Association for
Palliative Medicine
Of Great Britian and Ireland
Tel: 01489 668332 **Email:** Office@compleat-online.co.uk **Website:** www.apmonline.org

Evaluation of Palliative Care in England – APM response to Health and Social Care Committee

The Association for Palliative Medicine (APM) is the leading professional organisation representing over 1,400 healthcare professionals across the UK, the majority of whom are physicians working in palliative medicine. While our primary focus is on specialist palliative care (SPC) services, we appreciate that patients require available, responsive, trained and supported generalist services for good Palliative and End of Life Care (PEoLC).

SUMMARY

The problems;

Whilst there is good practice in PEoLC, services are patchy and inequitable, with inadequate investment and a lack of strategic direction for many years. There is insufficient detail in the SPC service specification about workforce such that ICBs can plan commissioning of care. There is no national patient-centred data collection for PEoLC to measure care and drive quality improvement. This also means it is impossible to know how much hospital-based PEoLC could be shifted to the community, and what resource that would require.

There is insufficient capacity to deliver PEoLC to meet NICE standards both in terms of access and quality. About 75% of people who die require palliative care and only 50% are currently receiving SPC. SPC medical workforce is in a critical situation, with widespread workforce shortages, increasing demand, and fragile service provision.

Coordination of care for PEoLC patients at home is poor. There is inadequate access to symptomatic medication at home when it is needed. There is insufficient recognition of the importance of social care in commissioning of care at the end of life out of hospital. Carers and families are poorly supported by the current level of PEoLC services.

A growing number of children with life-limiting conditions are living into adulthood with increasing complexity. There is no established national model for transition from children's to adult PEoLC. For young people, lack of services, insufficient workforce and unclear commissioning have a significant impact on ability to fulfil care plans for young people.

For patients dying in hospital, clinical care is better for those who had SPC input. However, not all hospitals have appropriately staffed SPC teams, and 40% are not resourced to provide 7 day face to face SPC.

Advance care planning can support achieving patient preferences and reduce avoidable hospital admission. However too few patients have advance care plans. For advance care planning to have the best impact, there needs to be better death awareness among public and professionals; resource for training to have these sensitive conversations; agreed records and fully interoperable electronic databases that support the patient across care settings. It is also vital for there to be sufficient resources that patient choice can be supported.

What we need;

Safe delivery of effective PEoLC requires adequate resource of appropriately trained and supported generalist and specialist staff to meet patient and carer needs at all times and in all settings.

- A national strategy for PEoLC to support ICBs to develop appropriate services delivered collaboratively by partners across all sectors to ensure equitable access for all.
- A national data set including patient centred outcomes to measure effectiveness, access and experience of PEOLC.
- The palliative care needs of all people to be addressed in all relevant care pathways by staff development to support earlier identification and holistic needs assessment and onward referral to supportive services as appropriate to the individual.
- Developing death literacy in the public; community partnership working between patients and the paid and unpaid workforce across all sectors;, and ensuring that the hidden costs of supporting people to die at home are not a barrier.
- Co-ordination in the community can be supported by single points of access for PEoLC with 24/7 advice from palliative care specialists; access to rapid response visits, and timely availability of equipment and medication.
- Well commissioned specialist palliative care, requiring:
    - A national service specification for palliative care provision including detail of SPC workforce required in hospice, community and hospital settings.
    - Ring-fenced funding, a tariff or other mechanism to support the development and consistency of specialist palliative care provision in all settings 24/7
    - Recognition of the importance of earlier SPC involvement so patients have the best QOL for the longest time.
    - Clinical leadership at the heart of care delivery, quality improvement and strategic development.

1. COMMISSIONING OF PALLIATIVE AND END OF LIFE CARE (PEoLC) IN ENGLAND

Resourcing

A survey of ICBs in 2023 with 62% response rate shows that only 35% said they significantly or fully understand the PEoLC needs of their local population[1]. This makes it impossible to know if ICBs are successfully rolling out provision of PEoLC, or if local needs are being met with current provision of PEoLC. Only 3 ICBs responded that they commissioned core components of the Ambitions Framework to a significant degree.

Only 54% of ICBs feel that current investment in PEoLC services is sufficient to meet PEoLC needs to at least a moderate extent[1]. This suggests that PEoLC is insufficiently funded and that ICBs are not able to commission PEoLC that meets demand.

Only 20% of ICBs reported they commissioned 24/7 access to care advice and support for PEoLC and only 25% reported 24/7 access to PEoLC medicines.

A separate review found that less than 25% of ICS strategies highlighted PEoLC as either a priority, area of focus, or an ambition[2].

A growing number of children with life-limiting conditions are living into adulthood with increasing complexity. Demand for PEoLC among young people (14-25 years) is expected to increase but current NHS service specifications and commissioning guidance do not acknowledge the service and funding implications of this growing need on existing adult providers (universal, core and specialist)[3,4,5].

Research and guidance recommends commissioning for transition to adult services to be integrated across adult and child health providers, and between health, education and social care[6,7,8]. It is essential that paediatric and adult PEoLC providers are included in this integrated approach for young people with life-limiting conditions. Historically only children's services have been commissioned to support transition. To enable adult PEoLC providers to step up to meet the needs of young people reaching adulthood, it is essential that they are specifically commissioned and adequately resourced to support transition.

Effectiveness

Effective commissioning is impeded by a lack of a national strategy, inadequate or incomplete guidance, and poor understanding of local needs resulting from an absence of agreed patient centred, meaningful data collection.

The statutory guidance for Integrated Care Strategies and Forward Plans needs to include the legal requirement to commission PEoLC[9]. Guidance also needs to reflect the need to ensure inclusion of specialist and generalist providers of PEoLC, all life-limiting conditions and all service settings. There needs to be a detailed national strategy for PEoLC to better guide commissioning.

There is insufficient understanding of local population PEoLC need to inform local commissioning decisions, and no nationally agreed way of assessing population PEoLC need. There is currently no national data collection for PEoLC which would demonstrate effective delivery of PEoLC services.

Digital Coding for young people with life-limiting conditions is inconsistent, due to the large number of rare conditions, and the wide range of presentations and need[10]. This creates a barrier to identifying the population needing PEoLC, and monitoring their access to the services they need, and their outcomes.

Just over half of ICBs felt they commissioned joined up and coordinated PEoLC services with NHS, primary care, hospices and local authorities[1]. However, only 40% have electronic care records to ensure coordinated delivery of care plans. PEoLC is poorly coordinated, with inequitable access by setting, geographical location, social deprivation and minority groups[11]. Out of hours care is even more variable with evidence of good practice in some areas in access to advice and urgent visits, medication, equipment and care, but in other areas some or all of these are unavailable. 40% of acute hospitals do not have seven day face to face services as required by NICE 2004[12]. A third of community areas do not have 24/7 specialist telephone advice for PEoLC.

Poor coordination is a significant barrier to care for young people with life-limiting conditions as they transition from paediatric to adult services. Young people may be under multiple specialties across several different trusts, with their records held on different electronic systems. Coordinating good transition between services requires significant clinical and administrative time[5].

Impact

The statement of intention from the Health and Care Act 2022 is impossible to measure because it requires ICBs to provide appropriate palliative care services without agreement of what this means in terms of a sufficiently detailed service specification, and without funding for a national data collection and without nationally agreed patient-centred outcomes.

At a service level, there are no agreed standards for transition in PEoLC and a great variation in palliative care service models. This means that “effective delivery of obligations” to young people with life-limiting conditions is unclear and often seen as optional or considered to be the responsibility of another service. In particular there is inconsistent application of age boundaries in both children’s and adult hospices which particularly effects the 16-25 age group, creating barriers to referrals for transition and inequity in end-of-life care provision.

We do not have evidence that equity of access, experience and outcomes are improving.

ICBs report that financial resource is inadequate and even with funding, gaps in workforce are barriers to any positive impact[1].

Appropriateness

It is unclear what “appropriate” provision of palliative care means with the risk that there will be different interpretations between ICBs resulting in inequitable provision. In addition, different age, disease and demographic groups have different needs for PEoLC but this is not recognised in commissioning, except between adults and children’s services.

There needs to be clarity about what core and specialist services should look like for all ages recognising that they are both essential to each other and to the provision of adequate care.

The service specification for Specialist Level Palliative and EOL Care is insufficiently detailed on workforce and skill mix to support adequate commissioning[13].

There is insufficient recognition of the importance of social care in commissioning of care at the end of life out of hospital.

2. DELIVERY OF PALLIATIVE AND END OF LIFE CARE (PEoLC) IN ENGLAND

Resourcing

PEoLC is delivered by specialists and generalists in all settings. Delivery requires adequate resource of staff and staff development. It also requires capacity in terms of service development to ensure best practice.

Specialist services need to be delivered in all settings:

- Consultant-led Palliative Care inpatient units delivered within the NHS or independent sector hospices or hospitals
- Community palliative care teams delivered within the independent hospices or the NHS
- Hospitals require palliative care teams supporting patients with palliative care needs working alongside hospital teams. Increasingly palliative care beds are developing within acute hospitals as patients with more unstable and complex situations emerge[14].

In all settings appropriately resourced and trained staff, equipped with essential equipment are required. Services need to be integrated, operating over 24 hours, seven days a week with central co-ordination.

There is insufficient capacity to deliver PEoLC to meet NICE standards both in terms of access and quality. About 75% of people who die require palliative care and only 50% are currently receiving SPC[12,15,16,17].

The impact of this is shown by over half of bereaved carers reporting inadequacies in PEoLC. They report that recognition of palliative care needs was too late with uncontrolled symptoms, poor coordination of care, difficulty in accessing health and care professionals in the community, and financial and emotional burdens on the informal carers[17].

SPC medical workforce is in a critical situation, with widespread workforce shortages, increasing demand, and fragile service provision. Recruitment to training in SPC has been adversely impacted by the introduction of dual accreditation in 2022 which has resulted in a reduction in specialist trainees from 227 in 2021 to 190 in 2024, with 48 vacant SPC training posts[18]. There are 78 SPC consultant vacancies in the UK and a bulge of expected consultant retirements (132 in the next 5 years) which the existing training capacity is insufficient to fill.

In 2024, 83% of senior SPC doctors reported workforce gaps in their service compared with 59% in other all specialties. Over half of senior SPC doctors reported that these gaps affected their ability to take annual and study leave[19]. The SPC medical workforce is inequitably distributed, both geographically, with underserved regions, and in terms of settings, with some hospital and hospice units struggling to recruit to consultant posts. Providing out of hours (OOH) cover is challenging, and staffing seven day face to services very difficult. The specialist paediatric palliative care workforce is unable to meet the MDT requirements outlined in the NICE guidelines and NHS service specification for paediatric palliative care[20,21]. This is due to lack of funding, and lack of training posts/sites/resources to develop specialist professionals.

Advance care planning requires recognition that a patient is in the last year or so of their life and patients to be fully aware of their current and future health. It requires a sensitive and skilled conversation with them to help them prepare for the future. Where a specific plan is made, it needs to be communicated electronically in a way that allows all other professionals who may be involved in care in all settings, and the patient, to be able to access the record 24/7 and update it. There is very limited advance care planning that meets this standard. If advance care planning is not communicated to all professionals in all settings then the simplest plan, such as preferred place of death, will not take place[22].

Advance care planning for young people may also involve identifying any additional training or resources that will be needed by providers to make reasonable adjustments and ensure person-centred quality care can be delivered at the end of life in the preferred location. (e.g. training learning disability support staff to care for someone at the end of life; or training hospice staff to use a Vagal Nerve Stimulator for seizures). This requires specialist oversight to anticipate needs and negotiate with service providers, and this is not always available.

Delivery of PEoLC requires specialists in Palliative Care and generalists in all settings. The majority of specialist palliative care input is advisory, and relies on generalists to identify need, refer and enact advice. The exception would be patients admitted to hospice/SPC inpatient beds for the duration of the admission. Primary care teams are therefore essential to continuity in provision of PEoLC in the community, provided they have established processes for accessing specialist support. The GP palliative care register provided a suitable forum for maintaining awareness of people with life-limiting conditions and identifying changes in their needs over time, but has been removed from the QOF framework in the new GP contract.

For young people, annual learning disability health checks and structured medications reviews have been a key source of proactive care and continuity during transition to adult services.

Families and carers are insufficiently considered in PEoLC. There should be an agreed carers' assessment tool which guides support, from emotional, to information, practical and financial support. These need to be made more available and professionals need to be made better aware of what support can be offered and where to find it.

Children's hospices often provide respite for young people with life-limiting conditions who are too medically complex to access other respite facilities. As well as providing quality time for the young person, this respite is often seen as a life-line for parent-carers to sustain their responsibilities to their work and other family members as well as self-care. Very few adult hospices are commissioned to offer respite, or feel competent to support young people with profound learning disability or rare/complex conditions.

Effectiveness

Effectiveness of PEoLC should be measured by holistic patient centred outcomes. We currently have no such agreed outcomes or any nationally supported data being collected for benchmarking or to use for quality improvement. Instead proxy measures of quality, such as recording of patient preferences at the end of life, are used which are inadequate and even harmful. Quality of PEoLC is greater with SPC involved but currently only 50% of patients who die receive SPC input.

There is evidence that advance care planning can support achieving patient preferences and reduce avoidable hospital admission. Indeed, implementing advance care planning conversations on emergency admission has been identified as an opportunity to improve patients quality of life and saving £502 million annually (2019/2020 values)[23]. However there are insufficient numbers of patients who have advance care plans, and they are not recorded in a way that makes them available to all who need them. Despite 30% of non-elective admissions to hospital being in the last year of life, only about 5% have advance care plans that are accessible to the admitting medical team[24].

In order for advance care planning to have the best impact, there needs to be better death awareness among public and professionals, resource for training to have these sensitive conversations, agreed records and electronic databases which are fully interoperable with all health, social care and third sector service systems that support the patient.

Communication and co-ordination is neither rapid nor effective between hospital and community but also between community organisations. Co-ordination in the community can be supported by single points of access for PEoLC with 24/7 advice from palliative care specialists, access to rapid response visits and availability or signposting to equipment and medication[25].

There is no established national model for transition from children's to adult PEoLC. While guidance has been developed which sets out broad principles[26], the huge variation in palliative care service models, referral criteria and workforce skill mix makes it challenging to implement guidance consistently. Transition mechanisms for young people with complex conditions are inadequate across multiple specialties – there are isolated examples of palliative care professionals taking strategic leadership roles in improving integrated transition processes for this population.

The evidence is that SPC has the biggest and most sustained impact only when patients are referred more than three months before death. Unfortunately the evidence suggests most SPC involvement is not of this length, with patients referred to hospice based SPC a median of 48 days before death[27]. It is essential that SPC is sufficiently resourced that patients can be supported early enough to improve their quality of life in a sustained way.

For young people, there is very little research evidence from any developed nations around the best models for appropriate palliative care however recommendations are drawn from research in other areas[28].

Impact

Advance care planning can support development of good understanding and better communication between patients and healthcare teams. At best it can support preferences being achieved and reduce avoidable hospital admissions.

However, it is really important that the primary aim of advance care planning is to serve the patient, not the system. In the past aspects of advance care planning, such as proportions of patients with preferred place of care and death recorded, have been used as key performance indicators. The risk is that this encourages conversations which patients may not wish to have. The value of advance care planning lies as much in patients having conversations which help them prepare for the future as it does in documented outcomes.

Advance care plans require recognition that the patient may have a life-limiting illness, professional confidence and training to help the patient navigate the sensitive conversation. As well as supporting all of these steps themselves, SPC professionals are needed to help non-specialist colleagues to engage with all of this through modelling, experiential and simulation teaching[29].

Carers and families are poorly supported by the current level of PEoLC services. There is no agreed and required carers' assessment and the services are not present to provide support that may be identified as required. Bereavement services are insufficient, geographically patchy and dependent on voluntary organisations.

There is evidence of unmet emotional, financial and physical impact of caring for a young person with a life-limiting illness needs in spite of current frameworks[30,31]. This is compounded where siblings are concerned there is additional impact as potential young carers and on child bereavement needs.

For advance care planning to work it must reflect realistic expectations of services. It is inappropriate to agree a plan for care at home with patients when the services do not exist to support this. Similarly, offering hospice at the end of life may result in disappointment and frustration as we know the capacity in the UK is for only 6% of deaths.

For young people, lack of services, insufficient workforce and unclear commissioning have a significant impact on ability to fulfil advance care plans for young people. Community nursing services vary and many children's community nurses lack experience in palliative care or do not provide 24/7 cover. District nursing teams are sometimes happy to provide end of life care for people under 18, but this varies from team to team. Not all Children's hospices are able to offer end of life care with some services only offering respite. Upper age ranges for children's hospices vary with some stopping at 18 and others continuing to 25+.

Appropriateness

We do not yet have an agreed holistic assessment tool for PEoLC patients neither do we have national reporting of collection of this data. As such it is impossible to know how many people have holistic assessments at the end of life, or whether this is improving.

Lack of adequate care at home, both specialist and generalist, does influence patients' and their families about whether home is feasible as a place of death. Specialist palliative care services in the community are under-resourced and overstretched, meaning that patients and non-specialist providers may not have frequent enough access to specialist support and advice. Hospices are massively underfunded, with many being dangerously insecure financially. They hope to raise enough money to support patients but may struggle to continue existing levels of service and cannot plan for the future including service improvements.

Some palliative care services, but not all, provide hospice at home which provides up to 24/7 carer presence in the patient's home. This can keep people at home who would otherwise be admitted to, and die in hospital. This service should be available to all patients at the end of life.

The maximum social care available for most patients at the end of life at home is four short visits during the day but nothing overnight which means that either patients have to choose to be alone overnight or family have to fill in.

Few nursing homes accept younger adults. People with physical or learning disabilities whose homes are in residential care or supported living are only able to remain in their "home" if their support workers are able to adapt to provide end of life care. There are examples of shared care models where this can work well but it involves additional training for health care staff as well as for the learning disability support workers and carers.

Where patients have special equipment to support their needs such as assisted ventilation, tracheostomy, feeding tubes or communication aids, it can be difficult to find or upskill professional carers or nursing homes that are able to care for them. Even where health or social funding is agreed, it is difficult to find sufficient carers to fulfil a package of care, particularly for complex conditions where care may be needed for many months. This limits choice for patients and adds burden for families.

Patients in pain at home at the end of life may have to wait for community nurses to come and deliver injectable pain relief and symptom control for some hours. GPs do not capacity to visit PEoLC patients at home to provide assessment and support to patients and families, and much of the primary medical care happens via telephone or video calls.

Equality and equity

There is clear evidence of geographical variability in provision of and quality of PEoLC services. As examples, proportion of patients dying in a hospice or at home vary enormously across the country[32]. Rates of hospital admission at the end of life also vary dramatically across England[11]. PEoLC for children and young people is significantly impacted by geography. Many children's palliative care services are unable to recruit to fully meet MDT membership specified in NHS service specification and do not cover the whole country[21,33,34].

Quality of PEoLC is best for those patients dying in hospices[35,36,37], but these were built without a national plan for geographical placement or number of beds resulting in inequity. Only around 6% of the population will die in a hospice. For patients dying in hospital, clinical care is better for those who had specialist palliative care (SPC) input[12]. However, not all hospitals have appropriately staffed SPC teams, and 40% are not resourced to provide 7 day face to face SPC.

In the UK, around 25% of people needing palliative care are not receiving it, with racialised groups, the oldest old, patients with non-malignant disease and those from socioeconomically deprived areas experiencing worse access, quality of care, and outcomes[38]. People from these groups spend more time in hospital in the last months of life and have less choice of where they die[39,40]. These inequalities are exaggerated by the patchy provision of palliative care across the country[17].

These inequalities are exacerbated by a lack of information about services, language barriers and lack of culturally competent (learning about different cultural norms), culturally sensitive (respecting differences) and culturally safe (addressing power imbalances and systemic inequalities) services.

Young people (14-25) with cancer or long-term conditions experience poorer health outcomes and higher risk of psychosocial problems than adults and they are underrepresented in research[41,42]. A large proportion of young people with life-limiting conditions have physical or learning disability associated with their condition, and many also experience poor mental health, socio-economic deprivation and other barriers to accessing services[5].

In adult PEoLC services, while there are good examples of bespoke transition/ young adult services (hospital, hospice and community-based), these often depend on charitable funding and are reliant on interested professionals, often working outside their job plans. Such services are rarely sustainably staffed or funded. In adult palliative care services, there is a huge variation in provision of age/developmentally appropriate care for young people.

3. SHIFTING TO COMMUNITY

Resourcing

There is currently no recording of what PEoLC is happening in any setting because there is no agreed national PEoLC data collection. As a result it is impossible to know how much of the PEoLC that happens in hospital could be shifted to the community, and what resource that would require.

Current funding models are not flexible to support a shift to community. There is not enough capacity for the current population to be appropriately cared for in the community. A shift to community will need an expansion in workforce of generalist and specialist palliative care services.

There has been a focus on supporting patients more in the community for at least 10 years and all providers are supportive of this where it aligns with patient wishes. Patients and families would want to understand that this shift still allows patients to be admitted to hospital if that is their wish.

For young people with palliative care needs, the primary care team play an essential role in maintaining continuity and routine involvement when they young person is well and reducing use of urgent and emergency hospital care[44,45].

The move to integrated neighbourhood care and in particular the neighbourhood MDTs for children and young people aims to enable proactive identification of patients who could benefit from personalised care and continuity, with opportunities for co-opting input from specialist teams. Current guidance recommends integrated neighbourhood teams (INTs) for children up to 18, but this needs to be mandated up to age 25 for young people with life-limiting conditions.

Effectiveness

Communication and coordination between hospitals and the community is not adequate in terms of the quality of information provided and the availability of shared data. There are important issues with the 24/7 access to symptomatic medication at home. GP services are not always set up to provide urgent prescriptions and pharmacies may not be open 24/7 or be able to keep stock of the medications that patients need.

For young people with life-limiting conditions to be managed well in the community GPs need robust routes for information-sharing with specialty teams, timely access to specialist advice, and clear referral processes. Ideally GPs should remain involved throughout a young person's childhood, enabling them to take on greater leadership in their care as they reach adulthood, however frequently GPs are not included as part of the care team during childhood leading to poor continuity at transition.

Equality and equity

There is a lack of specialist and non-specialist staff trained in developmentally appropriate healthcare or trained in working with people with learning disabilities or with complex life-limiting conditions usually associated with childhood. This gap could be addressed by increased joint working between organisations/departments, however busy workloads and lack of funding limit the implementation of this. Informally, some regions have expert teams who have developed a role in providing transition/YA training and clinical advice to other specialist and non-specialist professionals.

References

1. Palliative and end of life care in Integrated Care Systems: Exploring how Integrated Care Systems are responding to the Health and Care Act 2022. Marie Curie November 2023. [palliative-end-of-life-care-integrated-care-systems-survey-report-2023]
2. Chambers RL, Pask S, Higginson IJ, Barclay S, Murtagh FEM, Sleeman KE. Inclusion of palliative and end of life care in health strategies aimed at integrated care: a documentary analysis. AMRC Open Res. 2023 Jan 10;4:19. doi: 10.12688/amrcopenres.13079.2. PMID: 36987529; PMCID: PMC7614372.
3. Jarvis S, et al (2022). Numbers, characteristics, and medical complexity of children with life-limiting conditions reaching age of transition to adult care in England. NIHR Open Res. 2022 Apr 8;2:27.
4. Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. Estimating the current and future prevalence of life-limiting conditions in children in England. Palliat Med. 2021 Oct;35(9):1641-1651

August 2025

5. The National Confidential Enquiry into Patient Outcome and Death. 'The Inbetweeners' 2023. London
6. NICE. Transition from children's to adults' services for young people using health or social care services National Institute for Health and Care Excellence, 2016
7. Kolehmainen N, McCafferty S, Maniatopoulos G, et al. What constitutes successful commissioning of transition from children's to adults' services for young people with long-term conditions and what are the challenges? An interview study. BMJ Paediatrics Open 2017;1:e000085.
8. Colver A, Rapley T, Parr JR, McConachie H, Dovey-Pearce G, Couteur AL, McDonagh JE, Bennett C, Maniatopoulos G, Pearce MS, Reape D, Chater N, Gleeson H, Vale L. Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services - implications of a 5-year research programme. Clin Med (Lond). 2020 Jan;20(1):74-80.
9. NHS England. Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) Publication reference PR1673, 29 September 2022.
10. Hain R, Devins M, Hastings R, Noyes J. Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. BMC Palliative Care. 2013;12:43
11. Pask S et al 2022. Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. Better End of Life 2022 Research report. London (UK): Marie Curie. https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2022/better-end-of-life-report-2022.pdf
12. National Confidential Enquiry into Patient Outcome and Death. Planning for the end: A review of the quality of care provided to adult patients towards the end of life. 14 Nov 2024. https://ncepod.org.uk/2024eolc.html
13. NHS England. Specialist Palliative and end of life care services: adult service specification. NHSE publication reference PR1674, Jan 2023
14. Paes P, Ellershaw J, Khodabukus A, O'Brien B. Palliative care in acute hospitals - a new vision. Future Healthc J. 2018 Feb;5(1):15-20. doi: 10.7861/futurehosp.5-1-15. PMID: 31098525; PMCID: PMC6510048.
15. Gomez-Batiste X, Martinez-Munoz M, Blay C, Espinosa J, Contel JC, Ledesma A. Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. Curr Opin Support Palliat Care. 2012;6(3):371–8;
16. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med. 2017;15(1):102.
17. Johansson, T., Pask, S., Goodrich, J., Budd, L., Okamoto, I., Kumar, R., Laidlaw, L., Ghiglieri, C., Woodhead, A., Chambers, R., Davies, J., Bone, A., Higginson, I., Barclay, S., Murtagh, F., Sleeman, K. (2024). Better End of Life 2024 Report. https://www.mariecurie.org.uk/research-and-policy/policy/better-end-life-report
18. Palliative Medicine Specialist Advisory Committee (SAC) Workforce report 2024 (unpublished data)
19. Focus on Physicians: the UK 2023 census of physicians. RCP.

20. NICE. End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE NG61 2016
21. Specialist palliative and end of life care services. Children and young people service specification. PR1675 Jan 2023. NHS England
22. Malhotra C, Shafiq M, Batcagan-Abueg APM. What is the evidence for efficacy of advance care planning in improving patient outcomes? A systematic review of randomised controlled trials. BMJ Open. 2022 Jul 19;12(7):e060201. doi: 10.1136/bmjopen-2021-060201. PMCID: PMC9301802
23. NHSE. 2021. Improving communication between health care professionals and patients in the NHS in England Findings of a systematic evidence review and recommendations for an action plan. https://www.england.nhs.uk/wp-content/uploads/2021/07/SQW-NHS-England-Improving-communications-report-30June.pdf
24. Advance care planning in patients referred to hospital for acute medical care: Results of a national day of care survey. Knight, Thomas et al. eClinicalMedicine, Volume 19, 100235
25. Johansson T, Chambers RL, Curtis T, Pask S, Greenley S, Brittain M, Bone AE, Laidlaw L, Okamoto I, Barclay S, Higginson IJ, Murtagh FEM, Sleeman KE. The effectiveness of out-of-hours palliative care telephone advice lines: A rapid systematic review. Palliat Med. 2024 Jun;38(6):625-643. doi: 10.1177/02692163241248544. Epub 2024 May 6. PMID: 38708864; PMCID: PMC11158006.
26. Stepping up Transition pathway and Standards framework. 2023 Together for Short Lives https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/
27. Allsop MJ, Ziegler LE, Mulvey MR, Russell S, Taylor R, Bennett MI. Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. Palliative Medicine. 2018;32(8):1322-1333. doi:10.1177/0269216318781417

28. Colver A, Rapley T, Parr JR, McConachie H, Dovey-Pearce G, Couteur AL, McDonagh JE, Bennett C, Maniatopoulos G, Pearce MS, Reape D, Chater N, Gleeson H, Vale L. Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services - implications of a 5-year research programme. Clin Med (Lond). 2020 Jan;20(1):74-80.

29. Supporting Internal Medicine Trainees to meet curriculum competencies around end-of-life care: a novel simulation course. (2021) Caulkin R. & Robinson L. BMJ SPC 11(1)
30. Fisher V, Atkin K, Fraser LK. The health of mothers of children with a life-limiting condition: A qualitative interview study. Palliat Med. 2022 Oct;36(9):1418-1425.
31. Fisher V, Fraser L, Taylor J. Experiences of fathers of children with a life-limiting condition: a systematic review and qualitative synthesis. BMJ Support Palliat Care. 2023 Mar;13(1):15-26.
32. NHSE. Atlas of variation for palliative and end of life care in England http://tools.england.nhs.uk/images/EOLCatlas/atlas.html
33. Joint workforce statement from APPM and RCPCH CSAC for Paediatric Palliative Medicine 2023. https://www.appm.org.uk/_webedit/uploaded-files/All%20Files/News/Joint%20workforce%20statement%20from%20Paediatric%20Palliative%20Medicine%20CSAC%20and%20APPM%20%20-%20October%202023.pdf
34. Short Lives Can't wait full report. Together for Short Lives 2024 file:///C:/Users/joelv/Downloads/Short-Lives-Cant-Wait-Full-Report-Updated-19-June.pdf

35. National survey of bereaved people (VOICES) England, 2015 Office for National Statistics.
36. Zamora, B., Cookson, G. and Garau, M., 2019. Unrelieved Pain in Palliative Care in England. OHE Consulting Report, London: Office of Health Economics. https://www.ohe.org/publications/unrelieved-pain-palliative-care-england
37. Karakitsiou D et al. 2025 Satisfaction with end-of-life care by specialist palliative care teams: a 10-year retrospective service evaluation report using the FAMCARE-2 tool Submitted for publication
38. Tobin J, Rogers A, Winterburn I, Tullie S, Kalyanasundaram A, Kuhn I, Barclay S. Hospice care access inequalities: a systematic review and narrative synthesis. BMJ Support Palliat Care. 2022 Jun;12(2):142-151. doi: 10.1136/bmjspcare-2020-002719. Epub 2021 Feb 19. PMID: 33608254; PMCID: PMC9125370.
39. Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, Verne J, et al. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLOS Med [Internet]. 2019 Apr 23 16(4):e1002782. Available from: https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002782
40. Dixon J, King D, Matosevic T, Clark M, Knapp M. Equity in Provision of Palliative Care in the UK: Review of Evidence [Internet]. Online; 2015 Apr. Available from: https://eprints.lse.ac.uk/61550/1/equity_in_the_provision_of_paliative_care.pdf
41. Coe D, Bigirumurame T, Burgess M et al. Enablers and barriers to engaging under-served groups in research: Survey of the United Kingdom research professional’s views [version 2; peer review: 2 approved]. NIHR Open Res 2023, 3:37
42. Matthew J. Ehrhardt et al. Health Care Transitions Among Adolescents and Young Adults With Cancer. JCO 42, 743-754(2024).
43. Together for Short Lives: Make Every Child Count report 2022 Fraser, L et al https://www.togetherforshortlives.org.uk/resource/make-every-child-count/
44. Mitchell S, Harding S, Samani M, et al Experiences of general practice of children with complex and palliative care needs and their families: a qualitative study. BMJ Open 2021;11:e041476
45. Jarvis, S. W., Parslow, R., Hewitt, C. E., Mitchell, S., & Fraser, L. K. (2020). GPs’ role in caring for children and young people with life limiting conditions – a retrospective cohort study. BJGP 1-9.