

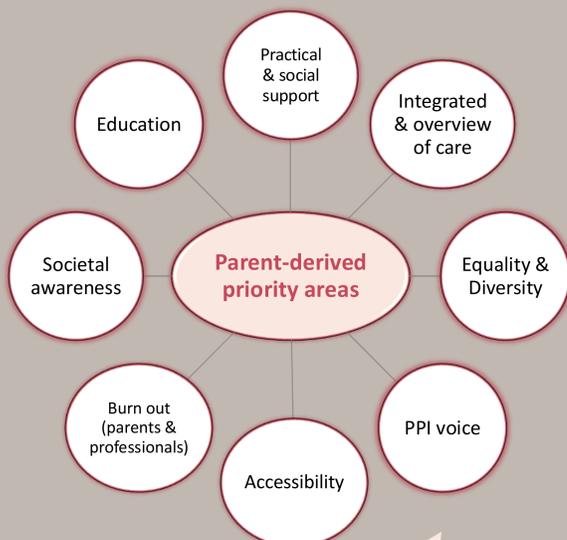
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On behalf of the CYP SE PEOLC PPI group (england.peolc-se@nhs.net)



Neve Tammam, 17.11.2012 - 30.04.2023
Painted by Emily Tammam

Parental core values

1. Being heard
2. Being held
3. Ensuring dignity for CYP & the family
4. Effective communication (both ways)
5. Avoiding disjointedness



Resources we have produced



Acronyms Used

SE PEOLC Southeast Palliative and End of Life Care
CYP Children and Young Person
ICBs Integrated Care Boards
MCNs Managed Clinical Networks

Project Aims

Children and Young Person (CYP) clinical leads team established in January 2022, to ensure an 'All Ages' approach to the SE PEOLC program

Aim To develop paediatric aspects of NHS maturity matrix across Southeast region, strengthening networks and enabling services to thrive (Matrix is a quality improvement tool with eight domains, one of which is Patient and Public Partnerships)

A parent/carers group was established, to ensure **meaningful co-production**

Identifying parents and nurturing their engagement

- Invitation sent to regional ICBs, MCNs, specialist services and children's hospices
- Initially 8 parents joined; increased to 12 over six months
- Representation of 5 out of 6 ICBs, a mix of bereaved parents and current users
- **Next steps:** production of a video resource to attract additional members

Using Group Meetings as an Intervention

- Initial meeting explored overarching principles and shared purpose. Open questions explored ideas, experiences and concerns.

Result Establishment of **Five core values** and **Eight priority areas**

- Next, established regular ongoing meetings (virtual, evenings) with rolling agenda items, topic focus and bidirectional learning.
- Opportunities for parents to attend other regional PEOLC meetings based on personal choice and area of interest.

Impact of Parent/carer Group

Co-production considered within each theme from the All-Ages matrix, including:

| | |
|------------------------|---|
| Workforce | Regular parent-led education program delivered twice yearly to professionals with topics focused on areas of regional need. |
| Governance | Develop and review of regional clinical guidelines |
| Integrated care | Develop a school education initiative |
| Leadership | Review local service plans |

Engagement from others

- Three ICBs have sought **direct guidance**
- Two ICBs have asked for **service review input**
- Two out-of-region groups and three local services have attended to gain guidance and expertise in **establishing own PPI groups**

Key Messages

- Early parent/user engagement brings **fresh perspective, energy and focus** with **meaningful co-production**
- **Confidence** in use of parent/user groups **spreads** across systems and services
- Parents gain awareness of **impact** of their child's illness on health professionals
- Parents can understand their role in **communication**

Parent/user groups should aim 'to ensure positive experiences are replicated and shared across the region and negative or could do better experiences are understood and a positive way forward is found to alter that experience for more children and their families'