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Hospice care access inequalities: a systematic review and narrative synthesis

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ABSTRACT

Background Inequalities in access to hospice care is a source of considerable concern; white, middle-class, middle-aged patients with cancer have traditionally been over-represented in hospice populations.

Objective To identify from the literature the demographic characteristics of those who access hospice care more often, focusing on: diagnosis, age, gender, marital status, ethnicity, geography and socioeconomic status.

Design Systematic literature review and narrative synthesis.

Method Searches of Medline, PsycINFO, CINAHL, Web of Science, Assia and Embase databases from January 1987 to end September 2019 were conducted. Inclusion criteria were peer-reviewed studies of adult patients in the UK, Australia, New Zealand and Canada, receiving inpatient, day, outpatient and community hospice care. Of the 45 937 titles retrieved, 130 met the inclusion criteria. Narrative synthesis of extracted data was conducted.

Results An extensive literature search demonstrates persistent inequalities in hospice care provision: patients without cancer, the oldest old, ethnic minorities and those living in rural or deprived areas are under-represented in hospice populations. The effect of gender and marital status is inconsistent. There is a limited literature concerning hospice service access for the LGBTQ+ community, homeless people and those living with HIV/AIDS, diabetes and cystic fibrosis.

Conclusion Barriers of prognostic uncertainty, institutional cultures, particular needs of certain groups and lack of public awareness of hospice services remain substantial challenges to the hospice movement in ensuring equitable access for all.

Key messages

What was already known?
- Hospice services traditionally mainly care for people with cancer.
- National policies have repeatedly called for greater equality of access to hospice care provision

What are the new findings?
- Certain groups continue to have unequal access to hospice care; the oldest old, ethnic minorities, people with non-cancer illness, those living in rural areas and areas of social deprivation.
- A combination of prognostic uncertainty, institutional cultures, unique needs of particular groups and a lack of public awareness of services exacerbate these problems.

What is their significance?
- Equity of access to hospice care for all is urgently needed and remains a major challenge for the hospice movement.
- Innovative and collaborative services need to be developed to meet the diverse needs of the whole community.

INTRODUCTION

When the modern hospice movement started in 1967 with Dame Cicely Saunders opening St. Christopher's Hospice in South London, the main focus of the early hospices was on excellence in the holistic palliative and end-of-life care of patients with cancer. Since those early days, hospices have sought to broaden their reach to include those with non-cancer diagnoses and other underserved groups.

In addition to inpatient beds, hospice care commonly includes specialist home care and community teams, Macmillan and Marie Curie nursing services, hospice at home services, day therapy and outpatient consultations. Working alongside colleagues in General Practice and District Nursing and hospital Palliative Care

teams, hospices are often leaders in education and local service developments.

However, inequalities of hospice provision persist. Of the 528 973 deaths in England and Wales in 2019, 71.5% (378,108) were from non-cancer conditions and 28.5% (150,865) from cancer.[1] Hospices were the place of death for 1.2% (4,503) of non-cancer deaths and 16.5% (24,925) of cancer deaths. Of the 29 428 deaths in hospices in 2019, 24 925 (84.7%) were from cancer and 4503 (15.3%) from non-cancer. While many more people receive hospice care than die there, these figures suggest that patients with cancer remain disproportionately served by hospice care. National mortality statistics from Scotland and Northern Ireland are very similar.

Over recent years there has been growing recognition of the palliative care needs of people dying from non-cancer conditions, alongside the development of palliative care teams in hospitals and the community. While the proportion of non-cancer deaths occurring in hospice in England and Wales has increased over the past decade, from 7.8% in 2010 to 12.4% in 2015 and 15.3% in 2019,[2] patients without cancer remain under-represented in these data.

Diagnosis is not the only inequality that persists in hospice care provision; evidence suggesting that the oldest old (aged 85+) are also under-represented, alongside considerable disparities across geographical regions of the UK.[1] To address these issues, there has been an impetus in many countries to improve the equity of palliative and end of life care provision. The 2008 UK Department of Health '*End of Life Care Strategy*' promoted a 'vision for a good death' that is 'irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status'.[3] This was echoed in the 2015 '*Ambitions for Palliative and End of Life Care*', which emphasised that each person should have 'fair access to care'.[4]

We therefore undertook a systematic review of the literature to investigate the characteristics of those who access hospice services, focusing on the evidence concerning the presence and nature of any inequalities. In contrast to a 2015 rapid review focused on the UK literature between 2010 and 2015,[5] we undertook a systematic review of the literature from 1987 to 2019 and included studies from the UK, Canada, Australia and New Zealand.

Aims

To systematically review and synthesise the peer-reviewed literature concerning referral to or receipt of hospice care with regards to eight characteristics: diagnosis and comorbid conditions; age; gender and sexuality; marital status; ethnicity and religion; geographical factors including rurality and distance to hospice; socioeconomic factors; other characteristics.

Box 1 PubMed search strategy

- ("Ethnicethnic Groupsgroups"[(Mesh]) OR ethnic differences OR racial differences OR poverty OR deprivation OR ethnicity OR culture OR minority OR marital status OR socioeconomic OR age factors OR intellectual disabilities OR rural OR urban OR demographic variation OR location OR sexuality OR nationality OR wealth OR gender OR cancer OR heart failure OR COPD OR Chronicchronic Obstructiveobstructive Pulmonarypulmonary Diseasedisease OR emphysema OR dementia OR Alzheimer's OR neurological OR multiple sclerosis OR motor neuroneneuron disease OR motor neuron disease OR cystic fibrosis OR haematological)
  AND
- (specialist palliative care OR hospice OR "Hospice Ca re"[(Mesh]) OR "Hospices"[(Mesh]) OR "Hospice and Palliative Care Nursing"[(Mesh]))

METHODS

Following an initial scoping search, inclusion and exclusion criteria were clarified and search strategies developed in discussion with the review team's Information Scientist (IK). Searches were undertaken for papers published between January 1987 (when Palliative Medicine became a recognised medical specialty in the UK) and the end of September 2019 in six databases: Medline, Embase and PsycINFO via OVID; CINAHL via EbscoHOST; ASSIA via Proquest; Web of Science. Additional searches included hand searches of Palliative Medicine and Journal of Palliative Care and reference and citation searches of included papers. Box 1 shows the PubMed search strategy.

Inclusion and exclusion criteria

Hospice care was broadly defined to include inpatient units and beds, day therapy, outpatients, hospice at home, community hospice teams, Macmillan and Marie Curie nurses, hospice chaplains and hospice social workers. Studies on deaths in hospice and referral to hospice services were included. Where studies included 'hospice' under a broader heading of 'specialist palliative care', they were included to ensure comprehensiveness. We restricted studies to those from countries with similar models of hospice care and health service provision: UK, Canada, Australia and New Zealand.

Publications were restricted to peer-reviewed journal papers, published in English and presenting new empirical data. Opinion pieces and editorials were excluded unless they contained original empirical data. Conference abstracts were included unless their data were subsequently published in full. The grey literature was not included. Publications on hospice care for people under 18 years of age were excluded, acknowledging the particular needs of children and young people.

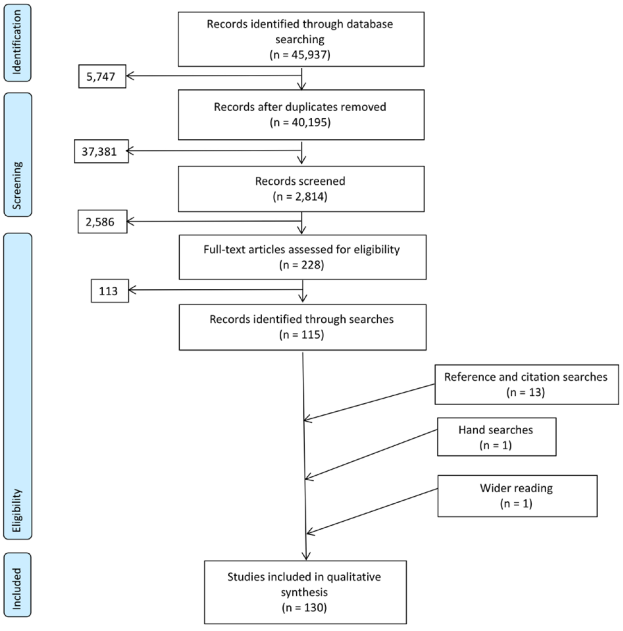

Figure 1 Preferred reporting items for systematic reviews and meta-analyses PRISMA diagram.

Search results were downloaded into EndNote X9 and duplicates removed. Titles, shortlisted abstracts and full-text articles were independently screened by AR, JT, ST and IW with uncertainty or disagreements resolved by discussion. From the 45 937 records identified, 115 papers met the inclusion criteria. Reference and citation searches of included papers identified a further 13 papers, hand searches yielded a further paper and 1 additional paper was identified from our wider reading. A total of 130 papers were included in the narrative synthesis. Figure 1 presents the PRISMA diagram.

Authors (AR, JT, ST and IW) extracted data independently into a review-specific data extraction form which recorded characteristics of included studies and key findings relevant to the review questions (see online supplemental file 1).

Extracted data were entered into NVivo V.11 for qualitative analysis, with data synthesis using a narrative approach.[6 7] This was chosen for its applicability to the synthesis of a range of qualitative and quantitative evidence. Three iterative stages were involved: (a) preliminary synthesis of each study from the data extraction forms; (b) study descriptions were grouped together and tabulated based on the review questions addressed and (c) an inductive thematic analysis to identify the main, recurrent and important evidence across the studies in answering the review questions.

Two researchers independently weighted each paper in terms of its strength, quality and contribution towards answering the review questions, using Gough's 'Weight of Evidence' (WoE) criteria with disagreements resolved by discussion (box 2).[8]

Box 2 Gough's 'Weight of Evidence'

- Gough D. Weight of evidence: a framework for the appraisal of the quality and relevance of evidence. Res Pap Educ 2007;22(2):213–28.
- Weight of Evidence A (WoE A). This is a generic and thus non-review-specific judgement about the coherence and integrity of the evidence in its own terms. The generally accepted criteria for evaluating the quality of this type of evidence by those who generally use and produce it.
- Weight of Evidence B (WoE B). This is a review-specific judgement about the appropriateness of that form of evidence for answering the review question, which is the fitness for purpose of that form of evidence.
- Weight of Evidence C (WoE C). This is a review-specific judgement about the relevance of the focus of the evidence for the review question. For example, a research study may not have the type of sample, the type of evidence gathering or analysis that is central to the review question or it may not have been undertaken in an appropriate context from which results can be generalised to the answer the review question.
- These three sets of judgements are then combined to form an overall assessment Weight of Evidence D (WoE D) of the extent that a study contributes evidence to answering a review question.

RESULTS

A summary of the included studies is presented in online supplemental file 2. Gough's 'Weight of Evidence'[8] for the 130 included papers assessed 49 as high, 54 medium and 27 low WoE.

Inequalities in access have been found in relation to diagnosis (reduced for non-malignant disease including heart failure, respiratory disease, renal and liver failure, mental health, learning disability, dementia and neurodegenerative disease (with the exception of motor neuron disease). The oldest old, people from ethnic minority groups, rural and more socioeconomically deprived area are under-represented in hospice services.

Diagnosis

Cancer versus non-cancer

A large literature of 29 papers, mostly high/medium WoE, evidence greater hospice referrals and/or deaths for patients with cancer compared with patients without cancer.[9–37] There is evidence of increasing hospice access for people with non-malignant illness in the UK,[31] Canada[18] and Australia.[28]

Haematological malignancy

Fifteen largely high WoE papers report lower hospice provision for those with haematological malignancies[16 23 31 38–49] with ORs compared with patients with cancer of around 0.4.[23 38 41] Recent years have seen increased deaths in UK hospices among patients with haematological malignancies.[16 31]

Heart failure

Twelve studies, generally medium/low WoE, evidenced that patients with heart failure are rarely referred to hospice services.[50–61] Referral rates of patients with heart failure are commonly lower than 5%[50 52 54 57 58] and patients with heart failure comprise less than 5% of palliative care clinicians' workload.[51]

Non-cancer respiratory disease

All 11 papers reported low rates of hospice referral,[34 62–71] markedly lower than lung cancer, with some indication of increased referrals between 2006 and 2008.[67] Cystic fibrosis patients are under-represented in hospices despite having significant symptom burden.[62]

Renal failure

Access to hospice care for patients with end-stage renal failure (ESRF) has been studied in the UK[34 72–76] and Australia[77] with evidence of increasing collaboration between renal units and hospice teams in recent years.[72 73] Hospice referrals are largely for those receiving conservative management for ESRF rather than people receiving renal replacement therapy.[74 75 77]

Liver failure

The five medium/low WoE papers concerning patients with liver failure[34 78–81] report them to represent less than 1% of hospice patient caseload[79] with referral often occurring late in the course of the illness.[34 78 79]

Neurodegenerative Ddisease

Papers concerning hospice care for patients with dementia, mostly medium WoE, identify that they are rarely referred for hospice care.[34 36 82–84] Referral is more frequent if there is also a cancer diagnosis;[82] otherwise, it occurs very late in the illness[83] or not at all.

In contrast, patients with motor neuron disease often receive hospice care,[34 85 86] with hospice death more common than those with multiple sclerosis or Parkinson's disease.[87] Patients with multiple sclerosis are more likely to die in hospice if they also have a cancer diagnosis.[88]

Mental health and learning disability

The limited literature of medium/high WoE papers reports patients with schizophrenia rarely access hospice care[89 90] and people with learning disabilities to be less likely to receive hospice care than the general population.[30 90]

Age

The extensive and high WoE literature concerning the 'oldest-old', people aged 85 years and older, reveals them to be under-represented in hospices across the UK, Australia, New Zealand and Canada.[10 11 15 16 23 25 27–34 36–38 45 47 48 91–106] Centenarians seldom die in UK hospices.[97 98] However, recent evidence suggests that more over 85-year-olds are accessing hospice care in the UK.[11 16 31] One low WoE study found age not to affect hospice referral.[107] One study reported the majority of patients accessing a hospice at home service were 78 years of age or older.[11]

Gender and sexuality

The literature concerning gender is inconsistent. Fifteen largely high WoE studies reported that women were more likely to access hospice care than men.[15 16 24 26–29 32 34 38 46 92 108] However, eight high WoE studies suggested the reverse,[10 11 25 31 102 103 109 110] and seven high/medium WoE studies reported no differences in access based on gender.[45 48 91 99 107 111 112] No papers were identified concerning LGBTQ+ populations, transgender patients or sexuality of couples.

Marital status

The literature concerning marital status is also inconsistent. While many high and medium WoE studies found married individuals were more likely to access hospice services,[16 24 27–29 31–33 38 102] other studies (mostly medium WoE) found marital status to be unrelated to hospice access.[91 97 107 108 111]

Ethnicity and religion

Of the large, mainly high WoE literature concerning ethnicity, the great majority of studies report certain ethnic minority groups to be less likely to receive hospice care than the majority populations in their areas.[13 24 25 29 33 46 93 102 113–118] In contrast, two papers reported some minority groups to be more likely to receive hospice care than their local majority populations.[119 120]

In the UK, reduced access has been reported for a Pakistani/Indian/Bangladeshi groups[113] and Caribbean/Chinese/African groups.[116] Other studies have reported this not to be the case.[34 120 121]

In Australia, indigenous populations are less likely to receive hospice care,[25 29 46 47 102 122] or if a patient's informal carer has a non-English speaking background.[13 123] The New Zealand Maori population is similarly less likely to receive hospice care.[33]

No research was identified concerning access to hospice care for travellers and prisoners: one study of homeless people reported limited access.[124]

Geography

Many papers evidenced geographical factors to influence receipt of hospice care.[15 16 111 123] Access is greater for those living in urban areas, with closer proximity to a hospice and associated services in Australia,[23 28 29 44 45 102 123 125 126] Canada[15 82 93] and the UK.[11 34 41 110 127–129] Availability of services also varies considerably between regions and countries,[11 34 41 103 110 127–130] which may act as a barrier to General Practitioner (GP) referral.[131]

Socioeconomic status

Many, mostly high WoE studies reveal lower hospice access for people living in areas of lower socioeconomic status (SES).[11 13 16 31 32 45–47 93 100 102 120 123 127 128 132–137] In the UK between 1993 and 2012, the proportion of hospice inpatients from the most deprived quintile reduced, while the proportion from the most affluent quintile increased.[31] However, several high WoE studies have found no association between SES and access.[28 29 38 91 94 96 99 107 108 111 138] In fact, some studies report greater access among those from lower SES areas.[41 103]

Other factors

Further factors identified while reviewing the above literature, but neither searched for systematically nor included in the synthesis included: negative public and professional attitudes towards hospice;[139–142] limited awareness of hospice services;[139–141 143–146] the challenges of difficult conversations surrounding the term 'hospice'[139 140] and the extent or lack of a patient' social support networks.[13 143 147 148] There is a web of multicollinearity between these factors and the demographic variables highlighted above.

DISCUSSION

Summary of findings

This review identifies that the literature evidences that certain groups continue to have unequal access to hospice care; the oldest old, ethnic minorities, people with non-cancer illness, those living in rural areas and areas of social deprivation. The literature concerning gender and marital status is inconsistent. The potential factors influencing the findings of this review, and how they might be addressed are explored below.

Strengths and limitations

This major systematic review has brought together the heterogeneous literature concerning access to hospice care up to late 2019. At times it was unclear how authors from different countries were using the term 'hospice'; broad inclusion criteria for 'hospice care' were employed, including inpatient beds, outpatient, day care, community specialist palliative care and hospice-at-home services while seeking to exclude palliative care wards in hospitals, care homes or other long-term care institutions.

Diagnosis, institutional culture and prognosis

Continuing greater access to hospice care of patients with cancer reflects a persistence of the early focus of the hospice movement on cancer care and the final period of life. The more predictable cancer dying trajectory[149 150] facilitates easier recognition of the final phase of life, better suiting time-limited hospice care. The greater prognostic uncertainty for people with chronic chest and heart disease, dementia or frailty of old age inhibits timely end of life care discussions and planning and is a continuing barrier to accessing hospice care. Despite their high symptom burden,[9] the prolonged needs of patients without cancer and difficulties in determining when the terminal stage has been entered, leads to late or no hospice referral.[146 151]

The fact that hospice care in practice continues to primarily address the needs of patients with cancer has been described as an 'historical anachronism'.[152] A new model of hospice care is urgently needed in which the historical cancer-appropriate 'one-size-fits-all' framework[153] is reorganised to prioritise whichever patients need it the most[152] and to better identify those patients with non-cancer illnesses who would benefit from hospice care.[154] The needs of the growing number of people approaching the end of their lives with multimorbidity and frailty presents a major challenge to health and social care services in general and the hospice movement in particular. Innovative collaborative services, based around patient, family and wider community are needed to ensure optimal care for all.

Unique Nneeds

The end-of-life care needs of some groups may be better met by services other than hospice care. The oldest-old, who are under-represented in hospices, may find their long-term care needs, associated with frailty and dementia are better addressed in a care home setting rather than hospice.[155] Many patients approaching the end of life may neither require nor desire specialist palliative care provision from hospice teams, preferring to continue to receive care from their General Practitioner and Community Nursing Team, with whom they have longstanding trusting relationships. Innovative and collaborative models of working are required; in many cases, hospice teams will have more of an educational role rather than direct care provision.

For some groups, therefore, lower use of hospice services may reflect care preferences and choices rather than inequality of provision. Ethnic minority groups also have particular needs at the end of life, including cultural and family expectations and religious practices around dying.[121] Indigenous Australians focus on maintaining spiritual connection to the land and on receiving culturally tailored care from members of the community.[156 157] However, for LGBTQ+ groups, concerns over social prejudice may affect access to hospice care in addition to particular care needs.[158–160]

Greater focus is needed on addressing the needs of minority groups; sensitive involvement of these communities in service codesign is required. 'Home-like' hospice services are needed for rural and less affluent patients as well as increased sensitivity towards the needs of LGBTQ+ patients and ethnic minority groups. The growing numbers of people reaching the end of their lives in multimorbid frail old-age is a challenge that hospice services need to address urgently.[161]

Public awareness of hospice care

A third factor involves different levels of public awareness of what hospice care provides and for whom. Variation in health literacy and knowledge of health services is present across ethnic minorities and socioeconomic groups.[114 162–165] The greater access to hospice care by people in more affluent groups may in part reflect their greater health literacy and the presence of articulate relatives who can advocate for hospice services they know to be available.

Similarly, the concentration of hospices in metropolitan areas limits rural patients' exposure to and knowledge of hospice care. Travelling times further exacerbate impaired access, alongside lack of transport links for relatives.[129 165]

Hospices need to improve their links with the diverse social and cultural groups in the areas they serve, focusing on enhancing their awareness of available hospice services. Particular focus is needed on reaching out beyond affluent metropolitan areas into deprived and rural populations, supported by telehealth and video consultations.[47 122]

The inequalities highlighted in this review are not just the responsibility of the hospice movement. System leaders, health and social care managers, policy makers and commissioners need to recognise and understand that while hospices have a vital contribution to palliative and end of life care provision, meeting patient and family needs requires a collaborative and innovative whole-systems approach.

Future research

This review has highlighted a number of areas in which the current literature is absent or very limited, including optimal ways to support ethnic minority groups, homeless people, LGBTQ+ populations, HIV, diabetes and cystic fibrosis.

CONCLUSION

This systematic literature review highlights the persisting unequal access to hospice services for many groups: people with non-malignant disease, the oldest-old, ethnic minorities, living in rural and socioeconomically deprived areas, are consistently reported to be referred to or to die in hospice less frequently. A combination of prognostic uncertainty, institutional cultures, unique needs of particular groups and a lack of public awareness of services exacerbate these problems. Equity of access for all is urgently needed, with innovative and collaborative services developed to meet the diverse needs of the whole community.

Equity of access for all remains a challenge for the hospice movement.

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Supplementary File. Data extraction form.

Data Extraction Tool	
Details of publication	
• First author	
• Title	
• Source	
• Year / volume / pages	
• First author's institution and country	
Introduction	
• Aim(s) • Research questions / hypotheses	
Study participants	
• Target population	
• Inclusion criteria	
• Exclusion criteria	
• Recruitment	
• Characteristics of participants: - Total nº - age - sex - social class - ethnicity - geographical location - other information -	
Methods	
• Date of fieldwork	
• Research methods / tools used	
Analysis	
• Quantitative analysis	
• Qualitative analysis	

Key findings relevant to review	
1. Diagnosis	
2. Age	
3. Gender	
4. Marital status, sexuality.	
5. Ethnicity & religion	
6. Geographical: rurality, distance to hospice, etc	
7 Socioeconomic	
8. Learning disability	
9. Comorbid conditions: dementia, etc	
10.	
11.	
Author(s) conclusion(s)	
References of interest	
Reviewer's quality assessment (Gough's Weight of Evidence)	
Weight of Evidence A Coherence and integrity of the evidence *in its own terms*	
Weight of Evidence B Appropriateness *of form of evidence* for answering review question	
Weight of Evidence C *Relevance of the evidence* for answering review question	
Weight of Evidence D *Overall assessment* of study contribution to answering review question	

First author + year with reference number	Title	Reference	Participants -	Death or referral	Key findings	Gough weight of evidence
9. Addington-Hall 1998	Specialist palliative care in non-malignant disease.	Palliative Medicine. 1998; 12: 417-427	3696 patients randomly selected from death registrations in the last quarter of 1990 in 20 self-selected English health districts.	Death	An estimated 71,744 further people dying from non-malignant disease in England and Wales each year may require specialist palliative care.	MMM = **M**
10. Bennett 2016	What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city.	BMJ Open. 2016; 6: e012576	4650 referrals made to three SPC units (one HPC and two CPCs) in Leeds (UK) from April 2012 to March 2014.	Referral	Referral to specialist palliative care services was more likely for those with cancer, those aged <85 years old and males.	MHL = **M**
11. Buck 2018	Persistent inequalities in Hospice at Home provision.	BMJ Supportive & Palliative Care. 2018 10: e23	321 patients accepted for care by the Cambridgeshire (UK) Hospice at Home service.	Referral	Those with cancer, high socio-economic status, males, aged 78 or older were more likely to access hospice at home. Those with non-malignant disease and who lived in less affluent or rural areas were less likely to access hospice at home.	MHH = **H**
12. Cox 2017	A review of specialist palliative care provision and access across London – mapping the capital.	London Journal of Primary Care. 2017; 9(3): 33-37.	Service mapping of SPC services in London (UK) in 2013 and 2014.	Death	There was variability in the proportion of patients with non-malignant diagnoses seen by SPC services.	MML = **M**
13. Currow 2008b	Populations who die without specialist palliative care: does lower uptake equate with unmet need?	Palliative Medicine. 2008; 22: 43-50.	Survey of 18,224 bereaved South Australian residents between 2000 and 2005.	Death	SPC referral was associated with cancer diagnosis and higher income.	MLL = **L**
14. Currow 2008a	Place of Death for People with Non-cancer and Cancer illness in South Australia: a Population-Based Survey.	Journal of Palliative Care. 2008; 24(3): 144-150.	Population survey of 9500 households in South Australia.	Referral	Those with non-malignant disease were less likely to die in hospice than cancer patients.	MLL = **L**
15. Gao 2011	Identifying Population Groups with Low Palliative Care Program Enrolment Using Classification and Regression Tree Analysis.	Journal of Palliative Care. 2011; 27(2): 98-106.	6892 adults who died of cancer in Nova Scotia (Canada) between 2000 and 2005.	Death	Increasing age, male gender and rural location were associated with reduced access to palliative care services.	HHM = **M**
16. Gao 2013	Changing patterns in place of cancer death in England: a population-based study.	PLoS Med. 2013; 10(3): e1001410.	All cancer deaths (n=2,281,223) in England collected by ONS between 1993 and 2010.	Referral	Elderly patients or those with haematological malignancies were more likely to access hospice services in 2006-2010 compared to 1993-1995.	HHM = **H**
17. Gao 2014	Geographical and temporal Understanding In place of Death in England (1984–2010): analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care).	Health Services and Delivery Research. 2014	All registered deaths (n = 13,154,705) that occurred between 1984 and 2010 in England.	Referral	17% of cancer deaths and 4% of deaths from neurological causes occurred in a hospice.	MLM = **M**
18. Gilbert 2010	Increased non-cancer admissions to hospice palliative care units – will this hurt cancer care?	Palliative Medicine. 2010; 1: S176.	3723 patients admitted to four hospice palliative care units in Canada between 2002 and 2009.	Death	There was an increase in non-cancer patient admissions to hospice units.	LMM = **M**
19. Gomes 2012	Reversal of the British trends in place of death: Time series analysis 2004-2010.	Palliative Medicine. 2012; 26(2): 102-107.	All decedents (n = 3,525,564) in England and Wales (UK) between 2004 and 2010.	Referral	There was an increase in the proportion of deaths taking place in inpatient hospices for both cancer and non-cancer patients.	HHM = **H**
20. Gomes 2008	Where people die (1974-2030): past trends, future projection and implications for care.	Palliative Medicine. 2008; 22: 33–41.	Aggregated ONS data on all deaths in England and Wales between 1974 and 2003.	Referral	There has been only a small change (0.1%) in the numbers of people dying in a hospice.	MLL = **L**
21. Grande 2006	The influence of patient and carer age in access to palliative care services.	Age and Ageing. 2006; 35: 267-273.	123 patients referred to a UK hospice at home service whose primary carer could be interviewed.	Death	Patients who received inpatient hospice care tended to be younger, female, and have cancer.	HHH = **H**
22. Harrison 2012	Are UK primary care teams formally identifying patients for palliative care before they die?	British Journal of General Practice. 2012; 62(598): e344-e342	201 patients from 6 GP surgeries in Scotland listed as palliative on records.	Death	Hospice death was more likely amongst cancer patients compared to patients with dementia and organ failure.	MMM = **M**

23. Hunt 1996	A population-based study of the coverage of cancer patients by hospice services.	Palliative Medicine. 1996; 10: 5-12.	2800 cancer decedents in South Australia in 1990.	Referral	Patients that missed out on hospice services included the elderly, those with a haematological malignancy, and rural residents.	HHH = **H**
24. McCarthy 1990	Hospice patients: a pilot study in 12 services.	Palliative Medicine. 1990; 4: 93-104	195 patients seen by 12 hospices across the UK in July 1998.	Death	The majority of patients referred to a hospice were married or widowed and were of UK or Irish descent.	MMH = **M**
25. McNamara 2007a	Factors affecting place of death in Western Australia.	Health and Place. 2007; 13: 356-367.	26,882 decedents in Western Australia between July 2000 and December 2002.	Referral	1.4% of those with a non-cancer condition died in a hospice compared to 17.1% of those with cancer.	HMH = **H**
26. Napolskikh 2009	Demographic profile and utilization statistics of a Canadian inpatient palliative care unit within a tertiary care setting.	Current Oncology. 2009; 16(1): 49-54.	508 referrals made to the Palliative Care Unit at the Sunnybrook Health Sciences Centre, Canada between 2005-6.	Death	Most patients referred to the inpatient palliative care unit were male and had a malignant diagnosis. Hematologic patients had less access.	LMM = **M**
27. Pivodic 2016	Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries.	Journal of Epidemiology and Community Health. 2016; 70(1): 17-24.	Decedents (n= 2,220,997) with diseases indicative of palliative care need in 14 countries in 2008.	Referral	Death in a palliative care institution were less likely for non-cancer patients, those over 80, those not married and male patients.	HHH = **H**
28. Rosenwax 2016	A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?	BMC Palliative Care. 2016; 15: 46.	12,816 decedents in Western Australia 2009-10 who had an underlying cause of death potentially amenable to receiving palliative care.	Death	SPC services were accessed by 14% decedents with non-cancer conditions, representing a 6% increase on SPC access reported for the same decedent group ten years earlier.	HHH = **H**
29. Rosenwax 2006	Who receives specialist palliative care in Western Australia – and who misses out.	Palliative Medicine. 2006; 20: 439-445.	26,882 decedents in Western Australia 2000-2 who died from cancer or selected non-cancer conditions.	Referral and death	Comorbid conditions, age >75, not being married, living in a rural location impacted negatively on SPC usage.	HMM = **M**
30. Sharpe 2016	"Don't leave me this way": Recognising the unrecognised need for specialist palliative care in the general hospital population.	Palliative Medicine. 2016; 30(4): S95	223 patients admitted to the Royal Sussex County Hospital (UK) between June and November 2014.	Referral	Those not identified as having specialist palliative care needs by health care professionals were more likely to have a non-cancer diagnosis, be over the age of 85 and have higher rates of cognitive impairment.	MLL = **L**
31. Sleeman 2016	The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993–2012.	Palliative Medicine 2016; 30(1): 45-53	446,615 patients dying in inpatient hospice units in England, from 1993-2012.	Death	Very few non-cancer patients died in hospice, despite this improving over time, including for haematological malignancies. The average age of hospice patients also increased, with more 85+ decedents. Most hospice patients were men and were married. There was a decrease in hospice deaths amongst the most deprived quintile, but an increase amongst the least deprived.	HHH = **H**
32. Sleeman 2014	Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001–2010.	BMC Neurology. 2014; 14: 59.	388,899 patients dying with dementia in England between 2001 and 2010.	Death	Few dementia patients died at hospice (0.3%). Those who were female, younger, married, lived in urban areas and had an underlying cause of death of cancer died in hospice more often. Those belonging to the most deprived quintile died in hospice the least compared to other quintiles.	HHH = **H**
33. Taylor 2011	Place of death related to demographic factors for hospice patients in Wellington, Aotearoa New Zealand.	Palliative Medicine. 2011; 26(4): 342-349.	1268 patients receiving services from the Mary Potter hospice in New Zealand from 2006-8.	Death	Asian ethnicity, cancer diagnosis, being married, younger age and being admitted initially to hospice for respite care were associated with an increased likelihood of hospice death. Other ethnic minorities had less access.	HMH = **H**
34. Allsop 2018	Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study.	Palliative Medicine. 2018; 32(8): 1322-33.	42,758 adult decedents with progressive, advanced disease, with a prior referral from 64 UK hospices.	Referral	Those with cancer, MND, heart failure, being female, being of black/ African/ Caribbean/ Black British ethnicity, or living in the south of England, had longer referral to death days. Those with a non-cancer diagnosis, increasing age, being male, dementia, stroke, lung/ liver cancer, liver/ kidney failure had shorter referral to death days.	HMH = **H**
35. Currow 2004	Specialist palliative care needs of whole populations: a feasibility study using a novel approach.	Palliative Medicine. 2004; 18(3): 239-47.	3027 randomly selected South Australians.	Referral	People with a cancer diagnosis were more likely to access specialised palliative care services. Those with an income above AU$60,000 per year were more likely to report the use of palliative care services.	HMH = **H**

					Rates of access to specialist palliative care services were similar regardless of country of birth, educational level, or residential region.	
36. Kelly 2018	The dementia patient's pathway through the Specialist Palliative Care services Part I.	European Journal of Palliative Care. 2018; 25(1): 37-39.	409 Referrals to an SPC service during 2012.	Referral	42% of referrals had a non-malignant diagnosis and 58% had a malignant diagnosis; 15% met the inclusion criteria of having been referred with a primary diagnosis of dementia (7%) or having a co-morbidity of a diagnosis of dementia (8%); 44% were aged 80–89 years.	LML = **L**
37. Verne 2013	Increasing numbers of colorectal cancer patients are dying at home or in care homes in England over the past decade	Colorectal Disease. 2013; 15: 102.	Mortality records for England (UK collected by ONS between 2002 and 2011 (N = not known).	Death	The total number of deaths from colorectal cancer in hospices remained stable between 2002 and 2011. Deaths in hospice for colon and rectal cancers were younger than 65.	LLL = **L**
38. Addington-Hall 2000	Which terminally ill cancer patients in the United Kingdom receive care from community specialist palliative care nurses?	Journal of Advanced Nursing. 2000; 32(4): 799-806	2074 cancer decedents in last quarter of 1990 in 20 self-selected English districts.	Death	Patients who had haematological malignancies, who were aged over 75 or who were not married were less likely to receive specialist palliative nursing care.	HML = **M**
39. Ansell 2007	What determines referral of UK patients with haematological malignancies to palliative care services? An exploratory study using hospital records.	Palliative Medicine. 2007; 21: 487-492.	122 adults registered with the Haematological Malignancy Research Network (UK) and diagnosed with a haematological malignancy between September 2004 and November 2005.	Death and referral	33 patients were referred to SPC services. Eight died in a hospice.	MHM = **M**
40. Auret 2003	Australasian haematologist referral patterns to palliative care: lack of consensus on when and why.	Internal Medicine Journal. 2003; 33: 566-571.	Questionnaire of 51 delegates attending the Haematology Society of Australia and New Zealand Congress 2000.	Referral	29% of respondents had difficulties referring to SPC services.	LLH = **M**
41. Gatrell 2003	Place of death: analysis of cancer deaths in part of North West England.	Journal of Public Health Medicine. 2003; 25(1): 53-55.	6900 deaths within the 89 electoral wards of the Morecambe Bay area (UK) between 1993 and 2000.	Death	Patients with cancer of the lymphatic system were less likely to die in hospice. Patients in wards close to the hospice were more likely to die in a hospice.	HMM = **M**
42. Howell 2013	Place of death in haematological malignancy: variations by disease sub-type and time from diagnosis to death.	BMC Palliative Care. 2013; 12: 42.	4839 patients dying of haematological malignancies in the UK who had been diagnosed between 2004 and 2010.	Referral	7.5% of patients died in a hospice and this percentage differed amongst different haematological malignancies.	HHM = **H**
43. Howell 2015	Variations in specialist palliative care referrals: findings from a population-based patient cohort of acute myeloid leukaemia, diffuse large B-cell lymphoma and myeloma.	BMJ Supportive and Palliative Care. 2015; 5: 496-502.	323 patients dying of haematological malignancies in the UK who had been diagnosed between 2005 and 2008.	Death	There was a difference in referral rates to SPC services between different haematological malignancies.	HHM = **H**
44. Hunt 1993	Trends in the terminal care of cancer patients: South Australia, 1981-1990.	Australian and New Zealand Journal of Medicine. 1993; 2: 245-251.	2715 cancer decedents in South Australia in 1990.	Referral	The location of care for terminal cancer patients shifted from hospital to hospice services from 1981-1990.	HHH = **H**
45. Hunt 1998	Coverage of cancer patients by hospice services, South Australia, 1990 to 1993.	Australian and New Zealand Journal of Public Health. 1998; 22(1): 45-48.	2800 and 2873 patients using hospice services in South Australia in 1990 and 1993 respectively.	Death	Similarly reports that rural residents, the elderly, and those with a haematological malignancy often miss out on hospice services.	HHH = **H**
46. Hunt 2001	Where patients with cancer die in South Australia, 1990-1999: a population-based review.	The Medical Journal of Australia. 2001; 175(10): 426-9.	29230 cancer decedents in South Australia between 1990 and 1999.	Death	Patients who were most likely to die in a hospice included females, those aged 70-79, and those from higher socioeconomic groups. Patients who were least likely to die in a hospice included those with haematological malignancies, and those with Aboriginal or Asian ethnicity.	HHH = **H**
47. Hunt 2019	Where patients with cancer die: a population-based study, 1990 to 2012.	Journal of Palliative Care. 2019; 34(4): 224-31.	Registry records of 86, 257 patients with cancer who died from 1990 to 2012.	Referral	Cancer patients were more likely to die in hospice if they were young and had a high socioeconomic status. Older patients and those with lower socioeconomic status were less likely to die in hospice. Those	HMM = **M**

					with primary cancers of breast, prostate, head and neck and melanoma had lower odds of dying in hospice. Asian and Aboriginal and Torres Strait Islander people were less likely than Caucasians to receive in-hospice care.	
48. Johnston 1998	Identifying potential need for cancer palliation in Nova Scotia.	Canadian Medical Association Journal. 1998; 158(13): 1691-8.	All adults (n = 14,494) who had died of cancer from 1988 to 1994 in Nova Scotia.	Death	Elderly patients, as well as those with a haematological malignancy, were less likely to be referred to palliative care services.	HHH = **H**
49. Vidrine 2016	Place of death in patients with haematological malignancy in North-East of England: Where does this happen and what factors may influence this?	British Journal of Haematology. 2016; 173 S1: 33	Case note audit of 39 haematological cancer decedents under the care of a cancer centre in Newcastle-upon-Tyne (UK) between March and August 2015.	Death	Only two patients (6.5%) with a haematological malignancy died in a hospice.	LLL = **L**
50. Campbell 2014	Discrepancy between preferred and actual place of death in patients with acute heart failure.	European Journal of Heart Failure. 2014; 16: 122.	114 patients with acute heart failure recruited between January 2013 and August 2013 in Glasgow (UK).	Death	5% of patients with heart failure died in a hospice.	MLL = **L**
51. Cheang 2015	Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals.	Open Heart. 2015; 2(1): e000188.	Survey of 499 medical professionals working in palliative care in the UK between June and December 2013.		The average heart failure burden was 3% of the total palliative care workload.	HHM = **H**
52. French 2011	Where do elderly patients with heart failure die?	Age and Ageing. 2011; 40: S23.	494 heart failure decedents who had been referred to a heart failure service at Sunderland Royal Hospital (UK) between 2001 and 2007.	Death	0.9% of the cohort died in a hospice.	LLM = **L**
53. Gibbs 2006	Survey of specialist palliative care and heart failure: September 2004.	Palliative Medicine. 2006; 20: 603-609.	Survey of 233 consultants of English SPC services.	Death	Each service had a mean number of 0.8 patients with heart failure.	LLL = **L**
54. Horne 2004	Removing the boundaries: palliative care for patients with heart failure.	Palliative Medicine. 2004; 18: 291-296.	Interview of 20 patients in Doncaster (UK) who had a clinical diagnosis of heart failure between October 2001 and March 2002.	Death	None of the patients had been referred to SPC services.	MLL = **L**
55. Chen 2017	General Practitioner Perceptions of Current Services for Heart Failure Patients: A Qualitative Study.	European Journal of Heart Failure. 2017; 19: S1.	Interviews with 20 GPs in Northern Ireland (UK), conducted between June and August 2016.	Referral	GPs reported poor awareness of the role of SPC services in heart failure.	LLL = **L**
56. Jones 1995	Palliative care in terminal cardiac failure.	British Medical Journal. 1995; 310: 805	Survey of 10 hospices in North-East London and Essex (UK).	Referral	Four of the surveyed hospices would consider admitting patients with a primary diagnosis of end stage cardiac failure, only two of these had admitted patients with this condition in the past year. However, this was matched by few requests for palliative care beds for patients with heart failure.	LMM = **M**
57. Kaul 2016	Home, hospital or hospice? Trends and predictors of location of death among patients with heart failure and acute coronary syndromes.	European Heart Journal. 2016; 37 S1: 532.	All patients discharged alive from hospitalisation with a primary diagnosis of HF (n=31,274) or ACS (n=54,886) in Alberta Canada between April 2002 and March 2014.	Death	Less than 2% of patients with HF or ACS died in a hospice, and these rates have not changed over time.	LLM = **L**
58. McKinley 2004	Care of people dying with malignant and cardiorespiratory disease in general practice.	British Journal of General Practice. 2004; 54(509): 909-913.	154 decedents with malignant or cardiorespiratory disease from two Leicestershire (UK) general practices between August 2000 and July 2002.	Death	18% of the cancer decedents died in a hospice compared to 0% of those with cardiorespiratory disease.	HML = **M**
59. Murray 2002	Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community.	British Medical Journal. 2002; 325(7370): 929.	Interview and focus groups of 20 outpatients with inoperable lung cancer and 20 patients with advanced cardiac failure and their main informal and professional carers in Edinburgh (UK).	Referral	Specialist palliative care and hospice referral was more likely for lung cancer patients than heart failure patients.	MMH = **M**

60. Thorns 2001	Management of severe heart failure by specialist palliative care.	Heart. 2001; 85: 93	9920 patients referred to St Christopher's Hospice, London (UK) between 1994 and 1999 for heart failure.	Referral	19 patients were referred to the hospice with heart failure.	HHH = **H**
61. Woolcock 2014	The role of Specialist Palliative Care Services in the Management of patients with pulmonary arterial hypertension; a review of current practice.	Thorax. 2014: 69: A144	31 UK patients with pulmonary arterial hypertension who died between June 2013 and June 2014.	Death	Only four patients received palliative care input in the community. Only 11 (35%) had documented evidence of specialist palliative care involvement.	LLL = **L**
62. Addy 2014	Improving care for adults with end stage cystic fibrosis at Bristol Adult CF Centre (BACFC).	Journal of Cystic Fibrosis. 2014; 13: S10	17 CF decedents at the Bristol (UK) Adult Cystic Fibrosis Centre between 2007 and 2013.	Death	Only one patient with CF died in a hospice.	LLL = **L**
63. Cohen 2017	Differences in place of death between lung cancer and COPD patients: a 14-country study using death certificate data.	Primary Care Respiratory Medicine. 2017; 27(1): 14.	561,151 decedents across 14 countries in 2008.	Referral	In England, Wales and New Zealand, COPD decedents had a significantly lower chance of dying in a palliative care institution than lung cancer decedents.	HLM = **M**
64. Edmonds 2001	A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer.	Palliative Medicine. 2001; 16: 287-295.	Interview of the bereaved relatives of 449 lung cancer and 87 chronic lung disease decedents in England.	Death	Patients with lung cancer were more likely to receive hospice care than those with chronic lung disease	HMH = **H**
65. Elkington 2005	The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life.	Palliative Medicine. 2005; 19: 485-491.	Questionnaire of bereaved informants of 209 chronic obstructive pulmonary disease decedents in London (UK).	Referral	Only one chronic obstructive pulmonary disease patient died in a hospice.	MLL = **L**
66. Gore 2000	How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer.	Thorax. 2000; 55: 1000-1006.	Questionnaire of R+C patients with COPD and 50 patients with NSCLC in Hull (UK).	Death	30% of patients with non-small cell lung cancer received help from a Marie Curie nurse, Macmillan nurse or hospice centre. In contrast, none of the patients with COPD received, or were offered access to these services.	HHH = **H**
67. Hayle 2010	Palliative care for patients with COPD: the impact of collaborative working in Salford.	Palliative Medicine. 2010; 24: 202-252.	Two retrospective case-note reviews of patients with COPD referred to specialist palliative care services in Salford (UK) in 2006-7 and 2007-8.	Referral	Referrals to palliative care for COPD patients increased from 12% to 38% within the period studied.	MLM = **M**
68. Higginson 2017	Which patients with advanced respiratory disease die in hospital? A 14-year population-based study of trends and associated factors.	BMC Medicine. 2017; 15: 19.	All deaths (n = 380,232) in England between 2001 and 2014 inclusive with COPD or IPD as a cause of death.	Death	Deaths within hospices accounted for just 0.9% of chronic obstructive pulmonary disease and 2.9% of interstitial pulmonary diseases cases.	HMM = **M**
69. McVeigh 2016	The provision of generalist and specialist palliative care for patients with non-malignant respiratory disease in the North and Republic of Ireland: a qualitative study.	BMC Palliative Care. 2016; 17: 6.	Interview and focus groups involving 17 bereaved carers and 18 healthcare providers for non-malignant respiratory disease patients in the North and Republic of Ireland (UK).	Death	Specialist palliative care was offered to a minority of these patients and only at the end of life.	MLL = **L**
70. Partridge 2009	Palliative Care Services for those with chronic lung disease.	Chronic Respiratory Disease. 2009; 6: 13-17.	Survey of 107 respiratory physicians working in 104 major hospitals in the UK.	Death	81% of respondents felt that there were gaps in current SPC services in their locality for patients with severe chronic non-malignant lung disease.	MMH = **M**
71. Smallwood 2016	Palliation of patients with chronic obstructive pulmonary disease at the end of life.	Respirology. 2006; 21 S2: p143.	Medical record audit of 113 patients who died from COPD at The Royal Melbourne Hospital, Australia between 2004 and 2013.	Death	Only 11 (16.7%) patients with COPD received specialist palliative care prior to terminal admission.	LLL = **L**
72. Gunda 2005	National Survey of Palliative Care in End Stage Renal Disease in the UK.	Nephrology Dialysis Transplantation. 2005; 20: 392-395.	Questionnaire of representatives from 69 UK Renal units.	Referral	Local hospices were 'usually' or 'always' involved with 20% of Renal Units.	MLL = **L**
73. Hobson 2011	National Survey of the Current Provision of Specialist Palliative Care Services for Patients with End Stage Renal Disease.	Nephrology Dialysis Transplantation. 2011; 26: 1275-1281.	Questionnaire of 318 lead clinicians in UK adult hospital, hospice and	Referral	Most specialist palliative care respondents believed that SPC has a role in providing care for end-stage renal disease patients.	MMH = **M**

			community SPC services. The survey was conducted in 2008.			
74. Hussain 2013	Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease.	Palliative Medicine. 2013; 27(9): 829-839	441 patients located within West Yorkshire (UK) who were referred for pre-dialysis care.	Death	Patients in the conservative management group had greater access to specialist palliative care services compared to those who underwent renal replacement therapy.	MHH = **H**
75. Lovell 2017	Understanding patterns and factors associated with place of death in patients with end-stage kidney disease: A retrospective cohort study.	Palliative Medicine. 2017; 31(3): 283-288.	Patients (n =321) with chronic kidney disease stage 4-5 aged 75 and above known to one UK renal team between 2006-2012.	Death	Place of death varied according to management pathway: patients who had conservative management were much less likely to die in a hospice than those receiving renal replacement therapy.	HMM = **M**
76. Okamoto 2015	Conservative Care for ESRD in the United Kingdom: A National Survey.	Clinical Journal of the American Society of Nephrology. 2015; 10(1): 120-126.	Survey of health care professionals from 67 of the UK's Renal units, in March 2013.	Death	All units worked with specialist palliative care services to care for chronic kidney disease patients.	MHH = **H**
77. Morton 2016	Conservative Management and End-of -Life Care in an Australian Cohort with ESRD.	Clinical Journal of the American Society of Nephrology. 2016; 11(12): 2195-2203.	721 patients commencing renal replacement therapy in 66 Australian Renal Units in 2009.	Death	Patients on renal replacement therapy were less likely to die in a hospice than patients managed conservatively.	HHM = **H**
78. Bablitz 2016	High CAGE score and late referral pattern typify end-stage liver failure patients referred to a regional palliative care program.	Journal of Pain and Symptom Management. 2016; 52(6): e111.	265 decedents with cirrhosis evaluated for liver transplantation at the University of Alberta Hospital (Canada) between January 2000 and December 2013.	Referral	22% patients were referred to regional SPC services.	LML = **L**
79. Low 2016	Palliative Care for Cirrhosis: a UK survey of health professionals' perceptions, current practice and future needs.	Frontline Gastroenterology. 2016; 7: 4-9.	Questionnaire of 517 UK health care professionals working in hepatology teams, specialist palliative care and general practitioners with an interest in gastroenterology.	Death	Patients with cirrhosis made up 1% of the specialist palliative care workload. Referrals made by hepatology professionals to specialist palliative care were low.	MMM = **M**
80. Low 2017	Advanced chronic liver disease in the last year of life: a mixed methods study to understand how care in a specialist liver unit could be improved.	BMJ Open. 2017; 7(8): e016887.	Interview and focus group of 30 patients with liver cirrhosis who attended a tertiary referral liver transplant centre in North London (UK) and died between April 2010 and September 2011.	Death	Only 7% of the patients died in a hospice.	HLL = **L**
81. Poonja 2014	Patients with cirrhosis and denied liver transplants rarely receive adequate palliative care or appropriate management.	Clinical Gastroenterology and Hepatology. 2014; 12: 692-698.	102 patients with cirrhosis in Edmonton, Canada who were delisted or declined liver transplant from January 2005 to December 2010.	Referral	Only 11 patients were referred for palliative care, and four died in a hospice, despite a large need for palliative care services.	MMM = **M**
82. Crowther 2013	Palliative care for dementia – time to think again?	QJM: An international Journal of Medicine. 2013; 106(6): 491-494.	Interview of 40 bereaved people who had cared for a patient with dementia in the UK between 2008 and 2011.	Death	There were only four referrals to SPC and end of life services.	MLM = **M**
83. Houttekier 2010	Place of death of older persons with dementia. A study in five European countries.	Journal of American Geriatric Society. 2010; 58(4): 751.	30,281 dementia patients across five European countries (England, Wales, Scotland, Belgium the Netherlands) in 2003.	Referral	Patients with dementia were referred to SPC less frequently, and often late in the course of the disease, explaining why so few died in a hospice.	HML = **M**
84. Zheng 2013	How good is primary care at identifying patients who need palliative care? A mixed methods study.	European Journal of Palliative Care. 2013; 20(5): 216-222.	Case note review of nine Scottish (UK) GP practices over a 12 month period, comprising the notes of 684 patients.	Referral	Palliative care was often initiated too late, and perceived as being appropriate only for patients who appeared to be reaching a terminal decline. Dementia patients had difficulties in accessing specialist palliative care.	HHH = **H**

85. Chaudri 2003	Patterns of mortality in patients with motor neurone disease.	Acta Neurologica Scandinavica. 2003; 107: 50-53.	179 decedents with motor neurone disease seen by a motor neuron disease clinic in Nottingham (UK) between 1990 and 2000.	Referral	25 motor neurone patients were referred to hospice care. Within this population, more females died in hospice compared to males.	MMM = **M**
86. O'Brien 1992	Motor Neurone Disease: a Hospice Perspective.	British Medical Journal. 1992; 204(6825): 471-3.	124 patients with motor neurone disease cared for by St Christopher's Hospice (UK) between January 1980 and November 1990.	Referral	In a 10 year period, only 124 patients with motor neurone disease were cared for at the hospice.	MMM = **M**
87. Sleeman 2013	Place of death, and its relation with underlying cause of death, in Parkinson's disease, motor neurone and multiple sclerosis: A population-based study.	Palliative Medicine. 2013; 27(9): 840-846.	All deaths (n=125,242) in England (UK) with a contribution from Parkinson's Disease (PD), Multiple Sclerosis (MS) or Motor Neurone Disease (MND) between 1993-2010.	Referral	Hospice deaths were extremely uncommon in PD and MS (0.6% and 2.5%) but more common in MND (11.2%).	HHM = **H**
88. Martin 2016	Progressive Dwindling in Multiple Sclerosis: An Opportunity to Improve Care.	PLoS One. 2016; 11(7): e0159210.	582 patients with multiple sclerosis (MS) who died between 1998 and 2015 and had been registered with the UK MS Tissue Bank.	Death	4.6% of patients died in a hospice. Those who died an MS-related death were far less likely to die in a hospice than those who died a non-MS related death.	HHM = **H**
89. Chochinov 2012	Comparative health care use patterns of people with schizophrenia near the end of life: a population-based study in Manitoba, Canada.	Schizophrenia Research. 2012; 141: 241-246.	A matched cohort study of 3943 decedents with schizophrenia and 11827 decedents without schizophrenia who died between 1995 and 2008 in Manitoba (Canada).		Decedents without schizophrenia were less likely to be using SPC services than those without schizophrenia.	MLM = **M**
90. Butler 2018	Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study.	International Journal of Mental Health Nursing. 2018; 27(2): 737-746.	147 individuals with serious and persistent mental illness were compared with the general population (n = 3956) in the Capital and Coast District Health Board (New Zealand) in 2008-2014.	Referral	People with serious and persistent mental illness were 3.51 times less likely to access SPC services than the general population.	HHH = **H**
91. Addington-Hall 1998	Which terminally ill cancer patients receive hospice in-patient care?	Social Science and Medicine. 1998; 46(8): 1011-1016.	2074 cancer decedents in the last quarter of 1990 in 20 self-selected English districts.	Death	Factors associated with increased likelihood of hospice inpatient care included being aged under 75 and having specific symptoms (pain in the last year of life or constipation).	HHH = **H**
92. Burge 2002	Population-based trends in referral of the elderly to a comprehensive palliative care program.	Palliative Medicine. 2002; 16: 255-256.	4376 cancer decedents in the Halifax Regional Municipality (Canada) between 1992 and 1997.	Referral	Patients aged over 65 were much less likely to be referred to SPC services compared to those under 65.	HMM = **M**
93. Burge 2008	A Population-based Study of Age Inequalities in Access to Palliative Care Among Cancer Patients.	Medical Care. 2008; 46(12): 1203-1211.	7511 cancer decedents in Nova Scotia (Canada) between January 1998 and December 2003.	Referral	Registration with a palliative care program was more likely amongst those with cancer, those <65 years old, women, and those living in upper income neighbourhoods. Patients in Francophone communities were less likely to be registered with a palliative care program.	HHH = **H**
94. Burt 2010a	Deprivation Scores and Access to Specialist Palliative Care Services in Cancer Patients in Dundee.	Palliative Medicine. 2010; 24: S172.	Audit of 108 patients in Dundee (UK) dying from cancer over the last three months of 2006.	Referral	Social deprivation did not affect access to SPC services. Younger patients were more likely to access services.	LLL = **L**
95. Cartwright 1993	Dying when you're old.	Age and Ageing. 1993; 22(6): 425-430.	Interview of 639 decedents in 10 areas of England in 1987.	Death	Increasing age was associated with a decreased likelihood of hospice death.	HMM = **M**
96. Davies 2006	How is place of death from cancer changing and what affects it? Analysis of cancer registration and service data.	British Journal of Cancer. 2006; 95(5): 593-600.	216,404 cancer decedents in South-East England between 1985 and 2002.	Referral	Hospice death was more likely for specific cancer diagnoses, and those aged <75.	HHH = **H**
97. Evans 2014	Place and Cause of Death in Centenarians: A Population-Based Observational Study in England, 2001 to 2010.	PLoS Medicine. 2014; 11(6): e1001653.	35,867 decedents aged ≥100 years in England who died between 2001 and 2010.	Referral	0.2% of centenarians died in a hospice.	HMM = **M**
98. Fleming 2010	Place of death for the 'oldest old': ≥85-year-olds in the CC75C population-based cohort.	British Journal of General Practice. 2010; 60(573): e171-e179.	320 decedents aged ≥85 years in Cambridgeshire (UK) 1985-2007.	Death	2% of this cohort died in a hospice.	HHM = **H**

99. Gray 1997	Factors associated with utilisation of specialist palliative care services: a population based study.	Journal of Public Health Medicine. 1997; 19(4): 464-469.	521 patients who had died in a Northern England Health District in 1991.	Referral	There was no variation in specialist palliative care provision according to gender, location, socioeconomic status or cancer site. Those who received specialist palliative care were younger compared to those who did not.	HMH = **H**
100. Kessler 2005	Social class and access to specialist palliative care services.	Palliative Medicine. 2005; 19: 105-110.	Survey and interview of 960 cancer decedents and 18 carers of these patients in Bristol (UK) between September 1999 and November 2002.	Death	Those from a lower social class were less likely to die in a hospice.	HHH = **H**
101. Lock 2005	Patterns and predictors of place of cancer death for the oldest old.	BMC Palliative Care. 2005; 4: 6.	All cancer deaths (n =314,462) in England and Wales in those aged 75 and upwards between 1995 and 1999.	Death	The proportion of people who died in a hospice increased between 1995 and 1999. There were marked differences between the 'younger old' and the 'oldest old', with the 'oldest old' less likely to die in a hospice.	HHM = **H**
102. McNamara 2007b	Specialist palliative care use for people dying of cancer in Western Australia.	Cancer Forum. 2007; 21(1): 18-22.	8007 decedents in Western Australia between July 2000 and December 2002.	Death	Patients who were single or widowed; those aged over 85 years old; and those living in a region other than a major city were significantly less likely to receive specialist palliative care services.	HHH = **H**
103. O'Dowd 2016	Place of Death in Patients with Lung Cancer: A Retrospective Cohort Study from 2004-2013.	PLoS One. 2016; 11(8): e0161399.	143,627 patients registered with the National (UK) Lung Cancer Audit between January 2004 and December 2011.	Referral	There was a small increase in patients dying within hospice beds. Factors associated with hospice death included younger age and higher Townsend quintile. There were regional inequalities in hospice provision.	HHM = **H**
104. Ziegler 2018	Age Variation in the Care from Diagnosis to Death for Cancer Patients: A Retrospective Longitudinal Study in a UK Cancer Population.	Palliative Medicine. 2018; 32 S1: 3-330.	Retrospective cohort study linking cancer registry and secondary care data for 13,499 adult cancer patients who died between January 2005 and December 2011.	Referral	Compared with adult patients under 60 years, patients aged 80 years and over were less likely to die in a hospice, but more likely to die in a care home.	MMM = **M**
105. Verne 2018a	What Does National Mortality Data Tell Us about Where Head and Neck Cancer Patients Die and What Influences This?	Palliative Medicine. 2018; 32 S1: 3-330.	Office for National Statistics (ONS) Mortality Dataset.	Referral	Younger patients more likely to die at home (28%) or in hospice (<65 years 25%), and older in care homes.	MHL = **M**
106. Kamisetty 2015	Where do patients treated for oral cancer die? A 20-year old cohort study 1992-2011.	British Journal of Oral and Maxillofacial Surgery. 2015; 53: 1015-1020.	1290 patients treated for primary squamous cell carcinomas at the Maxillofacial Unit in Liverpool (UK) between 1992 and 2011.	Referral	Patients treated for oral cancer were more likely to die at a hospice in 2011 than in the past. Those who were 85+ and those without cancer as underlying cause of death died in hospice less.	HMM = **M**
107. Burt 2010b	Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients.	Palliative Medicine. 2010; 24(6): 641-650.	Questionnaire involving 252 patients with either non-small cell lung cancer or small cell lung cancer, and 137 carers attending chest or oncology outpatient clinics at four NHS trusts in south London (UK) between June 2006 and April 2007.	Referral	39% of participants had confirmed use of SPC. Age, gender, deprivation, living alone, current or most recent line of treatment, number of co-morbidities and carer stress were not associated with receipt of such services.	MMM = **M**
108. Kamisetty 2011	Place of death of oral and oropharyngeal squamous cell carcinoma (OOSCC) patients 1992–2009: who dies at home?	British Journal of Oral and Maxillofacial Surgery. 2011; 49 S1: 9.	1392 newly diagnosed patients with OOSCC presenting to the Maxillofacial Unit in Liverpool (UK) between 1992 and 2009.	Referral	78 out of 541 deaths took place in a hospice.	MLM = **M**
109. Bradshaw 1993	Characteristics of clients referred to home, hospice and hospital palliative care services in Western Australia.	Palliative Medicine. 1993; 7: 101-107.	60 records of patients who had died in a six-month period in three SPC settings – hospice care service, cottage hospice and a palliative care unit within a general hospital in Perth (Australia).	Death	Older age, female gender and not having a primary caregiver were associated with a reduced likelihood of receiving care from hospice services.	MMM = **M**

110. Madden 2011	Using maps and funnel plots to explore variation in place of death from cancer within London, 2002–2007.	Palliative Medicine. 2011; 25(4): 323-332	Cancer deaths in London (UK) between 2002 and 2007 (n=84066).	Death	Primary care trusts with a hospice in their area tended to have higher proportions of hospice deaths.	HHM = **H**
111. Davison 2001	Where do patients with cancer die in Belfast?	Irish Journal of Medical Science. 2001; 170(1): 18-23.	Deaths attributable to cancer in Belfast (UK) in 1977 (n = 443), 1987 (n = 455) and 1997 (n = 426).	Referral	There was an association between place of death and age, marital status, type of cancer and area of residence, but not with social class or gender. Changes over time were reported.	HMM = **M**
112. Dunphy 1990	A comparison of hospice and home care patients: patterns of referral, patient characteristics and predictors of place of death.	Palliative Medicine. 1990; 4: 105-111.	404 hospice and 143 home care patients from St Joseph's Hospice London (UK) who had died during the first six months in 1988.	Death	Access to hospice was even across genders.	HHM = **H**
113. Coupland 2011	Does place of death from cancer vary between ethnic groups in South East England?	Palliative Medicine. 2011; 25(4): 314-322.	101,516 cancer decedents in South East England between 1998 and 2006.	Death	Death in a hospice was significantly less common for Pakistani, Bangladeshi and Indian patients than for Caucasian patients. Chinese, Black African and Black Caribbean patients had a similar likelihood of hospice death as Caucasian patients.	MHH = **H**
114. Gaffin 1996	Opening doors: improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities.	British Journal of Cancer. 1996; 29: S51-53.	Study of hospice services in two London boroughs (Brent and Newham) and in North Birmingham (UK).	Referral	Hospices tend to be located in white, middle class areas. People from minority communities were less likely to ask their GP for access to hospice services.	LLM = **L**
115. Karim 2000	Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctor's referral patterns.	Palliative Medicine. 2000; 14: 471-478.	Interview of 27 GPs from two wards in Birmingham (UK).	Death	Language and staff bias were barriers to the referral of black/ethnic minorities to specialist palliative care services.	MMH = **M**
116. Koffman 2004	Dying to be Home? Preferred Location of Death of First-Generation Black Caribbean and Native-Born White Patients in the United Kingdom.	Journal of Palliative Medicine. 2004; 7(5): 628-636.	106 black Caribbean patients and 110 white patients from the UK were contacted to produce a sample of 50 cases per ethnic group. These informants were surveyed over a 13 month period.	Referral	8% of Caribbean patients died in a hospice, compared to 16% of native-born white patients. This reflected patient preference.	HMM = **M**
117. Koffman 2014	Does Ethnicity Affect Where People with Cancer Die? A Population-Based 10 Year Study.	PLoS One. 2014; 9(4): e95052.	93,375 cancer decedents aged ≥65 years in London (UK) 2001-2010.	Death	Deaths in a hospice setting were significantly less likely among those born in Asia and Africa.	HHH = **H**
118. Worth 2009	Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study.	British Medical Journal. 2009; 338: b183.	92 interviews of patients, family carers and health professionals In Central Scotland (UK).	Referral	Only two patients accessed specialist palliative care services. Interviews revealed perceived advantages of, and barriers to the receipt of hospice care amongst ethnic minority patients.	MMH = **M**
119. Fountain 1999	Ethnic minorities and palliative care in Derby.	Palliative Medicine. 1999; 13: 161-162.	1035 new referrals to Derby (UK) SPC services.	Death	Ethnic minorities were slightly more likely than white patients to receive certain SPC services.	MMM = **M**
120. Sharpe 2015	Policy for home or hospice as the preferred place of death from cancer: Scottish Health and Ethnicity Linkage Study population cohort shows challenges across all ethnic groups in Scotland.	BMJ Supportive and Palliative Care. 2015; 5: 443-451.	All cancer patients (n=117,467) aged 25 years or older who participated in the 2001 Scottish census and died from cancer in Scotland between May 2001 and December 2009.	Referral	The Chinese cohort had the largest proportion of hospice cancer deaths (29.9%).	HHM = **H**
121. Verne 2018b	Choice and Place of Death - Does Ethnicity Affect where People Die? - Insights from Routine Data Analysis.	Palliative Medicine. 2018: 32 S1: 3-330.	National data set for England used, which linked Office for National Statistics mortality data to National Hospital Episode data.	Death	Among people who died from cancer: 18,11,20 and 22% people of White British, Pakistani, African, and Chinese origin died in a hospice respectively.	MHM = **M**
122. Waran 2017	The gap reversed: a review of site of death in the Top End.	The Medical Journal of Australia. 2017; 3(207) S1: 39.	308 people, most were men, and most were indigenous Australians.	Death	Indigenous people died in hospices much less frequently compared to non-indigenous people.	LML = **L**
123. Currow 2012	Referral patterns and proximity to palliative care inpatient services by level	BMC Health Services Research. 2012; 12: 424.	Service mapping of 10,064 patients documented in the Palliative Care	Death	People from the most disadvantaged socio-economic group were less likely to be referred to SPC services.	HHM = **H**

	of socio-economic disadvantage. A national study using spatial analysis.		Outcomes Collaboration (PCOC) in Australia in 2006.			
124. Shulman 2018	End-of-life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care.	Palliative Medicine. 2018; 32(1): 36-45.	127 participants, made up of: single homeless people (n=28), formerly homeless people (n=10), health- and social-care providers (n=48), hostel staff (n=30) and outreach staff (n=10).	Death	Accessing hospice services is challenging for homeless people because of stigma, complex multi-morbidities and trauma, substance misuse/ dependence, mental health problems, unstable housing conditions, previous experiences that hospices had with supporting homeless people and many more. Even for homeless cancer patients who were not misusing substances, placement within a hospice remained challenging.	HLL = **M**
125. Burns 2015	Who provides care for people dying of cancer? A comparison of a rural and metropolitan cohort in a South Australian bereaved population study.	Australian Journal of Rural Health. 2015; 23(1): 24-31.	23,588 survey responses on the death of 'someone close'.	Death	In rural areas, half as many people died in hospice compared to those in urban areas. Rates of home death were identical but more rural patients died in hospital compared to urban patients.	MMM = **M**
126. Rainsford 2018	Place of death in the Snowy Monaro region of New South Wales: A study of residents who died of a condition amenable to palliative care.	Australian Journal of Rural Health. 2018; 26(2): 126-33.	Residents, with advanced frailty or one of 10 conditions amenable to palliative care, who died between 1 February 2015 and 31 May 2016. The records of 224 residents who had died in the study period.	Death	In Rural regions: Much less likely to die in hospice compared to residence, hospital, or RACF.	MML = **M**
127. Gatrell 2012	Variation in geographic access to specialist inpatient hospices in England and Wales.	Health and Place. 2012; 18(4): 832-840.	Death records at 189 specialist adult inpatient hospices in England and Wales, 2003-5.	Death	There were geographical discrepancies in access to inpatient hospices. Urban areas were well served by hospices but large parts of England and Wales had poor access to hospices. There were many examples of mismatches between supply and demand.	HHH = **H**
128. Wood 2004	Equity of access to adult hospice inpatient care within north-west England.	Palliative Medicine. 2004; 18: 543-549.	Cancer deaths in the North-West of England (UK) in 2000 (n = not known).	Death	There were 3500 adults likely to have cancer who could have benefited from inpatient hospice care, but who were living in areas that were relatively inaccessible to one or more hospices.	LLL = **L**
129. Chukwusa 2019	Urban and rural differences in geographical accessibility to inpatient palliative and end-of-life (PEoLC) facilities and place of death: a national population-based study in England, UK.	International Journal of Health Geographics. 2019; 18(1): 8.	430,467 individual- level death data extracted from Office for National Statistics data.	Referral	Those who lived more than 10 minutes away from inpatient PEoLC facilities were less likely to die there. The larger the drive time, the less likely to die in hospice. The effect of drive time was greater in rural areas.	MMM = **M**
130. O'Dowd 2015	Place and Cause of Death in Patients with Lung Cancer in the United Kingdom.	Journal of Thoracic Oncology. 2015; 2: S518	143,627 patients registered with the National (UK) Lung Cancer Audit between January 2004 and December 2011.	Referral	17% of lung cancer patients died in a hospice.	LLL = **L**
131. Seamark 1995	Appropriate place of death for cancer patients: views of general practitioners and hospital doctors.	British Journal of General Practice. 1995; 45(396): 359-63.	Questionnaires sent to health practitioners in Exeter Health District (UK) regarding cancer deaths (n = 1053) between May 1991 to April 1992.	Death	Hospice involvement occurred in 39% of the total cancer deaths. The lack of availability of a city-based hospice affected the management of around a third of patients cared for by GPs and hospital doctors.	MMH = **M**
132. Campbell 2010	Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK.	Palliative Medicine. 2010; 24(4): 403-409.	UK National Census 2001 Data from 41 census wards in Salford and Trafford (UK), and referral data from St Ann's Hospice (UK) 2004-2006.	Referral	Patients from socially deprived areas have higher SPC needs but lower referral rates.	HHH = **H**
133. Cartwright 1992	Social class differences in health and care in the year before death.	Journal of Epidemiology and Community Health. 1992; 46(1): 54-57.	Interview of 639 decedents in 10 areas of England in 1987.	Death	Middle class decedents were more likely to die in a hospice compared to working class decedents.	HMM = **M**
134. Cunningham 2011	Income inequities in end-of-life health care spending in British Columbia, Canada: A cross-sectional analysis, 2004-2006.	International Journal for Equity in Health. 2011; 10(1): 12.	58,820 decedents aged 65 and older in British Columbia (Canada) between 2004 and 2006.	Referral	Lower income was associated with a decreased likelihood of using SPC services.	HHM = **M**

135. Sims 1997	Social class variation in place of cancer death.	Palliative Medicine. 1997; 11: 369-373.	831 cancer decedents in Doncaster (UK) in 1996.	Referral	Patients from higher social classes were more likely to die in a hospice.	HMH = **H**
136. Macfarlane 2016	Does place of death vary by deprivation for patients known to specialist palliative care services?	BMJ Supportive & Palliative Care. 2018; 8(4): 428-30.	Place of death and postcode for 485 consecutive patients known to Specialist palliative care services within NHS Lothian (UK), who died in 2014-2015.	Referral	Higher rates of in-hospice death for the least deprived, compared to the most deprived. Greater deprivation is associated with decreased likelihood of dying in hospice. Even after referral to SPC services, these discrepancies persist.	MMM = **M**
137. Bowers 2018	Socioeconomic status is associated with place of death in patients known to hospice services.	Scottish Medical Journal. 2018; 63(1): 53-53.	4585 patient deaths.	Death	As affluence increases percentage likelihood of dying in hospice increases. Deaths in hospice were most frequent in the least deprived quintile and least frequent in the three most deprived quintiles.	MMM = **M**
138. Ziwary 2017	Impact of place of residence on place of death in Wales: an observational study.	BMC Palliative Care. 2017; 16: 72.	Welsh (UK) population mortality statistics from 2005 to 2014.	Death	Hospice mortality rates appeared to be independent of deprivation quintile.	MLL = **L**