National End of Life Care Intelligence Network

Palliative care clinical data set

Guidance and definitions

V1.0/ December 2016

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Prepared by: National End of Life Care Intelligence Network
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The intelligence networks

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

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

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.

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Foreword

'My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible' Ambitions for Palliative and End of Life Care (2015)

The third ambition in the Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 focuses on 'maximising comfort and wellbeing'. Making a positive difference to the things that concern our patients is what motivates most of us in our day to day clinical work.

In palliative care, we have always struggled with objective measurement of our clinical effectiveness: the person's underlying condition is not static and often deteriorates regardless of what we do, there are concerns about imposing a burden through the process of collecting information and there is a lack of valid and reliable outcome measures.

The Palliative care clinical data set presented in this document represents a huge step forward in our collective effort to address this longstanding gap. It describes a set of data items, and specifies the conditions for collecting this data in a way that enables systematic and standardised measurement, analysis and comparison of some of the key outcomes that matter most to people who receive specialist palliative care. It provides information about direct care for three groups of people: clinicians and service providers who can use it to improve the quality of service delivered; commissioners who can use it to inform and improve commissioning processes, especially as it incorporates the data required for using palliative care currencies as the building blocks for local palliative care funding models; users and funders of our public and voluntary services who can use it as part of their evaluation of their local services.

This development has been made possible through the support of NHS England and Public Health England (PHE), working with Cicely Saunders Institute, Hospice UK, National Council for Hospice Care and the many individuals and organisations who have contributed considerable time, effort and resources. It represents an important milestone in our journey, not the end. Inevitably, it will need adjustment and fine-tuning as experience grows. Implementation is not quick or simple. It will require strong senior management and clinical leadership, enthusiastic engagement by staff at every level and constant commitment to the use of robust data to drive service improvements.

Although not mandated, we hope that clinicians, service providers and commissioners will recognise the value of this data set as an important and useful tool, and facilitate its integration into clinical practice. Some pilot sites have already reported that the use of the Data Set have streamlined and transformed their clinical practice. It would be great to see this experience spread more widely.

Professor Bee Wee
National Clinical Director for End of Life Care
NHS England

1. Introduction

This guidance has been developed to support the introduction of a new data collection from specialist palliative care services during 2016/17. It should be used after reviewing the document 'National End of Life Care Intelligence Network; Palliative care clinical data set Evaluation report' to understand the context in which this document is set.

The Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 identifies 'evidence and information' as one of the eight foundations that underpin all six ambitions. It emphasises that comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved.

The vision proposed in this guidance is for a single data set which captures patient care activity, complexity and outcomes from adult hospices and specialist palliative care providers across all care settings. It is intended to minimise the burden of data collection by incorporating routine clinical and care records wherever possible.

The purpose of this individual level data collection is to:

- improve care for individual patients and their families through reporting of patient centred outcomes
- better support patient 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

The vision is for a single data set that will support quality improvement in specialist palliative care and the data requirements of the definitive funding currencies which have been published by NHS England. The data set will be used to provide the data required to support a roll out of these currencies and of any future funding mechanism.

This data set also aligns with the Outcome assessment and complexity collaborative (OACC) initiative led by the Cicely Saunders Institute (CSI) at King's College London and in partnership with Hospice UK.

Pilot sites have tested the ease of data collection, the appropriateness of individual data items and have provided some information on the costs and feasibility of implementing the data set. The findings are published in the Palliative care clinical data set evaluation report.

A glossary of terms and definitions used in this document is provided in Appendix A.

2. Background

The need for a clinical data set was highlighted in the End of life care strategy of 2008 which outlined the developments required to achieve a continuous improvement in the provision of end of life care. It was apparent 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. An attempt to merge existing healthcare data sets to provide a picture of care during the last year of life proved unsuccessful. At the same time, following the publication of the Palliative care funding review in 2011, work had begun to collect data on individual patients following their pathway from referral to palliative care services until death. The data collected in this way was used for the work to develop palliative care currencies and has now been refined to be consistent with the clinical data set items.

3. Purpose

This guidance is limited to supporting the collection of a set of data for patients receiving specialist palliative care. The data, once collected, can provide a first step towards understanding how services and the quality of individual care can be improved within a local area. It is not intended as an implementation guide, and does not make reference to any organisational infra-structure, governance or capacity issues which may need to be addressed in order to facilitate the collection of data.

Details should be recorded for all adult patients (aged 18 or over) receiving care from specialist palliative care provider services once they have given consent.

The data will not specify whether care is provided by a specialist or generalist staff member.

It is recognised that in addition to direct patient care, specialist palliative care services provide much indirect care, eg advising colleagues outside the specialist palliative care service, attending multidisciplinary team (MDT) meetings, delivering training and education.

It is suggested that collecting this data also, outside the current data set, will be beneficial to services in ongoing discussions with commissioners and for future service planning.

4. Data entities

The data items in this data set may be considered as belonging to one of three different entities or groups. These are:

Client data
Client details contain information about the patient which is not expected to vary between providers (eg patient initials, NHS number, date of birth, and gender). These common identifiers can be used to identify individuals that may be treated at more than one provider.

Spell data
Spell details contain information which is not expected to change during a spell of care in a single setting. This includes referral date, reason for referral, GP, care setting, living circumstances, diagnosis, discharge destination. The question on carer views on care should be asked at the end of the spell.

Phase data
These details need to be assessed and recorded at initial assessment and then repeated each time the phase of illness changes. This includes:

- date of phase change
- phase data collection date
- phase of illness
- functional status
- pain status
- breathlessness status
- 'at peace' status
- anxiety/distress status
- information needs status
- views on care
- assessor type
- carer support

A full list of data items and their definitions is given in the next chapter. This chapter focuses on the data items that require more detailed explanation.

4.1   Spell and phase data

Information will be collected for each **phase** of a patient's illness within a longer **spell of palliative care**.

A **spell of care** is defined as each period of contact between a patient and a palliative care service provider or team of providers that occurs in one care setting (inpatient/outpatient/community). This is the setting where care will be provided within the spell and may, for example, be an inpatient stay in a hospital or hospice or a period of community care by a specialist palliative care provider in the patient's own home or care home. Whenever the patient moves to receive care in a different care setting, a new spell of care is initiated. A spell of care commences at the start of palliative care involvement with a patient and finishes when the patient moves to a different care setting or is discharged from palliative care.

Within each **spell of care** a patient may have numerous different **phases of illness**. The phase is driven by the clinically assessed phase of the patient's condition. One phase ends and another begins when a clinical decision is made that the patient has moved between one of the four phases of illness: stable, unstable, deteriorating, dying and a final phase of died. See Table 1 for a description of the four phases and Appendix B for the OACC phase of illness algorithm which describes phase of illness allocation in accordance with phase definition.

Table 1: Phases of illness

| Start	End
1. Stable • patient problems and symptoms are adequately controlled by established plan of care • further interventions to maintain symptom control and quality of life have been planned • family/carer situation is relatively stable and no new issues are apparent	• the needs of the patient and or family/carer increase, requiring changes to the existing plan of care

Start	End
2. Unstable An urgent change in the plan of care or emergency treatment is required because: • patient experiences a new problem that was not anticipated in the existing plan of care and/or • patient experiences a rapid increase in the severity of a current problem and/or • family/carers circumstances change suddenly impacting on patient care	• the new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (ie patient is stable or deteriorating) and/or • death is likely within days (ie patient is now terminal)
3. Deteriorating The care plan is addressing anticipated needs but requires periodic review because: • patient's overall functional status is declining and • patient experiences a gradual worsening of existing problem and/or • patient experiences a new but anticipated problem and/or • family/carers experience gradual worsening distress that impacts on the patient care	• patient condition plateaus (ie patient is now stable) or • an urgent change in the care plan or emergency treatment and/or • family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (ie patient is now unstable) or • death is likely within days (ie patient is now terminal)
4. Dying Death is likely within days.	• patient dies or • patient condition changes and death is no longer likely within days (ie patient is now stable or deteriorating)

Source: Palliative Care Phase: Inter-rater reliability and acceptability in a national study. Malcolm Masso, Samuel Frederic Allingham, Maree Banfield et al. Palliative Medicine. September 2014.

Figure 1 shows a potential **spell of care** for a patient and the points at which phase data need to be collected (ie at the start of each new phase).

Figure 1: Relationship between spell of care and phase of illness
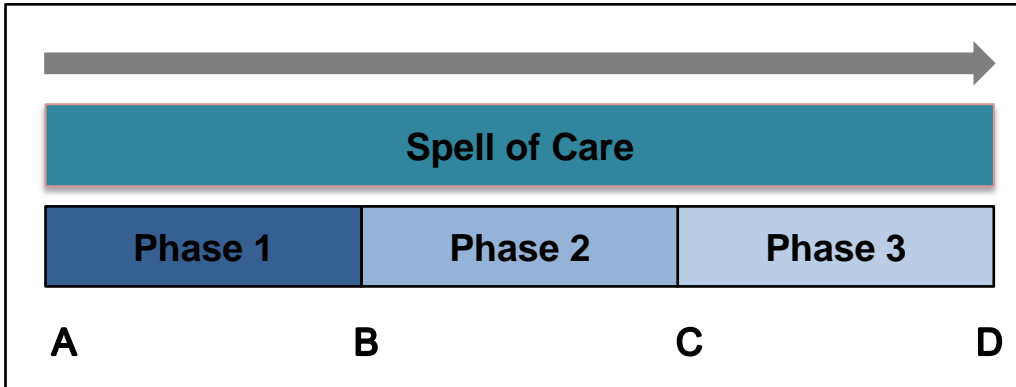
Changing place of residence

If a patient changes their place of residence (eg from own home to relative's home or a care home) but care continues from the same provider service in the same care setting (inpatient/community/outpatient): this is **not** a new spell.

Care delivered in parallel

In situations where people receiving community care are admitted as an inpatient (see glossary for definition) and discharged, the community spell will end at admission and need to restart when/if the community care service resumes. However, if the person, while continuing to receive community care, also receives care from another provider as an outpatient (includes daycare, see glossary for definition) a second spell should be opened, and then closed, in parallel.

Phase changes need not go in one direction only (eg from stable to unstable to deteriorating to dying). For example, a spell may have a number of phase changes that look like this (Figure 2).

Figure 2: Example of phase changes in a single spell of care
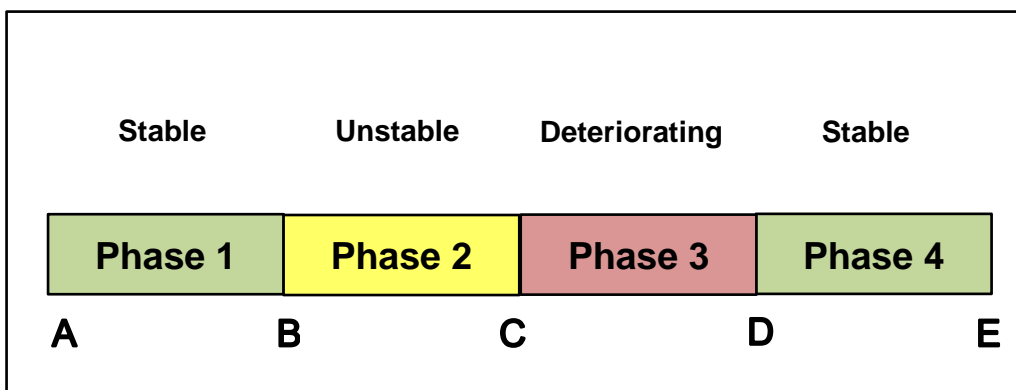
4.2   Outcomes data

Outcomes are collected to allow assessment of the impact of care. They are collected over two or more time points. The first assessment and recording is at initial assessment within the spell, though patient and carer questions do not have to be asked at first assessment (if deemed inappropriate). Further assessment and recording is carried out for each phase change, eg from unstable to stable or from deteriorating to dying, see Appendix C.

The outcomes included in the data set are:

- phase of illness
- functional status
- items from the Integrated palliative care outcome scale (IPOS) measure: pain, breathlessness, 'at peace', anxiety/distress, information needs
- questions on patient views are modified from SKIPP (St Christopher's Index of Patient Priorities)
- support for the carer: one data item

4.2.1 Additional information about IPOS

Clinically, the purpose of IPOS is to assist with the development of a new management plan based on the needs of the patient (see Appendix C).

IPOS has both a patient version be completed by the patient alone, with help from the family or with help from staff and a staff version for use when it is not possible for the patient to complete the questionnaire or answer the questions themselves. Template questionnaires for collecting IPOS are provided in Appendix D (one for patients and carers and one for professionals).

The questions are designed to reflect the situation (in the last three days) at the time of asking, which, as stated above is at first assessment (if appropriate) and on phase change.

It is permissible to ask IPOS questions over the phone if necessary, though face-to-face is preferred.

Additional resources for IPOS, which are free to use, are available from www.pos-pal.org. These include IPOS-5 which contains those items from the full IPOS for this data set.

Some palliative care teams are already using the full IPOS but others may prefer to use IPOS-5 initially as it is less burdensome to collect.

Patient versions of IPOS are available to download from the website and patients can also be offered this means of access to the IPOS tool.

At the time of writing there are already five translations and cultural adaptions of IPOS in progress - email the IPOS team via the website to find out what is currently available.

4.3 Other data entities

4.3.1 Reasons for referral

The reason for referral for specialist palliative care, **as identified by the referrer**, will be recorded at first assessment during a spell. Multiple selections are allowed:

- pain control (patient)
- other symptom control (patient)
- emotional/psychological/spiritual support (patient)
- emotional/psychological/spiritual support (family/carer)
- social/financial support (patient)
- social/financial support (family/carer)
- rehabilitation
- discharge planning
- care in the last days of life
- respite
- other

4.3.2 Location

Data item	Responses	Definition
Location	**10 Hospital** Acute* Community** Other **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** (free text eg secure and detained settings)	Where patient is residing. This may change during a spell, for instance if a patient is admitted from home to a care home.

*Acute hospitals provide a wide range of specialist care and treatment for patients. Services offered in acute hospitals include:

- consultation with specialist clinicians (consultants, nurses, dieticians, physiotherapists and a wide range of other professionals)
- emergency treatment following accidents
- routine, complex and life-saving surgery
- specialist diagnostic, therapeutic and palliative procedures

www.nrls.npsa.nhs.uk/resources/healthcare-setting/acutehospital

**The community hospital is a service that offers integrated health and social care and is supported by community-based professionals (Meads, G. Participate. University of Warwick, 2004).

***Hospice includes NHS and voluntary specialist palliative care inpatient beds, including those located in NHS hospitals or on NHS hospital grounds.

4.3.3 Preferred place of death

Recognising that a person may not wish to express a preference for a place of death or may change their preference over time, this data item should be recorded at the start of each spell. Options include 'discussion not appropriate' and 'patient declined discussion'.

4.3.4 Diagnosis

The diagnoses should reflect the primary and if appropriate additional diagnoses requiring palliative care involvement. ICD10 codes should be used whenever possible. If coding is not available, diagnosis should be selected from the ICD10 categories listed in Appendix E.

4.4 Collecting and recording the data

There are four points at which data should be collected, driven by clinical practice:

- on admission and/or at first assessment (client, spell and phase data)
- assessment of phase at each contact (phase data if there has been a change)
- at each phase change (phase data)
- at end of spell (phase and some spell data eg discharge destination or death)

Note that it is not necessary to collect phase data when a patient dies.

5. Data item definitions

Section 1: Client data

These items define a unique individual on the system. Data in this section should always be the same from any provider.

Item	Description
NHS Number	The NHS Number of the person receiving specialist palliative care.
Initial of client's first name	The first initial of the client's first name – for example Max would be 'M'.
Initial of client's surname	The first initial of the clients surname – for example Smith would be 'S', O'Brian would be 'O' and McNeil would be 'M'.
Person birth date	The day, month and year that the client was born.
Person gender at registration	The client gender at registration (self-reported).
Ethnicity	The ethnicity that the client states as defined in the OPCS census categories. If a client declines to answer then 'not stated' should be used, if a client is not asked then the field should be left blank.

Section 2: Spell data

This section contains information that is only reported once by a provider during a spell, but values may vary between providers.

Item	Description
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 fax was received or the date the client self-referred.
Reason for referral	The primary or main reason, as identified by the referrer, that a person is referred to the agency for specialist palliative care.
Reason for referral 2	The reason, as identified by the referrer, that a person is referred to the agency for specialist palliative care.
Reason for referral 3	The reason, as identified by the referrer, that a person is referred to the agency for specialist palliative care.
GP practice code	GP practice code.
Usual place of residence	The person's usual place of residence – eg home, care home or other.
Care setting	Setting from where care will be provided within the spell (inpatient/outpatient/community). Outpatient care and day care should be recorded as outpatient, unless there is a local desire to monitor a day care category. Care setting may change during a spell but this would only be recorded at the start of each spell.
Location	Where patient is residing. This may change during a spell, for instance if a patient is admitted from home to a care home.
Ready for service date	The date when a person is ready to start the spell intervention. This is required to take into account occasions when a person is referred before they are ready for care to start.

Item	Description
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.
Client reference	A unique number or ID allocated by the treatment provider to a client. The client reference should remain the same within a treatment provider for a client during all treatment episodes. (NB: this must not hold or be composed of attributors that might identify the individual). This may be a local case number allocated to clients.
Spell ID	A mandatory, technical identifier representing the episode, as held on the clinical system used at the treatment provider (NB: this should be a technical item, and should not be composed of attributors, which might identify the individual). A Spell ID would normally be a technical field used within the local clinical system to enable activity to be linked to a patient spell.
Living circumstance	Whether the patient lives alone.
Availability of Care Support	Whether the patient has family or friends to provide support.
Preferred Place of Death	Current 1st choice of preferred place of death. Preferences can be dynamic and changes should be recorded.
Primary end of life diagnosis	The primary reason for a patient's need for palliative care. This is recorded diagnostic code from ICD 10 (predefined list of broad groups to be used as an alternative if code is not available).
Diagnosis 2	A secondary reason for patient's palliative care. This is recorded diagnostic code from ICD 10 (predefined list of broad groups to be used as an alternative if code is not available).
Diagnosis 3	A secondary reason for patient's palliative care. This is recorded diagnostic code from ICD 10 (predefined list of broad groups to be used as an alternative if code is not available).
Phase of illness	The phase of illness at the time of data collection.

Item	Description
Postcode	Full postcode of the patient's usual place of residence at the start of the spell.
Spell end date	Date that patient was discharged from the provider.
Spell outcome	Discharged or died.
Discharge destination	Category of place where patient was discharged to.
Place of death	Category of place where patient died.

Section 3: Phase data

This section contains information that is recorded on phase change which may occur multiple times during a single spell with a provider.

Item	Description
Phase ID	Local clinical system generated Follow Up ID number. This is a technical item included within submission file, not normally visible to treatment providers.
Spell ID	Spell ID of spell that this phase data collection is linked to. This is a technical item included within submission file, not normally visible to treatment providers.
Phase data collection date	The date at which the phase data collection is recorded.
Date of phase change	The date when there is a change of phase of illness.

Item	Description
Phase of Illness	The phase of illness at the time of the data collection.
Duration of phase	Duration of the phase of illness (days).
Functional status	Assessment of an individual's ability to perform normal daily activities required to meet basic needs, fulfil usual roles and maintain health and wellbeing using the Australian Modified Karnofsky scale - 10 point scale - value at time of data collection. Full documentation can be found here.
Pain	Pain severity score of the client at the time of the data collection.
Breathlessness	Breathlessness score of the client at the time of the data collection.
At peace	At peace score of the client at the time of the data collection.
Anxiety/Distress	Anxiety score of the client at the time of the data collection.
Information needs	Assessment of whether the client's information needs are met.
Views on care	Assessment by the client on the overall impact of care. Should not be asked at first assessment.
Assessor	To identify the person making the assessment of these symptoms and concerns.
Carer support	The family member/carer's assessment of the adequacy of the help and support they have received from health and social care services.

Which data items should be updated as a spell of treatment progresses

Sect	Field Description	Rules and guidance
	NHS Number	Should not change.
	Initial of Client's First Name	MUST be completed. If not, record rejected. Should not change.
	Initial of Client's Surname	MUST be completed. If not, record rejected. Should not change.
	Person Birth Date	MUST be completed. If not, record rejected. Should not change.
	Person gender at registration	MUST be completed. If not, record rejected. Should not change.
	Ethnicity	Should not change.

Sect	Field Description	Rules and guidance
2	Referral Date	MUST be completed. If not data may be excluded from waiting times calculations. Should not change.
	Reason for referral	Should not change but could be added to.
	Reason for referral 2	Should not change but could be added to.
	Reason for referral 3	Should not change but could be added to.
	GP practice code	May change (ie current living situation).
	Care setting	May change (ie current situation).
	Location	May change (ie current situation).
	Spell start date	MUST be completed. If not data may be excluded from waiting times calculations. Should not change.

Sect	Field Description	Rules and guidance
	Agency code	MUST be completed. If not, record rejected. Should not change.
	Usual place of residence	Should not change.
	Living circumstance	May change (ie current living situation).
	Preference	May change (ie current preference).
	Primary end of life diagnosis	Should not change.
	Diagnosis 2	Could be populated during a spell.
	Diagnosis 3	Could be populated during a spell.
	Postcode	May change (ie current situation).
	Disability	Should not change.
	Spell end date	Required when spell is complete. Spell outcome required when spell is completed. Should only change from 'null' to populated as spell progresses.
	Spell outcome	Spell outcome required when spell complete. Spell end date MUST be given. Should only change from 'null' to populated as spell progresses.
	Discharge destination	Should only change from 'null' to populated as spell progresses.
	Place of death	Should only change from 'null' to populated after patient has died.

Sect No	Field Description	Rules and guidance
3	Follow Up ID	MUST be completed if any other items in this section are not null. If not, record rejected.
	Follow Up date	Should not change.
	Phase of Illness	Should not change (ie as at Follow Up date).

Sect No	Field Description	Rules and guidance
	Functional status	Should not change (ie as at Follow Up date).
	Pain	Should not change (ie as at Follow Up date).
	Breathlessness	Should not change (ie as at Follow Up date).
	At Peace	Should not change (ie as at Follow Up date).
	Anxiety/Distress	Should not change (ie as at Follow Up date).
	Information needs	Should not change (ie as at Follow Up date).
	Views on Care	Should not change (ie as at Follow Up date).
	Assessor	Should not change (ie as at Follow Up date).
	Carer support	Should not change (ie as at Follow Up date).

Where items are designated as 'Should not change' this does not include corrections or moving from a Null in the field to it not being populated.

Appendix A: Glossary and definitions

Term	Definition
Assessor	Person that assesses the patient outcome data items
Carer	The individual, excluding paid care workers or care workers from voluntary agencies, identified by the person to hold major responsibility for providing their informal care and support. Note: The main carer will be identified by the person's GP or key worker if the person lacks capacity to identify one for themselves. Source: Palliative care co-ordination: core content (SCCI1580) definition for main carer.
Community setting	A service provided by professional members of a specialist palliative care service to patients in their place of residence.
End of life	The General Medical Council defines people as 'approaching the end of life' as those likely to die within the next 12 months. This includes individuals whose death is imminent (expected within a few hours or days), and those with: advanced, progressive, incurable conditions general frailty and co-existing conditions that mean people are expected to die within 12 months existing conditions, if they are at risk of dying from a sudden, acute crisis in their condition life-threatening acute conditions caused by sudden catastrophic events those in a persistent vegetative state Source: Treatment and Care towards the end of life: good practice in decision making. General Medical Council (2010).

Term	Definition
End of life care	Care that helps all those with advanced, progressive and terminal conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and the family to be identified and met through the last phase of life and into bereavement. It includes the physical care, management of pain and other symptoms and provision of psychological, social care, spiritual and practical support. Source: End of Life Care Strategy: promoting high quality care for adults at the end of their life. Department of Health 2008 and Palliative care co-ordination: core content (SCCI1580)
Functional status	Assessment of an individual's ability to perform normal daily activities required to meet basic needs, fulfil usual roles and maintain health and wellbeing. Source: Palliative care co-ordination: core content (SCCI1580)
Inpatient setting	A patient receives care in a designated specialist palliative care setting or from a designated specialist palliative care team which includes at least one overnight stay, including a stay in A&E which spans midnight.
IPOS	IPOS - the integrated Palliative care (or Patient) Outcome Scale - is a brief measure of the symptoms and concerns most important to patients. It has been developed using detailed psychometric testing (ensuring it is valid, reliable, acceptable, and responsive to change), and including extensive patient, family and professional feedback, from the POS family of measures. It has been welcomed by patients and professionals as a streamlined measure which is brief, yet which still captures patients' most important concerns - both in relation to symptoms, but also extending to information needs, practical concerns, anxiety or low mood, family anxieties and overall feeling of being at peace.

Term	Definition
Karnofsky Scale	Modified Karnofsky Performance Scale The Australia-modified Karnofsky Performance Scale (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. The scale is revised for contemporary palliative care clinical practice. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status.
Mental capacity	Mental capacity is the ability to make a decision. An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. Under the Mental Capacity Act 2005 (England and Wales), anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity: Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.) If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made? Reference: Mental Capacity Act (2005) Code of Practice. Ministry of Justice 2007. Source: Palliative care co-ordination: core content (SCCI1580)

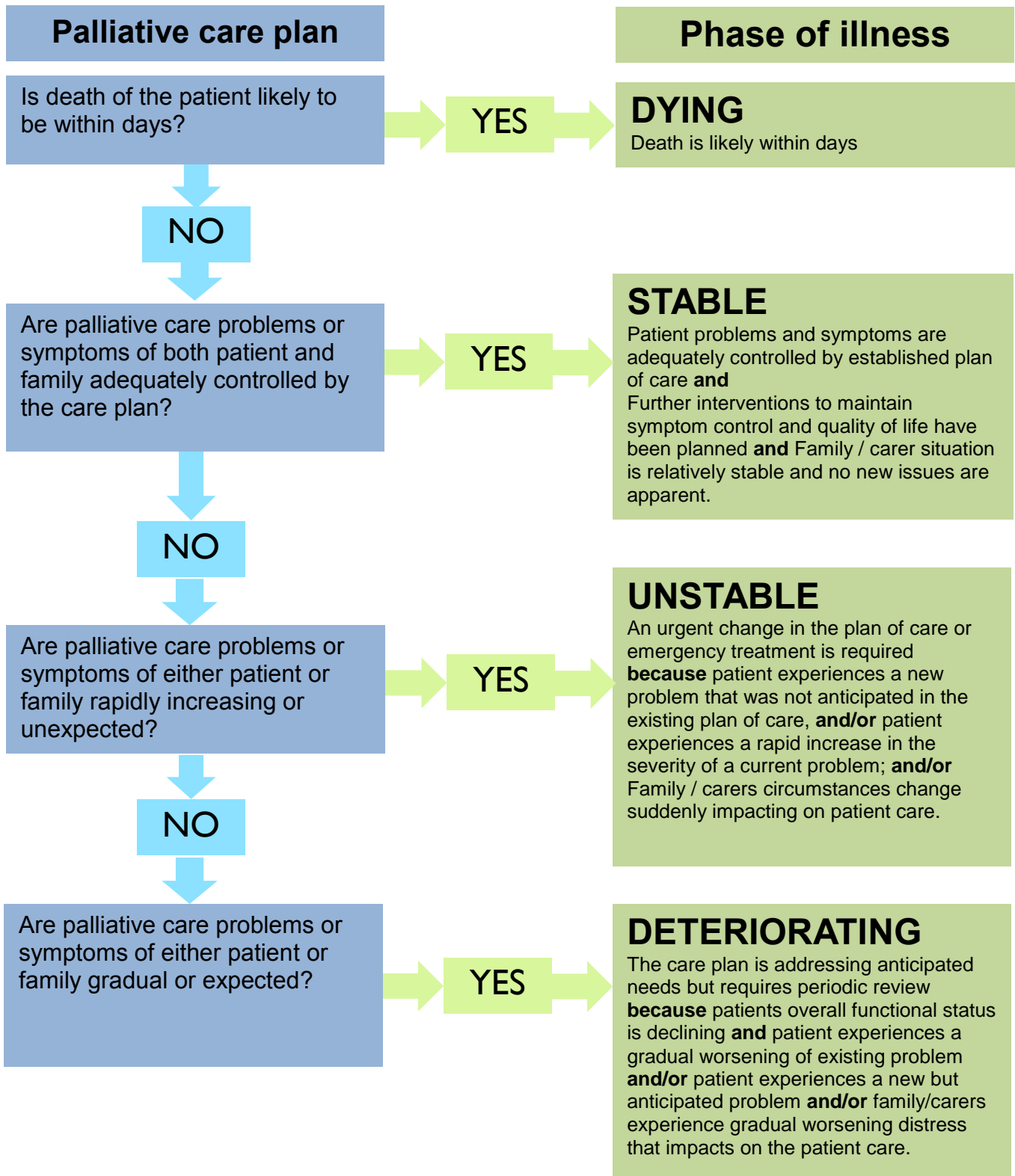| Term	Definition
Outcome	A change in a patient's current and future health status that can be attributed to preceding health care. Donabedian 1980 also: Dawson J, Doll H, Fitzpatrick R, Jenkinson A, Carr A. The routine use of patient reported outcome measures in healthcare settings. BMJ. 2010;340;c186. NHS Outcomes Framework Specifies the outcomes with corresponding indicators which measure performance in the health and care system.
Outcome measure	Outcome measurement involves the use of a measure to establish a patient's baseline health status, and then evaluates changes over time using that baseline. Outcomes can be measured using a variety of tools which are questionnaires or instruments used to capture the changes. An outcome measure provides a way to evaluate patient- or family-level health status and responses to treatment, measured at patient or family level. Measures need to be valid, reliable, sensitive to change, clinically applicable.(See definition of IPOS above)
Outpatient setting	A patient having an individual day time appointment with a specific member of a multi-professional palliative care team, within a healthcare facility. This includes DAY CARE.
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms affirms life and regards dying as a normal process intends neither to hasten or postpone death integrates the psychological and spiritual aspects of patient care offers a support system to help patients live as actively as possible until death

Term	Definition
	offers a support system to help the family cope during the patient's illness and in their own bereavement uses a team approach to address the needs of patients and their families enhances quality of life and may also positively influence the course of illness is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions. Source: World Health Organisation
Phase	Classification of patient's clinical status as stable, unstable, deteriorating or dying as specified for the Palliative Care Outcomes Collaboration in Australia and the Palliative Care Funding pilots. Within each spell of care a patient may have numerous different phases of care, the phase is driven by the clinically assessed phase of the patient's condition. One phase ends and another begins when a clinical decision is made that the patient has moved between one of the four phases of illness – Stable, Unstable, Deteriorating, Dying and a final record of 'Died'. Research evidence: Palliative Care Phase: Inter-rater reliability and acceptability in a national study. Malcolm Masso, Samuel Frederic Allingham, Maree Banfield et al. Palliative Medicine. September 2014. The phase needs to be assessed at each patient contact.

Term	Definition
Primary Diagnosis **Diagnosis 2** **Diagnosis 3**	Primary diagnosis: The diagnosis that is the main contributing factor to the need for end of life care. Other relevant diagnoses and clinical problems: relevant diagnoses and medical problems that need to be taken into account when making end of life care decisions Source: Palliative care co-ordination: core content (SCCI1580)
Referral	A formal request has been made for the Palliative care provider to become involved in the person's care.
Specialist palliative care	This has been defined as the 'active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team of professionals who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support'. Tebbit, National Council for Palliative Care, 1999 Commissioning Guidance for Specialist Palliative Care. (Note: data set will capture all face-to-face care provided by specialist palliative care services- specialist and generalist working together, often through multi-disciplinary teams)
Specialist palliative care provider	Specialist palliative care teams: those with palliative care as their core daily work. They are multidisciplinary teams, have specialist skills and experience, and deliver palliative care both directly and indirectly: directly by providing care to patients and families, and indirectly by supporting other professionals to deliver such care.

Term	Definition
Spell	A spell of care is defined as each period of contact between a patient and a palliative care service provider or team of providers that occurs in one setting. This may be a stay in a hospital or a hospice, or a period of care by a specialist palliative care provider in the patients' own home or care home. Whenever the patient moves to a different location, a new spell of care is initiated. A spell of care commences at the start of palliative care involvement with a patient and finishes when the patient moves to a different location or is discharged from palliative care.

Appendix B: OACC phase of illness algorithm

Phase of illness allocation in accordance with phase definition

Palliative care plan		Phase of illness

Is death of the patient likely to be within days? → YES → **DYING**
Death is likely within days

NO
↓

Are palliative care problems or symptoms of both patient and family adequately controlled by the care plan? → YES → **STABLE**
Patient problems and symptoms are adequately controlled by established plan of care **and**
Further interventions to maintain symptom control and quality of life have been planned **and** Family / carer situation is relatively stable and no new issues are apparent.

NO
↓

Are palliative care problems or symptoms of either patient or family rapidly increasing or unexpected? → YES → **UNSTABLE**
An urgent change in the plan of care or emergency treatment is required **because** patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** patient experiences a rapid increase in the severity of a current problem; **and/or** Family / carers circumstances change suddenly impacting on patient care.

NO
↓

Are palliative care problems or symptoms of either patient or family gradual or expected? → YES → **DETERIORATING**
The care plan is addressing anticipated needs but requires periodic review **because** patients overall functional status is declining **and** patient experiences a gradual worsening of existing problem **and/or** patient experiences a new but anticipated problem **and/or** family/carers experience gradual worsening distress that impacts on the patient care.

References for phase of illness:

- Centre for Health Service Development: University of Wollongong. (1997). The Australian National Sub-Acute and Non-Acute Patient (AN-SN AP) Case-mix Classification: Report of the National Sub-Acute and Non-Acute Case-mix Classification Study.
- Eagar K, Green J, Gordon, R (2004). An Australian case mix Classification for palliative care: technical development and results. Palliat Med 18: 217-226.
- Eagar K, Gordon R, et al. (2004). An Australian case-mix classification for palliative care: lessons and policy implications of a national study. Palliat Med, 18, 227-233.
- Masso M, Allingham SF, et al., (2015) Palliative Care Phase: Inter-rater reliability and acceptability in a national study. Palliat Med 29(1):22-30

Appendix C: Outcome data items

Data items are included which enable the outcomes for the patient and the carer to be assessed. These are:

- phase of illness (measuring change over time)   patient
- functional status   patient
- pain   patient
- breathlessness   patient
- at peace
- anxiety/distress   patient
- information needs   patient
- views on care   patient
- assessor   patient
- carer support   carer

Integrated palliative care outcome scale (IPOS)

Tool developed to measure palliative care needs of patients. It is a validated instrument that can be used in clinical care, audit, research and training.

IPOS is a brief measure of the symptoms and concerns most important to patients. It has been developed using detailed psychometric testing (ensuring it is valid, reliable, acceptable, and responsive to change), and including extensive patient, family and professional feedback, from the POS family of measures. It is a streamlined measure which is brief, yet which still captures patients' most important concerns - both in relation to symptoms, but also extending to information needs, practical concerns, anxiety or low mood, family anxieties and overall feeling of being at peace.

Data items for pain, breathlessness, at peace, anxiety/distress, information needs are taken from IPOS.

Views on care from St Christopher's Index of Patient Priorities (SKIPP)

SKIPP is an outcome measure which enables hospices/palliative care providers to assess the impact on patients of the care they deliver and show changes in symptoms over time. It was commissioned by St Christopher's and developed by Professor Julia Addington-Hall and her research team at Southampton University in collaboration with the St Christopher's. (SKIPP palliative care measure). This is a validated measure for use in palliative care.

Data items for views on care are based on SKIPP.

National survey of bereaved people (VOICES)

An annual survey carried by the Office for National Statistics where bereaved people in England are asked for their views on the quality of care provided to a friend or relative in the last three months for England.

The data item on carer support is taken from the VOICES questionnaire.

Appendix D: Templates for collection of outcome data

The following templates may be useful when the outcomes data is not recorded directly into the electronic record. The forms can be printed and given to the patient and or carer to complete and professionals may use to complete their assessment, when relevant. The information recorded on the templates will then need to be transferred to the electronic patient record.

There are two templates:

- a patient/carer form
- a professional form

Patient/Carer Form

NHS number/Client ID	
Patient Name	
Date	

TELL US HOW YOU ARE FEELING

Please complete the following questions. This information will help us to improve your care and to improve the care of others.

Thank you

Question 1

Over the past 3 days: (Please tick one box for each question)

	0	1	2	3	4
	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Have you been affected by pain?					
Have you been affected by breathlessness or feeling short of					

breath?					
Have you been feeling anxious or worried about your illness or treatment?					

Question 2

Over the past 3 days: (Please tick <u>one box</u> for each question)

	0	1	2	3	4
	Always	Most of the time	Sometimes	Occasionally	Not at all
Have you felt at peace?					
Have you had as much information as you wanted?					

Question 3

Do you think the service has made a difference to how things are going at present?
Please tick the box that best describes your experience.

i	Yes, it's giving a lot of benefit	
ii	Yes, it's giving some benefit	
iii	Yes, it's giving a little benefit	
iv	No, not much difference	
v	No, no difference at all	
vi	I don't know	

Question 4

Who has completed the above questions?
Please tick <u>one box.</u>

Patient	
Patient with some help from family or carers	
Patient with some help from the staff	

Question 5

To be completed by a <u>family member or carer.</u>

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?
Please tick the box that best describes your experience.

i	Yes, we got as much support as we wanted	
ii	Yes, we got some support but not as much as we wanted	
iii	No, although we tried to get more help	
iv	No, but we did not ask for more help	
v	We did not need help	

Professional Form

Palliative Care Data Collection: Phase Change

NHS number/Client ID	
New phase	Stable / unstable / deteriorating / dying
Date of phase change	
Patient Name	
Date of recording	

Instructions
Please complete the following information:

a) At initial assessment (Note that patient/carer questions do not have to be asked at first assessment if not appropriate).

b) **Each time the phase changes** (Note that the phase of illness should be assessed daily or each time the patient is seen, if less frequent).

c) At the end of a spell of treatment (ie when person's care in this setting ends).

1. Functional status*

Please tick <u>one box</u> which best describes the functional status of the patient <u>TODAY</u>

	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
	0%	Dead

2. Symptoms

Please tick <u>one box</u> that best describes how the patient has been <u>affected </u>by each of the following symptoms <u>over the past 3 days</u>

	0	1	2	3	4	
	Not at all	Slightly	Moder-ately	Severely	Over-whelming-ly	Unable to assess eg patient unconscious
**Has the patient been affected by pain						
**Has the person been affected by breathlessness-						
**Has the person been feeling anxious or worried about his/her illness or treatment						

3. Other

Over the past 3 days: (Please tick one box for each question).

	0	1	2	3	4	
	Always	Most of the time	Sometimes	Occasionally	Not at all	Unable to assess eg patient unconscious
**Do you think s/he has felt at peace?						
**Has the patient had as much information as s/he wanted?						

4. Views on care

Thinking about the patient, please tick one box.

	i	ii	iii	iv	v	vi	
	Yes, it's giving a lot of benefit	Yes, it's giving some benefit	Yes, it's giving a little benefit	No, not much difference	No, no difference at all	I don't know	Unable to assess eg patient unconscious
*** Do you think the service has made a difference to how things are going at present?							

Name of professional completing this form	

* Australia-modified Karnofsky Performance Scale
** Questions from Integrated Palliative Care Outcomes Scale (IPOS) reproduced with the kind permission of Cicely Saunders International. http://pos-pal.org/maix/ipos_in_english.php
*** Views on Care based on work by St Christopher's Hospice Group. http://pos-pal.org/maix/ipos-views-on-care.php

Appendix E: ICD10 diagnosis list (adults)

*Cancers of lip, oral cavity and pharynx	C00 - C14
*Cancers of digestive organs, including colon, rectum, stomach, excluding liver, GB, pancreas	C15 - C21, C26
Cancer of liver, intrahepatic bile ducts, gallbladder- specified separate from digestive (unlike MDS)	C22 - C24
*Cancer of pancreas- specified separate from digestive (unlike MDS)	C25
*Cancers of respiratory and intrathoracic organs, including lung	C30-C39
*Cancers of bone, skin, mesothelial and soft tissue, thyroid or endocrine	C40 - C49, C73 - C75
*Cancer of breast	C50
*Cancers of female genital organs	C51-C58
*Cancers of male genital organs, including prostate	C60-C63
*Cancers of urinary tract	C64-C68
*Cancers of brain, eye and other CNS	C69 - C72
*Cancer of unknown primary or other unspecified	C76 - C80
*Lymphoid & haematopoietic cancers	C81 - 96
*Cancer of independent multiple sites	C97
*HIV/AIDS	B20 - 24
*Motor Neurone Disease	G12
*Dementia including Alzheimer's	G30, F00 - F03
*Neurological conditions (excluding MND and Alzheimer's)	G00 - G99 excluding G12 & G30
Diabetes mellitus	E10 - E14
*Heart failure	I50
Stroke, infarction or haemorrhagic- – specified separate (unlike MDS)	I61, I63
*Other heart or circulatory, excluding heart failure and stroke	I00 - I99, not I50
*Chronic respiratory disease	J40 - J70
Liver failure, chronic liver disease, other non-malignant liver disease	K70 - K77
*Chronic renal failure	N18
All other non cancer diagnoses (everything not included above)- additions to MDS	
Multiple non cancer conditions – addition to help with multi-morbidity	
Unknown	

Note: data items marked * are currently included in the National council for palliative care minimum data et.