A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme

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This report

Abstract

A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme

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Background: The hospice movement has provided an excellent model of specialist palliative care for those with advanced illness approaching the end of life. However, there are marked inequities in provision of this care, and major geographical variations in the resourcing of palliative care, often resulting in a poor match between the needs of a patient/family and resources provided to meet those needs.

Objective: To develop/test a casemix classification to accurately capture the complex needs of patients with advanced disease, better quantify those needs and more fairly allocate resources to meet them. A 'casemix classification' groups patients into classes according to differing care needs to help inform the resources needed to meet those care needs.

Design: Workstream 1 comprised the validating and refining of patient-centred measures of health status and well-being. In workstream 2, stakeholder interviews with patients, families, policy-makers, service providers and commissioners were carried out to understand complexity/casemix and models of specialist palliative care. In workstream 2 the casemix classification was developed through a multicentre cohort study. Workstream 4 comprised a longitudinal mixed-methods study to test the casemix classification, with a nested qualitative study to explore experiences of transitions between care settings.

Setting: Voluntary sector and NHS specialist palliative care services across England.

Participants: Patients ≥ 18 years receiving specialist palliative care, their families and the professionals delivering this care.

Results: For the Integrated Palliative care Outcome Scale validation: data from 376 patient participants and 161 clinicians showed this measure has a strong ability to distinguish between clinically relevant groups, good internal consistency (α = 0.77), and acceptable-to-good test–retest reliability (60% of items

kw > 0.60). The Phase of Illness measure showed function and symptoms/concerns varied significantly by Phase of Illness, but Phase of Illness reflected additional construct(s) and so is important for casemix (workstream 1 conducted 2013–15).

To gain stakeholder perspectives, 65 participants were interviewed. Based on emergent themes, we developed a theoretical framework to conceptualise complexity in specialist palliative care. This framework emphasises that considering physical, psychological and social needs is not enough to characterise complexity. Number, severity and range of needs all need to be considered in the development of a meaningful casemix classification. To understand models of care, semistructured interviews were conducted with 14 participants, 54 further participants took part in a two-round Delphi survey and interviews were conducted with 21 service leads. Twenty criteria were adopted to define/distinguish models of specialist palliative care (workstream 2 conducted 2014–16).

For the development of the casemix classification, a total of 2469 patients were recruited, providing data on 2968 episodes of specialist palliative care. The mean age was 71.6 years, 51% of patients were male, 74% were white and 25% were non-cancer patients. Episodes of care lasted a median of 8 days (range 1–402 days) in hospital advisory care, 12 days (range 1–140 days) in inpatient units, 30 days (range 1–313 days) in the community. The median costs per day (lower–upper quartiles) were: £56 (£31–£100) in hospital advisory, £365 (£176–£698) for inpatient, and £21 (£6–£49) in community care. Seven hospital advisory, six inpatient and six community casemix classes for specialist palliative care were developed, based on levels of pain, other physical symptoms, psychological symptoms, functional status, palliative Phase of Illness, living alone and family distress (workstream 3 conducted 2016–18).

For the testing of the casemix classification, a total of 309 patients (mean age 66.9 years, 55% female, 85% white) provided data on 751 episodes of specialist palliative care. The casemix classification was able to accurately predict the actual cost-per-day of care, especially for hospital advisory and community care. The actual costs of inpatient hospice care were consistently higher than predicted class costs, although cost weights remained consistent. Interviews to understand transitions between care settings were conducted with 26 participants (mean age 68 years, range 36–91 years). Four themes emerged: uncertainty about the new care setting, biographical disruption, the importance of continuity of care and the need for emotional/practical support during transition (workstream 4 conducted 2018–19).

Limitations: Recruitment was challenging but adding new sites helped to overcome this. Models of palliative care proved more diverse and harder to categorise than expected. This casemix classification needs broader testing among those with non-cancer conditions, especially those with multiple conditions.

Conclusions: The Integrated Palliative care Outcome Scale is a valid, reliable outcome measure for use in advanced illness. We have developed (1) an evidence-based framework to conceptualise complexity of palliative care needs, (2) defined criteria to characterise/differentiate models of specialist palliative care and (3) a casemix classification for specialist palliative care. Each person needing specialist palliative care is different, with varying degrees of complex needs. We now have the casemix classification to understand and capture this, systematically and at scale, for practice, policy and research. This has the potential to help address inequities and provide more equitable specialist palliative care to all who need it. Future research is needed, including further validation of measures, more detailed research into models of care, and further testing of the casemix classification.

Study registration: This trial is registered as ISRCTN90752212.

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List of abbreviations

AKPS	Australia-modified Karnofsky Performance Status	IPOS-5	Integrated Palliative care Outcome Measure short version
CART	classification and regression tree	IQR	interquartile range
C-CHANGE	the name of this programme of research	PCPSS	Palliative Care Problem Severity Score
CI	confidence interval	PPI	patient and public involvement
CREDES	Conducting and REporting DElphi Studies in palliative care	REC	Research Ethics Committee
DRG	diagnosis-related group	RMSE	root-mean-squared error
EORTC QLQ-C15-PAL	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – 15 items measure	SD	standard deviation
		TRIPOD	Transparent Reporting of a multivariable prediction model for Individual Prognosis Or Diagnosis
HRG	Healthcare Resource Group	VoC	Views on Care
IPOS	Integrated Palliative care Outcomes Scale		

Plain language summary

Hospices have provided an excellent model of palliative care for those with advanced illness in the last months of life. However, some people do not get the care they need and provision varies considerably between different regions of England. We therefore aimed to develop a classification system to accurately reflect the care needs of those with advanced illness, so that resources can be better matched to needs.

We interviewed different patients, families, service providers and funders to understand the complex care needs that people have and how a system could be developed. Then we undertook a large study with those with advanced illness to develop a system. Finally, we tested the system with a new group of people experiencing advanced illness.

Sixty-five participants were interviewed. Based on these interviews, we developed a way to better understand complex needs, with the individual person at the heart of this understanding.

A total of 2469 people contributed to our large study. We established the resources used to provide palliative care: on average, the cost per patient was an additional £56 per day for those receiving specialist palliative care in hospital, £365 per day for those receiving inpatient hospice care and £21 per day for those receiving specialist palliative care at home. We developed a system based on factors such as pain and other symptoms, level of family distress, and whether or not the patient was living alone. These factors indicate what palliative care is needed and how much it might cost. We tested this system with 309 further people with advanced illness, and it was able to predict costs well.

Scientific summary

Background

The hospice movement has provided an excellent model of specialist palliative care for those with advanced disease in the last year of life. However, little is known about costs of care and there are marked inequities in provision across England. Older patients or those with non-cancer conditions access specialist palliative care less often and receive proportionately fewer resources when they do. There are also major geographical variations in resourcing palliative and end-of-life care, often resulting in a poor match between the needs of a patient/family, the resources provided to meet those needs and the improvement in well-being achieved.

Aims

The aims of this programme were to develop and test a person-centred, nationally applicable casemix classification for adult specialist palliative care provision in England, to accurately capture the complex needs of patients with advanced disease in last year of life, to better quantify those needs and to support more equitable allocation of resources to meet them.

Objectives

The C-CHANGE programme had five objectives:

1. to validate or refine new and existing person-centred outcome measures designed to assess the main health status and symptoms/concerns of patients receiving specialist palliative care
2. to utilise the perspectives of key stakeholders on the complexity in palliative care to inform subsequent casemix development
3. to understand the criteria which distinguish different models of palliative care to help inform how a casemix classification can be utilised across different models of specialist palliative care
4. to develop a person-centred palliative care casemix classification, based on individual patient needs and costs of care, for adults with both cancer and non-cancer conditions in the last year of life
5. to test this person-centred palliative care casemix classification in terms of ability to predict resource use in the last year of life and to better understand transitions between services in order to improve care.

Methods

Workstream 1: measures
In Workstream 1, several studies were undertaken from 2013 to 2015 to improve our knowledge of the psychometrics, relationships and clinical utility of the measures proposed for workstreams 3 and 4:

- A cognitive interview study to refine the prototype Integrated Palliative care Outcome Scale (IPOS), a brief measure of symptoms/concerns in advanced illness. Purposively sampled patients were recruited from four inpatient and community settings. Interviews were analysed using thematic analysis, and the prototype measure refined accordingly.
- A validation study for the IPOS to validate both the patient self-report and staff proxy-report versions. In a longitudinal cohort study, we tested construct validity (factor analysis, known-group comparisons and correlational analysis), reliability (internal consistency, agreement and test–retest reliability), and responsiveness.

- A secondary analysis of routinely collected clinical data to describe palliative Phase of Illness, and determine associations between Phase of Illness and the other measures proposed for this programme.
- A survey to examine patients' Views on Care (VoC), a brief measure of patient perspectives on the quality of their care. Adults receiving specialist palliative care in eight hospital, hospice inpatient and community settings across England were recruited. We reported associations between VoC and changes in health status.
- Secondary analysis of pre-existing qualitative interviews to understand patient experiences of uncertainty and how these influence understanding of care. Interviews were sampled using maximum variation sampling and analysed using a thematic approach.

Workstream 2: stakeholder perspectives

To explore the perspectives of key stakeholders on complexity in palliative care, we undertook a qualitative study using semistructured interviews with key stakeholders in specialist palliative care between 2014 and 2015. Participants were professionals from participating sites or were policy/national leads. Data were analysed using framework analysis.

To understand the criteria which characterise/distinguish different models of palliative care, we undertook a mixed-methods study during 2015–16, which comprised the following:

- Semistructured interviews about preliminary criteria with clinical leads from 14 participating sites. Findings were used to expand/refine these criteria.
- A two-round Delphi survey [conducted following CREDES (Conducting and REporting DElphi Studies in palliative care) guidance], which identified additional criteria, sought consensus on criteria definitions and ranked criteria by importance.
- Structured interviews with service providers to assess the acceptability and feasibility of the final criteria, with participants recruited from participating sites from workstreams 3 and 4.

Workstream 3: development of the casemix classification

To determine the costs of specialist palliative care and develop a casemix classification for UK specialist palliative care, we undertook a multicentre prospective cohort study between 2017 and 2018, collecting potential casemix variables and actual costs over episodes of specialist palliative care. Guidance for Transparent Reporting of a multivariable prediction model for Individual Prognosis Or Diagnosis (TRIPOD) was followed. Patients were recruited from four hospital advisory, five inpatient hospice and seven community-based services. Consecutive adult patients (aged ≥ 18 years) were included. Casemix variables included were age, sex, ethnicity, living circumstances, need for interpreter, primary diagnosis, palliative Phase of Illness, functional status, dependency and symptoms/problem severity. Our primary outcome was the cost of specialist palliative care per day. The sample size estimation was 2674 episodes of care. For the analyses we examined the distribution of costs by setting and developed a cost-predictive model using classification and regression tree analysis.

Workstream 4: testing of the casemix classification

To test the palliative care casemix classification developed in workstream 3, we undertook a multicentre prospective cohort study between 2018 and 2019, following patients during episodes of specialist palliative care, with a qualitative nested component (i.e. interviews with a subsample of participants to better understand the experience of transitions between care settings).

Patients were recruited from: three hospital advisory, eight inpatient hospice and five community-based services. Inclusion criteria were adult patients (≥ 18 years) able to consent. Exclusion criteria were < 18 years, unable to consent. Collected data included demographic and clinical variables, episode start and end dates, casemix variables and costs of providing care. The casemix classes developed in workstream 3 were applied to predict costs for episodes of care and this was compared/contrasted with the actual costs captured for each episode.

A subsample of participants experiencing at least two transitions between care settings were interviewed, using purposive sampling criteria of age, sex, diagnosis and types of transitions. We undertook thematic analysis, with attention to patient/family perspectives on the experience of transitions between care settings and how these were supported/resourced.

Results

Workstream 1: measures

Twenty-five cognitive interviews were conducted. Overall, comprehension and acceptability of the prototype IPOS was good. Identified difficulties were comprehension problems with some specific terms and judgement difficulties. Based on these findings, the prototype IPOS was refined.

In the IPOS validation study, we recruited 376 patients and 161 clinicians. We confirmed a three-factor structure (physical symptoms, emotional symptoms and communication/practical issues). The measure showed strong ability to distinguish between clinically relevant groups; total IPOS scores and IPOS subscale scores were higher – reflecting more problems – in those with 'unstable' or 'deteriorating' versus 'stable' Phase of Illness (F = 15.1; $p < 0.001$). The IPOS showed good internal consistency ($\alpha = 0.77$) and acceptable-to-good test–retest reliability (60% of items kw > 0.60).

In the study of Phase of Illness, function and symptoms/other concerns varied significantly by Phase of Illness. Mean function (scored using the Australia-modified Karnofsky Performance Status from 0–100, where 100 is best function) was highest in the stable phase [65.9, 95% confidence interval (CI) 63.4 to 68.3] and lowest in dying phase (16.6, 95% CI 15.3 to 17.8). Mean pain (scored 0–4 where 4 is worst pain) was highest in the unstable phase (1.43, 95% CI 1.36 to 1.51). Palliative Phase of Illness reflects additional construct beyond function and symptoms.

In the survey to examine VoC, 212 participants were recruited, with a mean age of 65.84 years [standard deviation (SD) 13.5 years]. Most indicated that palliative care was giving positive benefit. Participants reporting that 'things had got better' were more likely to have improved overall health status ($\chi^2 = 6.057$; $p = 0.48$). There was significant positive association between those reporting that 'things had got better' and improved physical symptoms ($\chi^2 = 11.254$; $p = 0.004$).

In the secondary analysis of pre-existing qualitative interviews to understand patient experiences of uncertainty, 30 transcripts were analysed. Participants had a median age of 75 years (range 43–95 years). A typology of patient responses to uncertainty was developed, depending on the level of engagement of each individual patient with their illness and treatment, their preferences for information and their temporal focus.

Workstream 2: stakeholder perspectives

In study of stakeholder perspectives on complexity, 65 participants (comprising patients, family, health-care professionals and policy makers) were recruited. Based on the emergent themes, we developed a theoretical framework – adapted from Bronfenbrenner's Ecological Systems Theory – to conceptualise complexity in specialist palliative care. This framework emphasises that considering physical, psychological, social and spiritual domains is not enough to characterise complexity. The number, severity and range of needs – as well as 'hidden' or overlooked aspects of complexity – all need to be considered in the development of a meaningful casemix classification for specialist palliative care.

Semistructured interviews were conducted with 14 service leads discussing 12 settings of care (five hospice inpatient units, two hospital advisory teams and five community teams). Of the 28 initial criteria to describe models of care, 11 were removed, 17 were refined and a further 17 were created. Thirty-four criteria were taken into the Delphi survey. Fifty-four participants took part in the Delphi survey. In round 1, six criteria did not reach the pre-defined consensus standard and four new criteria were

created; this resulted in a refined list of criteria. In round 2, the revised criteria were ranked and rated, and 16 criteria reached the pre-defined consensus standard. In the third component of this study, interviews were then conducted with 21 service leads from 19 different services (six hospice inpatients, four hospital advisory and nine community settings). Criteria were acceptable and feasible, but four contextual criteria were added, resulting in 20 final criteria to define a model of specialist palliative care.

Workstream 3: development of the casemix classification

In the multicentre prospective cohort study to develop the casemix classification, 2469 patients were recruited, providing data on 2968 complete episodes of specialist palliative care. Patients had a mean age 71.6 years (SD 13.9 years) and were 51% male, 74% white and 25% non-cancer patients. Episodes of care lasted a median of 8 days (range 1–402 days) in hospital advisory care, 12 days (range 1–140 days) in inpatient units and 30 days (range 1–313 days) in community-based care. The median costs per day (lower-upper quartiles) were £56 (£31–100) in hospital advisory care, £365 (£176–698) for inpatient care and £21 (£6–49) in community care. Seven hospital advisory, six inpatient, and six community casemix classes for specialist palliative care were developed, based on seven casemix variables (pain, other physical symptoms, psychological symptoms, functional status, palliative Phase of Illness, living alone and family distress). These casemix criteria, measured at the start of the episode of care, provided the optimal classes to predict costs per day for the episode of care. The per cent variance explained (and root-mean-squared error) were 20% (0.30), 51% (0.51) and 27% (0.36) for hospital advisory, inpatient hospice and community episodes, respectively.

Workstream 4: testing of the casemix classification

In the multicentre prospective cohort study to test the casemix classification, 309 patients (mean age 66.9 years, SD 13.1 years; 55% female, 85% white) were recruited, providing data on 751 episodes of specialist palliative care. As expected, the median duration of an episode of care was shortest for hospital advisory episodes (10 days) and longest for community episodes (26 days). The casemix classification was able to accurately predict the actual cost per day of care, especially for hospital advisory and community care. The actual costs of inpatient hospice care were consistently higher than the predicted class costs, although the cost weights remained consistent.

For the qualitative nested interviews, to understand transitions between care settings, 20 interviews with 26 participants were conducted (mean age 68 years, range 36–91 years). Fourteen interviews were individual and six were joint interviews. Four themes emerged:

1. uncertainty about the new care setting – a lack of information about the new setting of care added to feelings of uncertainty and stress
2. biographical disruption – a loss of independence and difficulty maintaining a sense of normality challenged participants' self-identity as they moved place of care
3. importance of continuity of care – continuity of care had an impact on feelings of safety in the new care setting and also influenced decisions about the transition
4. need for emotional/practical support – most participants expressed a greater need for emotional and practical support when transitioning to a new care setting.

Conclusions

The Integrated Palliative care Outcome Scale is a valid and reliable outcome measure, both in its patient self-report and staff proxy-report versions. It can assess/monitor symptoms and concerns in advanced illness, reflect the impact of healthcare interventions and demonstrate quality of care. This represents a major step forward internationally for palliative care outcome measurement.

Palliative Phase of Illness has value as a clinical measure of overall palliative need, capturing additional information beyond function and symptoms. In addition, VoC (reflecting patient perspectives on quality

of care) is brief and easy to use with patients receiving palliative care across different settings. To the best of our knowledge, it is unique in its brevity and ease of use for ill patients receiving palliative care, which allows the measure to provide patient-level feedback in real time.

To the best of our knowledge, workstream 2 provided for the first time in palliative care an evidence-based framework to conceptualise the complexity of palliative care needs of those with advanced illness. Overall, participants reported that they thought it acceptable to measure complexity at the individual patient level using the proposed criteria.

To our knowledge, until now there has not been a clear set of criteria to define models of UK specialist palliative care, making it challenging to compare different models of care provided by services. This component of the programme identified the criteria needed to characterise and differentiate models of specialist palliative care, a major paradigm shift to enable accurate reporting and comparison in practice and research.

Our detailed evidence on specialist palliative care costs and the casemix classification for specialist palliative care deliver a major advance for the sector. Each person needing specialist palliative care is different, with varying degrees of complex needs. We now have the means to understand this, systematically and at scale, for practice, policy (including resourcing of palliative care) and research. The casemix classes show cost weight variations up to 4.5-fold in inpatient hospices and almost 3-fold in community care. The needs of each person are varied – not fixed – and require different resources to deliver care effectively. Understanding this has the potential to help address inequities and provide more equitable specialist palliative care to all who need it. The casemix classification will inform NHS England currency development.

Study registration

This trial is registered as ISRCTN90752212.

Funding

SYNOPSIS

Background

The clinical challenge

People in the last year of life often suffer complex and multiple symptoms and distress because of their illness or impending death.[1-3] Functional status often deteriorates as the illness progresses, leading to increased dependency and greater care needs.[4] The families of those affected experience their own fears and losses.[5]

This occurs across a wide range of different life-limiting illnesses. Symptoms, distress, functional trajectories and family support needs have been most widely studied in cancer, but other life-limiting conditions (e.g. advanced cardiac and respiratory diseases, progressive neurological conditions, dementia, end-stage kidney disease and advanced liver disease) bring equally challenging symptoms and support needs.[6,7] Family support is particularly important if bereavement is to be well negotiated[8] and future psychological health maintained.[9]

As the population age distribution changes, these needs are also extending over longer time periods as the length of time living with advanced illness increases.[10]

Specialist palliative care: provision and inequities

Palliative care has developed to meet these complex needs of patients and families facing advanced progressive illness. It addresses physical and psychological symptoms and gives social, practical and spiritual support in the last months of life.[11] The UK ranked first in the 2015 Quality of Death Index, a measure of the quality of dying across 80 countries,[12] with UK hospices leading the way internationally, providing a world-leading model of excellence in palliative care.

However, the work of UK hospices – which deliver both inpatient and home-based specialist palliative care – has often come from grass-roots and local initiatives, meaning that there are marked geographical inequities in provision across England. Much of hospice and specialist palliative care is funded from the charitable sector; in 2018, charities contributed £3 for every £1 from the NHS.[13] The balance between NHS and charitable funding varies markedly around the country;[13] this and other factors has led to major inequities in palliative care provision.

A UK government-commissioned review into specialist palliative care[14] found high levels of inequity in the provision of palliative and end-of-life care. There was diversity in the type and range of providers in any one geographical area[15] and inequity in both the amount of funding (with money spent by the NHS in 2010 ranging from £186 to £6213 per person who died) and the source of funding (with the proportion funding coming from the NHS varying from 0% to 62%).[14] This could not be accounted for by variations in the populations served.[14]

Even more marked variation in the commissioning of palliative services across England has been demonstrated more recently.[16] A 'north–south' divide has been identified,[17] with substantial differences in the average time from referral to death between providers in the north and south of England. This is important: the benefits of specialist palliative care are notably greater if delivered earlier in the illness trajectory.[18]

Older people and those with non-cancer diagnoses are also less likely to access specialist palliative care,[19,20] often resulting in a poor match between individual needs, the resources provided to meet those needs and the health outcomes achieved.

Substantial differences in the approach to commissioning services suggests provision rather than population demographics account for a large component of the variation.[16]

The research gap

One major challenge in improving our ability to better match resources to needs is the lack of research into what accounts for these apparent inequities in provision and – in particular – a lack of a standardised way to assess and monitor palliative care needs. With growing constraints on resources, it is becoming imperative for individual-level needs to be mapped accurately to reduce inequities, match resources to needs and improve the quality, consistency of provision, and efficiency of palliative care. This has been endorsed as a high priority nationally,[14] but there is very limited evidence available to inform the best ways to match individual-level needs to resources. Most importantly, there is no 'standard' way to assess, capture and report the palliative care needs of individual people with advanced illness. This programme of research directly addresses this research gap.

What we already know

Illness in the last year of life places major resource burden on the NHS. Up to 20% of healthcare expenditure is spent on the last year of life.[21] Total NHS expenditure in 2017/18 was around £122B in England[22] – roughly £2200 per person – indicating that around £25B per year is spent on health care in the last year of life. Much of this is on acute care, but it is estimated that palliative care is needed for about 75% of all those approaching death.[23]

The amount of health and social care resources spent on those in the last year of their life is increasing and will increase further in coming years. Ageing populations, greater co-morbidity and longer chronic disease trajectories are all increasing this demand.[24,25] However, this is not a simple relationship; commonly used approximations of health, such as age or mortality, are not enough to capture the complex dynamics in healthcare requirements.[26] Population ageing particularly increases expenditures on acute and long-term care.[27] In this context, it is increasingly important to recognise palliative care needs and ensure they are effectively addressed with the best possible use of scarce resources.

Palliative care needs

Assessment of patients' needs plays an important role in improving outcomes in palliative care. Patient-reported outcomes – where 'outcome' here is defined as a 'change in current or future health status following intervention'[28] – are a way of measuring the changes in patients' health that they themselves perceive over time. These outcomes allow for assessment of intervention effectiveness. In terms of addressing needs, there is increasing evidence that home, hospital and inpatient specialist palliative care is effective and significantly improves patient outcomes, particularly for cancer patients with reduced pain and other symptoms, reduced anxiety, and reduced hospital admissions.[29] Similar evidence is emerging for patients with non-malignant disease.[30–32]

Further systematic reviews,[29,33,34] including meta-analyses and Cochrane reviews,[35,36] and randomised controlled trials of specialist palliative care services[30,37] provide consistent evidence of the effectiveness of palliative care services in improving symptoms, reducing family burden, improving satisfaction with care and preventing depression. There is wide acknowledgement that palliative care should be available to all, based on need not diagnosis and extending across settings,[38,39] and these principles underpin the NHS End of Life Care Strategy.[40]

Given the complexity of problems experienced in the last year of life, it is not surprising that a high proportion of healthcare resources is spent during this time: as much as 20% of all healthcare expenditure.[21] However, some of this may be poorly spent: hospital admissions may be prevented by better anticipatory symptom control, better family support and earlier facilitation of advance discussions about patient and family preferences for treatment and care.[41,42] Robust studies demonstrate improved patient outcomes and reduced costs when palliative care is provided early[30,37,43] and a systematic review of trials of palliative care interventions shows greatest positive impact on quality of life when these interventions are provided early.[18]

2

Casemix classifications: a potential way forward

Within health care, there is increasing use of casemix classifications to help gain a better understanding of how healthcare resources might be allocated in an equitable yet efficient way. Casemix classifications are based on patient-level criteria, which allow the grouping of patients into classes in terms of the resources needed to meet their needs.[44] Casemix is defined as 'a means to classify patients into groups in order to provide a useful measure to make meaningful performance comparisons, to cost healthcare, or to fund it' (information from NHS Digital, licenced under the current version of the Open Government Licence).[45] Casemix classifications are defined as 'a system assigning each person [patient] into a hierarchical system of groups or classes, according to various individual casemix criteria. Each group or class is associated with higher or lower resource requirement to meet needs.'[46]

The USA developed such casemix classifications, including diagnosis-related groups (DRGs)[47] and these have been used to develop prospective payment systems globally.[48] DRGs are a useful classification of healthcare needs driven by the diagnosis, but have been shown to be inappropriate for some areas of health care, such as mental health,[49] primary care[50] and palliative care.[46,51]

Palliative care needs are not diagnosis-driven, but instead by factors such as functional status, physical symptoms and emotional burden.[51] Palliative care needs a consistent method of classifying types of patients with complexity of needs, treatment and costs, using casemix criteria.[52–54] Healthcare Resource Groups (HRGs) underpin the main casemix classification adopted in England.[44]

It is necessary therefore to identify those with more complex palliative needs and requiring more resources.[55] An Australian casemix classification for palliative care was developed in 1997, empirically tested and progressively refined over time.[52–54] The Australian casemix classification consists of classes defined by five criteria most strongly predictive of resource use: Phase of Illness, problem severity, functional status and dependency, age and model of care.[55] Full class definition and categorizations are available at https://ahsri.uow.edu.au/pcoc/index.html (accessed 12 December 2021). Its implementation proved it was possible to consistently and routinely collect casemix data nationally;[56] this has enabled consistent casemix adjustment in outcome measurement, with year-on-year improvement in outcomes at a national level and a funding model which matches patient's needs.[51,57] Palliative care funding pilots in the UK have also suggested casemix data may be useful for these purposes.[58] However, it is unclear whether or not, and how, any existing palliative care classification can be easily applied to the UK to address unmet needs and reduce inequities.

What we do not know

Although casemix classifications have been widely used to manage resources across health care, they have rarely been applied to palliative care. Existing classifications (i.e. DRGs and HRGs) are based on diagnoses, but for patients receiving palliative care the priority is not on diagnosis but enhancement of well-being and quality of life, and the maintenance or maximisation of current health status in the face of advanced incurable illness.[52] A palliative care casemix classification must reflect these different goals.[53,54,57]

Australia is the only country to have developed such a casemix classification for palliative care.[57] Diagnosis and procedure criteria were found to be ineffective in classifying the complexity of needs for those receiving palliative care.[53] Instead, palliative Phase of Illness and 'problem severity' were better indicators of increased complexity and consequent greater resource use.[56,59] Despite these advances, key questions remain unanswered:

> How can the wide range of patient needs in palliative care provision best be classified across conditions and settings, so that services can be resourced to meet individual needs and deliver best outcomes? Without such a classification, it is difficult to ensure that sufficient resources can be matched to the right patient at the right time.

Within such a classification, how is complexity best understood/captured so that commissioners can commission, and providers can deliver, the optimal mix of services?

What are the best criteria for palliative care casemix? It is internationally acknowledged that diagnosis and procedures are not useful criteria in palliative care casemix categorisation[53,57] and UK specialist palliative care providers seek a model more attuned to patient needs across wide-ranging levels of complexity.

What are the most useful patient-level data in palliative care? There is a lack of specific patient-level data in palliative care with which to model casemix and resource use.[14] This is especially true in community settings, where provision cuts across the NHS and voluntary sectors.[60,61]

What evidence do we have to build on? Some work has been undertaken in recent palliative care funding pilots,[58] but no evidence has been published from these to help determine which casemix criteria are optimal for use in England.

Rationale for our approach

This programme responds to these challenges by developing a palliative care casemix classification across conditions and settings. Recent UK initiatives to improve the provision of high-quality palliative care[40,62] have not addressed the challenges of classifying needs and costs.

Worldwide, different palliative care funding models exist,[63] but a formal palliative care casemix classification has been developed only in Australia. This Australian casemix classification incorporates functional status/dependency with problem severity and palliative Phase of Illness,[57] and adopts a blended funding model.[64] There is no existing palliative care classification easily transferable to the UK, but the Australian model is a valuable starting point.

This programme leads directly to patient benefit through the improved matching of resources to needs at the individual patient-level, with corresponding outcome measurement, along with more effective and cost-effective use of resources through the following work:

the development of better patient-centred outcome measures that are relevant and meaningful for patients with advanced illness and their families

the development of a 'standard' way to assess, capture, and report the palliative care needs of individual people with advanced illness

the development of a casemix classification – casemix 'classes' based on individual-level criteria – which can predict the resources needed to address the symptoms/concerns of people with advanced illness needing specialist palliative care.

This approach has been directly recommended by the Palliative Care Funding Review,[14] and we have liaised closely with NHS England in progressing this work.

Aims and objectives of the C-CHANGE programme

Aims

The aims of the C-CHANGE programme were to report the costs of specialist palliative care; develop and test a person-centred, nationally applicable casemix classification for adult specialist palliative care provision in England; accurately capture the complex needs of patients with advanced disease in last year of life; better quantify those needs; and support more equitable allocation of resources to meet them.

The programme also aimed to identify ways to measure the improvements in health status and well-being which patients and families experience following specialist palliative care so that the casemix classification could be developed, but also so that quality and effectiveness of services can be more readily demonstrated to patients, families, commissioners and services.

Objectives

The C-CHANGE programme had five objectives:

- to refine, validate or test new and existing person-centred outcome measures to assess the main health status and symptoms/concerns of, and services received by, patients and families receiving specialist palliative care
- to utilise the perspectives of key stakeholders (i.e. patients, families, professional caregivers, commissioners and policy-makers) on complexity in palliative care to inform subsequent casemix development
- to understand the criteria which distinguish different models of palliative care to help inform how a casemix classification and per-patient funding models can best be utilised across different models of specialist palliative care
- to develop a person-centred palliative care casemix classification, based on individual patient and family needs and costs of care, for adults with both cancer and non-cancer conditions in the last year of life
- to test this person-centred palliative care casemix classification in terms of its ability to predict resource use in last year of life and to better understand transitions between services in order to improve care.

Overall design of the C-CHANGE programme

The C-CHANGE programme comprised six workstreams (see *Figure 1*):

Workstreams 1, 2, 3 and 4 ran consecutively.
Workstream 5 ran concurrently with workstreams 1, 2, 3 and 4 to integrate each workstream into the overall programme of work.
Workstream 6 also ran concurrently with workstreams 1, 2, 3 and 4, to maximise dissemination and outputs throughout the programme.

Changes to the overall programme design

We amended/expanded three components of the original workplan:

In workstream 1, emerging psychometric evidence changed the extent to which we needed to undertake validation of the different measures. We added a study of Phase of Illness, as new evidence[56] confirmed Phase of Illness would potentially be a key casemix criteria.
During workstreams 1 and 2, as a direct result of input from our patient and public involvement (PPI) group, we added a patient experience measure and included an additional secondary analysis to understand the role of uncertainty in the care needs of patients and families with advanced illness.
Within workstreams 3 and 4, we studied the models of specialist palliative care operating at the participating sites in more detail; the need for this became apparent as we tried to characterise models of palliative care in the context of a rapidly changing healthcare environment.
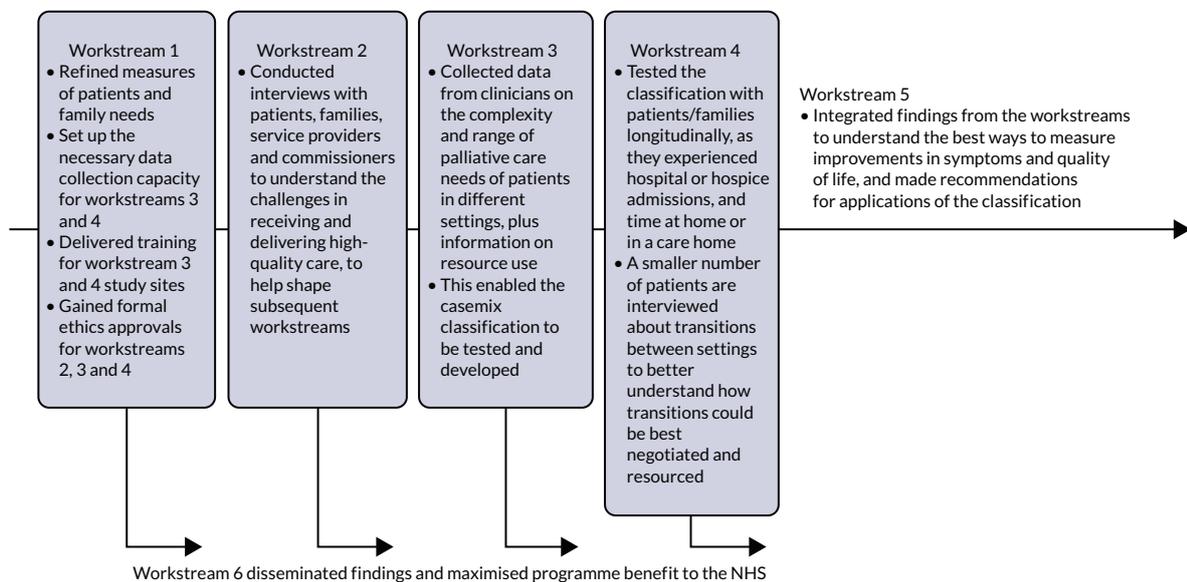
FIGURE 1 Research pathway diagram for the C-CHANGE programme.

Workstream 1: measures and training

Workstream 1 ('measures and training') was designed to meet objective 1: to refine, validate or test new and existing person-centred outcome measures to assess the main health status and symptoms/concerns of, and services received by, patients and families receiving specialist palliative care (for use in workstreams 3 and 4).

As planned, we undertook full validation of the Integrated Palliative care Outcome Scale (IPOS), which was the key measure of patients' symptoms and other concerns in workstreams 3 and 4. We also undertook further testing of the palliative Phase of Illness measure, which had limited previous psychometric assessment, mostly of reliability.[59] After discussion with our PPI group, we also adapted and tested an experience measure: Views on Care (VoC).

The following other measures adopted for workstreams 3 and 4 already had published validation work (or this work emerged before the commencement of workstream 1):

> the Client Service Receipt Inventory (CSRI),[65] including adaption for palliative care[66]
> the Zarit Caregiver Burden Interview – validity of the short version with 6 items,[67] including in advanced illness[68]
> the Medical Outcomes Study Short Form –12 (+ 4),[69] including in advanced disease[70]
> the Australian-modified Karnofsky Performance Scale (AKPS) – an adapted version of the widely-used Karnofsky Index to measure functional status and activity.[71]

We also undertook training of all participating sites in the use of the measures for workstreams 3 and 4, as planned.

An added component of workstream 1 – at the request of our PPI group – was a secondary analysis of existing qualitative data to understand the role of uncertainty in assessing the care needs of patients and families with advanced progressive illness.

More details of the measures are available in *Appendix 1*.

Validation and testing of measures

Validation of the Integrated Palliative care Outcome Scale– cognitive testing
This work has also been published in Schildmann *et al*.[72] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The text below includes minor additions and formatting changes to the original text.

Aim
Our aim was to explore patients' views on the IPOS, with a focus on comprehensibility and acceptability, and to subsequently refine the questionnaire.

Methods
We carried out a cognitive interview study using 'think aloud' and verbal probing techniques. Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis. The IPOS was then refined according to findings. Purposively sampled patients were recruited from four palliative care teams across different settings.

Results

A total of 25 interviews were conducted. Overall, comprehension and acceptability of the IPOS were good. Identified difficulties comprised (1) comprehension problems with specific terms (e.g. 'mouth problems') and length of answer options; (2) judgement difficulties owing to, for example, the recall period; and (3) layout problems.

Validation of the Integrated Palliative care Outcome Scale: full validation study

This work has also been published in Murtagh *et al.*[73]

Aim

Our aim was to validate the IPOS, a measure underpinned by early psychometric development, by evaluating its validity, reliability and responsiveness to change.[73]

Design

We designed a validation study for both the patient self-report and staff proxy-report versions of the IPOS. We tested construct validity (factor analysis, known-group comparisons and correlational analysis), reliability (internal consistency, agreement and test–retest reliability) and responsiveness (through longitudinal evaluation of change).

Results

We recruited 376 adults receiving palliative care and 161 clinicians from a range of palliative care settings. We confirmed a three-factor structure (physical symptoms, emotional symptoms and communication/practical issues).[73] The IPOS showed a strong ability to distinguish between clinically relevant groups; total IPOS and IPOS subscale scores were higher (i.e. reflected more problems) in those patients with 'unstable' or 'deteriorating' versus 'stable' Phase of Illness (F = 15.1; $p < 0.001$). Good convergent and discriminant validity was found for hypothesised items and subscales of the Edmonton Symptom Assessment System and Functional Assessment of Cancer Therapy–General.[73] The IPOS showed good internal consistency (α = 0.77) and acceptable-to-good test–retest reliability (60% of items kw > 0.60). Longitudinal validity in the form of responsiveness to change was good.

To assess how palliative Phase of Illness related to the other measures

This work has also been published in Mather *et al.*[74]

Aims

Our aim was to describe function, symptoms and other palliative care needs according to Phase of Illness, and to consider the strength of associations between these measures and Phase of Illness.

Design and setting

We performed a secondary analysis of patient-level data for a total of 1317 patients in three settings. Function was measured using the AKPS. Pain, other physical problems, psycho-spiritual problems and family and carer support needs were measured using the Palliative Care Problem Severity Scale (https://documents.uow.edu.au/content/groups/public/@web/@chsd/documents/doc/uow272193.pdf; accessed 21 August 2023).

Results

The AKPS and Palliative Care Problem Severity Scale items varied significantly by Phase of Illness. Mean function was highest in the stable phase [65.9, 95% confidence interval (CI) 63.4 to 68.3] and lowest in the dying phase (16.6, 95% CI 15.3 to 17.8). Mean pain was highest in the unstable phase (1.43, 95% CI 1.36 to 1.51). In multinomial regression, psycho-spiritual problems were not associated with Phase of Illness (χ^2 = 2.940, df = 3; p = 0.401). Family and carer support needs were greater in the deteriorating phase than the unstable phase [odds ratio (deteriorating vs. unstable) 1.23, 95% CI 1.01 to 1.49]. Overall, 49% of variance in Phase of Illness is explained by the AKPS and Palliative Care Problem Severity Scale.

A patient experience measure: Views on Care
This work has also been published in Pinto *et al*.[75]

Context
When patients face advanced illness, their experience of care is especially important. In palliative care, we often rely on the accounts of bereaved relatives to report the quality of end-of-life care, and there are no patient-reported measures of the experience of care. Our PPI group challenged us to consider and address this omission. We derived and tested a new questionnaire, called Views on Care (VoC), to address this gap.

Measure development
After research team, PPI group, and steering group discussions, VoC was derived from four questions selected from St Christopher's Index of Patient Priorities[76] that address patients' evaluation of changes in experience of palliative services, and quality of life [the quality of life items are adapted from the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – 15 items measure (EORTC QLQ-C15-PAL), which is well-validated in advanced illness].[77] The St Christopher's Index of Patient Priorities itself was considered too long.

Methods
We conducted a survey to examine patients' views on care and the relationship between these views and changes in health status. Participants were adults receiving specialist palliative care in eight hospital, hospice inpatient and community settings across England. We collected demographic details, plus a patient-reported survey at baseline and follow-up. We reported VoC at follow-up, and change in health status (measured using the IPOS) between baseline and follow-up. Descriptive statistics characterise sample demographics and VoC responses, and the chi-squared statistic tests the association between VoC scores and IPOS change scores. IBM SPSS Statistics version 22 (IBM Corporation, Armonk, NY, USA) was used throughout. Ethics approval was obtained from the Dulwich National Research Ethics Committee (REC), London, UK (reference number 124991).

Results
A total of 212 participants were recruited, with a mean age of 65.84 years [standard deviation (SD) 13.5 years]; 137 participants completed both baseline and follow-up surveys. Responses to VoC items 1, 3 and 4 were reasonably normally distributed. Responses to VoC item 2 were positively skewed with most participants indicating that palliative care was giving positive benefit. Participants reporting that 'things had got better' (item 1) were more likely to have improved overall outcomes (reduction in IPOS total score: $\chi^2 = 6.057$; $p = 0.48$). With regard to IPOS subscales, there was significant positive association between those reporting that 'things had got better' (item 1) and improved outcomes on the IPOS physical symptoms subscale ($\chi^2 = 11.254$; $p = 0.004$). Patients reporting benefit from palliative services (item 2) were more likely to have improved scores on the IPOS communication/practical issues subscale (χ^2 4.743; $p = 0.051$).

Exploring uncertainty in relation to palliative care needs

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Aim
Our aim was to understand patient experiences of uncertainty in advanced illness and develop a typology of patients' responses and preferences to inform subsequent research in this programme.

Design

We performed a secondary analysis of qualitative interview transcripts.[78] Studies were assessed for inclusion and interviews were sampled using maximum variation sampling. Analysis used a thematic approach with 10% of coding cross-checked to enhance reliability. Qualitative interviews from six studies were analysed, comprising patients with advanced heart failure, end-stage chronic obstructive pulmonary disease, end-stage renal disease, advanced cancer and advanced liver failure.[78]

Results

A total of 30 transcripts were analysed. The median patient age was 75 years (range 43–95 years) and 12 patients were women. The impact of uncertainty was frequently discussed: the main related themes were engagement with illness, information preferences, patient priorities and the period of time that patients focused their attention on (temporal focus). A typology of patient responses to uncertainty was developed from these themes (see *Figure 2*).[78]
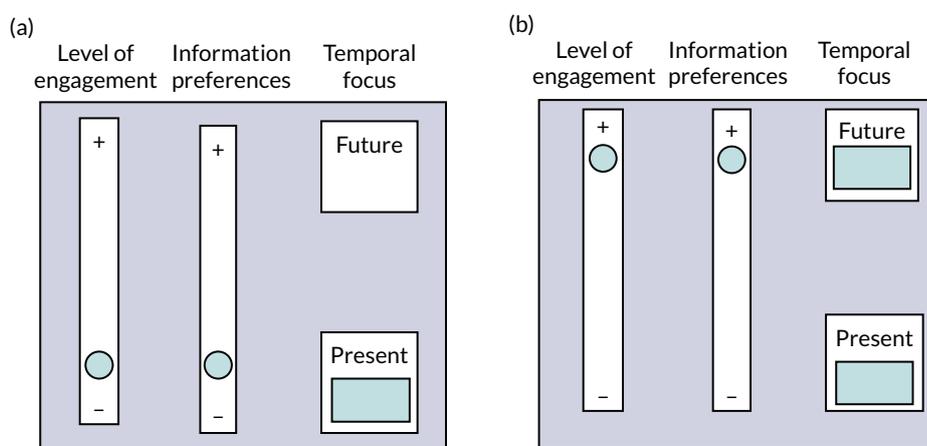
FIGURE 2 Two different examples of patient responses to uncertainty, dependent on level of engagement, information preferences and temporal focus. Reproduced with permission from Etkind *et al.*[78] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY-NC 3.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by-nc/3.0. The figure includes minor additions and formatting changes to the original figure.

Workstream 2: stakeholders' perspectives on measuring complexity

This work has also been published in Pask *et al.*[79]

Workstream 2 ('stakeholders' perspectives on measuring complexity') was planned to meet objective 2: to utilise the perspectives of key stakeholders (i.e. patients, families, professional caregivers, commissioners and policy-makers) on complexity in palliative care to inform subsequent casemix development.

Aim

Our aim was to explore the perspectives of key stakeholders on complexity in palliative care to inform subsequent casemix development.

Methods

Design
We designed a qualitative study using semistructured interviews with key stakeholders in specialist palliative care.

Recruitment and consent
We undertook audio-recorded, individual interviews with various stakeholders across specialist palliative care. Participants were either recruited from one of the C-CHANGE participating sites for workstreams 3 and 4 or – for policy and national leads – sought out by the wider research team at the Cicely Saunders Institute (the leading UK research institute for palliative care). Within this frame, participants were sampled purposively, by personal and/or professional background, geographical location and experiences of settings of care (hospital, hospice and community).

Data collection
A topic guide was developed from a review of evidence on complexity, potential criteria for casemix already used[46] or proposed,[58] existing casemix classifications in palliative care[57] and predictors of resource use in the last year of life. It was refined by our PPI group, by the research team, and through discussion with and feedback from the Programme Steering Committee.

Face-to-face, semistructured interviews were conducted by C-CHANGE researchers in the participant's preferred setting. To increase the credibility of the data, interviewers summarised the interview back to each respondent, to allow the participant to verify the data and clarify any misconceptions or add additional information. All interviews were digitally audio-recorded, anonymised and transcribed verbatim to ensure confidentiality.

Analysis
Interviews were analysed independently by two researchers from the C-CHANGE team using the five analytical steps of framework analysis: (1) familiarisation, (2) identifying a thematic framework, (3) indexing, (4) charting and (5) mapping and interpretation. Framework analysis was considered the optimal approach to allow both an inductive and deductive approach, which would facilitate comparison across stakeholder groups and support the service delivery and policy focus of this research. Emerging themes were discussed with the whole C-CHANGE research team to improve the confirmability and dependability of the findings. Charts were created for each theme, grouped by stakeholder type, and were used to explore stakeholder assonance and dissonance among perspectives on each theme

and subtheme. Analysis was managed using NVivo version 10 (QSR International, Warrington, UK). The framework was presented to the PPI advisory group, the Project Steering Committee and other qualitative research experts to refine and improve the presentation of the developed framework.

Ethics approval

Ethics approval was gained from the King's College London REC (BDM/14/15–2).

Results

Sixty-five participants – including patients and families – were recruited and interviewed (see Pask *et al.*[79] for full details of participant characteristics). Participants provided valuable insights into how complexity might best be understood. They largely understood and valued any use of individual person-level criteria to determine complexity and had nuanced perspectives on how this might be undertaken.

Based on these qualitative findings, we developed a theoretical framework – adapted from Bronfenbrenner's Ecological Systems Theory[80] – directly using the interview data provided by patient, family and professional participants to help understand complexity in specialist palliative care (see *Figure 3*). This framework emphasises that considering physical, psychological, social and spiritual domains (a classic approach in specialist palliative care) is not enough to characterise complexity. Other aspects – such as 'pre-existing' (often social), 'cumulative' and 'invisible' (such as unrecognised depression in the context of physical illness) complexity – are important too, yet frequently overlooked.

The way in which professionals and services interact with people and their families was also considered to be crucial to assessing, understanding and responding appropriately to complexity. Number, severity, range and temporality of needs – as well as 'hidden' or overlooked aspects of complexity, as noted above – all needed to be considered in the development of a meaningful casemix classification for specialist palliative care.
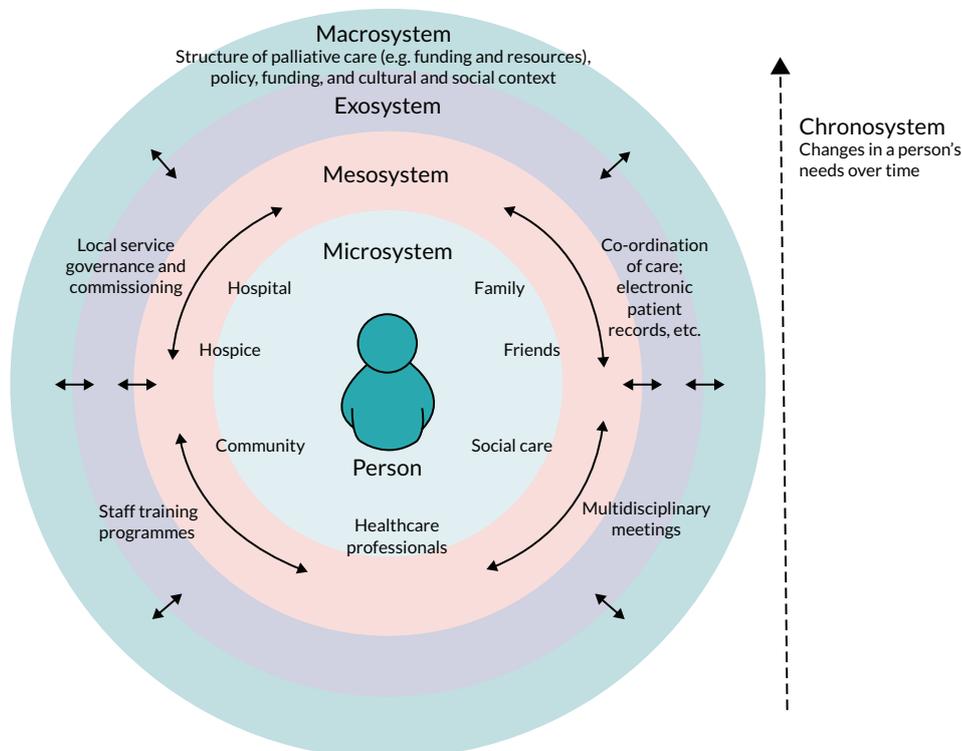
FIGURE 3 A theoretical framework of complexity in the palliative care context. Reproduced with permission from Pask *et al.*[79] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY NC 4.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by-nc/4.0. The figure includes minor additions and formatting changes to the original figure.

Workstream 2: models of specialist palliative care

This work has also been published in Firth *et al.*[81]

This work in workstream 2 ('models of specialist palliative care') was extended from that proposed in our original bid to meet objective 3: to understand the criteria which distinguish different models of palliative care, to help inform how a casemix classification and per-patient funding models can best be utilised across different models of specialist palliative care.

The originally planned work needed to be expanded to understand and describe the different models of palliative care, which were rapidly evolving in a changing healthcare environment (especially in community settings). This change was fully supported by the Programme Steering Committee and PPI group.

Aim

We aimed to understand the criteria which characterise and distinguish different models of palliative care.[81]

Methods

Design
We developed a mixed-methods study with (1) semistructured interviews to identify criteria for models of care, (2) a two-round Delphi study to rank/refine these criteria and (3) structured interviews to test the acceptability and feasibility of these criteria.[81]

Semistructured interviews
A rapid scoping review was conducted to identify literature related to models of palliative care. Original papers and reviews were examined for possible criteria which could help define models of specialist palliative care and a topic guide was created covering the 28 preliminary criteria identified from this literature. Semistructured interviews using a pre-specified topic guide were conducted with a range of palliative care service leads across organisations.[81]

Delphi study
We selected Delphi survey methods for this second stage because it enabled us to present potential criteria derived from the semistructured interviews to all respondents, allowed them time to absorb this complex information at their own pace and enabled us to sample a wide range of views in a way that gave all opinions equal weight. A two-round Delphi survey of UK clinical, policy or PPI leads were invited from the Outcome Assessment and Complexity Collaborative network (a multidisciplinary network of professionals engaged in the implementation of outcome measures in specialist palliative care in England), and the national C-CHANGE sites. Participants were advised that we were aiming to establish a list of key criteria to describe and compare models of care. The Delphi survey was conducted to refine the criteria from the semistructured interviews, identify any additional criteria, achieve consensus on how each criterion was defined and rank the criteria in terms of importance.[81] CREDES (Conducting and REporting DElphi Studies in palliative care) guidelines were followed.[82]

An online survey was developed using Bristol Online Survey (BOS) v1.0 Bristol, UK.[83] The survey was piloted for face validity prior to going live.

In the first Delphi round, panel members were presented with a list of 34 criteria. Participants were asked to state whether or not they agreed with the inclusion of each criterion as an important criterion for describing and comparing models of specialist palliative care (answering 'yes', 'no' or 'don't know') and their reasons for this. They were also asked to comment on the phrasing and clarity of the criterion, as well as the answer options listed. Finally, participants were asked to suggest any additional criteria they thought should be included.[81]

Each criterion was retained if at least 75% participants answered 'yes'. Free-text comments were analysed using content analysis and used to refine and expand the set of criteria.

In round 2 of the Delphi process, participants received anonymised feedback from round 1 and the amended list of criteria for further refinement and ranking. Participants were asked to rate the importance of each criterion for characterising and comparing different models of care on a five-point Likert scale (1 = not at all important; 2 = not very important; 3 = important; 4 = very important; 5 = extremely important). In addition to the rating scales, participants were also given the opportunity to add additional free-text comments to help refine criteria and answer options.[81]

Responses were analysed to capture both central tendency (median rating) and dispersion [interquartile range (IQR)]. Consensus was deemed to have been reached for criteria that received aggregated responses with an IQR of ≤ 1 and a median of 4 or 5. Both methods are considered to offer robust measurements for Delphi surveys.[84,85] Criteria reaching this consensus were then included in the final set.

Ranking responses were collated and analysed using IBM SPSS Statistics version 22. Free-text responses underwent content analysis and were used to refine the criteria and response options.

Structured interviews to test for acceptability and feasibility of the criteria
The criteria developed from the Delphi survey component were then tested with clinical leads from three different specialist palliative care settings (hospice inpatient care, hospital advisory teams and community-based care) using structured interviews. Participants consented to be interviewed and audio-recorded. The data from these interviews were classified according to the criteria used, and entered into Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) to identify whether or not the criteria could discriminate between services.[81]

Ethics approval
Prior ethics approval for all three components was gained from the King's College London REC (LRS-15/16–2449).

Results

Semistructured interviews
Semistructured interviews were conducted with 14 service leads from eight organisations, discussing 12 settings of care (five hospice inpatient units, two hospital advisory teams and five community teams).

An early finding was that the clinical leads struggled to know at which level within the organisation to describe their models of care.[81] It was often confusing when an organisation covered multiple settings of care (i.e. hospice inpatient, community, hospital inpatient and day services) and also provided multiple services within each setting, which often overlapped. For example, a hospice may have inpatient hospice, home care and ambulatory settings. Within any one of these settings, multiple services or teams were often operating. Within the day services there may be a physiotherapy clinic, a lymphoedema service and a day service, all operating with different models of care.

After all interviews were completed, out of the 28 criteria in the topic guide, 11 were not reported as useful and were removed; 17 criteria were refined; and a further 17 criteria were created. This resulted in 34 criteria to take forward to the Delphi survey.[81]

Delphi survey
A total of 190 participants were invited to take part in the Delphi survey. Of the 190 clinical, policy and PPI leads contacted, 54 agreed to participate (response rate 28.4%).

Results of Delphi round 1

Out of thirty-four criteria, six were removed due to not reaching the 75% consensus rate, and one removed due to poor comprehension. Three new criteria were added:

> How many referrals are accepted and seen annually by this service/team? (to reflect the size of service)
> Does this service/team accept patient or family self-referrals? (to reflect the approach to self-referral)
> Who undertakes the first assessment? (to reflect whether the model of care was doctor-led, nurse-led or another kind of model).

The out-of-hours criteria were heavily refined to improve comprehension and four new criteria relating to 'out-of-hours' were created. This resulted in a refined list of 34 criteria.[81]

Results of Delphi round 2

Thirty participants (out of 54 in round 1) completed round 2 (60% response rate). In round 2, the 34 revised criteria from round 1 were ranked and rated, and criteria not meeting the predetermined consensus level were excluded. Sixteen criteria reached consensus (see *Box 1*).

BOX 1 Final agreed criteria to define models of palliative care

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Sixteen criteria which reached consensus in Delphi rounds 1 and 2

> Setting of care (inpatient hospital, inpatient hospice, home based, etc.)
> Type of care delivered ('hands on' or advisory)
> Size of service (measured by number of referrals accepted annually)
> Number of disciplines delivering the care
> Mode of care (face-to-face, telephone or other remote delivery)
> Number of interventions available
> Whether or not out-of-hours referrals are accepted
> Whether or not out-of-hours care is available to patients already known to the service
> Time when out-of-hours care available
> Out-of-hours mode (face to face or advisory)
> Type of out-of-hours provision ('hands on' or advisory)
> Extent of education/training provided to external professionals
> Whether or not outcome and experience measures are used in the service
> Whether or not standard bereavement follow-up is provided
> Whether or not complex grief follow-up is provided
> The primary diagnosis of those patients receiving care (cancer/non-cancer)

Four further criteria included in the final set following testing/feedback from structured interviews

> Is the service a publicly funded or voluntary funded service?
> Whether or not there are patient or family self-referrals
> Whether or not there are standard discharge criteria
> Purpose of care provided.

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Structured interviews

Interviews were conducted with 21 service leads from 19 different services (six hospice inpatient, four hospital advisory and nine community settings). The responses to each criterion were compared to see if the criteria could distinguish and discriminate effectively between services. A further four criteria relating to context were also added (see *Box 1*); these were reported by the clinical leads as providing important context for the practical application of the criteria. These four contextual criteria were the purpose of the team, who funds/manages the team, the ability to self-refer and the discharging of patients.[81]

Workstream 3: development of the casemix classification

The protocol for this study has been published[55] was planned to meet objective 4: to develop a patient-centred palliative care casemix classification, based on individual patient and family needs, for adults with both cancer and non-cancer conditions in the last year of life.

Aim

Our aim was to develop a casemix classification for UK specialist palliative care, for use in hospital-based palliative care, inpatient hospices (palliative care units) and home-based palliative care.

Methods

Design
We designed a multicentre prospective cohort study, following patients during episodes of specialist palliative care and reported according to the Transparent Reporting of a multivariable prediction model for Individual Prognosis Or Diagnosis (TRIPOD) statement.[86]

Definitions
We defined an episode of care as a 'period of contact between a patient and palliative care service provider or team of providers that occurs in one setting'.[87] A new referral into palliative care or change of setting (e.g. re-location into an inpatient setting from home/care home, or vice versa) signalled the start of an episode of palliative care. Discharge from palliative care, change of setting or death signalled the end of an episode of care. We defined the setting of care as one of three types: hospital advisory (hospital-based specialist palliative care teams providing an advisory or consultant service), inpatient hospice (where patients are admitted to a hospice or specialist palliative care unit for an overnight stay of one or more days) or community-based specialist palliative care (where the patient receives care in their usual place of residence, either at home or in a care home).

Population and settings
Patients were recruited from 14 organisations providing specialist palliative care services in England: four hospital advisory services, five inpatient hospice services and seven community-based services (some organisations provided more than one setting of care). Sites were selected to ensure our study sample was representative of UK palliative care patients and services in terms of participant age, ethnic background, service size, proportion of cancer/non-cancer patients and urban–rural balance. We included more community services than hospital or inpatient hospital services.

Inclusion/exclusion criteria
We included consecutive adult patients (≥ 18 years) receiving specialist palliative care at all participating sites. Exclusion criteria comprised patients aged < 18 years, those who declined participation and/or those who previously expressed a wish not to participate in research.

Data collection and primary outcome
Data were collected from clinicians between July 2015 and October 2016, with completion of follow-up at the end of January 2017; no data were collected directly from patients. Collected data included demographic and clinical variables, episode start and end dates, potential casemix variables, and data on patient-level and other costs of providing specialist palliative care. All participants received the usual specialist palliative care at that site, including a multidisciplinary team with specialist training delivering

holistic care focused on physical and psychological symptom management, social/family support, planning ahead around priorities and preferences, and care into the dying phase including post-death care of the family, where relevant.

Potential casemix variables were selected based on (1) being patient-level attributes and (2) existing evidence of association with casemix/complexity.[88] The key casemix variables included were age, sex, ethnicity, living circumstances, need for interpreter, primary diagnosis, palliative Phase of Illness, functional status, dependency and symptoms/problem severity.

Details of the measures used are presented in *Appendix 1*.

Our primary outcome was the cost of specialist palliative care per day. We adopted a (palliative) provider perspective for costs. The costs of acute hospital care, primary care, generic end-of-life care (i.e. provided by non-specialist teams), and informal care costs were excluded, not because these are unimportant, but because we sought casemix criteria relevant to specialist palliative care. A broader perspective on costs is planned for future work.

Palliative Phase of Illness was assessed daily for people receiving inpatient (hospital or inpatient unit) care and at every contact for those receiving community-based care. Each change in Phase of Illness (or end of episode) triggered the collection of the AKPS, IPOS or Palliative Care Problem Severity Score (PCPSS), and the Barthel Index. All staff involved in patient care recorded the time spent delivering care to participants at the patient level using the staff activity matrix.

We collected data from participating sites on the costs of delivering their services and patient-level resource use data from the staff activity matrix to derive actual patient-level costs according to a standard costing methodology based on current NHS costing principles.[89] Note that costs captured for the hospital advisory and community-based settings represented the additional or 'top-up' costs for adding palliative care support to the hospital or community setting (and thus are reasonably compared). In contrast, the costs for inpatient hospices represented all the costs of inpatient care (and so are more reasonably compared with the costs of acute hospital admission). The full costing methodology (how costs were collected, classified and compiled) is available from the corresponding author on request.

Sample size
Based on standard recommendations for fitting multivariate models, a minimum of $50 + 8 \times m$ cases for testing multiple correlation (where m is the number of predictors) are required to test the null hypothesis that the population multiple correlation equals zero with a power of 80%, $\alpha = 5\%$ and a medium effect size for the regression analysis ($R^2 = 0.13$).[90,91] The unit of analysis was episodes within sites; therefore, 10 predictors required 130 episodes per site. Allowing an additional 15% for episodes with missing data and 20% for cost outliers, we estimated that a target of 2674 episodes of care (191 episodes × 14 sites) was required.

Data handling
Data were collected prospectively at each site, recorded on an electronic database, cleaned and checked. Checked data were transferred to statistical software [Stata® standard edition (SE) V.12 (StataCorp LP, College Station, TX, USA) and MATLAB® 8.2 (The MathWorks, Inc., Natick, MA, USA)] for analysis.

Analysis
An exploratory data analysis was undertaken first, examining variables of interest one at a time. Descriptive statistics (means, standard deviations, medians, ranges and correlations) were calculated. Comparative box plots were constructed to investigate the differences between sites, episodes and phases. Cost of care was used as the response variable, measured as the total cost per episode.

The aim of the analysis was to form distinct groups within the data, such that patients within each group were similar to each other, but different from patients in the other groups.

To discover which baseline casemix variables could best predict the cost of a particular episode of care, the following nine steps were then undertaken:

> We removed incomplete episodes, retaining only the complete episodes of care.
>
> Following a previously adopted approach,[46] high- and low-cost outliers were identified and removed using a trimming algorithm based on the IQR with the upper trim point at Q3 + 1.5 IQR and the lower trim point at Q1 – 1.5 IQR (where Q1 is first quartile and Q3 is third quartile).[46] The trimming algorithm was applied to each setting separately.
>
> We examined the distribution of costs of specialist palliative care, by setting.
>
> Then, following the same approach as the development of the Australian casemix classification,[88] we developed and validated a cost-predictive model using classification and regression tree (CART) analysis, which constructs decision rules in a hierarchical manner to form a branching classification. We used CART analysis to enable the more complex interactions between the predictor variables (both categorical and continuous) to be explored. CART has the advantage of being non-parametric and is not significantly impacted by outliers in the input variables. It enables the use of each variable more than once, if required for the optimal regression tree.
>
> Explanatory variables were compared to find the one which could best split the data into two homogeneous groups that were as different from one another as possible. These two groups would then be further split, using the same or another explanatory variable. Successive binary splits were performed on the data until there was no further improvement to be made and the best possible classification solution was reached.
>
> The best CART was deemed to be that which accounted for the largest proportion of variation in the cost of care (the response variable). The criterion used to compare the different 'trees' was the proportion of the variance of the response variable that could be explained by the selected groups. Costs were log-transformed for better modelling and back-transformed for providing mean costs per class or at each terminal node. Decisions about rules for splitting were informed by clinical utility (for instance, allowing branches that made clinical – as well as statistical – sense), as well as statistical performance as outlined in 7. We selected a maximum of four branches and a minimum of 30 cases per branch, for reasons of clinical utility. 10–fold cross-validation was used to prevent overfitting of the developed classification. No recalibration was undertaken. The analysis was done in R 3.5 (The R Foundation for Statistical Computing, Vienna, Austria) using the rpart, caret and (for bagging the trees) RWeka packages.
>
> For each setting, we reported the variance explained by the CART model and the root-mean-squared error (RMSE) (i.e. the square root of the variance of the residuals). The RMSE indicates the absolute (rather than relative, as with R^2) fit of the model to the data.

Ethics approval

The trial registration number is ISRCTN90752212. Ethics approval was received from the Camberwell St Giles National Research Ethics Service REC on 2 July 2015 [REC Reference: 15/LO/0887, Integrated Research Application System (IRAS) Project ID:172938].

Results

Subject characteristics

A total of 2469 patients were recruited, providing data on 2968 complete episodes of specialist palliative care (12 incomplete episodes were removed prior to analysis); 2087 participants contributed one episode of care, 283 participants contributed two episodes and 99 contributed three or more episodes. Demographic and clinical characteristics for the 2469 participants are reported in *Table 1*. No participants withdrew after recruitment. Further details are available in *Appendix 2*.

TABLE 1 Demographic and clinical characteristics for all study participants (N = 2469)

Characteristic	n (%)
Socio-demographic details	
Age	
Mean (SD)	71.6 (13.9)
Median (range)	73 (20–104)
< 65 years	740 (30.0)
≥ 65 years	1729 (70.0)
Missing	0 (0.0)
Sex	
Male	1258 (51.0)
Female	1205 (48.8)
Missing	6 (0.2)
Ethnicity	
White	1825 (73.9)
Black African or Black Caribbean	217 (8.8)
Asian	151 (6.1)
Mixed ethnic background	118 (4.8)
Other	32 (1.3)
Missing	126 (5.1)
Living alone	
Yes	548 (22.2)
No	1921 (77.8)
Missing	0 (0.0)
Interpreter needed	
Yes	22 (0.9)
No	2447 (99.1)
Missing	0 (0.0)
Primary diagnosis	
Cancer	1857 (75.2)
Lip, oral cavity and pharynx	83 (3.4)
Digestive organs	392 (15.9)
Liver and biliary	73 (3.0)
Pancreas	119 (4.8)
Respiratory and intrathoracic	349 (14.1)
Bone, skin and mesothelial	93 (3.8)
Breast	150 (6.1)
Female genital organs	116 (4.7)

TABLE 1 Demographic and clinical characteristics for all study participants
(*N* = 2469) (*continued*)

Characteristic	*n* (%)
Male genital organs, including prostate	142 (5.7)
Urinary tract	75 (3.0)
Brain, eye and other central nervous system	72 (2.9)
Unknown primary	52 (2.1)
Lymphoid and haematopoietic	131 (5.3)
Independent multiple sites	10 (0.4)
Non-cancer	612 (24.8)
HIV/AIDS	13 (0.5)
Motor neurone disease/ALS	9 (0.4)
Dementia, including Alzheimer's	45 (1.8)
Neurological (excluding MND)	7 (0.3)
Diabetes mellitus	6 (0.2)
Heart failure	17 (0.8)
Stroke, infarction or haemorrhagic	3 (0.1)
Other heart or circulatory	12 (0.5)
Chronic respiratory including COPD	39 (1.6)
Liver failure or chronic liver disease	12 (0.5)
Renal failure	8 (0.3)
All other non-cancer conditions	433 (17.5)
Multiple non-cancer conditions	8 (0.3)
Missing	0 (0.0)

AIDS, acquired immunodeficiency syndrome; ALS, amyotrophic lateral sclerosis; COPD, chronic obstructive pulmonary disease; HIV, human immunodeficiency virus; MND, motor neurone disease.

Episode characteristics
Details of the 2968 complete episodes of care and related casemix variables are reported in *Table 2*.

Outliers
Using the trimming algorithm described in *Methods*, *Analysis*, 123 (16.0%) hospital advisory episodes, 185 (24.2%) inpatient hospice episodes and 305 (21.2%) community episodes were removed to ensure that the principal cost and classification reporting was not based on outliers (a common challenge in costing studies).

Costs of specialist palliative care
The distribution of the total cost of specialist palliative care episodes, derived from the trimmed data set, is shown in *Table 3*; costs are shown (1) by day, (2) by day, broken down by Phase of Illness, and (3) by episode of care, together with details of length of episodes.

TABLE 2 Characteristics of the episodes of care and related casemix variables (*N* = 2968)

Episode characteristics	n (%)
Setting	
Hospital advisory	767 (25.9)
Inpatient hospice	764 (25.7)
Community	1437 (48.4)
Total	2968 (100.0)
Palliative Phase of Illness at episode start	
Stable	451 (15.2)
Unstable	1422 (47.9)
Deteriorating	834 (28.1)
Dying	261 (8.8)
Missing	0 (0.0)
AKPS score at episode start	
Mean (SD) [range]	45.9 (19.9) [10–100]
0–50	1759 (59.2)
60–100	934 (31.5)
Missing	275 (9.3)
Modified Barthel Index score at episode start	
Mean (SD) [range]	8.28 (6.6) [0–20]
Missing	1395/2469 (56.5)[a]
PCPSS at episode start	
Pain	
Mean score (SD) [range]	1.5 (1.06) [0–3]
Absent	615 (20.7)
Mild	703 (23.7)
Moderate	724 (24.4)
Severe	515 (17.4)
Missing	411 (13.8)
Other physical symptoms	
Mean score (SD) [range]	1.9 (0.88) [0–3]
Absent	188 (7.0)
Mild	630 (23.4)
Moderate	1096 (40.6)
Severe	659 (24.4)
Missing	125 (4.6)
Psychological symptoms	
Mean score (SD) [range]	1.8 (0.92) [0–3]

TABLE 2 Characteristics of the episodes of care and related casemix variables (*N* = 2968) (*continued*)

Episode characteristics	*n* (%)
Absent	335 (11.3)
Mild	827 (27.9)
Moderate	932 (31.4)
Severe	423 (14.2)
Missing	451 (15.2)
Family concerns	
Mean score (SD) [range]	1.8 (0.92) [0–3]
Absent	273 (9.2)
Mild	592 (20.0)
Moderate	1057 (35.6)
Severe	552 (18.6)
Missing	494 (16.6)
Length of episode (days)	
Hospital advisory	
Mean (SD)	19.3 (39.01)
Median (range)	8 (1–402)
Inpatient hospice	
Mean (SD)	15.6 (15.77)
Median (range)	12 (1–140)
Community	
Mean (SD)	50.4 (53.95)
Median (range)	30 (1–313)

a The modified Barthel Index score could not be collected in the community setting.

Classification and regression tree analysis

Figures 4–6 show the CARTs for each setting. The per cent variance explained (and RMSE) were 20% (RMSE = 0.30), 51% (RMSE = 0.51) and 27% (RMSE = 0.36), for hospital advisory, inpatient hospice and community episodes, respectively.

Seven different casemix variables provide the optimal combination to develop classes for each of the settings. *Table 4* shows which variables were used and how they were combined to constitute the casemix classes, including cost weights.

TABLE 3 The total cost and length of episodes of specialist palliative care, in Great British pounds and days

Setting of care	n	%
Hospital advisory	644	27.3
Inpatient hospice	579	24.6
Community	1132	48.1
Total	2335	100.0
	Mean (SD)	**Median**
Hospital advisory		
Cost per day: all episodes (£)	72.65 (57.18)	56.15 (31.22–100.03)
Cost per day by Phase of Illness (£)[a]		
Stable	60.03 (49.54)	48.11 (24.91–78.34)
Unstable	76.41 (58.71)	58.61 (35.20–105.71)
Deteriorating	68.55 (52.85)	53.87 (31.54–95.77)
Dying	81.28 (63.88)	61.76 (33.00–119.90)
Length of episode: all episodes (days)	15.18 (32.32)	7 (3–15)
Length of episode, by Phase of Illness (days)[a]		
Stable	26.35 (59.22)	7 (2–18)
Unstable	16.47 (30.91)	8 (4–17)
Deteriorating	10.90 (24.35)	6 (3–11.5)
Dying	7.58 (16.83)	3 (1–6)
Cost per episode: all episodes (£)	507.36 (446.38)	385.84 (176.15–698.85)
Cost per episode, by Phase of Illness (£)[a]		
Stable	387.57 (415.61)	244.67 (116.38–508.32)
Unstable	585.26 (268.11)	458.01 (229.71–839.04)
Deteriorating	431.33 (416.19)	307.33 (146.68–558.59)
Dying	335.53 (299.38)	206.89 (106.59–521.89)
Inpatient hospice		
Cost per day: all episodes (£)	716.38 (765.04)	434.33 (365.72–664.50)
Cost per day, by Phase of Illness (£)[a]		
Stable	669.55 (783.49)	407.69 (292.81–588.00)
Unstable	690.28 (726.03)	428.38 (388.53–527.13)
Deteriorating	832.60 (879.18)	458.01 (353.11–967.66)
Dying	645.08 (647.98)	453.44 (364.51–606.52)
Length of episode: all episodes (days)	14.74 (15.69)	11 (5–19)
Length of episode, by Phase of Illness (days)[a]		
Stable	19.55 (22.70)	12 (6–22.5)
Unstable	16.68 (16.25)	13 (6–22)
Deteriorating	12.29 (10.02)	10 (6–16)
Dying	9.17 (17.66)	6 (2–11)
Cost per episode: all episodes (£)	7202.25 (7679.24)	4428.28 (1601.00–10,533.93)

TABLE 3 The total cost and length of episodes of specialist palliative care, in Great British pounds and days (*continued*)

Setting of care	*n*	%
Cost per episode, by Phase of Illness (£)[a]		
Stable	8001.18 (9082.44)	4179.83 (2054.33–9346.56)
Unstable	7731.80 (7644.43	5345.43 (2069.59–10,654.10)
Deteriorating	7654.97 (7839.31)	4623.73 (1716.47–11,947.12)
Dying	3119.63 (4948.30)	1021.32 (463.39–2957.72)
Community		
Cost per day: all episodes (£)	35.76 (40.49)	21.37 (6.23–49.13)
Cost per day, by Phase of Illness (£)[a]		
Stable	23.20 (32.60)	10.58 (3.21–28.35)
Unstable	33.97 (38.13)	21.52 (6.23–47.03)
Deteriorating	40.02 (43.28)	24.01 (8.14–54.22)
Dying	61.86 (44.84)	55.87 (24.91–88.46)
Length of episode: all episodes (days)	49.45 (51.53)	30.5 (12–68)
Length of episode, by Phase of Illness (days)[a]		
Stable	65.03 (58.02)	46.5 (20.5–90)
Unstable	50.80 (50.91)	32 (15–70)
Deteriorating	45.42 (47.15)	28 (12–61.5)
Dying	16.67 (33.48)	5 (2–19)
Cost per episode: all episodes (£)	858.43 (780.77)	624.18 (264.18–1230.44)
Cost per episode, by Phase of Illness (£)[a]		
Stable	818.91 (798.19)	569.97 (207.24–1187.43)
Unstable	879.57 (782.01)	607.70 (282.47–1257.20)
Deteriorating	870.39 (781.96)	641.70 (274.30–1215.15)
Dying	806.66 (725.88)	577.93 (224.56–1230.57)

a Throughout this table, Phase of Illness refers to the Phase of Illness at start of the episode of care.
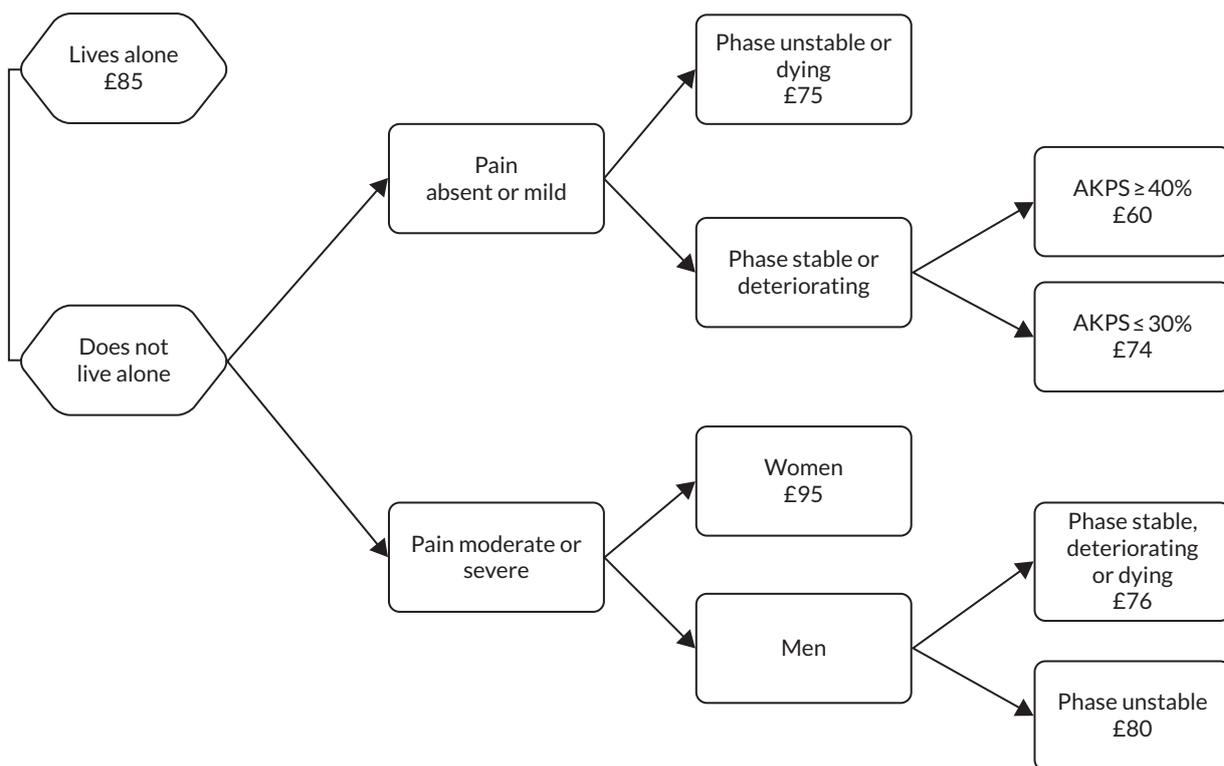
FIGURE 4 Classification tree of casemix criteria for hospital advisory episodes of specialist palliative care (costs per day reported for each class).
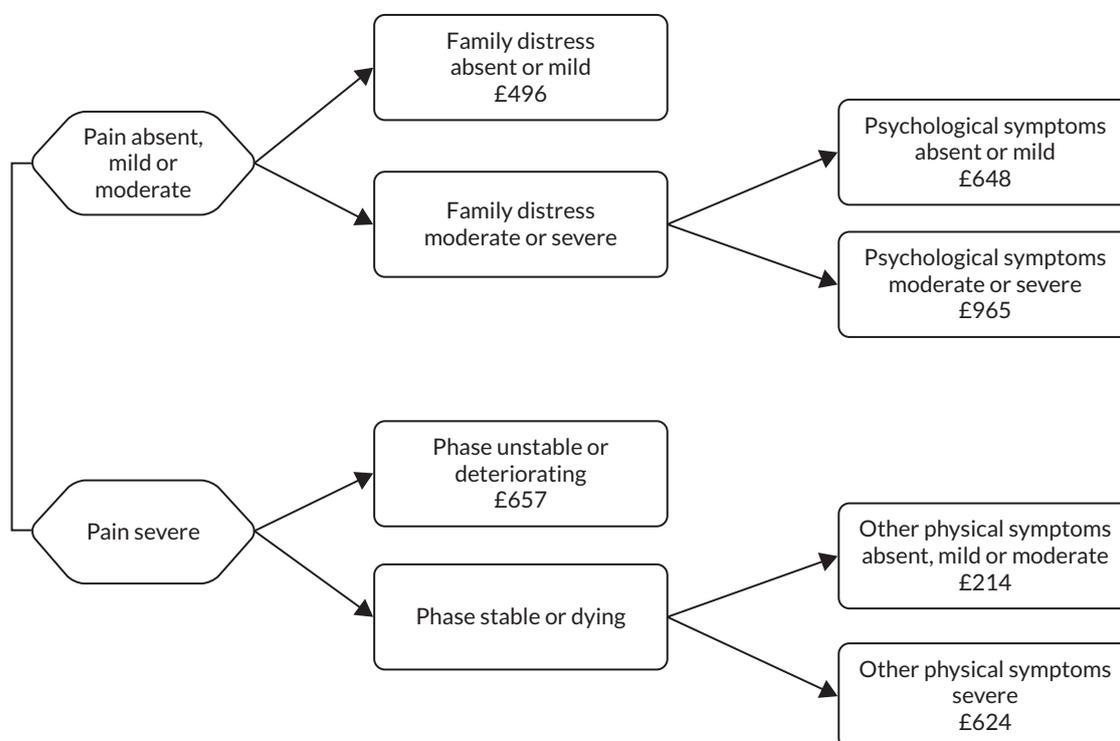
FIGURE 5 Classification tree of casemix criteria for inpatient hospice episodes of specialist palliative care (costs per day reported for each class).
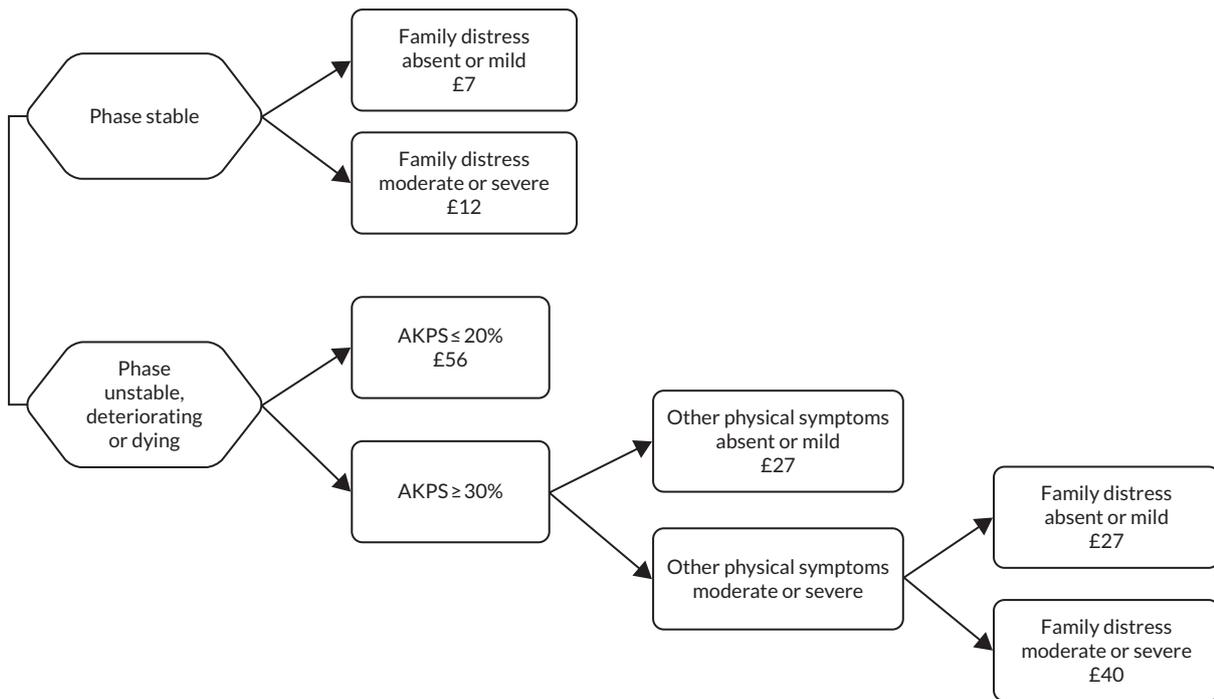
FIGURE 6 Classification tree of casemix criteria for community episodes of specialist palliative care (costs per day reported for each class).

TABLE 4 Casemix classification for specialist palliative care (all costs are costs per day)

Class	Living situation	Pain	Functional status	Palliative Phase of Illness	Family distress	Physical symptoms other than pain	Psychological symptoms	Sex	Class cost per day (£)	Cost weight[a]
Classes for hospital advisory episodes of care										
A	Lives alone	–	–	–	–	–	–	–	85	1.4
B	Does not live alone	Absent or mild	–	Unstable or dying	–	–	–	–	75	1.3
C	Does not live alone	Absent or mild	AKPS ≥ 40%	Stable or deteriorating	–	–	–	–	60	1.0
D	Does not live alone	Absent or mild	AKPS ≤ 30%	Stable or deteriorating	–	–	–	–	74	1.2
E	Does not live alone	Moderate or severe	–	–	–	–	–	Female	95	1.6
F	Does not live alone	Moderate or severe	–	Stable, deteriorating or dying	–	–	–	Male	76	1.3
G	Does not live alone	Moderate or severe	–	Unstable	–	–	–	Male	80	1.3
Classes for inpatient hospice episodes of care										
A	–	Absent, mild or moderate	–	–	Absent or mild	–	–	–	496	2.3
B	–	Absent, mild or moderate	–	–	Moderate or severe	–	Absent or mild	–	648	3.0
C	–	Absent, mild or moderate	–	–	Moderate or severe	–	Moderate or severe	–	965	4.5
D	–	Severe	–	Unstable or deteriorating	–	–	–	–	657	3.1
E	–	Severe	–	Stable or dying	–	Absent, mild or moderate	–	–	214	1.0
F	–	Severe	–	Stable or dying	–	Severe	–	–	624	2.9

TABLE 4 Casemix classification for specialist palliative care (all costs are costs per day) (*continued*)

Class	Living situation	Pain	Functional status	Palliative Phase of Illness	Family distress	Physical symptoms other than pain	Psychological symptoms	Sex	Class cost per day (£)	Cost weight[a]
Classes for community episodes of care										
A	–	–	–	Stable	Absent or mild	–	–	–	20	1.0
B	–	–	–	Stable	Moderate or severe	–	–	–	24	1.2
C	–	–	AKPS ≤ 20%	Unstable, deteriorating or dying	–	–	–	–	56	2.8
D	–	–	AKPS ≥ 30%	Unstable, deteriorating or dying	–	Absent or mild	–	–	27	1.4
E	–	–	AKPS ≥ 30%	Unstable, deteriorating or dying	Absent or mild	Moderate or severe	–	–	27	1.4
F	–	–	AKPS ≥ 30%	Unstable, deteriorating or dying	Moderate or severe	Moderate or severe	–	–	40	2.0

a The cost weight is relative to the lowest cost class (i.e. calculated as the ratio of the cost per day for that class to the cost per day of the lowest cost class).

Note Classes are labelled alphabetically with letters to indicate that they are in no specific numerical order.

Workstream 4: testing of the casemix classification

This work has also been published in Guo *et al.*[92]

Workstream 4 (testing the casemix classification) was planned to meet objective 5: to test this person-centred palliative care casemix classification in terms of its ability to predict resource use in the last year of life, and to better understand transitions between services in order to improve care.

Aim

Our aim was to test the palliative care casemix classification developed in workstream 3 in terms of its ability to predict resource use for patients receiving episodes of specialist palliative care, and to explore the experience of transitions between care settings for those receiving specialist palliative care.

Methods

Design
We designed a multicentre prospective cohort study, following patients during episodes of specialist palliative care, with a qualitative nested component (interviews with a subsample of participants to better understand the experience of transitions between care settings).

Definitions
We defined both an episode of care and the setting of care as in *Workstream 3: development of the casemix classification, Definitions*.

Population and settings
Patients were recruited from 12 organisations providing specialist palliative care services in England, comprising three hospital advisory services, eight inpatient hospice services and five community-based services (some organisations provided more than one setting of care). Sites were selected for diversity in terms of participant age, ethnic background, service size, proportion of cancer/non-cancer patients and urban–rural balance

Inclusion/exclusion criteria
The inclusion criteria comprised adult patients aged ≥ 18 years who were able to consent and receiving specialist palliative care at any of the participating sites. The exclusion criteria were patients aged < 18 years and those unable to consent.

Data collection and primary outcome
Data were collected from patient participants and clinicians between December 2016 and May 2018. Collected data included demographic and clinical variables, episode start and end dates, casemix variables as required for the casemix classification developed in workstream 3, and data on patient-level and other costs of providing specialist palliative care. All participants received the usual specialist palliative care at that site, including a multidisciplinary team with specialist training delivering holistic care focused on physical and psychological symptom management, social/family support, planning ahead around priorities and preferences, and care into the dying phase including post-death care of the family, where relevant. Details of the measures used are presented in *Appendix 1*.

Palliative Phase of Illness was assessed daily for people receiving inpatient (hospital or inpatient unit) care and at every contact for those receiving community-based care. Each change in Phase of Illness (or end of episode) triggered the collection of the AKPS, IPOS or PCPSS and Barthel Index score. All staff involved in patient care recorded the time spent delivering care to patient participants at a patient level using the staff activity matrix.

We also collected data from participating sites on the costs of delivering their services, plus patient-level resource use data, as in workstream 3.

A subsample of participants who had experienced at least two transitions between care settings were invited for interview. A purposive sampling approach was used to include participants from a range of age groups, sex, diagnoses, types of transitions in either direction and geographical areas.

Data handling
Quantitative data were collected prospectively at each site, recorded on an electronic database, cleaned and checked. Checked data were transferred to statistical software (Stata SE V.12) for analysis. Qualitative data were recorded, transcribed verbatim and handled using NVivo version 12.

Analysis
For the quantitative data, the casemix classes developed in Workstream 3 were applied to predict costs for episodes of care and this was contrasted with the actual costs captured for each episode of care. For the qualitative data we adopted a similar approach to Pinnock *et al.*'s qualitative study,[93] undertaking a thematic[94] and narrative analysis of interviews, exploring how perspectives on transitions evolve over time, with detailed attention to patient and family perspectives on their experience of care in each setting and during transitions, including their experience of interventions that potentially influenced changes in settings of care.

Ethics
The trial registration number is ISRCTN90752212. Written or oral witnessed consent was taken and documented for each participant, and continuing consent was confirmed at follow-up. Ethics approval was received from Bromley REC on 5 September 2016 (REC Reference: 16/LO/1021, IRAS Project ID: 204926).

Quantitative results

Subject characteristics
A total of 309 patients were recruited, providing data on 751 episodes of specialist palliative care. Of these participants, 309 contributed one episode of care, 177 (57%) contributed a second episode of care and 119 (39%) contributed a third episode of care. Only 63 (20%) participants contributed four or more episodes of care. Demographic and clinical characteristics for the 309 participants are reported in *Table 5*. Just over three-quarters (76%) of participants had cancer, but we were able to recruit one-fifth with a range of different non-cancer conditions.

Episode characteristics
Details of the episodes of care are reported in *Table 6*. Seventy-seven episodes of care (10% of all episodes) occurred at sites not participating in the study; although we had endeavoured to include all specialist palliative care sites in each geographical area, inevitably some episodes of care (especially in hospital) were outside of our C-CHANGE sites. *Tables 7* and *8* report the duration of episodes of care, by setting and by episode number, respectively. As expected, the median duration of episode was shortest for hospital advisory episodes (10 days) and longest for community episodes (26 days). Note that the absence of the dying Phase of Illness strongly affects these data; those first seen in the dying phase had the shortest length of stay yet are effectively excluded from these data because of the requirement for consent.

TABLE 5 Demographic and clinical characteristics for study participants (N = 309)

Characteristic	n (%)
Socio-demographic details[a]	
Age	
Mean (SD)	66.9 (13.15)
Median (range)	68 (18–96)
< 65 years	117 (37.9)
≥ 65 years	183 (59.2)
Missing or prefer not to say	9 (2.9)
Sex	
Male	134 (43.4)
Female	170 (55.0)
Missing or prefer not to say	5 (1.6)
Ethnicity	
White	265 (85.8)
Black African or Black Caribbean	9 (2.9)
Asian	8 (2.6)
Mixed ethnic background	9 (2.9)
Other	11 (3.6)
Missing or prefer not to say	7 (2.2)
Marital status	
Married or partner	165 (53.4)
Separated or divorced	43 (13.9)
Widowed	46 (14.9)
Single	46 (14.9)
Missing or prefer not to say	9 (2.9)
Living alone	
Yes	107 (34.6)
No	191 (61.8)
Missing or prefer not to say	11 (3.6)
Interpreter needed[b]	
Yes	2 (0.6)
No	302 (97.8)
Missing	5 (1.6)
Primary diagnosis[b]	
Cancer	237 (76.7)
Lip, oral cavity and pharynx	1 (0.3)
Digestive organs	55 (17.8)
	continued

TABLE 5 Demographic and clinical characteristics for study participants (*N* = 309) (*continued*)

Characteristic	n (%)
Liver and biliary	8 (2.6)
Pancreas	10 (3.2)
Respiratory and intrathoracic	46 (14.9)
Bone, skin and mesothelial	11 (3.6)
Breast	28 (9.1)
Female genital organs	16 (5.1)
Male genital organs including prostate	25 (8.1)
Urinary tract	11 (3.6)
Brain, eye and other central nervous system	4 (1.3)
Unknown primary	7 (2.3)
Lymphoid and haematopoietic	15 (4.8)
Independent multiple sites	0 (0.0)
Non-cancer	59 (19.1)
HIV/AIDS	1 (0.3)
Motor neurone disease/ALS	11 (3.6)
Dementia including Alzheimer's	0 (0.0)
Neurological (excluding MND)	8 (2.6)
Diabetes mellitus	0 (0.0)
Heart failure	5 (1.6)
Stroke, infarction or haemorrhagic	0 (0.0)
Other heart or circulatory	0 (0.0)
Chronic respiratory including COPD	28 (9.1)
Liver failure or chronic liver disease	1 (0.3)
Renal failure	1 (0.3)
All other or multiple non-cancer conditions	4 (1.3)
Missing	13 (4.2)

AIDS, acquired immunodeficiency syndrome; ALS, amyotrophic lateral sclerosis; COPD, chronic obstructive pulmonary disease; HIV, human immunodeficiency virus; MND, motor neurone disease.
a Reported by patient participants.
b Reported by staff.

TABLE 6 Sequence and setting for all episodes of care (N = 751)

Episode of care	Setting, n							
	Community	Hospice inpatient	Hospital inpatient (advisory)	Non-C-CHANGE site: community[a]	Non-C-CHANGE site: hospice inpatient[a]	Non-C-CHANGE site: hospital inpatient (advisory)[a]	Other	Unknown	Total, n
1st	136	64	107	2					309
2nd	88	33	13	13	1	25	2	2	177
3rd	40	43	19	2	1	12	1	1	119
4th	21	24	4	2		10	2		63
5th	13	12	4			5			34
6th	10	8	2			2			22
7th	5	4	2						11
8th	2	4				2			8
9th	3	2							5
10th			1						1
11th	1								1
12th		1							1
Total	319	195	152	19	2	56	5	5	751

a Data from episodes of care at non-C-CHANGE sites are limited to setting, duration and status at episode end; casemix and cost data could not be collected.

TABLE 7 Duration of first, second and third episodes of care, by setting (*N* = 543)

	Duration of episode of care (days)[a]			
	Community	**Hospice inpatient**	**Hospital inpatient (advisory)**	**All settings**
Mean (SD)	52.67 (67.17)	25.31 (29.07)	18.38 (29.18)	36.48 (53.84)
Median (range)	26 (1–365)	15.5 (1–168)	10 (1–250)	17 (1–365)
Missing, *n*	24	3	4	35[b]

a Episodes of care starting and ending on the same day were counted as a duration of 1 day.
b Includes two episodes in 'other' setting and two episodes with no information on setting.

TABLE 8 Duration of first, second and third episodes of care, by episode (*N* = 543)

	Duration of episode of care (days)[a]			
	Episode 1 (*n* = 307)	**Episode 2 (*n* = 134)**	**Episode 3 (*n* = 102)**	**All (*n* = 543)**
Mean (SD)	41.18 (56.73)	34.86 (55.74)	28.24 (39.76)	36.48 (53.84)
Median (range)	20 (1–304)	15 (1–365)	16 (1–250)	17 (1–365)
Missing, *n*	23	3	9	35

a Episodes of care starting and ending on the same day were counted as a duration of 1 day.

Casemix variables
Details of the casemix variables are reported in *Table 9*. Apart from the dying Phase of Illness, the casemix variables extended across the full range of categories or scores.

Actual and predicted costs per day
Table 10 presents the actual costs per day, whereas *Table 11* compares the predicted class costs with the actual costs per day. The actual cost of inpatient hospice care are consistently higher than the predicted class cost, perhaps because of the 2-year interval between the collection of costs for workstreams 3 and 4 (no uplift was applied) or possibly because of improvements in the application of our costing methodology (the same costing methodology was used in both workstreams, but the teams were more familiar with how to apply it).

Qualitative results

A total of 20 interviews with 26 participants were conducted. Participants' ages ranged from 36 to 91 years (mean 68 years). Of these 20 interviews, 14 were conducted with patients and family caregivers separately and six jointly.

Four main themes and various subthemes were identified from the data analysis.

Theme 1: uncertainty about the new care setting
Lack of information about the new setting of care and patients' uncertainty regarding their discharge plan predominated in interviews.

Many participants commented on the 'bad' timing of a transition in care setting (e.g. emergency admissions during out of hours) and uncertainty around access to care.

TABLE 9 First, second and third episodes of care: settings and casemix variables (*n* = 543)

Episode characteristics	Episodes, *n* (%)[a]
Setting of care	
Hospital advisory	139 (25.6)
Inpatient hospice	140 (25.8)
Community	264 (48.6)
Total	543 (100.0)
Palliative Phase of Illness at episode start	
Stable	193 (35.6)
Unstable	195 (35.9)
Deteriorating	148 (27.2)
Dying	0 (0.0)
Missing	7 (1.3)
AKPS score at episode start	
Mean (SD) [range]	53.5 (14.4) [20–90]
0–50	260 (47.9)
60–100	271 (49.8)
Missing	12 (2.3)
Modified Barthel Index score at episode start	
Mean (SD) [range]	15.00 (5.2) [1–20]
Missing	16 (2.9)
PCPSS at episode start	
Pain	
Mean score (SD) [range]	1.52 (1.06) [0–3]
Absent	118 (21.8)
Mild	140 (25.7)
Moderate	162 (29.8)
Severe	118 (21.8)
Missing	5 (0.9)
Other physical symptoms	
Mean score (SD) [range]	1.03 (0.63) [0–3]
Absent	83 (15.2)
Mild	358 (66.0)
Moderate	80 (14.7)
Severe	12 (2.2)
Missing	10 (1.9)
	continued

TABLE 9 First, second and third episodes of care: settings and casemix variables (*n* = 543) (*continued*)

Episode characteristics	Episodes, *n* (%)[a]
Psychological symptoms	
Mean score (SD) [range]	1.62 (0.88) [0–3]
Absent	49 (9.0)
Mild	186 (34.3)
Moderate	186 (34.3)
Severe	91 (16.7)
Missing	31 (5.7)
Family concerns	
Mean score (SD) [range]	2.03 (0.99) [0–3]
Absent	53 (9.8)
Mild	70 (12.9)
Moderate	169 (31.1)
Severe	192 (35.3)
Missing	59 (10.9)

a Costs are derived from the first three episodes of care.

TABLE 10 Actual cost per day and length of episodes of care, in Great British pounds and days

Setting of care	n	%	
Hospital advisory	139	25.6	
Inpatient hospice	140	25.8	
Community	264	48.6	
Total	543	100.0	
	Mean (SD)	**Median**	
Hospital advisory			
Cost per day (£)[a]	50.83 (10.88)	51.45 (38.17–57.84)	
Length of episode (days)	18.38 (29.18)	10 (5.5–15)	
Inpatient hospice			
Cost per day (£)[a]	602.02 (257.73)	699.61 (536.90–772.66)	
Length of episode (days)	25.31 (29.07)	15.5 (7.75–24.25)	
Community			
Cost per day (£)[a]	34.56 (8.22)	32.83 (25.75–40.79)	
Length of episode (days)	52.67 (67.17)	26 (23–207)	

a Costs are derived from the first three episodes of care.

TABLE 11 Actual and predicted cost of episode by casemix class (all costs are per day)

Class	Living situation	Pain	Functional status	Palliative phase of illness	Family distress	Physical symptoms other than pain	Psychological symptoms	Sex	Predicted class cost (£)	Actual cost (£), median
Classes for hospital advisory episodes of care										
A	Lives alone	–	–	–	–	–	–	–	85	86.44 (75.99–88.94)
B	Does not live alone	Absent or mild	–	Unstable or dying	–	–	–	–	75	76.87 (70.99–86.33)
C	Does not live alone	Absent or mild	AKPS ≥ 40%	Stable or deteriorating	–	–	–	–	60	62.12 (53.79–73.61)
D	Does not live alone	Absent or mild	AKPS ≤ 30%	Stable or deteriorating	–	–	–	–	74	78.22 (70.72–84.51)
E	Does not live alone	Moderate or severe	–	–	–	–	–	Female	95	96.55 (89.68–98.44)
F	Does not live alone	Moderate or severe	–	Stable, deteriorating or dying	–	–	–	Male	76	74.47 (69.01–80.37)
G	Does not live alone	Moderate or severe	–	Unstable	–	–	–	Male	80	81.55 (69.87–89.99)
Classes for inpatient hospice episodes of care										
A	–	Absent, mild or moderate	–	–	Absent or mild	–	–	–	496	597.18 (531.80–642.03)
B	–	Absent, mild or moderate	–	–	Moderate or severe	–	Absent or mild	–	648	–
C	–	Absent, mild or moderate	–	–	Moderate or severe	–	Moderate or severe	–	965	1003.67 (931.49–1088.67)
D	–	Severe	–	Unstable or deteriorating	–	–	–	–	657	757.07 (710.46–823.62)
E	–	Severe	–	Stable or dying	–	Absent, mild or moderate	–	–	214	351.34 (279.67–386.68)
F	–	Severe	–	Stable or dying	–	Severe	–	–	624	–

TABLE 11 Actual and predicted cost of episode by casemix class (all costs are per day) (*continued*)

Class	Living situation	Pain	Functional status	Palliative phase of illness	Family distress	Physical symptoms other than pain	Psychological symptoms	Sex	Predicted class cost (£)	Actual cost (£), median
Classes for community episodes of care										
A	–	–	–	Stable	Absent or mild	–	–	–	20	24.80 (21.76–30.56)
B	–	–	–	Stable	Moderate or severe	–	–	–	24	25.82 (24.88–28.96)
C	–	–	AKPS ≤ 20%	Unstable, deterio-rating or dying	–	–	–	–	56	–
D	–	–	AKPS ≥ 30%	Unstable, deterio-rating or dying	–	Absent or mild	–	–	27	29.57 (27.92–31.33)
E	–	–	AKPS ≥ 30%	Unstable, deterio-rating or dying	Absent or mild	Moderate or severe	–	–	27	26.90 (25.66–28.92)
F	–	–	AKPS ≥ 30%	Unstable, deterio-rating or dying	Moderate or severe	Moderate or severe	–	–	40	40.17 (38.67–41.67)

Classes are labelled alphabetically with letters to indicate that they are in no specific numerical order.

Participants highlighted the fact that clear and effective communication is as important as the quality of care delivered; receiving the right information in the right place at the right time helped them to gain a better understanding of their health status and care plan, which reduced their anxiety and worries.

Theme 2: biographical disruption

Sense of identity was considered important but participants felt that transitions often compromised one's sense of self, which linked to an inevitable loss of control and independence.

Theme 3: importance of continuity of care

Both family and patients praised clinicians who provided continuity and got to know them as individuals. They appreciated not having to retell their stories and recognised the difference in care when staff knew them and their stories.

Participants highlighted the importance of the correct and timely transfer of patient information, medical notes and medication prescriptions; when things were disjointed, patients and their families felt unsafe and that lack of continuity could lead to medical mistakes.

Theme 4: need for emotional and practical support

Family members often act as advocates in the healthcare setting and the majority of participants specified a great need for support from family and friends not only in practical matters, such as arranging transport or coordinating care, but also in the emotional aspect of transitions in care.

Patient and public involvement

Over the course of the programme we have followed our plan for PPI at three levels, as originally proposed:

> through our dedicated C-CHANGE PPI group
> through patient/carer participation in the Programme Steering Committee
> through engagement with a wider Consumer Panel at the Cicely Saunders Institute, King's College London, where the research team is based.

The C-CHANGE Patient and Public Involvement Group

Throughout the programme, we have been strongly supported by a committed and active C-CHANGE PPI Group. Initially this consisted of four members, then expanded to seven members from 2015. The Group supported the work of the programme in a variety of ways: through regular face-to-face quarterly meetings; through Skype (Microsoft Corporation, Redmond, WA, USA) and e-mail consultations about specific elements of the work; through contributing to test surveys and interviews prior to data collection from patient participants in our studies; through the attendance of one or two delegated members at Ethics Review meetings; and through the active involvement of the whole group in providing invaluable feedback on the extent to which our work was patient and family centred (or not), and the effectiveness of the programme in delivering relevant evidence.

The PPI group sought to widen and improve its ethnic diversity, and this was addressed by recruiting six new members from diverse ethnic backgrounds from October 2015 onwards. The group changed again in the final year of the programme when two members chose to leave owing to deteriorating health. The group was kept informed of the programme and provided advice through regular contact by telephone, e-mail and Skype, and in face-to-face meetings: the Group has been an integral part of the team. There were also numerous individual or smaller group meetings by telephone and Skype, and at home (according to preference and to accommodate those less well). Payment for involvement and related expenses were in accordance with the recommendations of the NIHR.

Engagement with the Consumer Panel

We also worked with a more diverse group, the Consumer Panel (a network of patients, families and the public developed and sustained at the Cicely Saunders Institute; see Brighton *et al.*[95] for further details), which enabled engagement with a wider and more diverse group constituency. The following individuals and organisations especially contributed in this respect: Carolyn Morris and Kirstie Newson (who worked with us on our Dissemination and Engagement Group at the Cicely Saunders Institute); our Macmillan Information & Support Centre (which was located in the Cicely Saunders Institute, provided information and support to patients and public, and hosted several patient/family support groups who were able to contribute); and Hospice UK (London, UK) (a national organisation which supports palliative care providers).

We engaged with the Consumer Panel throughout the programme, largely by phone, Skype and e-mail but also through several smaller face-to-face group meetings (according to need) to discuss issues that emerged. The focus of our work with the Consumer Panel was on considering and discussing individual measures, considering which measures could be used together, how the measures met the priorities and domains of concern of patients/families with advanced illness, how the measures work both individually and together for this population, and how a casemix classification might best support good quality care and reduce inequities in access and care. Through the Consumer Panel we were able to test the training materials for the use of measures, and review and refine participant and other materials for workstreams 3 and 4. The Consumer Panel was kept informed through our quarterly newsletter,

although we also met with a number of individuals on the Consumer Panel for specific pieces of work, as the programme required.

Patient participation in the Programme Steering Committee

Mr Jonathan Hope and Mrs Sue Farr (co-leads for PPI) regularly attended the meetings of the C-CHANGE Programme Steering Committee, where they were updated on the programme's progress, provided feedback from the PPI group, informed the planning of next steps, addressed challenges that arose and helped the committee to better consider patient and family perspectives. We owe them both a great debt for their wisdom, their contributions, their ability to challenge us, and the insight they brought from extensive experience of both serious illness and providing care.

Innovation and evolution in our patient and public involvement and engagement

Patient and public involvement in palliative care is challenging because of the severity of illness and short survival time of those affected (some of our PPI partners, for example, were very seriously ill), the substantial caring demands on families, and the impact of bereavement often experienced. However, we linked to Collaborations for Leadership in Applied Health Research and Care (CLAHRC) South London to help us develop and sustain a sufficient 'critical mass' within the C-CHANGE PPI group to support effective PPI engagement over the years of the programme.

In addition to the PPI described above, over the course of the programme we held three PPI workshops across the Cicely Saunders Institute (14/06/2016, 15/11/2016 and 10/04/2017) to improve the quality and relevance of the research and maximise its impact on improving care. Both the C-CHANGE researchers and our PPI C-CHANGE group members were actively involved and engaged in this work. These workshops focused on increasing dialogue and collaboration, listening to our PPI partners, facing challenges, and seeking ideas and solutions together.

Impact of patient and public involvement to date

Involvement in identifying the research topic, prioritising the research questions and preparing the application

Patients and the public contributed to (1) the prioritisation of the research topic and questions, (2) the development of the research design and (3) the preparation of the application. The research topic was identified and prioritised with the involvement of the Consumer Panel of the National Cancer Research Institute collaborative in supportive and palliative care as part of our Programme Development Grant bid. There was universal agreement from our patient and public partners that patient and family needs towards end of life are often poorly matched to resources, leading to inequity and, for some, major gaps in provision.

We made changes to the protocols and ethics submissions as a result of PPI feedback. In addition, we had encouragement from our PPI partners throughout, which was very supportive of the team.

Developing and refining research resources (i.e. participant information sheets and topic guides)

All patient-facing materials within the programme were reviewed, amended and/or written by our PPI group.

In workstream 2, the PPI group recommended that certain groups were represented within the stakeholders' interviews (e.g. spiritual leads and social workers) to diversify the sample. Workstream 2 was extended to include patient and family stakeholders on the recommendations of our PPI group and with agreement from our Programme Steering Committee. We therefore increased the number of interviews from the planned 40–50 to 65. This allowed us to identify the most important domains for patients and carers across a range of diagnoses and backgrounds and ensure they were captured in workstreams 3 and 4.

We continued to engage with and consult members of our PPI group on the design and data collection for workstreams 3 and 4. This included enlisting support for drafting the questionnaires, developing the interview topic guide and refining our methods for collecting data. The PPI group suggested that we shorten the patient questionnaires to reduce overall research burden and we have had direct discussion on how best to do this.

Modification of research plans

As a consequence of PPI feedback, carer questions were added to workstreams 3 and 4 to further assess the strain or burden for the main family caregiver of caring for their relative. This question was derived from the Zarit Carer Interview.[96] The PPI group also suggested that we include a question to measure whether or not the care received is sensitive to religious beliefs and cultural needs, based on their own direct experiences of caring for family members at the end of life. The PPI group encouraged the team to include pre- and post-bereavement written materials for patients, families and carers, especially regarding the needs of bereaved carers.

Secondary analysis on complexity

We were urged to further consider the role of uncertainty in the complexity of care and domains relevant for patients and families. As a result of this dialogue, a secondary analysis was conducted that examined the main priorities and concerns of patients and carers in advanced illness and how uncertainty shaped their experience. This work was published in *Palliative Medicine* in 2017.[78]

Dissemination

As a way to disseminate the C-CHANGE project and the PPI work, our PPI group developed a video diary, taking a 'reflections and responses' approach. The aim was to capture PPI perspectives on video and enable the research team to consider and respond to the evolution of the research. In total, our PPI group, alongside a C-CHANGE researcher, produced six videos (see *Table 12*). The process for creating the videos was as follows:

> The PPI group suggested a topic for a video log.
> A PPI member co-wrote a script with a C-CHANGE researcher.
> A PPI member and C-CHANGE researcher edited and refined the script and filmed the video.
> The PPI member and/or group provided feedback on how best to edit the video.

The main topics raised in the videos comprised: (1) identifying different cultural needs, (2) the individual concerns of people with advanced illness, (3) capturing emotional distress, (4) thinking about goal-based outcomes, (5) the experiences of patients alone and (6) the safety of patients and their family members.

TABLE 12 C-CHANGE short videos to capture the impact of PPI

Video title	URL
The C-CHANGE research project: A Carer's Experience – How can we improve coordination of care? 1/3	https://youtu.be/RnOYg0myU0M
The C-CHANGE project: A Carer's Experience – Supporting families when the news is difficult 2/3	https://youtu.be/v_NxKMlGNgc
The C-CHANGE research project: A Carer's Experience – Bereavement care 3/3	https://youtu.be/0Bt67hIOHMc
How are patients' needs supported by C-CHANGE?	https://youtu.be/SFuArqcpkEU
Patient and Public Involvement impact on developing study questionnaires	https://youtu.be/Ho87sRWn-Xg
How the C-CHANGE project responds to patient distress	https://www.youtube.com/watch?v=1-6Po1aeOuA

Contribution to dissemination documents (i.e. lay summaries and newsletters)
Throughout the course of the programme, we enlisted the help of our PPI members to provide feedback on lay summaries of our published academic papers. In addition, the PPI group contributed to and reviewed quarterly C-CHANGE newsletters that have been circulated to research sites, local community groups and organisations of interest.

Summary

Throughout the programme we attempted to achieve a careful balance between incorporating and reflecting the invaluable insights from our PPI group, which we were very keen to adopt, and yet working within the constraints of our existing timelines and resources. The Programme Steering Committee was very helpful in advising on this and we believe we successfully achieved this balance.

Successes and limitations in the C-CHANGE programme

One of our major successes in workstream 1 was the refinement and validation of the IPOS. This represents a major step forward internationally for palliative care outcome measurement, for several reasons. First, we have demonstrated that this is a valid and reliable outcome measure, both in patient self-report and staff proxy-report versions. There are very few measures to assess well-being and health status in advanced illness which include both patient-report and proxy-report versions, with detailed evidence on how these correlate.[73] Proxy-report is often required in palliative care as patients become too ill or fatigued to self-report. Second, although there are pre-existing psychometrically robust symptom measures (such as the Edmonton Symptom Assessment Scale[97] and the Memorial Symptom Assessment Scale[98]) and quality of life measures (such as EORTC QLQ-C15-PAL[77,99]) for palliative care, there are no measures for advanced illness which capture the full range of symptoms/concerns which affect people with advanced illness. The IPOS reflects not just their physical or psychological symptoms, but also their information needs, family distress and support needs, and practical concerns. Third, our IPOS validation study included a high proportion of people with poor functional status, strengthening our conclusions for the advanced illness population. These are often the most difficult participants to recruit into studies, but our close working with participating sites helped to maximise recruitment and ensure that we included participants across the full range of functional status.

The IPOS is now freely available on our measures webpage: https://pos-pal.org/. It is already widely used both nationally and internationally; we have a network of UK-based palliative care services who link into an Extension of Community Healthcare Outcomes (ECHO) webinar network hosted by Hospice UK to support implementation and use, and there are already 12 translated versions of the IPOS (following our manual for translation and cultural adaption) in Czech, Estonian, French, German, Greek, Hindi, Italian, Korean, Polish, Portuguese, Swedish and Turkish, for use both in the UK and internationally. At least seven further translations are in process.

In addition, we were able to complete further work on the palliative Phase of Illness measure during Workstream 1, which was essential for the later casemix work. Preliminary work in the UK[100] and Australia[59] had suggested that palliative Phase of Illness is important in determining casemix within palliative care. However, little psychometric or clinical testing had been undertaken; we were able to show that Phase of Illness has clinical utility as a measure of overall palliative need, capturing additional information beyond other measures such as the AKPS and PCPSS.[74] A limitation of this work was that we did not have any scope to analyse how Phase of Illness and the IPOS relate to each other; it was too early in validation of the IPOS to use the measure in this preliminary work. Nevertheless, our work confirmed the importance of including palliative Phase of Illness in workstreams 3 and 4 and that it reflected a distinct (and different) dimension of palliative care needs.

A further achievement was being able to derive and test a patient experience measure. VoC is brief and easy to use on a large scale with patients receiving palliative care across different settings.[75] Patient, PPI and clinical feedback on this measure has been good; it has been clinically adopted across a range of palliative care services (e.g. St Christopher's Hospice) and it too is freely available at https://pos-pal.org/.

Through discussion with our PPI group, it became much clearer to us how uncertainty influences patient experience during advanced illness by affecting patients' information needs, preferences and future priorities for care. Assessment of these three factors is a useful starting point to guide clinical assessment and shared decision-making, and we considered how to include them in workstreams 3 and 4. However, it proved difficult to incorporate these findings into workstreams 3 and 4; this work was already complicated, and finding a workable way to add this dimension to our data capture (such that it would help inform the casemix classification) proved unfeasible.

In workstream 2, we conducted and analysed a large number and diverse range of interviews exploring stakeholders' perspectives on measuring complexity. A major success from this workstream was the production of a novel framework for understanding complexity in palliative care. The findings from this piece of work were very well received by clinicians and researchers working in palliative care. The Field-Weighted Citation Impact in Scopus (Elsevier, Amsterdam, the Netherlands) is already 4.16 (as of 1 August 2020), indicating 316% more citations than average for the field.

We had several challenges with recruitment in workstream 2, particularly with recruiting a representative sample of the various stakeholder groups, but we overcame these to achieve a balanced sample by approaching additional sites and participants. Our study was able to represent views from stakeholder groups that are usually under-represented in complexity research, including patients and families, allied health professionals and national leads. To develop a well-integrated and meaningful theoretical framework to understand complexity, we presented the findings to internal and external experts at different stages of our data analysis. This meant going through several iterations to develop and refine a comprehensive and meaningful framework. Although this required more time and effort, the resulting output was a more integrated and useful framework to describe complexity in palliative care. In terms of informing workstreams 3 and 4, this work was invaluable in helping to ensure we measured psychological symptoms, social concerns, information needs (reported as highly relevant for pre-existing complexity), and practical concerns were identified.

Our work on models of specialist palliative care was, to the best of our knowledge, one of the first attempts at deriving empirical criteria to distinguish different specialist palliative care models. Using mixed methods in a sequential approach, we developed a set of criteria from these primary data to characterise and distinguish different specialist palliative care services in the UK. These criteria comprised setting, type of care, size of service, diagnoses accepted, disciplines, mode of care, types of interventions, out-of-hours characteristics, external education provision, use of outcome/experience measures, and bereavement provision, plus the purpose of the team, who funds/manages the team, ability to self-refer and discharge processes. These criteria capture the key differentiating components between different models of specialist palliative care across settings (i.e. hospice inpatient care, hospital-based care and community-based care) and, to our knowledge, enable these different models of care to be described and compared accurately for clinical and commissioning purposes for the first time. This study also provides the foundational work for improved research on which components of a model of care are most effective. A strength of this work is that it sought expert consensus from 'real world' professionals to identify the key criteria to characterise and differentiate these highly varied models of specialist palliative care.[81] Our criteria, taken together, provide a defined and workable way to characterise and distinguish different models of specialist palliative care. These criteria are not exhaustive and they are not intended to be; however, they do help to discriminate between different models. We recognise that they do not reflect all models of palliative care across England but they provide a starting point in terms of evidence on which to build. In recent years, and particularly since this programme began, there has been a growing number of different models of palliative care developing,[101–103] especially in community settings;[104] distinguishing them in both practice and research is important.

In workstreams 3 and 4 we have for the first time, to our knowledge, demonstrated robustly which casemix variables are associated with higher or lower costs for specialist palliative care across different settings of care, and tested these classes. A casemix classification was developed for each of the three settings: hospital advisory, inpatient hospice and community specialist palliative care. Casemix classes are presented in the casemix classification and are based on the clinical criteria of pain, other physical symptoms, psychological symptoms, family distress, palliative Phase of Illness, functional status and living situation. This is a major achievement. Some work was previously undertaken on this by NHS England and Public Health England using similar casemix criteria,[58] but there was limited evidence of how the classes were derived, and classification and regression tree analyses were not applied.

In our work on the casemix classification, it became clear that each participating site had very different models of care. A challenge was attempting to use the multiple criteria meaningfully in the work to develop the casemix classification. There were too many models of care and too many variables to describe them for any attempt to stratify or adjust for the different models. To some extent, we allowed for differing models of care in our sample size calculation (and we achieved our sample size), but the wide range of different models of care we encountered across participating sites was unexpected. When fitting 'site' as a variable into the CARTs to explain costs for inpatient hospice and community episodes of specialist palliative care, we found that site (as a proxy variable for model of care) explained a notable amount of variance in the outcome and more than the patient-level complexity factors. In all settings, there seemed to be a clustering of sites offering more traditional models of care versus sites with innovative/new care models. Owing to the limit on the number of sites per model of care in our design, however, we did not explore this independent variable in the trees and deliberately restricted the CART to patient–level complexity levels only. In some ways, this was helpful; the casemix classification is derived from patient-level variables alone; it is not the model of care which dictates the casemix class. However, clearly the model of specialist palliative care delivered does – at some level – influence costs. We need far more evidence about which models of care (when properly characterised) are most cost-effective.

Lastly, two factors had a major impact on the completion of the final report and the preparation of the remaining two main papers for publication; the Chief Investigator left the programme to take up a new position – with a part-time transition period during 2018 and 2019 – and the COVID-19 pandemic interrupted and severely delayed the completion of this report.

Conclusions

In workstream 1, we were able to refine, validate and test new and existing patient-centred outcome measures to assess the main symptoms and concerns of patients and families receiving specialist palliative care, for use in workstreams 3 and 4. In addition – at the request of our PPI group – we completed a secondary analysis of existing qualitative data to understand the role of uncertainty in assessing the care needs of patients and families with advanced progressive illness.

The IPOS is a valid and reliable outcome measure, both in its patient self-report and staff proxy-report versions.[73] It can assess and monitor symptoms and concerns in advanced illness, determine the impact of healthcare interventions and demonstrate quality of care. This represents a major step forward internationally for palliative care outcome measurement.[73]

We demonstrated that palliative Phase of Illness has value as a clinical measure of overall palliative need, capturing additional information beyond the AKPS and PCPSS. In addition, we have shown that VoC (a measure of quality of life and experience of care) is brief and easy to use on a large scale with patients receiving palliative care across different settings. It is brief and easy enough to use for ill patients receiving palliative care, which, to the best of our knowledge, makes VoC uniquely able to provide patient-level feedback in real time when compared with the institutional-level indicators that are often used to assess the quality of healthcare services.

Uncertainty influences patient experience in advanced illness through affecting patients' information needs, preferences and future priorities for care.[78] Our typology aids understanding of how patients with advanced illness respond to uncertainty. Assessment of these three factors may be a useful starting point to guide clinical assessment and shared decision-making.

To the best of our knowledge, workstream 2 provided for the first time in palliative care a structured and evidence-based framework to conceptualise and consider the complex palliative care needs of those with advanced illness and their families. It also enabled us to characterise more fully what needed to be measured for workstreams 3 and 4 (the development of the casemix classification). Overall, participants reported that they thought it acceptable to measure complexity at the individual patient-level, but that any system to do so needed to incorporate the key dimensions of complexity included in the framework.

To our knowledge, until now there has not been a clear set of criteria to define models of UK specialist palliative care, making it challenging to compare different models of care provided by services. This component of the programme identified the criteria needed to characterise and differentiate models of specialist palliative care, a major paradigm shift to enable accurate reporting and comparison in practice and research.

Our detailed evidence on specialist palliative care costs and our casemix classification for specialist palliative care deliver a major advance for the sector. Each person needing specialist palliative care is different, with varying degrees of complex needs. We now have the means to understand this, systematically and at scale, and for practice, policy (including resourcing of palliative care) and research. The casemix classes show cost weight variations of up to 60% in hospital advisory care, up to 4.5-fold in inpatient hospices, and up to almost threefold in community care. The needs of each person are varied – not fixed – and require different resources to deliver care effectively. Understanding the casemix of those needing care, how this affects what outcomes can be achieved, how this varies across services and regions, and how this changes over time has the potential to help address inequities and provide more equitable specialist palliative care to all who need it.

Finally, our exploration of the impact of transitions between settings of care has clearly highlighted the human cost of poor communication and information-giving, the sometimes lack of continuity of care and the need for emotional and practical support for patients and families to ensure that moves between settings are better negotiated.

Recommendations for future research

The research recommendations from this programme fall into three areas: (1) research recommendations about the measures themselves, (2) research recommendations on the models of palliative care and (3) research recommendations about the casemix classification.

Research recommendations about the measures

Implementation research using the IPOS – particularly on the best ways to implement it into clinical services and how to assess which is the best version for use (patient-reported or proxy-reported) – is much needed. Some of this research has been subsequently undertaken[105] and more research is already in process (see Bradshaw et al.[106] and www.hyms.ac.uk/research/research-centres-and-groups/wolfson/resolve).

In addition, the IPOS needs to be adapted for specific advanced disease populations, for example those with end-stage kidney disease[107] and heart failure[108] – this work is developing rapidly.

Research recommendations about the models of palliative care

Our theoretical framework to understand the complexity of palliative care needs is a useful advance for both clinical practice and research, but we need to study more fully certain aspects of complexity within the exo-system (services/systems) and macro-system (societal influences). These areas are much less studied than the micro- and meso-levels, and yet they are crucial if integrated care (i.e. care that cuts across service and community boundaries) is to become a reality. It is important to determine and explore socioeconomic status, and how this affects palliative care needs. 'Cumulative' and 'invisible' complexity may interact with socioeconomic status and so influence some of the known inequities in provision according to socioeconomic position.[109]

The research on models of care needs to be extended and externally validated beyond the C-CHANGE sites, which – by nature of their willingness to participate – may not reflect all models of specialist palliative care.

Although a systematic review of the components of models of palliative care has been undertaken,[110] it is not yet clear which components are used in different models of care, let alone whether or not they are clinically effective and cost-effective. Brereton et al.[111] identified the importance of defining and describing the components of models of care to differentiate them in both practice and research, and to truly understand clinical effectiveness and cost-effectiveness. We have progressed work on defining models of care (see *Workstream 2: models of specialist palliative care*),[81] but much more is needed. There is also a major need to understand how primary and community services work with specialist palliative care; some of our data suggested that specialist palliative care models were significantly adapted according to the primary- and community-based services for end-of-life care available, and especially in relation to COVID-19.

Research recommendations about the casemix classification

The casemix classification for specialist palliative care provides a standard way to measure complexity of needs, enable services to compare workload between teams and determine whether or not outcomes are achieved as expected for different levels of complexity. The classification could also – if used

judiciously – allow teams and services to make a better case for sufficient resources, and – in the longer term – support casemix-adjusted outcome measurement. There are a range of implications for research.

First, these casemix classes should be applied within research studies to better characterise study populations and therefore improve understanding of generalisability of research findings.

Second, whether or not these casemix classes work across the full range of non-cancer conditions should be tested, especially as the proportion of people with multiple long-term conditions increases.

Third, further research should determine how these casemix classes hold over time as the population age distribution changes and the patterns of end-of-life conditions changes. The classes developed within this programme are similar to those developed in the UK by the Palliative Care Funding Pilots[58] and to the Australian casemix classification,[57] with some of the same criteria found to predict variance in resource use, notably symptoms, palliative Phase of Illness, functional status and family distress. The combination of criteria within each class is, however, somewhat different in this programme than in these earlier studies. These differences may reflect a changing palliative care population since the Australian classification and UK Funding Pilots were completed. The proportion of those with non-cancer conditions receiving specialist palliative care, for instance, is increasing steadily[112] and 20% of participants recruited had non-cancer conditions to reflect this change.

Fourth, it is important that these casemix classes and related costs are tested across a wider range of NHS and non-NHS services. This study provides reasonably current patient-level cost data for episodes of specialist palliative care. NHS unit costs for specialist palliative care do exist,[113] but their reliability is unclear and they do not reflect non-NHS services (which includes most specialist palliative care in the UK). A recent systematic review of the cost of UK palliative care[114] found very limited cost evidence (only 10 studies over 20 years), with most studies combining estimates of resource use with potentially unreliable unit cost data. Compared with the 2018 NHS unit costs collected in 2017[113] (i.e. at the same time as the collection of cost data for this study), we found actual costs of specialist palliative care – at least in hospital and community settings – to be lower: hospital advisory care cost an average of £73 per day (compared with £201 in NHS unit costs[113]), and community care was £36 per day (compared with the unit cost for a specialist nurse of £64[113]). In part, this may reflect the challenges of collecting accurate cost data, particularly in community settings, but it may also reflect the range of staff providing care and the frequency of visits (i.e. less visits under cost constraints leading to reduced costs per day). Models of specialist palliative care are also increasingly diverse,[81] especially in the community,[110] and workforce shortages are leading to new models, for instance with senior staff supporting less experienced staff with skilled work, a reduced frequency of visits and new models for older people with multimorbidity.[100] By contrast, we found that at an average of £716 per day, inpatient palliative care was notably more costly than the 2018 unit cost of £404 per day;[113] this may reflect the increasingly complex needs of those needing inpatient specialist palliative care.

Implications for decision-makers

Our theoretical framework developed in workstream 2 provides a structured and comprehensive way of considering complexity in palliative care. This understanding of complexity can help move both clinicians and policy-makers towards a more meaningful response to complexity, highlighting as it does the need for services to move away from 'standard' and 'one size fits all' care, and towards more individualised and tailored delivery.

Stakeholders – including decision-makers – highlighted the importance of having a shared understanding of complexity across different specialist palliative care providers and settings. Frameworks that accurately capture patient-level complexity can allow us to communicate the specialist palliative care provider role more clearly to other specialists and generalists providing palliative care to patients and families.

An important consideration is that these criteria should not be used to inform a 'baseline' level of specialist palliative care service; by the very nature of this study, we have identified criteria which differentiate between existing models. It follows therefore, that – inevitably – some specialist palliative care services will provide some elements and not others; this is to be expected, given the purpose and methodology of our work. Other characteristics, such as holistic care, training in specialist palliative care and the use of multidisciplinary teams in delivery of care, are considered to be 'core' to the definition of specialist palliative care[11] and so are not included in these differentiating criteria.

The casemix classes enable providers of specialist palliative care to determine the likely resources needed for care, at the individual patient level. If the specified criteria are measured and combined into these classes at the start of an episode of care, they provide systematic insight into the level of complexity of needs and the probable resources required to meet those needs. The Pricing Team at NHS England and Improvement are currently working on a Community Currency Development Project, work somewhat delayed by the COVID-19 pandemic, and propose introducing a currency for last year of life (www.england.nhs.uk/pay-syst/development/palliative-care-development-currency/; accessed 21 August 2023). This work will help inform this project.

Managers and senior leads should reconsider communication and information-giving in relation to transitions, in particular what information and preparation is provided when and in how much detail. Continuity of care and emotional and practical support for patients and families as they make necessary transitions between settings needs to be well resourced to prevent future distress and difficulties.

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Contributions of authors

Fliss EM Murtagh (https://orcid.org/0000-0003-1289-3726) was the joint lead investigator. She wrote the study protocols, analysed the quantitative data, undertook the qualitative data analyses and drafted the report manuscript. They contributed to the analysis plan and provided critical revision of the manuscript for important intellectual content. Fliss Murtagh is the guarantor of the data.

Ping Guo (https://orcid.org/0000-0003-0979-7047) wrote the study protocols, liaised with sites, undertook data collection and undertook the qualitative data analyses. They contributed to the analysis plan and provided critical revision of the manuscript for important intellectual content.

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Data-sharing statement

Access to anonymised data may be granted following review. In particular, applications for the use of workstream 3 and workstream 4 data will be considered on a case-by-case basis. All requests for data access should be addressed to the corresponding author, Fliss Murtagh, at fliss.murtagh@hyms.ac.uk.

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Appendix 1 Measures

*T*able 13 provides details of the measures used in workstreams 3 and 4.

The Integrated Palliative care Outcome Scale

The IPOS is a person-centred assessment and outcome measure for palliative care (for the full measure, see https://pos-pal.org/).

The IPOS questionnaire measures the symptomatic, psychological and spiritual needs of palliative care patients over 3 or 7 days in a variety of care settings. There are currently four different versions of the IPOS measure, which have been designed for use by staff and patients in different settings:

TABLE 13 Workstreams 3 and 4 study measures for data collection

Measure	Details of measure	Background, validation and source
Palliative Phase of Illness	A single staff-reported item collected daily (inpatient hospice or hospital) or at each contact (community) to provide the context of the current palliative Phase of Illness, with five categories: stable, unstable, deteriorating, dying and deceased	Palliative Phase of Illness categorises seriously ill patients according to the urgency of the care plan to address palliative care needs, and has been used in the Australian casemix classification. It shows good inter-rater reliability and clinical utility in populations with advanced progressive illness[59,100]
AKPS	A single score between 0% and 100% (in 10% increments) based on a patient's ability to perform common tasks relating to activity, work and self-care. A score of 10% signfies the patient is 'comatose or barely rousable, unable to care for self', whereas 100% signifies 'normal physical abilities with no evidence of disease'	The AKPS is based on the Karnofsky Performance Status, but is adapted for advanced illness. It has been validated in both cancer and non-cancer conditions[71]
Modified Barthel Index	The modified Barthel Index is a measure of a person's ability to perform 10 common activities of daily living relating to toileting, mobility and eating. Each item is scored 0, 1 or 2. A total score is produced by adding up the scores; the highest possible summary score is 20, indicating complete independence, and the lowest score is 0, indicating complete dependence	The Barthel Index of Activities of Daily Living was first developed by Mahoney and Barthel[115] as an index of independence to monitor improvement in the rehabilitation of patients with long term conditions. Wade and Collin[116] proposed a modified version that includes the original items but with a simplified scoring system
IPOS	The IPOS combines the items from the Palliative care Outcome Scale (POS) and those from its symptom module Palliative care Outcome Scale-symptom module (POS-S) into one integrated measure. There are two versions of the IPOS: a patient self-reported and staff proxy-reported version. Both consist of 17 scorable items on physical, psychological, spiritual problems, communication needs including with family, and practical support, scored on a 5-point Likert scale from 0 (best) to 4 (worst). The IPOS total score ranges from 0–68 and is an overall measure of how symptoms and concerns are affecting the individual. The full IPOS measure is available at https://pos-pal.org; see *The Integrated Palliative care Outcome Scale* for additional information	The original POS included 10 items covering the domains most important to patients with advanced illness.[117] Following patient and staff feedback, a symptom module (POS-S) was added.[118] This was recently combined into the 19-item IPOS which is valid, reliable and responsive to change in a palliative care population.[73] The POS and IPOS have also been translated, culturally adapted and validated for use in a range of different languages and are widely used internationally[119,120]
PCPSS	The PCPSS has four items: pain, other symptoms, psychological/spiritual concerns and family/carer concerns. Each item is scored 0 (absent), 1 (mild), 2 (moderate) or 3 (severe)	PCPSS is used by the Australian Palliative Care Outcomes Collaborative,[121] and has been shown to have good reliability and acceptability[122]

POS, Palliative care Outcome Scale.

IPOS Patient version, 3-day recall period – for use by patients in inpatient settings
IPOS Patient version, 1-week recall period – for use by patients in community settings
IPOS Staff version, 3-day recall period – for use by staff in inpatient settings
IPOS Staff version, 1-week recall period – for use by staff in community settings.

This clinical and research measure supports the assessment of the physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs of patients in a hospice, at home, in hospital and in other community settings. When repeated, it provides individual-level outcomes data that reflect the most common symptoms and concerns reported by people with advanced illness.

The Integrated Palliative care Outcome Measure short version

For the full measure, see https://pos-pal.org.

The Integrated Palliative care Outcome Scale short version (IPOS-5) is a briefer version of the full IPOS. It contains the five items considered most important to patients and families (such as pain, breathlessness, anxiety and information needs) but that also relate to their healthcare provision (e.g. breathlessness is one of the commonest reasons for emergency admission[123]). It also includes the 'at peace' question, as this globally reflects psychological and existential domains across diverse backgrounds, cultures and beliefs.[124]

Owing to its shortened content, the IPOS-5 has increased the usability and adaptability of the IPOS while continuing to capture the needs and concerns that are most important to patients and families.

Views on Care measure
The VoC measure is an assessment of patient quality of life and experience of care (for the full measure, see https://pos-pal.org).

Views on Care focuses on the patient's quality of life and perceived impact of the palliative care service, and provides staff with an indication of whether or not they are having a positive impact on patients' lives.[125]

Appendix 2 Summary of casemix classification paper: developing a casemix classification for specialist palliative care – a multicentre cohort study to develop a multivariable prediction model for the cost of specialist palliative care using classification and regression tree analysis

Introduction

People with advanced illness suffer multiple physical and psychological symptoms, plus family/social concerns,[6,7] because of their illness and impending death.[3] Their families often provide day-to-day care, as well as being affected by their own distress and imminent losses.[126] These issues bring increased need for health services' support, which escalates in the weeks and months before death.[127] Palliative care needs – with 'need' defined as 'the ability to benefit' from care[128] – are met by a range of services. For individuals approaching the end of life and their families, the level and complexity of their palliative care needs vary widely, yet this complexity has rarely been quantified or measured. 'Casemix' is a method to classify patients with similar needs and/or resource consumption into clinically meaningful groups, using patient-level criteria. An Australian casemix classification for palliative care was developed in 1997,[88] empirically tested,[46] and progressively refined over time.[51,57] This classification consists of classes defined by patient factors including palliative Phase of Illness,[59] problem severity,[122] functional status,[71] and dependency.[46] However, it is unclear whether this classification can be directly applied in other countries. We therefore aimed to develop a casemix classification for UK specialist palliative care, for use across settings.

Methods

Design
We designed a multicentre prospective cohort study, following patients during episodes of specialist palliative care and reported according to the TRIPOD statement.[86] The study was registered with a International Standard Randomised Controlled Trial Number on 2 March 2017 (https://doi.org/10.1186/ISRCTN90752212).

Definitions
We defined an 'episode of care' as a 'period of contact between a patient and palliative care service provider or team of providers that occurs in one setting'.[87] We defined the 'setting of care' as: hospital advisory (specialist palliative care teams providing an advisory or consultation service within hospitals), inpatient hospice (patients admitted to a hospice or specialist palliative care unit for an overnight stay of one or more days) or community-based specialist palliative care (when the patient receives care in their usual place of residence, i.e. at home or in a care home).

TABLE 14 Casemix classification for specialist palliative care (all costs are costs per day)

Class	Living situation	Pain	Functional status	Palliative Phase of Illness	Family distress	Physical symptoms other than pain	Psychological symptoms	Sex	Class cost per day (£)	Cost weight[a]
Classes for hospital advisory episodes of care										
A	Lives alone	–	–	–	–	–	–	–	85	1.4
B	Does not live alone	Absent or mild	–	Unstable or dying	–	–	–	–	75	1.3
C	Does not live alone	Absent or mild	AKPS ≥ 40%	Stable or deteriorating	–	–	–	–	60	1.0
D	Does not live alone	Absent or mild	AKPS ≤ 30%	Stable or deteriorating	–	–	–	–	74	1.2
E	Does not live alone	Moderate or severe	–	–	–	–	–	Women	95	1.6
F	Does not live alone	Moderate or severe	–	Stable, deteriorating or dying	–	–	–	Men	76	1.3
G	Does not live alone	Moderate or severe	–	Unstable	–	–	–	Men	80	1.3
Classes for inpatient hospice episodes of care										
A	–	Absent, mild or moderate	–	–	Absent or mild	–	–	–	496	2.3
B	–	Absent, mild or moderate	–	–	Moderate or severe	–	Absent or mild	–	648	3.0
C	–	Absent, mild or moderate	–	–	Moderate or severe	–	Moderate or severe	–	965	4.5
D	–	Severe	–	Unstable or deteriorating	–	–	–	–	657	3.1
E	–	Severe	–	Stable or dying	–	Absent, mild or moderate	–	–	214	1.0
F	–	Severe	–	Stable or dying	–	Severe	–	–	624	2.9

TABLE 14 Casemix classification for specialist palliative care (all costs are costs per day) *(continued)*

Class	Living situation	Pain	Functional status	Palliative Phase of Illness	Family distress	Physical symptoms other than pain	Psychological symptoms	Sex	Class cost per day (£)	Cost weight[a]
Classes for community episodes of care										
A	–	–	–	Stable	Absent or mild	–	–	–	20	1.0
B	–	–	–	Stable	Moderate or severe	–	–	–	24	1.2
C	–	–	AKPS ≤ 20%	Unstable, deteriorating or dying	–	–	–	–	56	2.8
D	–	–	AKPS ≥ 30%	Unstable, deteriorating or dying	–	Absent or mild	–	–	27	1.4
E	–	–	AKPS ≥ 30%	Unstable, deteriorating or dying	Absent or mild	Moderate or severe	–	–	27	1.4
F	–	–	AKPS ≥ 30%	Unstable, deteriorating or dying	Moderate or severe	Moderate or severe	–	–	40	2.0

a The cost weight is relative to the lowest cost class (i.e. calculated as the ratio of the cost per day for that class to the cost per day of the lowest cost class).
Note Classes are labelled alphabetically with letters to indicate that they are in no specific numerical order.

Population and settings

Patients were recruited from 14 organisations providing specialist palliative care services in England: four hospital advisory services, five inpatient hospice services and seven community-based services (some organisations provided more than one setting of care). We included consecutive adult patients (≥ 18 years) receiving specialist palliative care at all participating sites. The exclusion criteria were being aged < 18 years, declining participation and/or previously expressing a wish not to participate in research.

Data collection and primary outcome

Collected data included demographic and clinical variables, episode start and end dates, potential casemix variables, and data on patient-level and other costs in providing specialist palliative care. Potential casemix variables were selected based on (1) being patient-level attributes and (2) prior evidence of association with casemix/complexity.[88] The key casemix variables included were age, sex, ethnicity, living circumstances, need for interpreter, primary diagnosis, palliative Phase of Illness, functional status, dependency and symptoms/problem severity. Our primary outcome was the cost of specialist palliative care per day, measured over an episode of care.

Sample size

Based on standard recommendations for fitting multivariate models, a minimum of $50 + 8 \times m$ cases for testing multiple correlation (where m is the number of predictors) were required to test the null hypothesis that the population multiple correlation equals zero with a power of 80%, α = 5% and a medium effect size for the regression analysis ($R^2 = 0.13$).[90,91] The unit of analysis was episodes within sites, therefore, 10 predictors required 130 episodes per site. Allowing an additional 15% for episodes with missing data and 20% for cost outliers, we estimated a target of 2674 episodes of care (191 episodes × 14 sites) was required.

Analysis

To discover which baseline casemix variables could predict the cost of that episode of care, the following steps were undertaken:

We removed incomplete episodes, retaining only the complete episodes of care.
Following a previously adopted approach,[88] high and low cost outliers were identified and removed using a trimming algorithm based on the interquartile range (IQR) with the upper trim point at Q3 + 1.5 IQR and the lower trim point at Q1 − 1.5 IQR (where Q1 is first quartile and Q3 is third quartile).[57]
We examined the distribution of costs of specialist palliative care by setting.
Following the same approach as in the development of the Australian casemix classification,[88] we developed and validated a cost-predictive model using CART analysis, which constructs decision rules in a hierarchical manner to form a branching classification.

Results

Subject characteristics

A total of 2469 patients were recruited, providing data on 2968 complete episodes of specialist palliative care (12 incomplete episodes were removed prior to analysis). Demographic and clinical characteristics of the 2469 participants, and details of the 2968 episodes of care and related casemix variables are reported in *Workstream 3: development of the casemix classification*, *Results*, with 767 episodes in the hospital advisory setting, 764 episodes in the inpatient hospice setting and 1437 episodes in the community setting.

Costs of specialist palliative care

The distribution of the total cost of specialist palliative care episodes, derived from the trimmed data set, is shown in *Table 3*; costs are reported (1) per day, (2) per day, broken down by Phase of Illness, and (3) by episode of care, together with details of length of episodes.

Classification and regression tree analysis

Seven different casemix variables provided the optimal combination to deliver classes in each of the settings. *Table 14* shows these variables and how they are combined to constitute the casemix classes, including cost weights.

Discussion

To our knowledge we have for the first time, and in different settings of care, demonstrated robustly which casemix variables are associated with higher or lower costs for specialist palliative care. A casemix classification was developed for each of the three settings: hospital advisory, inpatient hospice and community specialist palliative care.

These casemix classes enable providers of specialist palliative care to determine the likely resources needed for care, at the individual patient level. If the specified criteria are measured and combined into these classes at the start of an episode of care, they provide systematic insight into the level of complexity of needs and the probable resources required to meet those needs.

For instance, a patient receiving care from a hospital advisory palliative team is likely to need 40% more daily resources (largely staff time) if they live alone (compared with the lowest cost class), and between 30–60% more daily resources if they have moderate/severe pain. In contrast, within an inpatient hospice setting, a patient needs 4.5-fold more resources if there are moderate/severe psychological symptoms and moderate/severe family distress (again, as compared with the lowest cost class). Pain, other physical symptoms and Phase of Illness also drive costs in this setting, with unstable or deteriorating phase and severe pain plus severe other physical symptoms associated with threefold higher costs. In the community setting, almost threefold more resources are needed if the patient is in the unstable, deteriorating or dying phase with poor functional status (AKPS ≤ 20%). It is important to note that costs in the hospital advisory and community settings are simply the extra costs of the specialist palliative care (the costs of primary care and other community services are not included). In contrast, the inpatient hospice costs include all the costs of care, including the cost of occupying a hospice inpatient bed.

This study also provides reasonably current patient-level cost data for episodes of specialist palliative care. NHS unit costs for specialist palliative care do exist,[113] but their reliability is unclear and they do not reflect non-NHS services (which includes most specialist palliative care in the UK). A recent systematic review of the cost of UK palliative care[114] found very limited cost evidence (only 10 studies over 20 years), with most combining estimates of resource use with potentially unreliable unit cost data.

Some limitations need consideration. First, participating sites had different models of care; to some extent, we allowed for this in our sample size and in oversampling community episodes, where there is the greatest diversity of models of care. Second, the casemix variables accounted for a limited amount of variance in costs when using a bias-corrected bootstrapped estimation of R^2 values in all three settings. This is perhaps unsurprising, given that patient-level variables explain only an additional amount of variance over the total length of an episode. The number of days of each episode of care is the bigger determinant of the overall cost of the episode of care, hence our focus on costs per day and the acknowledged need for blended payment models (which combine per day, per episode and outcome-based elements).[129,130]

Conclusions

Together, our detailed evidence on specialist palliative care costs and our casemix classification deliver a major advance. Each person needing specialist palliative care is different, with varying degrees of complex needs. We now have the means to understand this, systematically and at scale, for practice, policy and research. This delivers the potential to help address inequities and provide more equitable specialist palliative care to all who need it.