

Ten years of the Neonatal Palliative Care Programme: the journey so far, impact & sustainability

Insights from the independent evaluation

Evidence presented at the National Neonatal Palliative Care Programme Conference,
12 March 2025

Anne Pinney, Independent Evaluator
anne@kirton.org.uk

*You are welcome to use evidence from this slidepack,
please credit: Independent Evaluation of the National
Neonatal Palliative Care Programme (March 2025).*



Structure

1. Independent Evaluation
2. The journey so far
3. Learning outcomes
4. Sustainability



1: Independent Evaluation: our evidence

Baseline audit All participating NNU's	Education & training surveys Online after all sessions
Semi-structured interviews End of phase Focus groups	Projects Sustainability 'Gold Standard' approaches Family feedback tool

Phase 1

- Summative, retrospective
- Paper-based
- National report 2019

Phase 2

- Formative
- Online
- Regional reports, 2023-24

Phase 3

- Formative
- Projects, focus on sustainability

2: The journey so far ...

2014 - Tripartite funding partnership established (on-going):

True Colours Trust,
Chelsea & Westminster NHS
Foundation Trust and its charity, CW+

2012 - Alex Mancini appointed
neonatal palliative & bereavement
specialist nurse at Chelsea &
Westminster Hospital
- first such role

2012 - True Colours Trust
roundtable, leading to new
regional development role:
Pan-London Lead Nurse for
Neonatal Palliative Care

2010 - Pilot education
programme (London)

Phase 3: 2024-2028

Thames Valley & Wessex
Kent, Surrey & Sussex
Northern

July 24 – Feb 25:
13 introductory sessions to 325 participants
On-going Monthly Mondays ...

Phase 2: 2021-23

North West
South West
Yorks & Humber

158 introductory sessions to 1,368 participants *plus*
29 **enhanced** sessions to 1,301 participants
Monthly Mondays: 43 sessions to 3,152 participants

Covid 19 pandemic: 2020-21

First **virtual intro. training** in London in May 2020
Weekly Wednesdays (national) launched July 2020
54 virtual sessions delivered to 1,965 participants

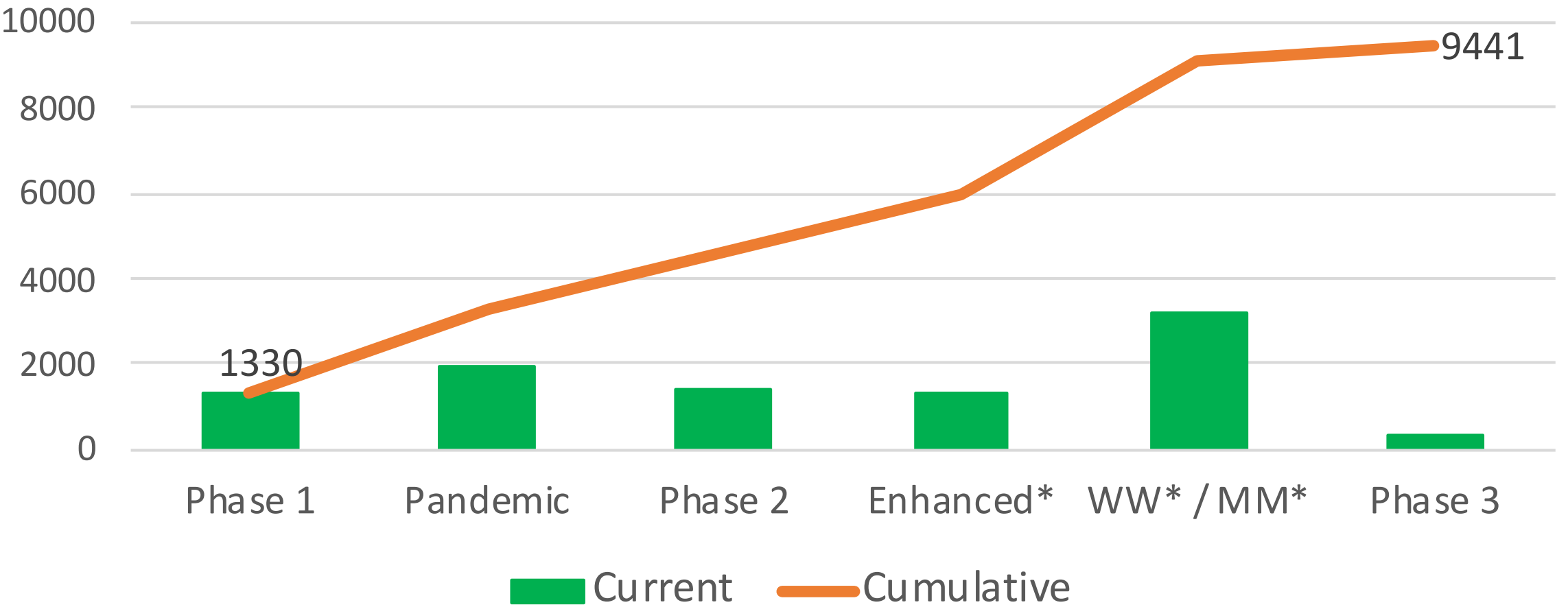
Phase 1: 2015-19

London

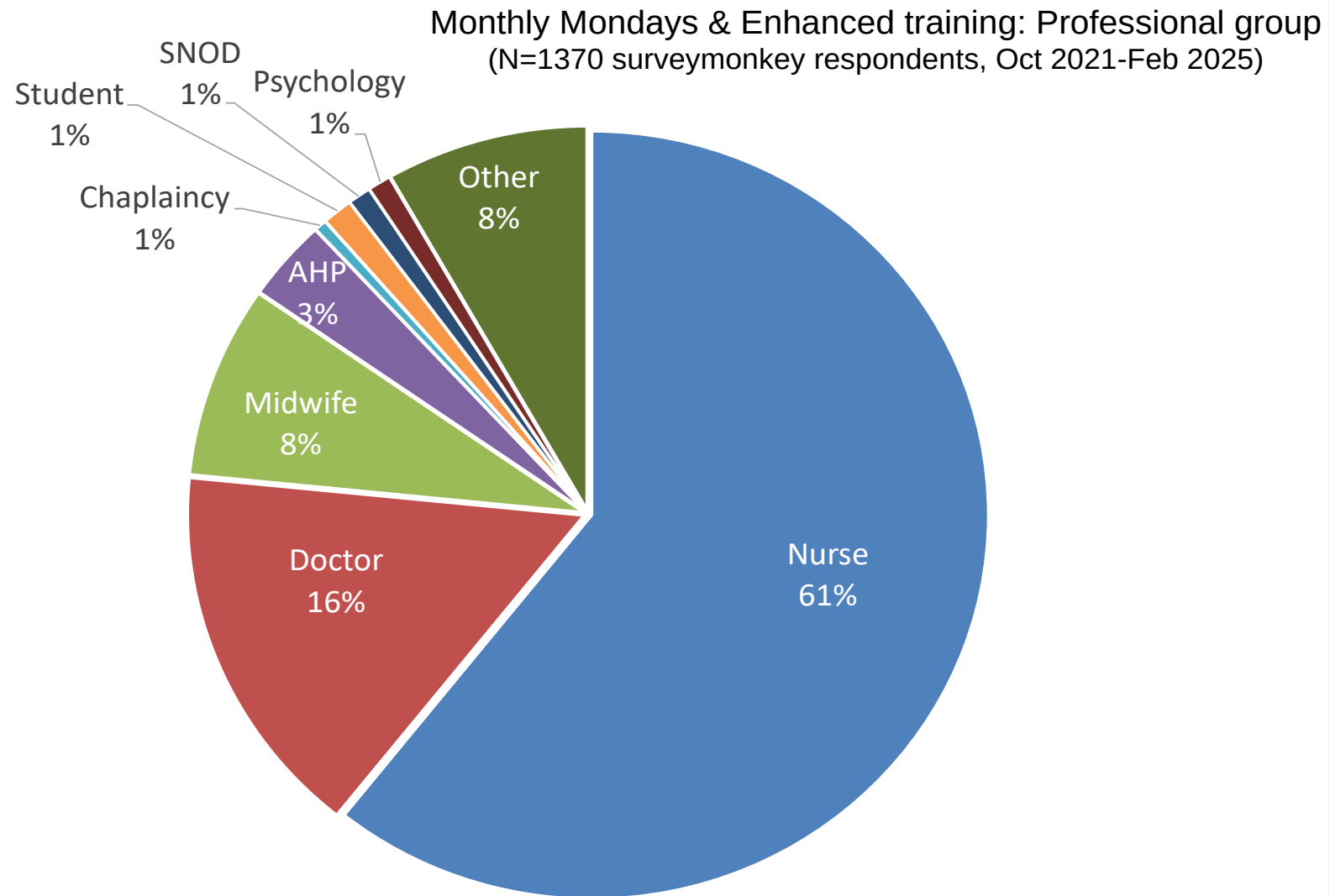
88 **Study Days** in NNUs and children's hospices
>1,330 participants

Cumulative education & training participants

* sessions with repeat attendees



All sessions are multi-disciplinary, with nurses as the key audience

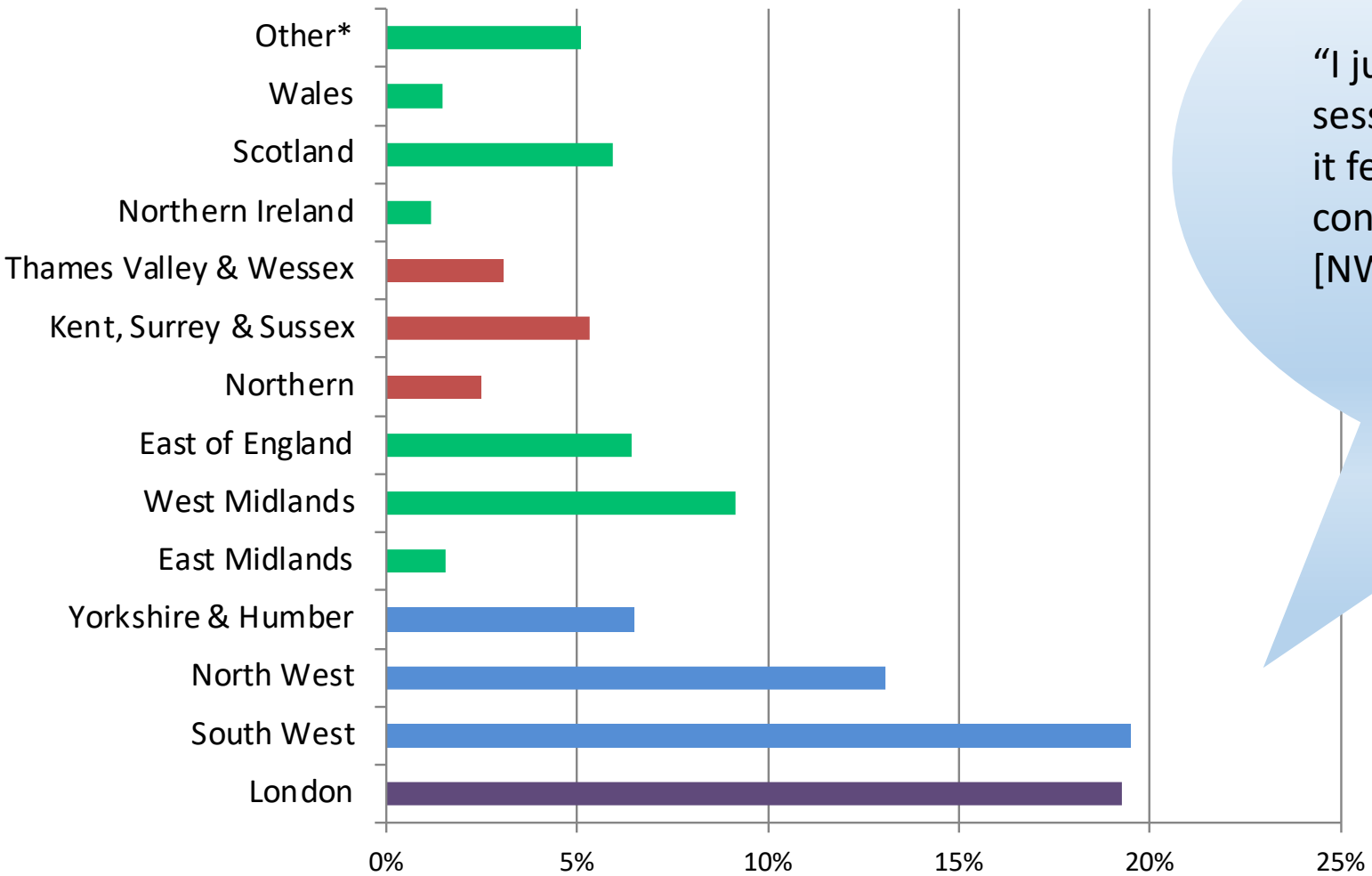


Relationship building & sustainability

Monthly Mondays & Enhanced sessions: Regional breakdown

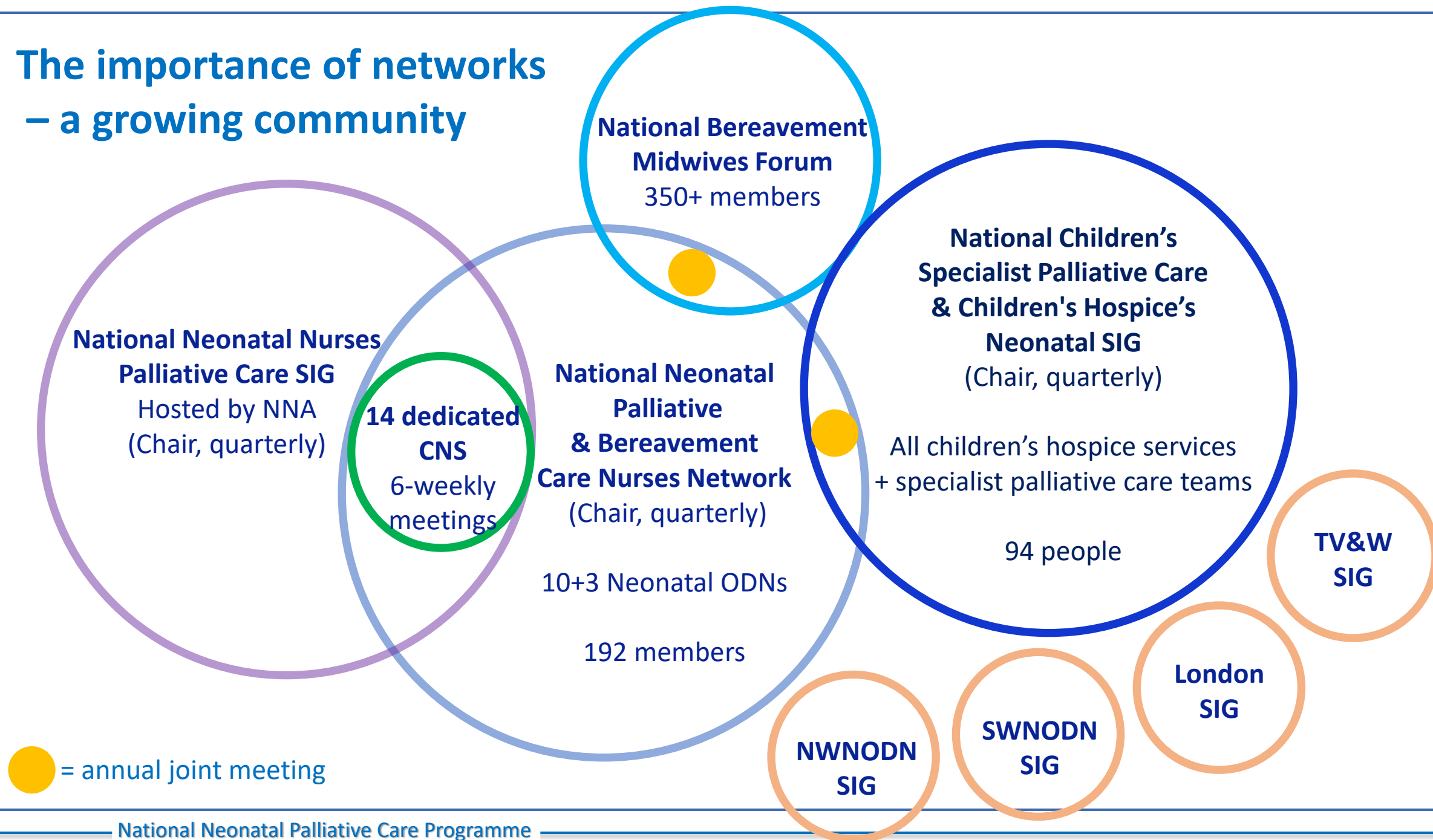
(N=1369 surveymonkey returns, Oct 2021 - Feb 2025.

*Other: mainly International & Republic of Ireland.)



“I just want to express my gratitude for your sessions, they are influential to my practice and it feels so inspiring to be part of the collective contributing to such a specialised area of care.”
[NW enhanced training, Jan. 2023]

The importance of networks – a growing community



3: Learning outcomes

Percentage of participants reporting that **the introductory training met their expectations ‘completely’**:

Phase 1 Study Days	89%
Phase 2 Virtual introductory	86%
Phase 3 Virtual Introductory	88%
Enhanced & Monthly Mondays Virtual, Phase 2 onwards	90%

“In all honesty, it's hard to imagine a better session. The variety of speakers, the presentations, the discussion and question answering - everything was at such a high standard.”

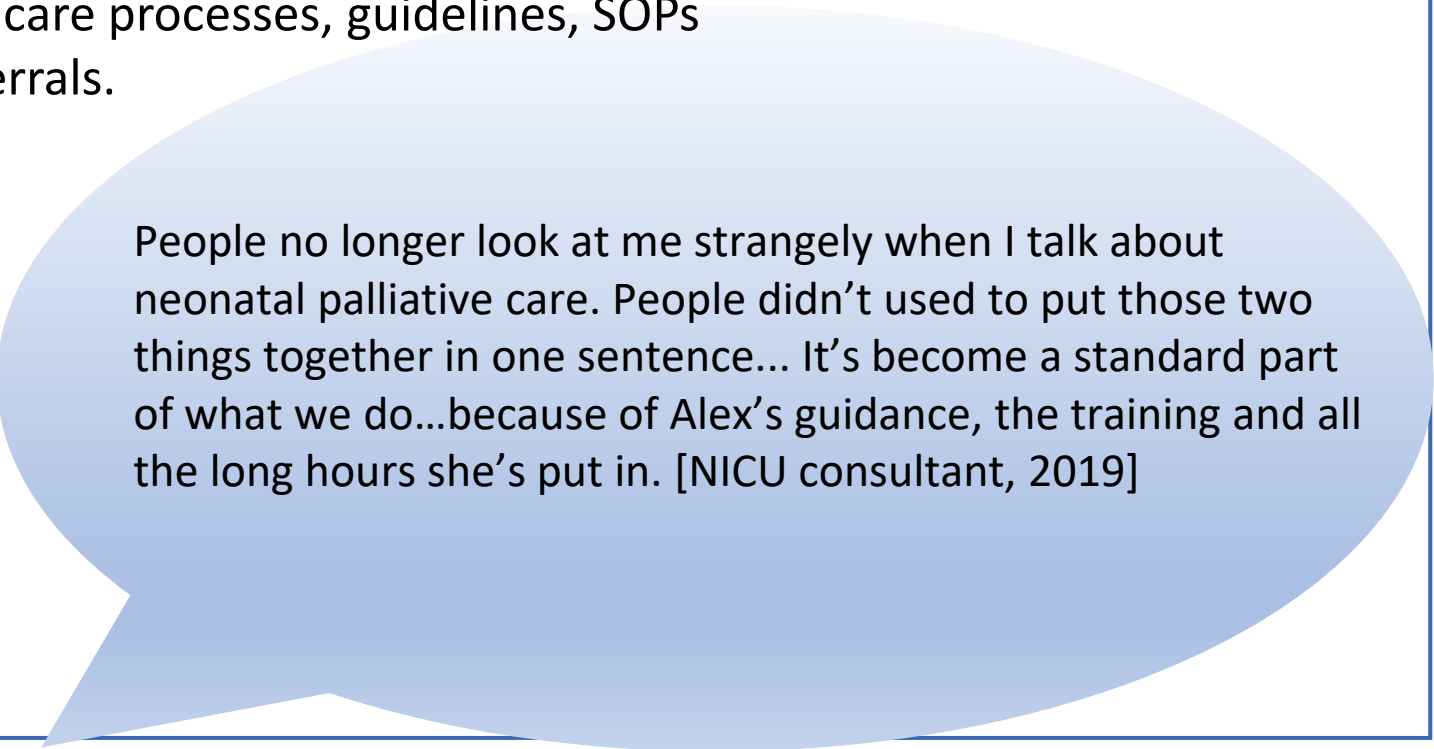
[SW intro training, Nov. 2022]

Impact on practice (phase 1 evaluation, 2019)

Improved knowledge and confidence to discuss palliative care and offer choices to families:

- Better understanding of palliative care
- Improved knowledge of palliative care and hospice services
- Improved knowledge of palliative care processes, guidelines, SOPs
- Greater confidence in making referrals.

Raising awareness and cultural change ...



People no longer look at me strangely when I talk about neonatal palliative care. People didn't used to put those two things together in one sentence... It's become a standard part of what we do...because of Alex's guidance, the training and all the long hours she's put in. [NICU consultant, 2019]

Impact on practice (Phase 2 on, 2021 to present)

Reflecting on learning from today's session, what one thing will you take back to your practice?

Top learning outcomes (in order of frequency):

1. Offering and supporting families' choices
2. Supporting families
3. Communicating well
4. Improved knowledge and understanding
5. Developments in neonatal units
6. Multi-disciplinary working
7. Hospice partnerships.

Evidence, coded in Nvivo: SurveyMonkey (all sessions); semi-structured interviews; follow up survey; 2 focus groups.

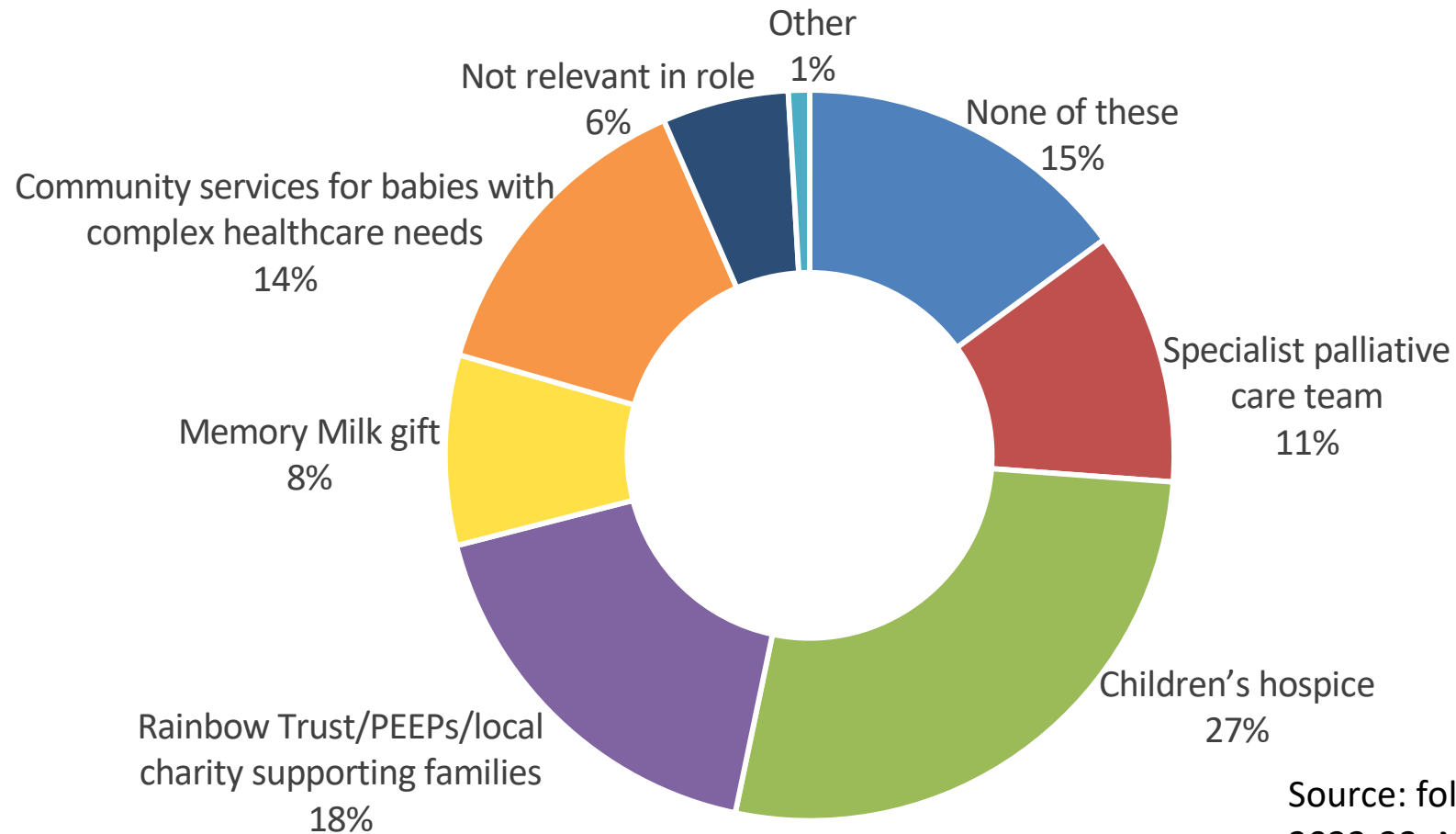
Learning outcome no. 1: Offering and supporting families' choices

"We only have the choices you give us" really resonated with me, making me reflect on how we communicate with families and the possibilities we offer them. The talks were excellent, providing valuable insight into how we can support families not only during a loss but also afterward, helping to reduce their trauma and offering them a sense of control in their journey. [Phase 3 introductory training]

- Feeling confident to ask families what they want and well informed about options e.g. hospice care or going home
- Having helpful information to share with families e.g. PEEPs (HIE) info packs
- Parallel planning and advanced care planning, starting those conversations early
- Being mindful and aware of options like breast milk donation after loss, organ donation.

Offering and supporting families' choices

Since attending the training, which services have you worked with or referred a family to?



Source: follow up survey
2022-23, N=70

Learning outcome no. 2: Supporting families

To try and ensure care remains consistent for each family, regardless of the change in consultants. To advocate for families after the death of their baby and ensure they are allowed all the time in the world to have those last moments and make those memories, regardless of staffing.

[NW introductory training, phase 2].

- Understanding families' experience of neonatal care – valued insights from parent speakers
- Supporting for families at end of life and through bereavement
- Supporting transition to hospice, home or local hospital (pathways of care)
- Support in the community from charities like PEEPs, the Rainbow Trust and children's hospices.

More recent theme: responding to families' cultural needs.

Learning outcome no. 3: Communicating well

Your parent speaker was amazing and as ever makes you think 'how did we not ask that?' or 'check that?'.

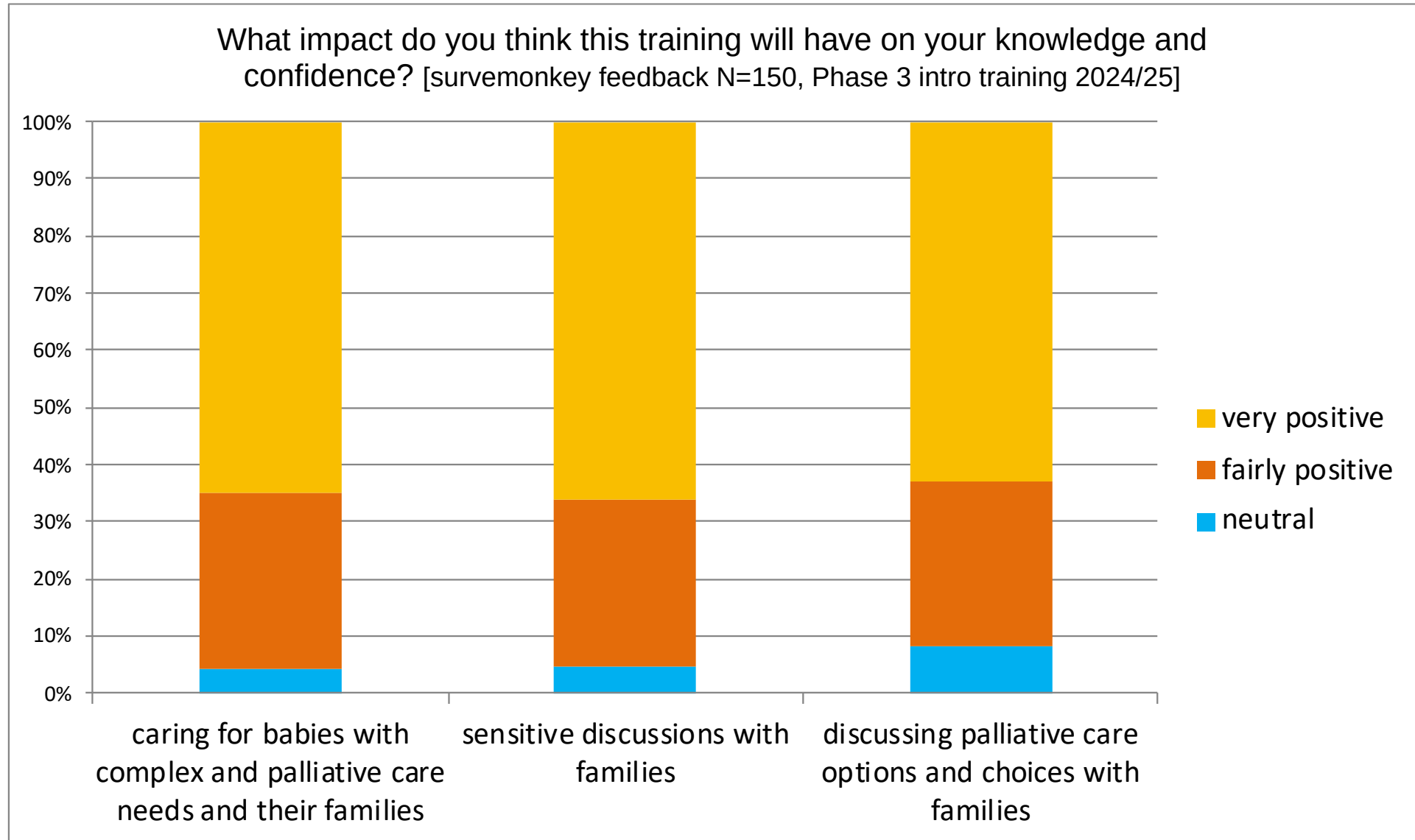
[Email feedback from an AHP, August 2021]

The voice of the parent is such a powerful reminder to have the conversations, no matter how awkward for us as professionals. It was really insightful.

[Monthly Mondays, 2022]

- Feeling more confident about having sensitive conversations with families
- Preparing well, thinking about language
- Listening skills, giving families time
- Feeling confident to discuss palliative care and/or hospice services

More than 90% report a positive impact on knowledge and confidence ...



4: Sustainability

Building blocks

Evidence (coded in
nvivo): Interviews
phases 1&2, London
sustainability research,
P2 follow-up survey

Sustainability 'enablers'

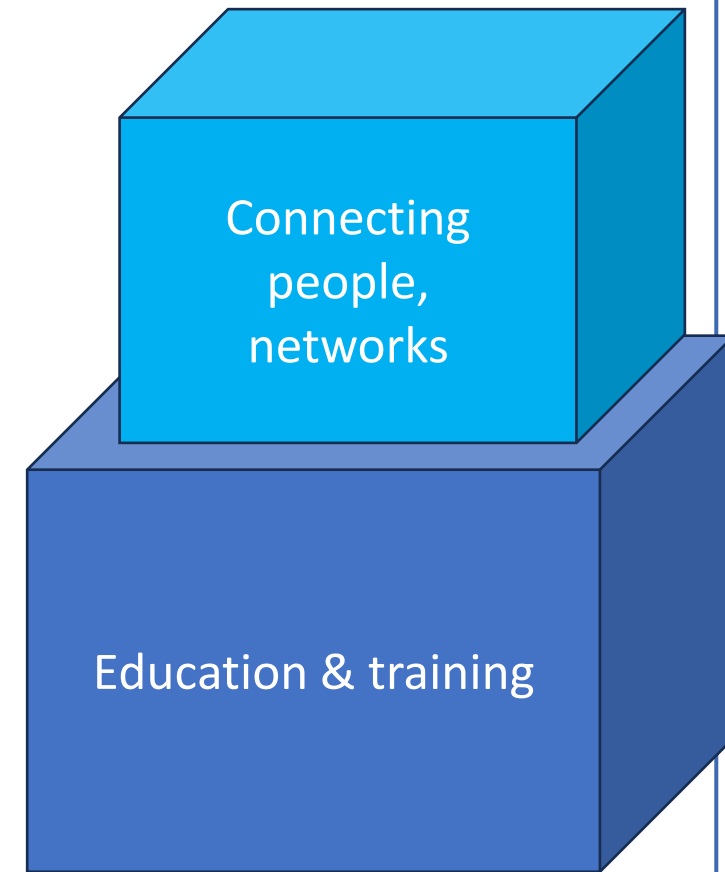


What is needed to sustain progress?

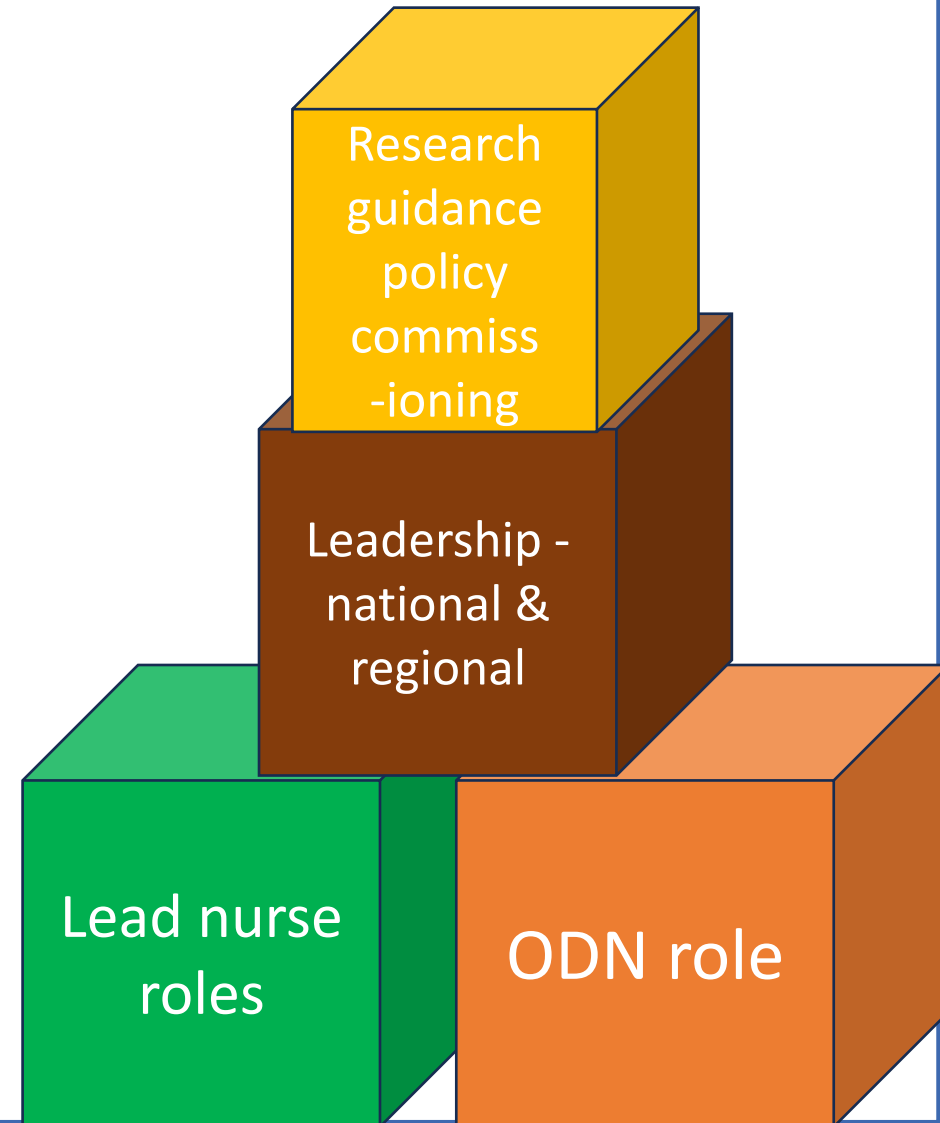
Keep up the education and training! Suggestions include:

- Make introductory training mandatory (some Trusts have)
- Embed in Preceptorship & QIS status
- Undergrad & post grad courses ...
- Online resources, recordings (will curate a collection)
- Refresher sessions (now in the pipeline)
- In person sessions
- Consultants sessions ...

Biggest barriers: Staffing shortfalls (& time for training), turnover



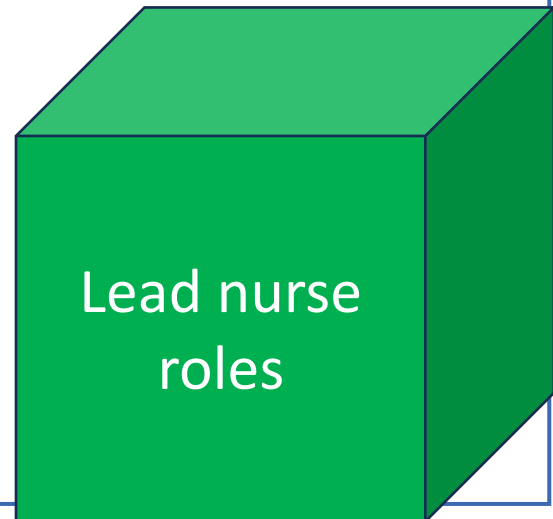
Sustaining progress: Infrastructure challenges



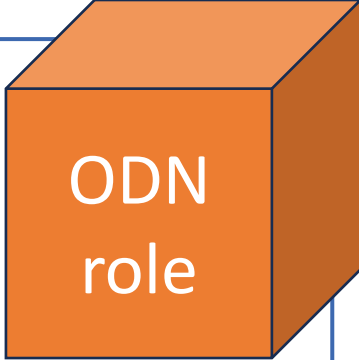
Sustaining progress: Infrastructure challenges

- Almost every NNU has a link nurse, but most have little if any dedicated time (audit of all units in participating regions)
- 14 dedicated Clinical Nurse Specialist roles – slowly increasing
- 4 of the 5 consultants interviewed in Phase 2 evaluation spoke of need for these roles (spontaneously)

Dedicated and funded time for lead roles is essential to provide equitable, consistent, safe and effective Core Perinatal Palliative and Bereavement Care. BAPM framework for practice (*Recognising Uncertainty*, July 2024)



Sustaining progress: Infrastructure challenges



ODN
role

“It being network-wide is absolutely brilliant, because it means then we're all kind of singing off the same song sheet and hopefully giving very similar packages of bereavement care.” (SW focus group, July 2022)

SWNODN approach added to the programme's reach, impact & sustainability:

- Support from Senior Lead Nurse, alignment with ODN strategic objectives
- Lead nurse role (0.3-0.5 fte) in ODN, supporting NPC programme delivery
- Perinatal Palliative Care Guideline & SW Special Interest Group developed
- Job Description for NPC link nurse roles shared with all units, funding secured for 2 people per unit to take a postgrad module
- Neonatal palliative care embedded in education programme.

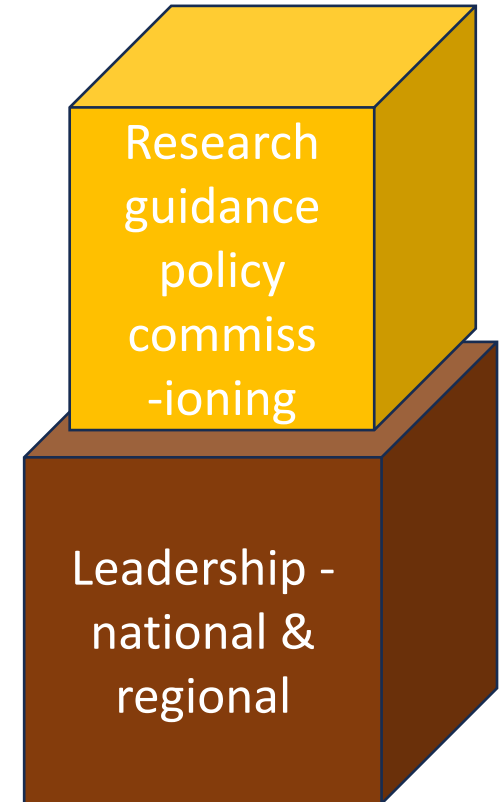
Sustaining progress: Infrastructure challenges

It's just through passion and voluntary work that they are supporting with this!

I think that makes it very difficult when you talk about sustainability going forward, not having a specific funded role in place, that's their only role.

Keep it up! Make it highly visible at the national level!
Bring it up to that level, there needs to be a nationally funded work programme .

It needs to be prioritised! It needs to be embedded somewhere!



Extracts from recent interviews in London, sustainability research (on-going)

Ten years of the Neonatal Palliative Care Programme: the journey so far, impact & sustainability

Insights from the independent evaluation

Evidence presented at the National Neonatal Palliative Care Programme Conference,
12 March 2025

Anne Pinney, Independent Evaluator
anne@kirton.org.uk

*You are welcome to use evidence from this slidepack, please credit:
Independent Evaluation of the National Neonatal Palliative Care Programme (March 2025).*