Seeking Excellence in End of Life
Care UK (SEECare UK): a UK multi-­
centred service evaluation
Simon Tavabie ‍ ‍,1 Yinting Ta ‍ ‍,2 Eleanor Stewart,3 Oliver Tavabie,4
Sarah Bowers ‍ ‍,5,6 Nicola White ‍ ‍,7 Cate Seton-­Jones,8 Stephen Bass,9
Mark Taubert,10 Anja Berglund,11 Suzanne Ford-­Dunn,11 Sarah Cox,12
Ollie Minton ‍ ‍11
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For numbered affiliations see end
of article.
Correspondence to
Dr Simon Tavabie, Transforming
End of Life Care, University
College London Hospitals NHS
Foundation Trust, London WC1E
6BT, UK; ​simon.​tavabie@​nhs.​net
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ABSTRACT
Objective To evaluate the care of patients dying
in hospital without support from specialists in
palliative care (SPC), better understand their
needs and factors influencing their care.
Methods Prospective UK-­wide service
evaluation including all dying adult inpatients
unknown to SPC, excluding those in emergency
departments/intensive care units. Holistic needs
were assessed through a standardised proforma.
Results 88 hospitals, 284 patients. 93%
had unmet holistic needs, including physical
symptoms (75%) and psycho-­socio-­spiritual
needs (86%). People were more likely to have
unmet needs and require SPC intervention at a
district general hospital (DGH) than a teaching
hospital/cancer centre (unmet need 98.1% vs
91.2% p0.02; intervention 70.9% vs 50.8%
p0.001) and when end-­of-­life care plans
(EOLCP) were not used (unmet need 98.3% vs
90.3% p0.006; intervention 67.2% vs 53.3%
p0.02). Multivariable analyses demonstrated
the independent influence of teaching/cancer
hospitals (adjusted OR (aOR)0.44 CI 0.26 to 0.73)
and increased SPC medical staffing (aOR1.69 CI
1.04 to 2.79) on need for intervention, however,
integrating the use of EOLCP reduced the impact
of SPC medical staffing.
Conclusion People dying in hospitals have
significant and poorly identified unmet needs.
Further evaluation is required to understand the
relationships between patient, staff and service
factors influencing this. The development,
effective implementation and evaluation of
structured individualised EOLCP should be a
research funding priority.

BACKGROUND
The 2022 Health and Care Act requires
adequate provision of specialist palliative
care (SPC) across England, in community,
hospice and hospital settings.1 In the UK it

WHAT IS ALREADY KNOWN ON THIS TOPIC
⇒ Patients dying in hospital have variable
access to and input from specialist
palliative care (SPC) services.
⇒ Little is known of the care provided in the
absence of such support.
WHAT THIS STUDY ADDS
⇒ SPC would intervene in the care of more

than half of those dying inpatients not
referred for their services.
⇒ End-­of-­life care plans (EOLCP) appear to
be a powerful support to non-­specialists in
providing end-­of-­life care in hospital.
HOW THIS STUDY MIGHT AFFECT
RESEARCH, PRACTICE OR POLICY
⇒ This study may encourage non-­specialists
in palliative care to consider whether their
dying patients may benefit from SPC input.
⇒ Researching the most effective structure
and function of EOLCP should improve
the care received by patients managed by
non-s­ pecialists.

is estimated that one in three adult hospital
inpatients is in the last year of life, with
one in ten likely to die while admitted.2
In UK hospitals, SPC teams often function
as a consult service, relying on referral
from the managing team to support with
holistic assessment and management of
multidimensional care needs. However,
complexities around recognising dying
and stigma associated with palliative care
mean patients are often not referred to
SPC, living with unmet needs until they
die.2
Meeting the holistic needs of dying
people in UK hospitals has been challenging, with previous attempts such
as the Liverpool Care Pathway causing
public and professional upset.3 Baroness

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Original research


Neuberger’s review ‘More Care, Less Pathway’, highlighted the need for greater involvement of patients and those important to them in the development of individualised end-of-life care plans (EOLCP). The review also noted a paucity of evidence to guide the effective structure and implementation of EOLCP and their impact on care delivered. The Leadership Alliance for Dying People offered ‘Five Priorities of Care for the Dying Person’ outlined in ‘One Chance to Get it Right’ to guide and support the delivery of individualised care at the end-of-life. These reports have triggered the development of local individualised EOLCP to support non-SPC healthcare professionals in the complexities of caring for the dying. However, the gaps in research largely remain.

Retrospective evaluation of care at the end-of-life is undertaken by NHS Benchmarking’s National Audit of Care at the End of Life (NACEL). Due to delays in reporting associated with large national audits, attempts at contemporaneous reporting to support quality improvement, such as the Hospital Deaths Dashboard, have also been trialled. These evaluations include deaths with and without SPC involvement without differentiation. Furthermore, both rely on retrospective case-note reviews and questionnaires of loved ones and staff, limiting their ability to capture the care delivered to what was documented, or what can be remembered. There is a need to explore other methodologies in evaluating care to ensure services are meeting the standards and requirements outlined in the Health and Care Act.

In response to the perceived unmet needs of people dying in hospitals, a collaborative of four acute UK NHS Trusts undertook a pilot evaluation (SEECare) against set standards. They prospectively reviewed the care of patients dying in hospital without SPC involvement and found that this group often had unmet care needs where 56% required immediate intervention from the SPC reviewer. This present study’s aim was to expand this pilot across the UK and prospectively evaluate the holistic care of dying people unknown to SPC and the factors influencing their experiences.

AIM
To pilot a UK-wide prospective 1-day snapshot evaluation of holistic care provided to hospital inpatients unknown to SPC.

Objectives
1. To assess the acceptability of a prospective outreach service evaluation
2. To report the level of unmet need in hospital inpatients dying unknown to SPC
3. To explore the patient and service factors influencing whether a dying inpatient unknown to SPC is unlikely to have their needs met or require SPC intervention following review

METHODS
A Seeking Excellence in End-of-life Care working group was convened by the Association for Palliative Medicine of Great Britain and Ireland (APM) bringing expertise from consultant, trainee, research and clinical governance backgrounds. The processes and documents of the prior project were reviewed and refined (see online supplemental appendices 1–3: SEECare data collection guide, excel database and paper collection tool).

Design
A prospective multi-site cross-sectional study with evaluations completed on a single day. All evaluations took place between 25 April 2022 and 01 May 2022.

Site recruitment
UK NHS hospital SPC services were recruited via the membership networks of the APM and UK Palliative Trainees Research Collaborative. Sites registered the project following local clinical governance processes.

Participant identification
The SPC representative (nurse or doctor) visited every adult ward in their hospital on the same day and identified eligible patients against the following criteria.

Inclusion criteria
All hospital inpatients recognised as being in the last days of life, identified through discussion with the clinical staff on the ward.

Exclusion criteria
Patients under 18 years old, those in emergency departments or intensive care units and those currently known to SPC.

Data collection
At registration, sites provided data on country of service, hospital type (district general vs teaching hospital/cancer centre), team staffing (from each professional group including the presence of a dedicated end-of-life care team), working patterns (7 day service and referral systems), geography (urban, rural, mixed) and estimated population served.

Included patients were assessed by the SPC nurse/doctor using an anonymised standardised proforma (see online supplemental appendices 1–3). This proforma recorded the ward specialty, patient demographics (age, gender, ethnicity, diagnosis (cancer/non-cancer)), presence and severity of physical symptoms at the point of review; whether psychological, spiritual and social needs were being addressed; and whether a plan for hydration and nutrition was in place. A review of medical and nursing notes was conducted for evidence of elements of an individualised EOLCP addressing the identified needs. ‘Unmet need’ was identified as an unaddressed issue on the collection
tool. If the SPC reviewer suggested an immediate intervention to better serve an identified area of unmet need this was also recorded and considered as ‘SPC intervention’.

A proforma was completed for each patient transcribed, or directly entered, into an excel database by teams. These databases were cleaned and anonymity assured by site leads prior to forwarding to the central project team via dedicated secure email. At central collation all sites were assigned an anonymous coded identifier, held password protected by the project lead and administrative support lead.

On return of sites’ databases, they were invited to provide feedback on the process of registration, planning for, staff experience and the tools provided.

Analysis
Data extracted underwent univariable and multivariable analyses to understand which factors were associated with presence of unmet need (defined as unaddressed issue identified on collection proforma) and need for SPC intervention following review. Continuous data was analysed for normality using the D’Agostino and Pearson tests. All data were non-normally distributed and analysed using Mann-Whitney U tests with results reported as median (IQR). Categorical data were analysed by Fisher’s exact tests and results reported as number (%). For ease of interpretation, data on staffing levels were presented per 100 000 population served and categorised as above or below mean staffing of the sample for further analysis.

Where multiple categories existed, the predominant category was analysed against the remainder (district general hospital (DGH) vs teaching hospital/cancer centre; white vs all non-white ethnicity; referrals only (reactive) vs all proactive methods of patient identification; medicine and specialties vs all other ward types).

Multiple logistic regression was used to identify site and patient variables independently associated with unmet need or need for intervention following review. Variables with a p value of <0.2 were included in each model and backwards elimination was performed until all variables within the model achieved a p value of <0.05. An $r^2$ threshold with other variables within the model was set at <0.50 to reduce collinearity. Goodness of fit was assessed using Hosmer-Lemeshow (HL) test, log-likelihood ratios and pseudo $r^2$ values. Results were recorded as OR with 95% CIs and p values. A p<0.05 was considered statistically significant and signified by *. All univariable and multivariable analyses were performed using Prism V9.2.0 (GraphPad, San Diego, USA).

RESULTS
In total, 69 sites representing 88 hospitals across the 4 UK nations registered for the study (76 England, 6 Northern Ireland, 4 Scotland, 2 Wales). The estimated population served by these hospitals was 35 782 123 (mean 526 000, range 100 000–3 000 000). 65% (57/88) were teaching hospitals/cancer centres. SPC staffing per 100 000 population ranged from 0.38 to 11.45 doctors, 1.01 to 30.23 Clinical Nurse Specialists (CNS) and 0.35 to 10.6 Allied Health Professionals (AHP). Forty-five percentage (40/88) provided 7-day in-person cover. 38.6% (34/88) of teams used proactive measures of patient identification (such as daily focused ward outreach and electronic flagging from patient records). Eight hospitals withdrew due to staffing and service challenges.

Description of the patient cohort
Two hundred and eighty-four patients were identified. The majority were between the ages of 75 and 94 (216/284, 76%). Most had non-cancer diagnoses (240/284, 85%). See table 1 for patient demographics.

Acceptability
8/64 sites withdrew due to difficulties with staffing and service provision during the collection window. Feedback from remaining sites was that data collection was straightforward and acceptable to patients and other clinical teams. Proactive support was ‘warmly welcomed’ by ward teams and ‘reviews have triggered educational intervention’, ‘review of policies’ and helped team functioning (eg, ‘improving Administrator’s insights into team’s work in clinical areas’).

Nineteen of the thirty-five sites returning qualitative feedback stated they would be keen to repeat the exercise regularly through the year. 7/35 felt that for significant ‘extra’ work the patient numbers were small and wondered about more efficient methods of identification.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Demographics and clinical characteristics of identified patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age range</strong></td>
<td><strong>N (%)</strong></td>
</tr>
<tr>
<td>18–74</td>
<td>40/284 (14)</td>
</tr>
<tr>
<td>75–84</td>
<td>101/284 (36)</td>
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<tr>
<td>85–94</td>
<td>115/284 (40)</td>
</tr>
<tr>
<td>95+</td>
<td>27/284 (10)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td><strong>N (%)</strong></td>
</tr>
<tr>
<td>Female</td>
<td>153/284 (54)</td>
</tr>
<tr>
<td>Male</td>
<td>131/284 (46)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td><strong>N (%)</strong></td>
</tr>
<tr>
<td>White/white other</td>
<td>271/277 (98)</td>
</tr>
<tr>
<td>Other</td>
<td>3/277 (1)</td>
</tr>
<tr>
<td><strong>Primary diagnosis</strong></td>
<td><strong>N (%)</strong></td>
</tr>
<tr>
<td>Cancer</td>
<td>44/284 (15)</td>
</tr>
<tr>
<td>Frailty</td>
<td>57/284 (20)</td>
</tr>
<tr>
<td>Medicine</td>
<td>170/284 (60)</td>
</tr>
<tr>
<td>Surgical</td>
<td>37/284 (13)</td>
</tr>
<tr>
<td><strong>Ward specialty</strong></td>
<td><strong>N (%)</strong></td>
</tr>
<tr>
<td>Medicine and specialties</td>
<td>170/284 (60)</td>
</tr>
<tr>
<td>All other ward types</td>
<td>114/284 (40)</td>
</tr>
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</table>

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Evaluation findings
Seventy-five per cent of patients (213/284) had physical symptoms (pain 24%, 67/284; dyspnoea 24%, 68/284; respiratory secretions 21%, 61/284; agitation 23%, 66/284; nausea/vomiting 8%, 22/284), with 31% (88/284) experiencing moderate to severe physical symptoms. Mouthcare was poor in 56% (159/284). There were further unmet holistic care needs in 86% (244/284) (spiritual needs 67%, 190/284; psychological needs 60%, 170/284; social needs 18%, 51/284, no plan for hydration/nutrition 28%, 80/284). A locally agreed EOLCP was in place for 57% (162/284), communication with relatives that the patient was dying had occurred in 85% (241/284), and anticipatory prescribing was present in 82% (233/284). Overall, an overwhelming majority of 93% (264/284) of patients reviewed had demonstrable unmet need.

Interventions were required from the SPC reviewer in 57% (162/284) of cases. Thirty-nine per cent (63/162) of changes made focused on prescribing, 15% (24/162) on psychosocial or spiritual care, 12% (19/162) on mouthcare, 11% (18/162) on engaging with EOLCP and 10% (16/162) on immediate administration of symptom focused medication. Other interventions included stopping therapies that were no longer appropriate, advance care planning and rapid discharge.

Factors associated with unmet need
Patients’ needs were significantly less likely to be met at a DGH compared with a teaching hospital/cancer centre (98.1% vs 91.2% p 0.02). While a high proportion of patients with EOLCPs in place had unmet needs, this was significantly fewer than when an EOLCP was not in place (EOLCP 90.3% vs no EOLCP 98.3%, p 0.006). The negative predictive value of an EOLCP on all needs being met was 0.98 (CI 0.94 to 0.997) meaning for those who did not have an EOLCP, needs were very unlikely to be met.

Factors associated with the need for intervention from SPC team
Patients were significantly more likely to require intervention in a DGH compared with a teaching hospital/cancer centre (70.9% vs 50.8% p 0.001), where there was higher than average SPC staffing/100 000 (65.9% vs 51.6% p 0.02), where there was a 7-day SPC service (67.1% vs 54.0% p 0.03) and where there was no EOLCP in place (67.2% vs 53.3% p 0.02) (see table 2).

Multivariable analysis
Multivariable analysis demonstrated that need for intervention was independently associated with site type (teaching hospital/cancer centres (site type adjusted OR (aOR) 0.44 CI 0.26 to 0.73 p 0.002)) and SPC medical staffing, (higher-than-mean SPC doctors (SPC doctor numbers aOR 1.69 CI 1.04 to 2.79 p 0.04)) (see figure 1A). When the presence of an EOLCP was included the number of SPC doctors did not remain independently significantly associated with the need for intervention (site type aOR 0.45 CI 0.27 to 0.79 p 0.005*, SPC doctor numbers aOR 1.61 CI 0.98 to 2.67 p 0.06, EOLCP aOR 0.65 CI 0.39 to 1.08 p 0.09) (see figure 1B). No other variables were found to be independently significantly associated with the need for intervention including nursing staffing levels, 7-day service, proactive referral seeking and cancer diagnosis.

DISCUSSION
Key findings
This is the first prospective UK-wide evaluation of care provided to people dying in hospitals without the support of specialists in palliative and end-of-life care. Nearly all identified patients (93%) suffered unmet needs, with more than half (57%) requiring immediate intervention from SPC. Inequity was demonstrated in the care provided to patients, with those in DGHs requiring higher rates of SPC intervention even when accounting for all other measured variables. SPC medical staffing and working patterns demonstrated significant relationships with need for intervention but this was mitigated in the multivariate model by the presence of an EOLCP. EOLCP were associated with significantly fewer unmet needs and significantly lower rates of intervention but were not enough to independently guarantee the provision of holistic care.

Strengths and weaknesses
The multi-site, multi-setting involvement across county and country borders allows for interrogation of the data to demonstrate local and overall trends. The cross-sectional design and minimal exclusion criteria maximise representative data. The convenience sampling outreach approach was acceptable to SPC and wider hospital teams.

The convenience sampling methodology used to identify patients relied on the senior ward nurse/doctor’s ability and openness to identify patients dying on the ward. The varying culture and ability to recognise dying across specialties/hospitals/regions will have been in some way accounted for in the multi-site nature of this evaluation, however, the suggested differences in this ability between nurses and doctors has not been accounted for in this study.9 This study did not attempt to evaluate the differences in outcome dependent on profession of SPC reviewer (eg, nurse vs doctor), nor day of week of data collection.

This study did not include evaluation of patients known to SPC, nor a measure of the actual count of those dying in hospitals. The lack of representative diversity in our ethnicity data with only six patients identified from non-white backgrounds and six with incomplete data is difficult to interpret, though may represent reduced recognition of dying in patients of non-white ethnic groups as is reported elsewhere.10
The use of population served as an indicative measure for staffing was an intentional choice, as opposed to reporting by number of inpatient beds. This was an attempt to account for some hospitals offering specialist services, however, it's likely that to truly capture the staffing relative to service need, future studies will need to consider services offered, bed base, population served and other variables.

### Table 2

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>N</th>
<th>Unmet needs%</th>
<th>P value†</th>
<th>Intervention%</th>
<th>P value†</th>
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<td>0.02*</td>
<td>70.9</td>
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<td>50.8</td>
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<td><strong>Geography</strong></td>
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<td>Rural</td>
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<td>84.2</td>
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<td>0.5</td>
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<td>Drs&lt;avg/100 000</td>
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<td>51.6</td>
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<td>No EOLC team</td>
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<td>54</td>
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<td><strong>Patient characteristics</strong></td>
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<td>59.1</td>
<td>&gt;0.999</td>
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<td>No</td>
<td>119</td>
<td>98.3</td>
<td>0.006*</td>
<td>67.2</td>
<td>0.02*</td>
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<tr>
<td>Yes</td>
<td>165</td>
<td>90.3</td>
<td></td>
<td>53.3</td>
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</tbody>
</table>

† Two-sided Fisher’s exact.
* Indicates a result achieving statistical significance
CNS, Clinical nurse specialist; EOLCP, end-of-life care plans.

Figure 1  Comparison of models for specialists in palliative care medical staffing, site type and presence of an EOLCP against need for intervention following review. (A) n=284, Area Under Curve 0.637, CI 0.57 to 0.70, Hosmer-Lemeshow 5.091, (B) n=284, AUC 0.651, CI 0.59 to 0.72, Hosmer-Lemeshow 6.948. EOLCP, end- of- life care plans.
Our findings demonstrate less frequent use of EOLCP (National Audit of Care at the End of Life (NACEL) 73%, Seeking Excellence in End of Life Care UK (SEECareUK 57%), communication with relatives (NACEL 98%, SEECareUK 85%) and anticipatory prescribing (NACEL 89%, SEECareUK 82%) for our patient cohort when compared with the population as a whole. With the included consideration of broader holistic aspects of care, the level of unmet need demonstrated is significantly higher than the SEECare pilot and highlights the often-reported medicalisation of death in inpatient settings.

Individualised and structured EOLCP are recommended as one of the Five Priorities of Care for the Dying Person and we have found their use to be lower when SPC are not involved. Though absence of an EOLCP has been demonstrated to predict unmet need (Negative Predictive Value of EOLCP on all needs met 0.98), there remains significant need where they are in use. Nearly 10 years after Baroness Neuberger’s report, still, little is known about the elements of EOLCP that are most effective in supporting care and how they might best be implemented to ensure care provided meets the needs of patients whether they are referred to SPC or not.

The impact of SPC working patterns (eg, 7-day working) and behaviours (eg, proactive seeking of referrals) is poorly described in the literature though certain practices are called for in multiple reports and policies. This project did not seek to evaluate the direct impact this has on patients reviewed by SPC, but to investigate any cultural impact this may have on the care of dying people in their hospitals. That increased medical staffing and 7-day working was significantly associated with increased need for SPC intervention (though not with unmet need), must be interpreted with caution. One might infer a level of reliance on SPC that deskills the generalist, alternatively, that increased SPC and medical presence drives higher standards and therefore increased likelihood to intervene.

With the Health and Care Act legislation for access to palliative care services wherever and whenever needed, these findings raise significant questions about the methods of delivery best suited to meeting the complex needs of dying people. In future iterations of SEECare, repeated sampling or extending the sampling window may allow for higher patient numbers to increase the utility of data on a local level and improve validity nationally. Requesting that sites provide mortality data for the collection period may allow for better understanding of the issues non-specialists face in recognition of dying.

Attempts to formally investigate the impact of EOLCP have relied on retrospective case-note review and bereaved interview-based measures, and focused on specific patient groups. As such, our findings again emphasise the need for prioritisation of research funding here to more robustly understand and guide the development, implementation and evaluation of EOLCP for all people dying in hospitals.

The lack of variance and low levels of ethnicity data reported is important to explore further. Patterns in ethnicity representation in mortality data which do not match those identified prospectively may prompt further investigation into the recognition of dying and whether unconscious bias, access issues or other factors influence care received.

This evaluation focuses on acute inpatient care excluding emergency and intensive care departments. It may be appropriate to include these clinical areas in future iterations for further insights into the way in which hospitals care for those that are dying. Furthermore, expansion into intermediate care, residential care environments, patients’ homes and other potentially underserved environments is likely to reveal significant unmet specialist palliative care needs.

CONCLUSION

This first multi-centred prospective evaluation of care of those dying in hospitals without SPC input has demonstrated almost universal multidimensional unmet need. Given the 2022 Health and Care Act’s legislation for access to palliative care services wherever and whenever needed, these findings should prompt further research and give service leads and commissioners stimulus to revisit their specialist palliative care strategic planning.

Future research

In future iterations of SEECare, repeated sampling or extending the sampling window may allow for higher patient numbers to increase the utility of data on a local level and improve validity nationally. Requesting that sites provide mortality data for the collection period may allow for better understanding of the issues non-specialists face in recognition of dying.

Twitter Simon Tavabie @simontavabie, Oliver Tavabie @OTavabie, Sarah Bowers @SarahPBowers, Nicola White @nicolagwhite, Stephen Bass @lumpyeggblack, Mark Taubert @ProfMarkTaubert and Ollie Minton @drol007

Acknowledgements Thanks to all participating sites, staff and patients and their loved ones. Thanks to the APM Office, in particular Georgina Bulla who provided exceptional administrative support.

Contributors ST, OM, SF-D and SC conceived the project. ST, YT, ES, SPB, CS-J, SB, MT, AB, SC and OM designed the project.
project plan and resources. ST and OM oversaw the collection and collation via the APM Office. ST, OT, NW and OM performed statistical analyses. ST, YT, ES, OT, SPB, NW, CS-J, SB, MT, AB, SF-B, SC and OM contributed to the manuscript. ST acts as guarantor to the project.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available. All data relevant to the study are included in the article or uploaded as supplementary information.

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ORCID iDs
Simon Tavabie http://orcid.org/0000-0001-9420-8168
Yinting Ta http://orcid.org/0000-0002-4507-2417
Sarah Bowers http://orcid.org/0000-0003-0722-8318
Nicola White http://orcid.org/0000-0002-7438-0072
Ollie Minton http://orcid.org/0000-0002-4258-8995

REFERENCES
APM Seeking Excellence in End-of-life care – User guide to data collection

Thank you for agreeing to participate in the APM SEECare service evaluation. Please identify 1 day in the collection week (25/04-01/05/22) on which your team will collect data. Please use either the excel spreadsheet or the paper tool, whichever is easiest for you and your team. Please note that for ease of collation, and to make this data more useable for yourselves we ask that data recorded on the paper tool is transcribed to the excel database prior to return.

- For the paper questionnaire – please put a tick in the box next the appropriate answers. Opportunities to write free text are indicated by a dotted line.
- When completing the excel database, please use the tab labelled “Data entry” to input your data. Please select from the dropdown boxes and write free text where appropriate.
- If you cannot find a piece of information requested. Please leave the box blank and write a brief explanation at the end of the questionnaire or excel document.
- Please send the completed data to APM Office office@compleat-online.co.uk
- Prior to returning the database, please ensure there is no patient identifiable information included and that the formatting of the document has not been altered.

Areas Predicted to Cause Consternation:

Identification of patients for inclusion
- On the day of collection, a member(/members) of the hospital palliative care team (doctors, CNSs, ANPs or PAs – please contact APM office if any questions) will attend each inpatient ward (excepting ED, ITU/HDU areas) and identify patients who are recognised as dying but not yet known to the hospital palliative care team.
- Sites will vary in the best method of identification on the ward - we advise speaking to the nurse in charge of the ward, +/- a member of the responsible medical team & asking them to identify any patients meeting inclusion criteria. If other methods are used then please include this when returning registration form (if predicted) or database (if discovered during collection).

Patient number
- **This should not be the identifiable patient medical record number** but instead a separate number allocated to the patient for this project to keep information recorded psuedonymous. If using the paper collection sheet then these can be pre-allocated when printing. Otherwise, this can be reformatted when ‘cleaning’ the excel spreadsheet prior to return. Some sites will have multiple people collecting data, in which case you are welcome to use prefixes on your numbering (for example Simon Tavabie’s patients may be ST1-5 and Ollie Minton’s might be OM1-5 for ease of psuedonomysation).

Grading of severity of symptoms
- As specialists in palliative care, we recognise that there may be differences in the professional’s assessment of severity of symptoms and so have left some prompts around how this might best be guided. These are available in both formats of the collection tool.

If, on reviewing the collection tools prior to the snap shot day, there are any other areas of confusion/concern please do not hesitate to get in touch with the SEECare team via office@compleat-online.co.uk
<table>
<thead>
<tr>
<th>Patient number</th>
<th>Date</th>
<th>Site</th>
<th>Type of ward</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Primary diagnosis</th>
</tr>
</thead>
</table>

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<table>
<thead>
<tr>
<th>Admissions</th>
<th>Male</th>
<th>Asian or Asian British</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>Female</td>
<td>Black, African, Caribbean or I</td>
</tr>
<tr>
<td>Surgical</td>
<td>Other</td>
<td>Mixed or Multiple Ethnicities</td>
</tr>
<tr>
<td>Frailty</td>
<td></td>
<td>White or white other</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other ethnic group</td>
</tr>
</tbody>
</table>
Is the **patient** aware that they are dying?  
Is the **NOK** aware that the patient is dying?  
Is the patient supported by an agreed end-of-life care plan?
<table>
<thead>
<tr>
<th>Cancer</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-cancer</td>
<td>Not possible</td>
<td>Not possible</td>
<td>No/Not Clear</td>
</tr>
<tr>
<td></td>
<td>No/Not Clear</td>
<td>No/Not Clear</td>
<td></td>
</tr>
<tr>
<td>In there evidence of anticipatory symptom focused prescribing?</td>
<td>Is a syringe driver</td>
<td>If yes, what meds/dose</td>
<td>Pain</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>---------------------</td>
<td>------------------------</td>
<td>------</td>
</tr>
</tbody>
</table>
0 - None
1 - Mild (occasional groan
2 - Moderate/Severe (w
<table>
<thead>
<tr>
<th>Respiratory distress</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory noises</td>
<td>Comment</td>
</tr>
<tr>
<td>Agitation</td>
<td>Comment</td>
</tr>
<tr>
<td>Score</td>
<td>Description</td>
</tr>
<tr>
<td>-------</td>
<td>------------------------------</td>
</tr>
<tr>
<td>0</td>
<td>Comfortable</td>
</tr>
<tr>
<td>1</td>
<td>Distressed breathing</td>
</tr>
<tr>
<td>2</td>
<td>High respiratory effort</td>
</tr>
<tr>
<td>0</td>
<td>Not audible</td>
</tr>
<tr>
<td>1</td>
<td>Only audible near patient</td>
</tr>
<tr>
<td>2</td>
<td>Clearly audible at end of bed</td>
</tr>
<tr>
<td>0</td>
<td>Calm</td>
</tr>
<tr>
<td>1</td>
<td>Restless</td>
</tr>
<tr>
<td>2</td>
<td>Agitated and distressed</td>
</tr>
<tr>
<td>Nausea and/or vomiting</td>
<td>Comment</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>0 - None</td>
<td>0 - Healthy</td>
</tr>
<tr>
<td>----------</td>
<td>-------------</td>
</tr>
<tr>
<td>1 - Mild (occasional/manageable symptoms)</td>
<td>1 - Dry/slightly coated</td>
</tr>
<tr>
<td>2 - Moderate/Severe (constant or over days)</td>
<td>2 - Ulcerated/thick secretion</td>
</tr>
<tr>
<td>Other symptom severity</td>
<td>Comment</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Are the NOK being appropriately supported?</td>
<td></td>
</tr>
<tr>
<td>Has preferred place of care/death been discussed?</td>
<td></td>
</tr>
<tr>
<td>Is there an appropriate plan for hydration and nutrition?</td>
<td></td>
</tr>
<tr>
<td>Is it being followed?</td>
<td>Comment</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Yes</th>
<th>Administration of immediate symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Alteration of ongoing symptom control</td>
</tr>
<tr>
<td></td>
<td>General prescribing advice</td>
</tr>
<tr>
<td></td>
<td>Mouth care</td>
</tr>
<tr>
<td></td>
<td>Holistic and NOK support</td>
</tr>
<tr>
<td></td>
<td>Engaging with end-of-life care plans</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>
symptom control medication

trol medication (including PRN dose changes and CSCI)
### Patient Information
- **Patient number:**  
- **Gender:** M/F/..  
- **Age:** ..y  
- **Ethnicity:**  
- **Primary diagnosis:** Cancer  
- **Is the patient aware that they are dying?** Yes  
- **Is their NOK aware that the patient is dying?** Yes  
- **Is the patient supported by an agreed end-of-life care plan?** Yes  
- **Is there evidence of anticipatory symptom focused prescribing?** Yes  
- **Is a syringe driver in use?** Yes  

### Assessment Criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Severity</th>
<th>Tick</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pain</strong></td>
<td>0: None 1: Mild 2: Moderate/severe</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respiratory distress</strong></td>
<td>0: Comfortable 1: Distressed breathing 2: High respiratory effort</td>
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<td></td>
</tr>
<tr>
<td><strong>Agitation</strong></td>
<td>0: Calm 1: Restless 2: Agitated and distressed</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Nausea and/or vomiting</strong></td>
<td>0: None 1: Mild 2: Moderate/severe</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mouth care</strong></td>
<td>0: Healthy 1: Dry/slightly coated 2: Ulcerated/thick secretions/oral thrush</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other Symptom e.g. itch, constipation</strong></td>
<td>0 1 2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Additional Notes
- **Are the patient’s spiritual needs being addressed?** Yes  
- **Are the patient’s psychological needs being addressed?** Yes  
- **Are the NOK being appropriately supported?** Yes  
- **Has preferred place of care / death been discussed?** Yes  
- **Is there an appropriate plan for hydration and nutrition?** Yes  
- **Is the plan for hydration and nutrition being followed?** Yes  
- **Any comments on hydration and nutrition?**  
- **Did you instigate any changes?** Yes  
- **What changes did you make?**  

---

Eligibility:

Inclusion criteria:
1. Hospital inpatient, recognised by managing team as in last hours to days of life.
2. Not currently known to hospital specialist palliative care team.

Exclusion criteria:
1. Not admitted (e.g. Emergency Department) or on Intensive Care/High Dependency Units.
2. Not recognised as in last hours to days of life.
3. Under age of 18 years.

Descriptors:

**Type of ward** – please specify if Admissions; Medical; Surgical or Frailty

**Ethnicity** – Please consider ‘Asian or Asian British’; ‘Black, African, Caribbean or Black British’; ‘Mixed or Multiple Ethnicities’; ‘White or White other’; ‘Other ethnic group’

**Grading of symptoms not specified overleaf:**

**Pain**
0 – None
1 – Mild (occasional groaning, looking tense, fidgeting, sighing, increased heart rate)
2 – Moderate/Severe (whimpering, frowning, guarding body, crying out, withdrawn, clenched fists, rigid body, perspiring, flushed/pale)

**Nausea and/or vomiting**
0 – None
1 – Mild (occasional/manageable symptoms)
2 – Moderate/Severe (constant or overwhelming sensation of nausea or troubling vomiting)

**What changes did you make?**

Some examples could be:
Administration of immediate symptom control medication
Alteration of ongoing symptom control medication (including dose changes and CSCl)
General prescribing advice
Mouthcare
Holistic care and NOK support
Engaging with end-of-life care plan
“Significant and poorly identified unmet needs” very common among the dying in UK hospitals

Experienced by nearly all (93%) of those assessed in first of its kind UK-wide evaluation
Deficit more likely in district general hospitals than teaching hospitals and cancer centres

People dying in UK hospitals without specialist palliative care input frequently have “significant and poorly identified unmet needs,” finds a UK-wide evaluation—the first of its kind—published online in the journal *BMJ Supportive & Palliative Care*.

Nearly all (93%) of those assessed had demonstrable unmet need, with this deficit more apparent in district general hospitals than it was in teaching hospitals or cancer centres.

It is estimated that 1 in 10 patients admitted to UK hospitals will die during their inpatient stay. As specialist palliative care teams often function as a consult service, referral from the managing team is required.

But complexities around recognising that a patient is dying and the stigma associated with palliative care mean these referrals are frequently not made, say the researchers.

In response to the perceived unmet needs of people dying in hospitals, the Association of Palliative Medicine coordinated the first ever prospective evaluation of end of life care against set standards in 88 hospitals across the UK: Seeking Excellence in End-of-life Care UK or SEECareUK.

Palliative care specialists assessed how well the holistic needs of 284 adult patients nearing death, but not referred to palliative care services, were being met on one single day between 25 April and 01 May 2022. Patients in emergency care departments or intensive care units weren’t included.

The assessment included the ward specialty; age, gender, ethnicity and diagnosis of the patient; presence and severity of physical symptoms; whether psychological, spiritual, and social needs were being met; and whether a plan for nutrition and hydration was in place.

The medical and nursing notes were also reviewed to check for evidence of an end of life care plan to address identified needs. Any immediate need for specialist palliative care intervention was also noted.
Three quarters (76%) of the dying patients were between 75 and 94 years old; over half (54%) were female; and most (98%) were of white ethnicity. Only 44 out of 284 (15%) had cancer as their primary diagnosis.

The evaluation showed that 3 out of 4 patients (213/284) had physical symptoms—pain 24% (67); breathing difficulties (dyspnoea) 24% (68); respiratory secretions 21% (61); agitation 23% (66); nausea/vomiting 8% (22).

Physical symptoms were moderate to severe in nearly a third (31%, 88). Mouth care was poor in over half (56%, 159).

Most (86%, 244) had other unmet holistic care needs. These included spiritual needs in two thirds (67%;190); psychological needs (60%;170); and social needs in nearly a fifth (18%, 51). And there was no plan for nutrition/hydration in 28% (80).

Overall, nearly all (93%, 264) the patients reviewed had demonstrable unmet need, the evaluation revealed.

A locally agreed end of life care plan was in place for 57% (162). And relatives had been told that the patient was dying in 85% (241) of cases, with anticipatory prescribing of meds to ease the symptoms frequently associated with the dying process in 82% (233).

Immediate specialist palliative care intervention was required in over half the patients (57%, 162): prescribing changes in 39% (63); provision of psychosocial or spiritual care in 15% (24); mouth care in 12% (19); implementing aspects of the end of life care plan in 11% (18); and immediate administration of meds for symptom relief in 1 in 10 patients (16).

Other interventions included stopping treatments that were no longer appropriate, advance care planning, and rapid discharge to home or residential care.

Patients’ needs were significantly less likely to be met at a district general hospital than they were in a teaching hospital or cancer centre (98% vs 91%). Dying patients in district general hospitals were also significantly more likely to require intervention (71% vs 51%).

Patients were less likely to need intervention with a higher than average headcount of specialist palliative care staff /100,000 of the population (66% vs 52%); where there was a 7-day specialist palliative care service available (67% vs 54%); and where there was no end of life care plan in place (67% vs 53%).

Although a high proportion of patients with end of life care plans had unmet needs, this was still significantly more likely without any such care plan in place (98% vs 90%).

This is an observational snapshot study, precluding the ability to draw firm conclusions, added to which the researchers didn’t evaluate the care of patients known to palliative care services, nor measure the actual number of those dying in hospitals—factors that may be influential.
Nevertheless, they highlight: “With the Health and Care Act [2022] legislating access to palliative care wherever and whenever needed, these findings raise significant questions about the methods of delivery best suited to meeting the complex needs of dying people.”

They add: “Furthermore, expansion into intermediate care, residential care environments, patients’ homes and other potentially underserved environments is likely to reveal significant unmet specialist palliative care needs.”

And at the very least, they conclude: “These findings should prompt further research and give service leads and commissioners stimulus to revisit their specialist palliative care strategic planning.”
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