

## Terms of Reference

### APPM Perinatal Palliative Care Special Interest Group

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#### **1. Purpose:**

To promote and support advancing the provision of high quality perinatal palliative care across the United Kingdom and Ireland through collaborative working.

#### **2. Background**

The practice of perinatal palliative care has become a central aspect of providing high quality care to families facing significant uncertainty for their baby, before, during or after birth, including time on the neonatal unit for many.

Mortality data shows more than half of all childhood deaths occur in infants under 1 year with the majority of these occurring in babies under 28 days of age. Babies born preterm are disproportionately represented with causation attributed to prematurity related issues in 46% of neonatal deaths. As we move to an era of more individualised family centred care, including offering intensive care to babies born profoundly preterm (70% of infants born at 22 weeks gestation die despite intensive care) we must acknowledge that families and teams face huge uncertainty when caring for these babies. High quality perinatal palliative care is not limited to providing compassionate end-of-life care, where appropriate, but rather providing holistic physical, emotional, social and spiritual support to families whose baby faces a potentially life-limiting condition.

The practice of perinatal palliative care by perinatal teams has evolved regionally across the UK in response to need in the past 2 decades but there remains a lack of agreed standards and resources to support this area of perinatal practice. Alongside this, the field of specialist paediatric palliative medicine has also grown significantly with better recognition of the role of specialist PPM teams in optimising care for many families. Collaborative multidisciplinary team working is therefore essential but variable provision of palliative care services has affected how perinatal teams interface and integrate with specialist services regionally, leading to further variation.

We need to consider how we train and support perinatal teams to support families facing uncertainty by empowering them with high quality perinatal palliative care skills. Alongside this we

must invest in the specialist paediatric palliative care workforce across the UK. To provide the highest standard of care we must build collaborative working relationships between perinatal teams and specialist palliative care teams to fit the needs of local populations. We must create standards that define what good looks like for these families and this must have the patient and parents voice at its heart.

A consultant Neonatologist joined the APPM Executive Committee in 2022 in recognition of the need for more collaborative work in this area and the APPM neonatal sub-group was created. In the past 18 months the APPM group have worked closely with BAPM for the first time to develop a joint framework 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine' which was released for consultation in April 2024.

The APPM group has evolved. This document aims to formalise the terms of reference for the group to continue as the APPM Perinatal Special Interest Group going forward.

### **3. Aims**

3.1: The overarching aims of the APPM Perinatal SIG are:

- Creating standards of care and integrated interdisciplinary working between the perinatal team and specialised PPM professionals.
- Developing Education and Training opportunities in Perinatal Palliative Care.
- Developing resources including standardised national templates and resources for families.
- Creating channels for more collaborative working with other professionals, third sector organisations and parent groups.
- Supporting QI and Research in perinatal palliative care
- Raising awareness of the roles of specialist PPM teams in perinatal palliative care including at a societal level
- Advocating for advancing perinatal palliative care by engaging with public policy and perception through policymakers.

3.2: We will achieve these through a

- a quarterly APPM forum for discussion, idea creation, updates on workstreams and holding ourselves to account in order to meet the groups agreed aims.
- Creating opportunities for collaborative working including formalising the affiliation with BAPM
- Sharing successful regional models of integrated work, resources, educational opportunities .
- Developing 3 year aims for the group and reporting back on delivery of these to the APPM executive

### **4. Membership**

The group membership is largely drawn from APPM members but recognising the multidisciplinary nature of perinatal palliative care in the UK we will endeavour for membership to include other key multidisciplinary professionals. This will include:

- UK nation representation (Ireland & Scottish representatives needed)
- Perinatal team representatives including (bereavement) midwife, nurse, obstetrician (fetal med interest) and neonatologist
- Trainee member
- Parent member (a PPI link must be identified within the group to check in after meetings)

We will invite input to specific APPM PPC SIG work-streams through APPM membership and through other relevant organisations, such as BAPM, as appropriate.

A password protected members list with contact details will be held by the APPM administrator and shared with the SIG coordinators/chairs. All members will be encouraged to become members of APPM but if not will be made aware that APPM will hold their contact details for the duration of membership of the APPM group. If APPM or non-APPM members wish to be removed from this list and opt out of the group, the APPM administrator should be informed through (email) and this will be actioned within 1 month.

## **5. SIG Chair/Coordinators**

The SIG will be co-chaired by a perinatal professional and a specialist in paediatric palliative medicine. The chairs should be elected by the group on a 3 yearly basis and expressions of interest sought.

The chairs will be responsible for jointly:

- Coordinating and leading the regular forums (with agendas)
- as a point of contact for the group and related queries
- producing regular updates for the APPM newsletter
- maintaining the APPM website PPC SIG space
- Creating 3 year work plan, with the SIG membership, to identify key objectives to achieve their goal of advancing perinatal palliative care in the UK and Ireland.

## **6. Reporting**

The SIG chairs will be co-opted members of the APPM executive committee and report to the APPM board twice yearly as well as preparing annual reports for the AGM.

## **Funding**

There will be no dedicated funding for this group

## References

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