

was highest in the group with SNI [feeding devices (n=48,86%), respiratory support devices (n=33,59%)]. The AYA mainly died at home. Later referral to SPC was seen for AYA with malignancy, with 32.5%(n=5) referred < 3 months before their death.

**Conclusions:** The high symptom burden and relatively late referral of some AYA to SPC highlights the need for early referral to palliative care professionals with an appropriate skillset and access to adequate and equitable psychological supports. Utilisation of medical devices in the home adds complexity to end-of-life decision making and indicates the need for access to professionals, educated in their use.

**Conflict of interest to declare?:** No

**Abstract ID: OA10.3**

#### Agitation in Paediatric palliative care: A clinical guideline

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**Background/aims:** Robust clinical guidance in paediatric palliative care is lacking. This is due to the paucity of high-level research, mixed disease cohort, and small numbers encompassing a wide range of ages. The Association of Paediatric Palliative Medicine, sought to develop a series of clinical guidelines with the symptom Agitation, being identified through a national prioritisation exercise.

The aim was to develop a clinical guideline on agitation in the child or young person with life limiting conditions in the palliative care setting where episodes of agitation may occur at any point in the disease process.

**Methods:** A Clinical guideline group was established including patient and parent representation, following the Royal College of Paediatric Child Health methodology. A systematic review was undertaken with the support of Cochrane Response using the GRADE methodology. A consensus meeting was then held, with an Evidence to Decision table created. A draft guideline was reviewed by stakeholders prior to dissemination. Data sources: The Cochrane Library, MEDLINE, EMBASE, PsycInfo and reference lists of all relevant systematic review (April 2001-April 2021) including non-English language papers.

**Results:** Of the 790 papers retrieved, there was only one retrospective cohort study and two observational non-comparative studies identified. Most guidance was therefore informed by expert opinion consensus. The management of agitation in the life limited child requires clear communication, recognition and management of reversible causes, and non-pharmacological and pharmacological management tailored to their specific requirements.

**Conclusions:** Creation of a national agitation clinical guideline for children with palliative care needs is a first step in supporting consistent clinical practice across the sector. The lack of high-quality evidence suggests a pragmatic approach is needed, where the use of clinical guidelines can inform both clinical practice and be used as a springboard for further areas of research.

**Conflict of interest to declare?:** No

**Abstract ID: OA10.4**

#### Advanced Care Planning in Adolescents and Young Adults (AYA) with Life-Limiting or Life-Threatening Illness; A Scoping Review

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**Background/aims:** Advance care planning (ACP) discussions are crucial in the management and support of individuals living with life-limiting/

life-threatening conditions. Engaging young people in discussions about ACP, dying, and end-of-life care are increasingly recognised as an essential part of standard of care (1). To date, few studies have examined best practices for ACP discussions with AYA with life-limiting/life-threatening conditions.

**Aim:** To identify core components of current guidelines, frameworks and tools to facilitate ACP discussions with AYA with life-limiting/life-threatening conditions and their families.

**Methods: Design:** This scoping review was conducted according to the Joanna Briggs Institute approach to the conduct of scoping reviews (2). An extensive literature search from the inception of five databases [Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews, PsycInfo, PubMed and Scopus] until January 23, 2023, was carried out.

**Results:** The search yielded 2976 papers, of which 9 met the inclusion criteria. Five main themes were identified: (i) utilisation of standardised documents and protocols; (ii) shared decision-making between the AYA, their families, and the healthcare team; (iii) the importance of open and honest communication with AYAs during ACP discussions; (iv) individualisation and flexibility in the ACP process; and (v) timing of ACP initiation and discussions.

**Conclusions:** Our findings highlight the importance of engaging AYAs in ACP discussions and the importance of considering their unique needs when initiating and framing these discussions. These key components of ACP discussions with AYA can be used by healthcare professionals to inform and enhance ACP discussions. Further research is needed to test the effectiveness of these guidelines and frameworks in improving end-of-life care for AYAs and to explore experiences with ACP discussions from the perspective of AYA patients and their families.

**Conflict of interest to declare?:** No

**Abstract ID: OA10.5**

#### Diversity in place of death among children who died between 2012 and 2021 in 32 countries

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**Background/aims:** More than 21 million children globally need access to palliative care and the place of death (PoD) of children is important to them and their family. PoD is also an important indicator for end-of-life care yet information on PoD for children is limited.

To analyse the diversity in PoD of children at an international level, to describe the distribution of the PoD and its evolution, and to assess the level of ill-defined PoD data.

**Methods:** We obtained mortality data from vital registration systems from 32 countries on children who died in 2012-2021 (0-17years: 27 countries, 0-19years: 3 countries, 0-14years:1 country, 0-20:1 country). PoD categories included hospital or health institution (H-Hi), home, other defined and ill-defined. We analysed the distribution of deaths by place (all countries and per country), age group (< 1year,1-10years,1-17years), cancer vs. non-cancer [cancer ICD-10 codes: C0-C97 (except C91-95)] and year.

**Results:** We identified 1,994,819 pediatric deaths in 32 countries (range per country: 336 - 696,183). 58.1% aged <1year (range per country: 46.0%-87.4%), 3.0% died of cancer (range per country:1.3% - 8.2%),70.0% died in H-Hi (range per country: 48.5%-92.5%),12.8% at home (range per country: 3.9% -30.1%) and 11.0% at ill-defined places (range per

country:0.1%-33.3%).The percentage of deaths at H-Hi decreased with age < 1year: 83.4% (range per country: 46.0% -97.1%),1-10years: 61.0% (range per country: 33.2%-81.6%) and 11-17years: 44.3% (range per country: 25.7%- 66.5%).The death percentage at H-Hi, was lower among children dying from cancer: 67.7% (range per country: 34.2%-92.6%) vs. non-cancer: 73.7% (range per country: 56.3%-93.0%).The death percentage in H-Hi varied per year between 72.8% (2020) and 74.9%(2019).

**Conclusions:** The majority of children died in H-Hi, mostly< 1year from non-cancer causes, and with small variations over time. Less than a third died at home. Ill-defined PoD still exists with up to a third of pediatric deaths depending on the country.

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**Conflict of interest to declare?:** No

**Abstract ID: OA10.6**

### A helicopter view of children's palliative care in 2023

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**Background/aims:** With >21 million children globally needing palliative care (PC) & this number expected to increase, the need for children's PC (CPC) has never been greater. An understanding of the state of play is important to underpin future activity to support better care for these children.

**Aim:** To map the global development of CPC to understand how the levels of CPC have developed since 2018 & inform ongoing activities.

**Methods:** A survey was distributed to CPC stakeholders in 174 countries. Stakeholders were identified through an international children's palliative care organisation & where no contacts were known we reached out to other stakeholders. The 2018 survey was updated & included: availability of service models; policies; sustainable funding streams; national associations; education programmes; research capacity; & medicine availability. Respondents also estimated the development of CPC according to the categories of PC development outlined in the Global Atlas. Data collection took place between June – October 2023. The results have been collated and sent to regional bodies to be moderated, prior to a full report being published.

**Results:** 124 (71%) countries responded and a wealth of data received, with data on levels of CPC development finalised following feedback from the regional organisations. Initial analysis of the data indicates that there is an overall increase in the ratings for the level of service development between 2018 & 2023.

**Conclusions:** The survey indicates positive development of CPC. Many low- & middle- income countries have moved up from levels 1 or 2. However, there are indications that CPC development in high income countries has slowed, or even regressed.

**Conflict of interest to declare?:** No

Level	2018	2023
1 - No known CPC activity	30%	15%
2 - Evidence of CPC capacity building activities	30%	20%
3 - Evidence of localised CPC provision	20%	41%
4 - Evidence of multiple CPC services, training & some integration into health system	11%	16%
5 - Evidence of integration of CPC into health system	9%	8%

**Abstract ID: OA19.1**

### Professionals' experiences of delivering paediatric end-of-life care: a multi-site qualitative study across the UK

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**Background/aims:** Around 4,500 infants and children die in England and Wales each year. However, evidence has consistently shown availability, access, and delivery of palliative care is inconsistent and incoherent. This raises implications for quality of care and potential impacts on families. Supporting parents during this time is challenging for staff and may not have been adequately covered in professional training. Whilst good care cannot remove parents' pain and grief, poor care can significantly add to their distress. There is little high-quality evidence on the ways this type of care is delivered and experienced.

**Aim:** To explore professionals' experiences of delivering end-of-life care to infants, children and young people.

**Methods: Design:** Multi-site qualitative study, grounded in the phenomenological approach.

**Data collection:** Online, semi-structured, focus groups with professionals, recruited via UK: neonatal and paediatric intensive care units, and children and teenage cancer centres. All were audio-recorded, transcribed verbatim, and informed consent obtained. Data were collected by 4 researchers.

**Analysis:** Data analysis of focus groups employed a thematic framework approach.

**Results:** 172 professionals were recruited. Data highlighted examples of best practice, as well as areas to be improved. Professionals believed confidence and skills came from experience, influencing planning and introduction of end-of-life care. Involvement of palliative care teams varied depending on availability, provision, connotations, and perceptions of palliative care. Professionals identified a need for parallel planning and earlier referrals to enable time to build relationships. They felt it was a privilege to care for families, however staff support was variable. There was substantial reliance on charities to provide bereavement support.

**Conclusions:** Findings have informed clinically relevant recommendations for practice, to ensure high quality care is consistent and embedded within routine practice.

**Conflict of interest to declare?:** No

**Abstract ID: OA19.2**

### Beyond Nutrition: Parental experiences with their child's declining food intake near the end of life

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**Background/aims:** Feeding in Paediatric Palliative Care poses a grave concern as disease progression occurs due to reduced oral intake towards the end of life. Declined food intake for children is described as a prognostic indicator of a patient entering the terminal phases of their illness. Feeding in Palliative Care involves social, emotional, cultural, physical, and ethical components and significance. There is a paucity of information on parental experiences with feeding in Pediatric Palliative Care and how we can improve Quality of Life of both patients and their family members. This study aimed to explore what parents experience or have experienced when food intake declines in caring for their child with life-limiting illnesses and/or life-threatening illnesses towards the end of life.

**Methods:** A Constructivist Grounded Theory approach was used to provide a theoretical understanding of parental experiences when their child's feeding is declining towards end of life. Purposive theoretical sampling was utilised to identify parents caring for children with palliative care needs or bereaved parents. Data was collected using semi structured in-depth interviews aided by a topic guide that allowed reasonable flexibility in questioning and probing. In line with Charmaz's Constructivist Grounded Theory, data collection and analysis took take