Aims To explore and discuss the barriers faced by senior paediatricians in initiating and implementing palliative and end of life care (EOLC) for children with life-limiting conditions (LLC). Specifically, the objectives were to explore barriers associated with leadership of the patient, communication with families, initiating and preparing advance care plans and the issues associated with dealing with other teams and professional colleagues.

Methods A mixed methods study using semi-structured interviews and an online questionnaire was carried out in a UK children’s hospital that provides general and community paediatrics and multiple tertiary sub-specialties, between December 2020 and August 2021. All senior paediatricians (n=37) above registrar level were invited to take part including general paediatricians, paediatric subspecialists and associate specialists. Twelve interviews were conducted and analysed to identify themes. Questions asked were; professional experience of palliative and EOLC, leadership of care of children with LLC, communication difficulties with family and colleagues, communication issues with multidisciplinary teams and barriers to developing and implementing advance care plans.

Eighteen consultant paediatricians responded to the SurveyMonkey® online questionnaire, which was a pragmatic approach to engage with paediatricians not able to be interviewed. It included questions on barriers faced in planning palliative care and who was involved in the planning process. Using a rating scale, respondents were asked to identify to what degree they agreed or disagreed with a list of barriers. (figure 1)

Results Five themes emerged from the interviews: (i) problems with the leadership of end-of-life planning and care provision; (ii) problems with preparing advance care plans (ACP); (iii) lack of training in paediatric palliative care and advanced communication; (iv) problems communicating with professional teams and (v) problems communicating with families.

Five barriers rated highest from the questionnaires, based on the degree to which respondents agreed or strongly agreed with listed items including; lack of training in advanced communication skills (12/18), lack of recognition of children with LLC (12/18), high profile cases (11/18), communication issues with other teams or hospitals (17/18) and family beliefs (16/18). (figure 1).

Duplicates and recurring themes from both studies were further analysed and the following seven themes emerged; (i) problems with the leadership of palliative planning and care provision; (ii) problems with preparing advance care plans; (iii) lack of training in paediatric palliative care and advanced communication; (iv) problems communicating with other professional teams; (v) problems communicating with families; (vi) lack of recognition of children with LLC and (vii) high-profile cases.

Conclusion Barriers to effective palliative/end-of-life planning are multifaceted. Healthcare professionals must work together to establish clearer pathways to address this subject. Discussing palliative care for children with LLC at departmental meetings, peer review meetings and morbidity and mortality meetings, and advanced communication training in palliative/EOLC could help reduce these barriers.

Abstract 454 Figure 1 Barriers to palliative and end of life planning

Conclusion Barriers to effective palliative/end-of-life planning are multifaceted. Healthcare professionals must work together to establish clearer pathways to address this subject. Discussing palliative care for children with LLC at departmental meetings, peer review meetings and morbidity and mortality meetings, and advanced communication training in palliative/EOLC could help reduce these barriers.

Abstract 309 GENETIC TESTING IN CHILDHOOD: ETHICS IN PRACTICE

Aims The British Society for Genetic Medicine established a working group to review its guidance on the practical ethics of genetic testing in childhood. The review was timely, given the challenges presented by mainstreaming genomics and with the progress in laboratory technology and bioinformatics.

Methods A multi-disciplinary working group of geneticists, paediatricians, social scientists, philosophers and lawyers collaborated to prepare the report. A workshop was held in February 2020 to agree a draft structure and the group then worked iteratively to finalise the report.

Results The new guidance describes relevant ethical and legal frameworks and provides a clinical section of worked examples highlighting specific ethical issues. These include the importance of balancing the benefits and risks of genetic testing in childhood, and potential challenges of generating variants of uncertain significance and unexpected findings. Expansion of genetic testing to broader panels, whole genome sequencing and whole exome sequencing is proving challenging. Genetics specialists will need to support colleagues during the process of ‘mainstreaming’. 
Proposals for the genomic screening of healthy children need to be weighed carefully before being introduced. While it may be proper to use genetic test results on a child to benefit other family members, undertaking a test with that as the primary goal of testing would usually be inappropriate.

**Conclusion** This document brings together current thinking on the ethical issues that are potentially generated by genetic and genomic testing in children. By illustrating these issues through worked examples to highlight particular ethical challenges, it facilitates any users of genomic testing in children to navigate some of the potential issues that may arise. This report builds on broader guidance from the British Society for Genetic Medicine publication dealing with ethical issues relating to consent and confidentiality. Rather than providing guidance on detailed clinical management (although links are provided to relevant publications), both these publications support best practice and support the need for good understanding of genomic testing and interpretation of results in order to provide informed consent to families about their testing.

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**Abstracts**

**542 PARENTAL DISCRETION WHEN USING A HARM THRESHOLD TO ADJUDICATE CONTESTED MEDICAL TREATMENT Decisions FOR CHILDREN, AN INTERNATIONAL COMPARISON**

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10.1136/archdischild-2022-rcpch.486

**Aims** It is often assumed that the introduction of a harm threshold to adjudicate medical treatment decisions for children in the courts of England & Wales will increase the parental ability to decide for their children. There is however little evidence that supports this assumption. The aim of the investigation is to clarify whether the use of a harm threshold in court decisions does indeed increase parental discretion.

**Methods** An international comparison how harm thresholds evolved and currently operate in England & Wales, the Netherlands and Germany and analysis of court decisions using a harm threshold when deciding on medical treatment for children (in the context of residency orders).

**Results** The investigation revealed that differences in the legal context between the three jurisdictions in which the harm threshold operates determine to a large extent the court’s decisions. The welfare of the child as the paramount consideration in the courts of England & Wales as opposed to a primary consideration in the Netherlands and Germany affects both the question whether the harm threshold is reached as well as the extent of justifiable limitations of parental authority after the harm threshold is reached.

**Conclusion** The introduction of the harm threshold for all medical treatment decisions for children within the context of the paramountcy of the child’s best interests in the courts of England & Wales is unlikely to lead to more parental discretion.

**1130 DESCRIBING THE EVOLUTION IN THE ETHICS EDUCATION PROVIDED BY A PAEDIATRIC BIOETHICS CENTRE (PBC) BEFORE AND DURING THE PANDEMIC**

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**Aims** One important PBC function is to provide ethics education for members, hospital staff & other students. Educational activities are open to national and international healthcare students and workers. No standardised guidance exists on how to run or evaluate such activities, though national UKCEN core competencies provide an ethics curriculum.

**Conclusion** The objective of this work is to describe the evolution of PBC educational activities over the pandemic period 2019-22.

**Methods** PBC educational activities database review

**Results** The PBC provides training to its members, hospital staff, trainees and students, as well as external educational activities. These include:

- PBC members - monthly 1-hour Bioethics Educational Forum with local/regional speakers evolved with videoconferencing to involve national/international speakers. Similarly, annual PBC Away Day now has more international speakers with positive feedback, tempered slightly by loss of team bonding. Each (of 10) new associate-member presents at bespoke 1-hour monthly online sessions, supported by mentor, unchanged by pandemic.

- Hospital staff, trainees & students – vary in methods and scope, i.e., standalone sessions and ethics/law lectures embedded in other courses. e.g., 8 Weekly Autumn ethics interactive lectures open to hospital AND sessions on request to tackle moral injury. Feedback surprisingly positive, though efficacy not formally assessed.

- External educational activities – include annual Medical Student Bioethics Day with lectures, workshops & abstract presentations; a one-week Paediatric Ethics & Law MSc Module and ad-hoc seminars/conferences to address timely hot topics (i.e., 2019 ‘Recent Court Judgements: should we change clinical practice?’ & 2020 ‘Role of Faith & Non in Society’s Pandemic Emergence’) Again, broader speaker pool facilitated, very positive feedback scores maintained online.

The pandemic brought both challenge and opportunity. Educational activities were adapted to the online format, raising concerns about the loss of face-to-face discussion and interaction. However, videoconferencing allowed greater participation of national/international ethics experts and delegates. Informal and formal feedback from participants was entirely positive regarding the change; however, educators found entire day sessions arduous– these evolved to shorter sessions/fewer per teacher.

**Conclusion** Remote learning offers new opportunities for ethics education/training activities. Further work should be done to evaluate not just participants’ and educators’ experience but to compare the efficacy of different modes of training.