

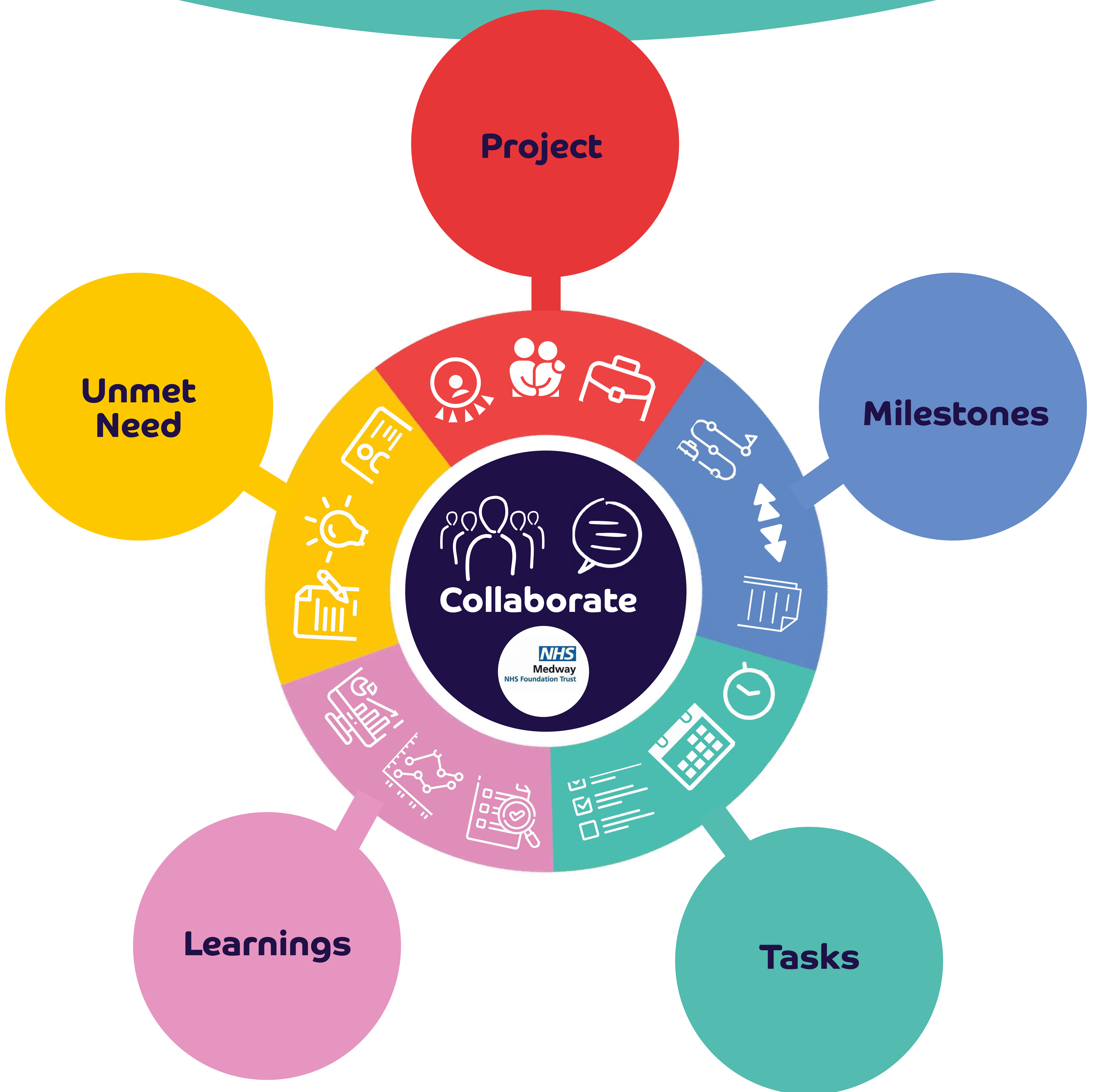


# demelza

extraordinary care for extraordinary children

## Breaking down barriers: The development of neonatal pathways into a children's hospice

Lauren Stoner-Harris, Senior Family Liaison Practitioner (Inreach)  
Vicky Arnold, Referrals & Service Improvement Lead



### Unmet Need:

- Demelza's 5 year strategy – 'Extend our reach'. The objective is to increase referrals from expectant parents, neonates and babies under one and encourage earlier engagement with the service.
- To enhance awareness and understanding of children's hospice care and support within various community settings, including hospitals, outreach programmes and community teams. We aim to extend our educational efforts to encompass the entirety of our services, not limited to end-of-life care.
- Clinical teams not having the capacity to meet social need as well as medical needs, providing emotional and practical support.
- To meet potential new families.
- Business cases to create new posts.

### Project:

- Agreed six-month pilot project with single hospital, based on unmet need from clinical team.
- Providing holistic support for family whilst child medically supported in hospital.
- Identifying families needing practical and emotional support provided by Family Liaison Practitioners.

### Milestones:

- Link with Demelza Inreach very well received by neonatal ward, pilot extended.
- Biggest barrier in making referral was the process and eligibility criteria. The process was reviewed.
- New neonatal pathway and criteria created to provide rapid support for premature babies from 22-27 weeks.
- Antenatal and early referral for babies diagnosed with life-limiting and life-threatening conditions.
- Post-death referral – if baby died before referral they were not accepted to Demelza – now changed to accept referral up to post-death for six weeks.
- Neonatal steering group created.
- Neonatal pathway trial started.
- Neonatal referrals panel.
- Development of neonatal link nurses, utilising clinical expertise and competencies.
- Specialist events focussing on peer-to-peer support for families with babies aged one and under, including Wave of Light remembrance event during Baby Loss Awareness Week.

- Music therapist going onto the ward to provide support at the bedside.
- Hosted neonatal study day.
- Showcasing a distinctive program whilst acknowledgment from diverse professional communities champion the support Demelza provides.

### Tasks:

- Neonatal steering group focused on developing pathway and referral process.
- Using family engagement to understand impact and benefits on families.
- Exploring specific information useful to parents in neonatal environment, making printed information available.
- Attendance at multi-disciplinary team meetings, grand rounds and visibility on wards, key to developing working relationships with clinical teams alongside presentations on referrals and offers of support.
- Increasing knowledge about support available locally to families to appropriately signpost to other sources of support.
- Streamlining referral processes so Demelza is aware of families from in-reach, and celebrating discharges if no longer in need of hospice care.
- Better use of data to inform future decision-making.
- Sharing project across children's hospices for greater collaboration and opportunities for joint working.

### Learnings:

- Collaborative approach critical and development of pathway essential.
- Social versus medical model and recognition of need for holistic support at a challenging time for families.
- Professionals in hospital learning through conversation, presentations, knowledge-sharing carried out by Demelza Inreach.
- Learning about Demelza is broadcasted as professionals move between hospitals.
- Families could have an increased likelihood of utilizing hospice services at a later stage if they have initial earlier contact.
- Regular review of data and family journey.

[demelza.org.uk](http://demelza.org.uk)

Registered Charity No. 1039651

