Split into two items  Lives alone <ol style="list-style-type: none"> <li>1. Yes</li> <li>2. No</li> </ol> Are there family or friends who provide care for you?  <ol style="list-style-type: none"> <li>1. Yes, Currently providing care</li> <li>2. Yes but not providing care at present</li> <li>3. No</li> <li>4. Don't know</li> </ol>
Preference	Labelling	Change item name to 'Preferred place of Death'
Personalised Care Plan offered	Data Item	Dropped
Disability	Data Item	Dropped
Discharge Destination	Codes	Align with Information Standard for End of Life Care Coordination
Diagnosis	Data Model	To enable new diagnosis to be added at different points during the spell
Phase of Illness	Codes	Add 'Died' to codes
Duration of Phase	Data Item	Dropped
All IPOS	Codes	Add 'Cannot Assess'

Item(s)	Change Type	Notes
Client ID	Item	Dropped
Assessor	Data Model	Now recorded separately for each IPOS item
Carer Support	Codes	Add options for why carer questions are not completed
Carer Views on Care	Data Item	Dropped

## 13. Conclusions and key messages

### 13.1 Conclusions

The data set was found to be a feasible and acceptable way to collect information about patient outcomes and currency data. Most sites reported that the reception to the new data collection by local staff had been positive, and there also was very positive feedback from all pilots regarding the use of Australian Karnofsky Performance Status (AKPS) and Phase. There was a consensus that these terms provided a useful common shorthand to describe patients. Four sites mentioned that implementation of the data set had improved the working operations of the unit, and two reported that they felt the process had improved patient care.

Estimated technical costs ranged between £0K-£55k. Two pilots were able to get the configuration work completed as part of an ongoing procurement or rollout, with no additional costs to the host organisation. Implementation costs were estimated from £3K-£100K. However, pilots generally reported that it was not possible to disaggregate the staff time spent on implementation from other duties. This was especially the case where providers had used the data set pilot as part of a wider service re-development. The reported staff time spent on implementation is therefore likely to be an over-estimation of the input required to collect and report the patient data.

The most frequently mentioned challenge from the pilot sites was the need to gain patient consent for the data collection (seven sites). Most sites reported that there had been staff resistance to consenting patients for this purpose. However, most sites also reported that consent had been successfully integrated into clinical record keeping, and occasionally reported that the process of seeking consent from patients had been helpful in enabling better communication with them about their wishes. The ability of patients to consent to sharing of their data was expected to be an issue in view of the

frailty of the patient group. However, in comparison to initial predictions, only 13% of patients were unable to consent to data sharing. This may represent a selection bias as it is much lower than figures reported elsewhere in the literature. Consent to data sharing will be an issue if this data is collected as part of a national data set; local collection can take place as part of clinical care and without consent.

Collection of family and carers views also presented challenges to the pilot sites and this has important implications for the quality of SPC delivery of family and carer support, which is an important component of SPC.

The major challenges for implementation were IT system readiness and leadership (leading to clinical engagement). These determined the time to implementation and also cost in our pilots. Some pilots considered the timescale of the pilot to be overambitious and lead times of 12 months should be expected to embed the data collection.

Six pilot sites reported that amending IT systems was a challenge. A survey of IT capacity of SPC services in 2014 revealed a poorly developed IT infrastructure. About a third of respondents did not have a maintenance contract with IT suppliers and a similar number could not make data changes within their contracts. IT systems have been developed that are capable of collecting the data set as part of this project which are available for providers to commission.

The data set was assessed for clinical risks and most have been closed or passed on to providers as they are common to data sets in current clinical use. However, one remains open which is that this data set does not collect information about indirect care delivered by Specialist palliative care teams and therefore should not be used as a complete record of activity for the service.

Towards the end of the pilot project, it became clear that funding could not be secured to establish the national collection that had originally been hoped would follow the pilot. As a result the objectives relating to establishing the technical specification and legal gateways for a national collection system have not been met. We hope that opportunities for a national data collection will become available in the future as this would allow continuous quality improvement through national benchmarking. If a national data set is proposed then there will need to be a review of procedures such as for data sharing in those patients who are unable to consent.

## 13.2 Key messages from evaluation

1. Providers should consider implementing the data set to measure outcomes and complexity, to improve clinical communication and streamline clinical processes and to benchmark their service. The core data set should be used to ensure standardisation, but local providers may wish to collect additional data items.



2. Providers would be able to use the data set to collaborate and share good practice in outcome measurement with other local teams and across local regions.
3. The data set should be used alongside the Palliative care clinical data set Guidance and definitions document.
4. The most important factor for implementation in the pilots was the engagement of clinical leaders in the project. This should be the first step to ensure successful implementation.
5. IT system readiness is the next most important factor in implementation and the cause of most delays. Providers will need to ensure that their IT system is able to collect and report on the data set prior to rolling it out.
6. Commissioners would be able to use the data set as a way of monitoring outcomes and case-mix of their SPC services and to benchmark those services, so they may wish to encourage the services they commission to implement this.
7. Commissioners should be aware that this data set does not collect data about indirect care delivered by Specialist palliative care teams and therefore cannot be used as a complete record of activity of the service.
8. The pilot exercise provided limited, but positive, evidence that the data set could enhance quality and consistency of care. Further validation of the data set as a tool to measure and assure care quality should be undertaken.

# Appendix A: Consultation and feedback on data set

## 1. Introduction events

Public Health England, NCPC and Help the Hospices (now Hospice UK) hosted an exploratory consultation event on 7 October 2013. The objectives of the day were to identify the need for data from specialist palliative care services, learn about developments in other sectors (National drug treatment monitoring service and rehabilitation data), consider opportunities and barriers and to identify the next steps. There was support for development of a new national data collection of individual level data from the sector.

Time also allocated was allocated to consider a new national data collection at the research symposia held by Public Health England in partnership with Cicely Saunders International in December 2013 and March 2014.

## 2. Stakeholder event June 2014

A stakeholder consultation event was held on 25 June 2014. A range of key stakeholders were invited. Delegates were asked to review and comment on a proposed data set. There was consensus from the group on the need for individual-level data collection that includes outcomes.

## 3. Follow up survey

Those attending the June stakeholder event and others identified by the group and the steering group were invited to provide feedback on the proposed data set. See the [consultation survey report](#) for feedback.

## 4. Regional engagement events

From September 2014 to February 2015 there were nine engagement events held with the National End of Life Care Intelligence Network and NHS England's Palliative and End of Life Care Clinical Networks. There were also ten consultation events with palliative care clinicians and NHS England. Presentations were made to inform on the proposal for a new national data collection and comments invited at these events.

These events included table discussions and voting on questions (responses below):

Question asked	Response receive by no of votes
Do clinicians in your organisation currently capture clinical outcomes for individual patients?	Yes: 62 No: 83
The proposed data set includes clinical outcomes. Will these have the potential to improve care?	Yes- a lot 30 Yes- some 108 No 22 Not sure 40
Is the number of clinical outcomes included in the data set:	About right 90 Too many 35 Not sufficient 60
If you are a provider service- do you currently have IT system capacity to collect and report individual level data?	Yes 95 No 55 Not sure 41
Do you think that the ambitions for a national clinical data collection are:	Too ambitious 44 Not ambitious enough 32 About right 123

### Key message from table discussions

#### Benefits and opportunities:

- provision of robust, credible, timely and reliable data (an analyse trends)
- provides fuller picture of care
- can demonstrate complexity and that care makes a difference
- supports benchmarking and service improvement
- supports informed commissioning
- understanding patient need, workloads, patient flows and referral patterns
- lever for change, drives strategies
- equality of resource allocation
- raise profile of end of life care and specialist palliative care
- supports clinicians to improve patient care
- engages staff and commissioners, supports communication
- drives research and audit
- identifies gaps in service provision
- reducing inequalities

### **Weaknesses and threats:**

- does not cover all aspects of specialist palliative care
- time for data collection could impact on clinical care
- implementation costs - could be financial threat for voluntary sector hospices
- Reliant on accurate data input - could be tick box exercise, manipulation of data, inaccurate data
- very clinically focussed and need more data on social and spiritual needs
- complexity is difficult to capture and may not be able to demonstrate quality of care
- doesn't show patients not accessing services
- confusion over episode, spell, phase
- hard to reflect phase in real time and how to keep data up to date
- difficult and a burden for patients to express views at end of life
- training requirements IPOS
- consent model - difficulty of getting explicit consent (need clear model)
- reluctance/difficulty in engaging
- risk of adverse incentives eg not wanting to accept patients in lower cost phases
- risk that data collection will result in targets
- need regular reporting to be relevant to staff
- need for patient information about the data collection

## Appendix B: Focus group response

### 1. Composition of the focus groups

It was decided to run two focus groups each with a different type of participant.

**Group one (public)** which was held on 13 August comprised members of PHE's People's Panel who were selected on the basis that they had some experience of unpaid care of someone at the end of their life and/or had a life limiting condition themselves. All members of the group had been carers at some point for partners and or family. The panel members came from London, the South East and the East of England regions.

**Group two (stakeholders: patients and their carers/advocates)** which was held on 20 August comprised patients and carers/advocates recruited through voluntary sector and research organisations from the field of palliative care. Like the public group they had either cared for someone at end of life or were living with a terminal illness themselves. They were drawn from the following organisations: Cicely Saunders Institute of Palliative Care, the National Council for Palliative Care and the MacMillan Cancer Voices network.

#### **Participants:**

Group one (13 August) five participants: one female and four males aged 44 to 86.

Group two (20 August) nine participants: eight females and one male aged 54 to 70.

The groups were told that the aims of the discussions were to explore their views of end of life and palliative care in relation to PHE's plans for a new data collection service. And that the discussions they participated in would inform a wider consultation whose findings would feed into the collection of information which is acceptable to the public and of demonstrable value.

### 2. Knowledge of specialist palliative care data collection

The focus groups began with some background information about data collection and why PHE undertakes this work, specifically focussing on the benefits.

#### About the project:

- why we want to collect information about specialist palliative care and what difference it will make
- why we believe collecting individual patient information is important

- what information PHE currently collects and what is different and helpful about the new information we wish to collect
- what we hope to achieve and why we are consulting with patients and public
- what we have to do to make this happen

PHE wants to find out:

- whether people agree that this new data collection would be valuable
- to find out if you have any concerns with the collection and use of the information
- whether you feel that consent is required for using this information for analysis and reporting
- what sort of information about specialist palliative care services would be useful for the public

### 3. Topline findings

#### Group one topline findings

1. Immediate reaction to the dataset was a sense that the new questions on outcomes are difficult questions to ask when people are in a vulnerable state so training for staff asking the questions/collecting the information will be key.
2. Consent is less of an issue although we need to accept that it is important that people are able to withdraw their consent if they change their mind.
3. People assume that information is automatically shared beyond your GP and hospital so were surprised when for example dentists couldn't access it.
4. People more worried that their employers and insurance companies might have access to their information than other health and social care organisations.
5. Overall they liked the concept of data sharing and felt it is of value.
6. Carers are important so we need to ask them how they are doing.
7. Asking people what makes a good death is a challenging cultural question.
8. The information needs to be publicly available and may be available by regions to show variations but not necessarily as league tables.
9. Questions about dignity and carer assessment should be added to help develop ways of measuring them.
10. The information should inform a public debate about end of life and what is a good death. In general people need to prepare for their death.
11. Timing of the collection of information is important. Recommend that clinicians are provided with guidance on when questions should be asked.
12. Some questions feel very loaded and challenging for the vulnerable such as asking people about their preferred 'place of death'.
13. While there is a general acceptance that a lot of their information is already 'out there' nevertheless we should still try to anonymise what we collect.

14. There was a concern that we should not over burden the NHS with unnecessary data collection ie it has to have a proven value rather than for research's sake.
15. Not only should we be protecting the information from corporations but also there may be times when beneficiaries or relatives may want to access to the patient's information for negative reasons.

### Group two topline findings

1. The group was familiar with the terms palliative care and end of life care but they felt there should be agreed definitions which include quality of life as a consideration/indicator.
2. The group seemed less knowledgeable about the way their health information in general was collected although they knew a lot about their life limiting conditions.
3. Improved consistency of data recorded in hospitals, hospices and community would support information sharing which is currently lacking.
4. Surprised and disappointed by the lack of integration of their clinical records across services.
5. The group was less knowledgeable about their rights although one person mentioned the NHS Patient Constitution.
6. People with dementia are often missed or left out of data collection.
7. Asking people to rate pain levels was viewed as problematic because of the subjective nature of the question. It was therefore considered not a robust absolute measure of pain. However, they did see the value of the measure as a way of tracking change in pain over time.
8. Additional questions should be about the whole person ie holistic questions.
9. Consent was not an issue but security was identified as a priority when sharing information particularly where hospices lack the technological infrastructure to ensure secure data.
10. Care homes were an omission and that they should be included in the data collection.
11. Transparency was important and data should be publicly accessible but we should recognise its limitations for example not everyone felt producing league tables from the data would be a good thing.
12. The group was worried that Alzheimer's patients could not answer the questions so either they would go unanswered (representing an absence data) or carers might not feel qualified to answer on the patient's behalf.
13. Anxiety levels can be caused by factors other than the specific health problem or condition for example money worries for the family after they pass away.

Overall group two said they thought the project was valuable but there are challenges. And that hospices might need some resources to implement the programme. Generally they were disappointed but not surprised that information is not shared more consistently between hospitals, hospices, GPs and other health professionals.

#### 4. Conclusion based on findings from both groups

Who asks the questions is key to receiving the right information while a health professional would be acceptable equally important would the style and empathy displayed by the questioner therefore training will be important.

Both groups were disappointed about the lack of patient information sharing across primary, acute and tertiary care.

Both groups had relatively low levels of awareness of their rights and data protection legislation.

There should be questions for carers not just because they can provide extra insight into the patient experience but also to check on their health and wellbeing as well. Overall consent was not a big issue as long as the aims and objectives of the information being shared were clearly stated and that there would be opportunities for patients to withdraw their consent at any stage of their journey in case they changed their minds.

Both groups said that this kind of data collection was useful and valuable but if it was used for any measurement of services then it needs to recognise the benefit of holistic care. They felt otherwise subtle nuances like this would be lost if the data was used to create league tables especially when there was often limited choice with only one hospice available locally.



## Appendix C: System configuration and implementation costs

### System configuration costs

Pilot	IT System	How configured	Costs/Staff time
Addenbrooke's Hospital, Cambridge University Hospitals	EPIC	In-house	The work was done as part of the hospital EPR roll-out, and did not require additional funding. The work took two weeks, from which a nominal figure of <b>£3k</b> is estimated.
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	Graphnet	In-house	4 months full time (Applications Developer) 7 hours (Information Analyst) Estimate <b>£15k</b>
Greenwich & Bexley Community Hospice	Infoflex	External contractor	The total staffing costs outlined below were for implementation and progress of the pilot. These costs include consultancy for electronic patient record development to support the measures, systems administration, nursing, medical, training, admin and management time and were estimated at <b>£16k</b> . Staff time for training has not been included in these costs. These costs pertain to the months Oct 2015 to Feb 2016.
King's College Hospital	Checkware	Supplier	The work was done by the supplier as part of the procurement contract with King's College Hospital, and did not require additional funding. <b>£0</b>
Marie Curie Hospice West Midlands	SystemOne	In-house Supplier (for codes)	The total staffing costs for implementation (consultant, systems administration, nursing lead, business manager) were estimated £55k. However, it is not possible to disaggregate time spent by in-house staff on system configuration from time spent on other project tasks.  The supplier did not charge to implement local (Y-codes) on the clinical system.

Pilot	IT System	How configured	Costs/Staff time										
Newcastle upon Tyne Hospitals NHS Foundation Trust	Cerner Acute Setting  SystemOne Community setting)	Not completed within pilot time-frame  Completed within pilot time frame	Data was collected on spreadsheets, and submissions were manually created.										
Rennie Grove Hospice Care	Infoflex	In-house	<p>Time per month allocated to internal systems development;</p> <table> <tr> <td>Clinical Staff</td> <td>30 hours</td> </tr> <tr> <td>Admin Staff</td> <td>6 hours</td> </tr> <tr> <td>IT Staff time</td> <td>3 hours</td> </tr> <tr> <td>Management</td> <td>20 hours</td> </tr> <tr> <td>Other</td> <td>2 hours</td> </tr> </table> <p>A rough ball-park estimate of <b>£35-40k</b> is consistent with the use of these staff over a four month period (July-September 2015).</p>	Clinical Staff	30 hours	Admin Staff	6 hours	IT Staff time	3 hours	Management	20 hours	Other	2 hours
Clinical Staff	30 hours												
Admin Staff	6 hours												
IT Staff time	3 hours												
Management	20 hours												
Other	2 hours												
St Luke's Hospice, Sheffield	Infoflex	In-house	<p>Time per month spent on internal system development was;</p> <table> <tr> <td>Admin Staff</td> <td>10 hours</td> </tr> <tr> <td>IT Staff time</td> <td>25 hours</td> </tr> <tr> <td>Management</td> <td>4 hours</td> </tr> <tr> <td>Other</td> <td>2 hours</td> </tr> </table> <p>Around £700 was also spent on consultancy.</p> <p>The total costs for system development are estimated from these at <b>£54k</b>.</p>	Admin Staff	10 hours	IT Staff time	25 hours	Management	4 hours	Other	2 hours		
Admin Staff	10 hours												
IT Staff time	25 hours												
Management	4 hours												
Other	2 hours												
St Luke's Hospice, Plymouth	Crosscare	In-house	Administration (including IT) costs for the pilot were estimated as 691 hours. However system development costs cannot be disaggregated from these.										
East Cheshire Hospice	EMIS	In-house Suppliers	The supplier did not charge to implement local (Y-codes) on the clinical system.										

As most providers were unable to disaggregate costings into the categories of activity listed above, all other estimated costs of local implementation are grouped together, and shown in implementation costs.

### Implementation costs

Pilot	Costs/Staff time										
Addenbrooke's Hospital, Cambridge University Hospitals	The clinical team at Addenbrooke's Hospital, Cambridge University Hospitals were already familiar with both currency data and IPOS. Implementation required a manager to coordinate setting up the collection over a three week period, from which a nominal figure of <b>£3k</b> is estimated.										
Forest Holme Hospice - Poole Hospital NHS Foundation Trust	The following non-IT staff time was required: <table border="0"> <tr> <td>Clinical staff time</td> <td>152 hours (Consultant)</td> </tr> <tr> <td>Admin staff time</td> <td>113 hours (Bands 5 &amp; 6)</td> </tr> <tr> <td>Nursing staff time</td> <td>54 hours Band 7</td> </tr> <tr> <td>Other staff time</td> <td>6 hours (IG dept)</td> </tr> </table> <p>These figures can be used to produce an estimated (non-IT) cost of around <b>£60k</b>.</p>	Clinical staff time	152 hours (Consultant)	Admin staff time	113 hours (Bands 5 & 6)	Nursing staff time	54 hours Band 7	Other staff time	6 hours (IG dept)		
Clinical staff time	152 hours (Consultant)										
Admin staff time	113 hours (Bands 5 & 6)										
Nursing staff time	54 hours Band 7										
Other staff time	6 hours (IG dept)										
Marie Curie Hospice West Midlands	The total staffing costs for implementation (consultant, systems administration, nursing lead, business manager) were estimated <b>£55k</b> . However, it is not possible to disaggregate time spent by in-house staff on system configuration from time spent on other project tasks.										
Newcastle Hospitals NHS Foundation Trust	Staff time required for implementation was recorded as; <table border="0"> <tr> <td>Clinical staff time</td> <td>224 hours (Consultant/G7 Nurse)</td> </tr> <tr> <td>Admin staff time</td> <td>128 hours</td> </tr> <tr> <td>IT staff time</td> <td>114 hours</td> </tr> <tr> <td>Nursing staff time</td> <td>54 hours Band 7, 27 hours Band 8</td> </tr> <tr> <td>Management time</td> <td>70 hours (Band 8)</td> </tr> </table> <p>A nominal figure of around <b>£25k</b> can be estimated from these. However, as the data set could not be configured onto the hospital clinical system during the pilot, this includes costs to develop a work-around solution using spreadsheets.</p>	Clinical staff time	224 hours (Consultant/G7 Nurse)	Admin staff time	128 hours	IT staff time	114 hours	Nursing staff time	54 hours Band 7, 27 hours Band 8	Management time	70 hours (Band 8)
Clinical staff time	224 hours (Consultant/G7 Nurse)										
Admin staff time	128 hours										
IT staff time	114 hours										
Nursing staff time	54 hours Band 7, 27 hours Band 8										
Management time	70 hours (Band 8)										

Pilot	Costs/Staff time
Rennie Grove Hospice Care	<p>Staff time spent on project management, training developing internal processes from the start until the first submission was</p> <p>Clinical staff time      160 hours  Admin staff time        36 hours  IT staff time              26 hours  Management time       80 hours</p> <p>A nominal figure of around <b>£20k</b> is estimated from these.</p>
St Luke's, Hospice, Sheffield	<p>Staff time on project management, data collection, developing internal processes and the estimated annualised costs for these were estimated as;</p> <p>Clinical staff time      63.5 hours/week    £10k  Admin staff time        22 hours/week     £14.5k  IT staff time              22 hours/week     £24k  Management time       13 hours/week     £42k</p> <p>In addition, there were approx. £11.5k of training costs, producing an estimate for the implementation (excluding system costs) of around <b>£100k</b></p>
St Luke's, Plymouth	<p>The full costs of implementation, <b><i>including</i></b> system changes, are estimated as</p> <p>Clinical staff time      103 hours  Admin staff time        691 hours</p> <p>A nominal figure of around <b>£25k</b> is estimated from these.</p>

## Appendix D: Palliative care clinical data set

All changes to the data-set used during piloting are listed in Table 7.

No	PATIENT ID	Description	Format	Reference data (or source)	Change *
<b>SECTION 1 - CLIENT DATA</b>					
1	NHS number	The NHS Number of the person receiving specialist palliative care	n10	NHS Data Dictionary	
2	NHS number indicator	Status of patients NHS Code	n2	NHS Data Dictionary	
3	Client ID	A technical identifier representing the client, as held on the clinical system used at the agency (treatment provider)	an36		
4	First initial	The first initial of the patient	an1		
5	Last initial	The last initial of the patient	an1		
6	Date of birth	Patients date of birth	an10 CCYY- MM-DD	NHS Data Dictionary	
7	Gender	The individuals self-declared gender at registration	an1	Person Gender Code	
8	Ethnicity	The ethnicity that the individual states as defined in the OPCS census categories.	an20	NHS Data Dictionary	
<b>SECTION 2 - SPELL</b>					
9	Spell start date	The date of entry into the setting and delivery of care from the provider reporting this spell of care – for example, start of spell of home-based palliative care, start of inpatient hospice admission, start of hospital-based palliative care spell	an10 CCYY- MM-DD		
10	Referral date	The date that the client was referred to the agency for this spell of treatment – for example it would be the date a referral letter was received, the date a referral phone call or	an10 CCYY- MM-DD		

Palliative care clinical data set: evaluation report

No	PATIENT ID	Description	Format	Reference data (or source)	Change *
		fax was received or the date the client self-referred			
11	Reason for referral	The reason that a person is referred to the agency for care	an2	1. Pain control 2. Other symptom control (patient) 3. Emotional/psychological/spiritual support (patient) 4. Emotional/psychological/spiritual support (family/carer) 5. Social/financial support (patient) 6. Social/financial support (family/carer) 7. Rehabilitation 8. Respite Care 9. Discharge planning 10. Other 11. Care in the last days of life	<b>M</b>
12	Ready for service	The date when the person was ready to start spell of care	an10 CCYY-MM-DD		
13	Usual place of residence	Place of residence of patient	an2	10 Hospital (acute, community, other) 20 Private residence 21 Patient's own home 22 Other private residence (eg relative's home, carer's home) 30 Hospice (inpatient specialist palliative care) 40 Care home 50 Other (free text, eg secure and detained settings)	<b>S</b>
14	Care setting	Setting from where care is provided	an2	1 Inpatient 2 Outpatient 3 Community	<b>S</b>
15	Location	Where patient is residing.	an2	10 Hospital (acute, community, other) 20 Private residence 21 Patient's own home 22 Other private residence (eg relative's home, carer's home) 30 Hospice (inpatient specialist palliative care) 40 Care home 50 Other (free text, eg secure and detained settings)	

Palliative care clinical data set: evaluation report

No	PATIENT ID	Description	Format	Reference data (or source)	Change *
16	Diagnosis	Local clinical code, or select from code set.		A *Cancers of lip, oral cavity and pharynx B *Cancers of digestive organs, including colon, rectum, stomach, excluding liver, GB, pancreas C Cancer of liver, intrahepatic bile ducts, gallbladder- specified separate from digestive (unlike MDS) D Cancer of pancreas- specified separate from digestive (unlike MDS) E *Cancers of respiratory and intrathoracic organs, including lung F *Cancers of bone, skin, mesothelial and soft tissue, thyroid or endocrine G *Cancer of breast H *Cancers of female genital organs I *Cancers of male genital organs, including prostate J *Cancers of urinary tract K *Cancers of brain, eye and other CNS L *Cancer of unknown primary or other unspecified N *Lymphoid & haematopoietic cancers O *Cancer of independent multiple sites P *HIV/AIDS Q *Motor neurone disease R *Dementia including Alzheimer's S *Neurological conditions (excluding MND and Alzheimer's) T *Diabetes mellitus U *Heart failure V Stroke, infarction or haemorrhagic- – specified separate (unlike MDS) W *Other heart or circulatory, excluding heart failure and stroke X *Chronic respiratory disease Y *Liver failure, chronic liver disease, other non-malignant liver disease Z Chronic renal failure AA All other non-cancer diagnoses (everything not included above)- additions to MDS BB Multiple non cancer conditions – addition to help with multi-morbidity Unknown	<b>M</b>
17	GP Practice code	Patients GP Practice	an6	<b>NHS Data Dictionary</b>	<b>S</b>

Palliative care clinical data set: evaluation report

No	PATIENT ID	Description	Format	Reference data (or source)	Change *
18	Lives alone	Does the patient live alone	an1	1. Yes 2. No	<b>S</b>
18	Carers	Are there family or friends who provide care for the patient?	an1	1. Yes, Currently providing care 2. Yes but not providing care at present 3. No 4. Don't know	<b>S</b>
19	Postcode	Full postcode of the patient's usual place of residence at the start of the spell	an8		
20	Spell end date	Date that patient was discharged from the provider	an10 CCYY- MM-DD		
21	Spell outcome	Discharged or died	an1	1. Discharged 2. Died	
22	Discharge destination	Place where patient was discharged to	an2	10 Hospital 20 Private residence 21 PATIENT's own home 22 Other private residence (eg relatives home, carers home) 30 Hospice (inpatient specialist palliative care) 40 Care Home 50 Other	
23	Preferred place of death	Preferred place of death		10 Hospital (acute, community, other) 20 Private residence 21 Patient's own home 22 Other private residence (eg relative's home, carer's home) 30 Hospice (inpatient specialist palliative care) 40 Care home 50 Other (free text, eg secure and detained settings)	<b>S</b>



Palliative care clinical data set: evaluation report

No	PATIENT ID	Description	Format	Reference data (or source)	Change *
24	Place of death	Place where patient died	an2	10 Hospital 20 Private residence 21 PATIENT's own home 22 Other private residence (eg relatives home, carers home) 30 Hospice (inpatient specialist palliative care) 40 Care Home 50 Other	
<b>SECTION 3 - PHASE ASSESSMENT</b>					
25	Phase assessment date	The date at which an assessment of the individuals illness, severity of problems or functional status is recorded.	an10 CCYY-MM-DD		
26	Phase of illness	The phase of illness at the time of the assessment	an1	1 Stable 2 Unstable 3 Deteriorating 4 Dying 5 Unknown 6 Deceased	
27	Functional status	Australian Modified Karnofsky scale- 10 point scale	an3	100 Normal, no complaints or evidence of disease 90 Able to carry on normal activity, minor signs or activity 80 Normal activity with some effort, some signs of symptoms of disease 70 Care for self, unable to carry on normal activity or to do active work 60 Occasional assistance but is able to care for most of own needs 50 Requires considerable assistance and frequent medical care 40 In bed more than 50% of the time 30 Almost completely bedfast 20 Totally bedfast and requiring nursing care by professionals and/or family 10 Comatose or barely arousable, unable to care for self 0 Dead	<b>M</b>

Palliative care clinical data set: evaluation report

No	PATIENT ID	Description	Format	Reference data (or source)	Change *
28	Pain	Has pain affected you / Has the patient been affected by pain - over the past 3 days?	an3	0 Not at all 1 Slightly 2 Moderately 3 Severely 4 Overwhelmingly 999 Cannot assess	M
29	Pain assessor	Source of IPOS score	an2	1 Person themselves 2 Person with family 3 Person with professional help 4 Professional	M
30	Breathlessness	Has breathlessness affected you/Has the person been affected by breathlessness- over the past 3 days?	an3	0 Not at all 1 Slightly 2 Moderately 3 Severely 4 Overwhelmingly 999 Cannot assess	M
31	Breathlessness assessor	Source of IPOS score	an2	1 Person themselves 2 Person with family 3 Person with professional help 4 Professional	M
32	At peace	Have the patient felt at peace? Over the past 3 days.	an3	0 Always 1 Most of the time 2 Sometimes 3 Occasionally 4 Not at all 999 Cannot assess	M
33	At peace assessor	Source of IPOS score	an2	1 Person themselves 2 Person with family 3 Person with professional help 4 Professional	M
34	Information needs	Have you had / has the patient had as much information as s/he wanted - over the past 3 days (inpatient ) or 1 week (community-based)?	an3	0 Always 1 Most of the time 2 Sometimes 3 Occasionally 4 Not at all 999 Cannot assess	M

Palliative care clinical data set: evaluation report

No	PATIENT ID	Description	Format	Reference data (or source)	Change *
35	Pain assessor	Source of IPOS score	an2	1 Person themselves 2 Person with family 3 Person with professional help 4 Professional	M
36	Carer support	Overall do you feel you and your family are receiving as much help and support from services as you need when caring for him/her?	an1	1 Yes, we got as much support as we wanted 2 Yes, we got some support, but not as much as we wanted 3 No, although we tried to get more help 4 No, but we did not ask for more help 5 We did not need help 6 No main carer 7 Main carer unavailable	M
37	Carer support score	Source of carer support score	an2	1 Person themselves 2 Person with family 3 Person with professional help 4 Professional	M

\*Changes, additions or updates to fields

S: single updatable field which may change during a spell or phase

M: multiple fields over course of spell or phase

## Appendix E: Membership of the Palliative Care Steering Group and Expert Reference Group

### Palliative care steering group

Representative	Post	Organisation
Bee Wee (Chair)	National Clinical Director for End of Life Care	NHS England
Malcolm Roxburgh	Palliative Care Data Set Project Lead	Public Health England
Julia Verne	Clinical Lead, NEOLCIN	Public Health England
Barry James	Palliative Care Programme Manager	NHS England
Sarah Cox	Chair of Expert Reference Group	Royal College of Physicians and Association of Palliative Medicine of Great Britain and Ireland
Louise Corson	Programme Manager (End of Life Care)	NHS England
Nicola Spencer	Business Domain Manager	NHS England
Ian Townend	Data Projects Lead	NHS England
Alex Porter	Senior Data Development Manager, Data Services for Commissioner	NHS England
Barry James	Palliative Care Programme Manager	NHS England
Nicholas Richman	Service Development Manager for Community, Child Health & Maternity Services	Health and Social Care Information Centre
Dilwyn Sheers	Palliative Care Funding Pilots Team	NHS England
Sadaf Dhalabhoy	Pricing Development Team	Monitor
Giovanna Polato	Team Leader – Intelligence	Care Quality Commission
Karen Thomson	Head of Data Sharing and Privacy, Information & Transparency Group, Patients & Information	NHS England

## Expert Reference Group

<b>Representative</b>	<b>Title</b>	<b>Representing Organisation</b>
Sarah Cox (Chair)	Chair of APM Professional Standards Committee	Royal College of Physicians and Association of Palliative Medicine of Great Britain and Ireland
Teresa Tate	Palliative care consultant, Palliative Care	Palliative care funding review and Vice chair of ERG
Malcolm Roxburgh	Palliative care clinical data set Programme Manager, Public Health England	Public Health England
Simon Chapman	Director of Policy, Intelligence & Public Affairs	The National Council for Palliative Care
Ros Taylor	National Director for Hospice Care	Hospice UK
Fliss Murtagh	Reader and Consultant in Palliative Medicine	Cicely Saunders Institute, King's College London
Jean Gaffin		Lay member
Mary Brice	Heart Failure Nurse Consultant	National Palliative care Nurse Consultant Group
Bill Noble	Medical Director	Marie Curie Cancer Care
Nicole Woodyatt	Interim Programme Lead for End of Life Care	Macmillan Cancer support
Julian Abel	Specialist palliative care consultant Weston Area Health Trust	Regional representation - Clinician from South West
Nigel Sykes	Medical Director, Consultant in Palliative Medicine. St Christopher's Hospice	Lead for St Christopher's PCF pilot site consortium
Myer Glickman	Head of Life Events Modernisation	Office for National Statistics
Gunn Grande (co-optee)	Professor of Palliative Care, School of Nursing, Midwifery and Social Work	University of Manchester
Barry James	Palliative Care Programme Manager	Pricing Team, NHS England
Bridget Johnston	Florence Nightingale Foundation Professor of Clinical Nursing Practice Research, School of Medicine, Dentistry & Nursing	College of Medical, Veterinary & Life Sciences, University of Glasgow

<b>Representative</b>	<b>Title</b>	<b>Representing Organisation</b>
Lynne Russon	Consultant in Palliative medicine at Wheatfields hospice and Leeds teaching hospitals trust representing Sue Ryder	Sue Ryder
Kerry Archer-Dutton	NEoLCIN Project Administrator, Public Health England	Public Health England
David Currow	Professor, Discipline of Palliative and Supportive Services	Flinders University
Joan Teno	Professor of Medicine	Cambria Palliative Care Center of Excellence, University of Washington

## Appendix F: Data submitted during pilot

	Patients	Spells	Assessments
Addenbrooke's Hospital	236	404	413
Greenwich and Bexley Community Hospice	56	440	743
King's College Hospital	84	117	152
Marie Curie West Midlands	90	528	551
Newcastle upon Tyne NHS Foundation Trust	300	899	1025
Rennie Grove Hospice Care	275	379	379
St Luke's Hospice, Plymouth	208	627	957
St Luke's Hospice, Sheffield	431	810	1031
<b>Total</b>	<b>1680</b>	<b>4204</b>	<b>5251</b>

### Spell type

	Community	Inpatient	Outpatient
Addenbrooke's Hospital	0	236	0
Greenwich and Bexley Community Hospice	89	20	19
King's College Hospital	0	84	0
Marie Curie West Midlands	53	47	1
Newcastle upon Tyne NHS Foundation Trust	168	361	20
Rennie Grove Hospice Care	275	0	0
St Luke's Hospice, Plymouth	218	199	0
St Luke's Hospice, Sheffield	342	67	56
<b>Total (spells)</b>	<b>1145</b>	<b>1014</b>	<b>96</b>

### Spell outcome

	Not stated	Died	Discharged
Addenbrooke's Hospital	4	74	158
Greenwich and Bexley Community Hospice	128	0	0
King's College Hospital	4	7	73
Marie Curie West Midlands	34	33	34
Newcastle upon Tyne NHS Foundation Trust	112	62	375
Rennie Grove Hospice Care	218	55	2
St Luke's Hospice, Plymouth	58	103	256

St Luke's Hospice, Sheffield	0	188	277
<b>Total (Spells)</b>	<b>558</b>	<b>522</b>	<b>1175</b>

### Phase at first assessment

	Stable	Unstable	Deteriorating	Dying	Unknown	Missing
Addenbrooke's Hospital	61	92	41	42	0	0
Greenwich and Bexley Community Hospice	37	46	41	0	0	4
King's College Hospital	11	60	8	0	3	2
Marie Curie West Midlands	35	45	15	2	0	4
Newcastle upon Tyne NHS Foundation Trust	81	332	99	14	0	23
Rennie Grove Hospice Care	103	66	92	14	0	0
St Luke's Hospice, Plymouth	110	111	99	12	28	57
St Luke's Hospice, Sheffield	137	98	177	43	6	4
<b>Total (1<sup>st</sup> assessment in spell)</b>	<b>575</b>	<b>850</b>	<b>572</b>	<b>127</b>	<b>37</b>	<b>94</b>



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