

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

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# Background

- Marked improvement in mortality, but in the UK >4,300 infants, children and young people die each year.
- Availability, access, and delivery of care is inconsistent and incoherent.
- Implications for quality of care and impacts on families.
- Supporting parents is challenging.
- Whilst good care cannot remove pain and grief, poor care can significantly add to distress.
- Little evidence on how this type of care is delivered.



# Methods

- **Aim:** To explore professionals' experiences of delivering EoL care to infants, children and young people.
- **Context:** Workstream of major UK wide study ENHANCE.
- **Design:** Qualitative study, across all UK nations.
- **Setting:** Account for the place of death of more than 50% of the children who die in the UK each year: NICU, PICU, PTC-C, PTC-TYA.
- **Participants:** Health professionals who provide EoL care.
- **Recruitment:** Identified through NHS sites.
- **Data collection :** Online focus groups.
- **Data analysis:** Thematic Framework Analysis.

NICU: 57



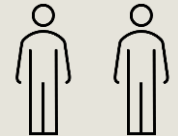
PICU: 62



PTC-C: 24



PTC-TYA: 24



# Parent and Public Involvement



- Collaboratively and in partnership.
- Study Parent Advisory Panel – 15 members, diverse experiences:
  - Study design, recruitment materials, topic guide, preliminary and final findings.
- Parent co-applicant:
  - Recruitment video, guided data collection, heavily embedded within analysis, findings, outputs.
- Family Advisory Board – 19 members:
  - Identifying, study design, findings.



# Results – 1. Professional perceptions of end-of-life care



## Readiness and pace:

- Conversations as early as possible.
- Confidence, perceived family and professional readiness.

## Roles in palliative care:

- Collaborative, multidisciplinary working.
- Variations in involvement with palliative care.
- Diminishing hope.

## Planning ahead:

- Advance care plans – difficult, emotionally laden, enabled by good relationships, takes time.

*“The earlier you can implement all of these conversations, the easier it is down the line.” (Doctor, PICU)*

*“The push is for active treatment and cure for much of the journey, it’s a really difficult shift to start to consider that that may not be what’s going to happen for that family.” (Doctor, C-PTC)*

*“Paediatricians generally are people that like working with kids and the thought of children dying is something they’re not very comfortable with.” (Doctor, PICU)*

*“It’s not a one-off conversation...it’s almost like a dance that happens over many, many weeks or even months.” (Social worker, C-PTC)*

# Results – 2. What we want to provide versus what we can



## Providing choice:

- Important, where feasible.
- Dependent on: relationships, capacity, geography, links with services, resources.

## Space and time to be a family:

- Time and space to fulfil their role.
- Availability and access to private spaces.
- Reliance on charities for provision.

## Supporting parents during EoL care and beyond:

- Variability in access and provision.
- Falls to one person.
- Fragmented provision, failing families.

*“One of the big challenges we’re certainly facing now is offering families choice because of all the issues around capacity and pressures on services. It is a huge challenge at the moment for us ensuring that parental choice is offered.” (Nurse, TYA-PTC)*

*“Giving somebody a good death is the one thing I always think that I want to do right because you’ve got one shot at it, once it’s done it’s done. And giving somebody privacy and having their last moments with the child in a place they can remember” (Nurse, PICU)*

*“We give good end-of-life care and then they die and they get nothing and that just feels terrible, but I can’t fix it myself, we can’t fix it.” (Doctor, NICU)*

# Results – 3. Workforce & sustainability: professional support



- All found it a privilege to provide EoL care.
- Emotionally difficult, long-term well-being.
- Series of support mechanisms.
- Variability in access due to workplace pressures and lack of time.

*"We've had the privilege of being able to arrange weddings in the hospital, and for the young people and their families to allow us to be part of that is a total privilege." (Nurse, TYA-PTC)*

*"I do wonder what sort of long-term impact it's going to have on me, I don't have an answer to that. For me it's mainly emotional and quite hard." (Doctor, PICU)*

*"We do try and organise debriefs following the death of a child. It's an open invitation to anybody that was involved in the child's care to come and attend, and we do try to facilitate online and face-to-face to get as many people to attend as we can." (Nurse, C-PTC)*

*"Everyone's invited to the meetings but it's time, it comes back to time again, doesn't it? There's no time allocated." (Doctor, NICU)*

# Conclusions

- Largest UK-based study.
- Reveals professional, personal, and organisational barriers to delivering optimal care.
- Professionals aware of, and want to deliver, high-quality care.
- Systems and processes that are limiting delivery, need urgent attention.
- Many issues resolved by investment in funding, time, specialised education, and support to enable professionals.







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**Thank you, any questions?**

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End of Life Care for Infants, Children and Young Adults