



Matthew Lievesley: *associate professor in design*

Project: Tiny Lives Trust - towards family integrated care for pre-term babies.



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Today (17th November) is World Prematurity Day, to raise awareness of preterm birth and the concerns of preterm babies and their families worldwide.

Approximately 15 million babies are born preterm each year, accounting for about one in 10 of all babies born worldwide.



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Project Background and Aims

The project aimed to identify ways to support preterm infants and their families as they transition from Newcastle Neonatal unit to home.

- It has engaged both staff and families in exploring potential service improvements through co-design approaches.
- It responds to policy drivers from the UK's NHS England.

“A seamless, responsive and multidisciplinary service built around the needs of new-born babies and the involvement of families in their care.”

From NHS England's Neonatal Critical Care Transformation Review 2014/2019

This research is funded by the Tiny Lives Trust, as a three-way partnership with Newcastle Neonatal Service and Northumbria School of Design.



Images courtesy of the Tiny Lives Trust

Progress before and during Covid

Exploratory workshops with the Neonatal Service's staff teams took place at Newcastle's Royal Victoria Hospital (pre Covid-19).

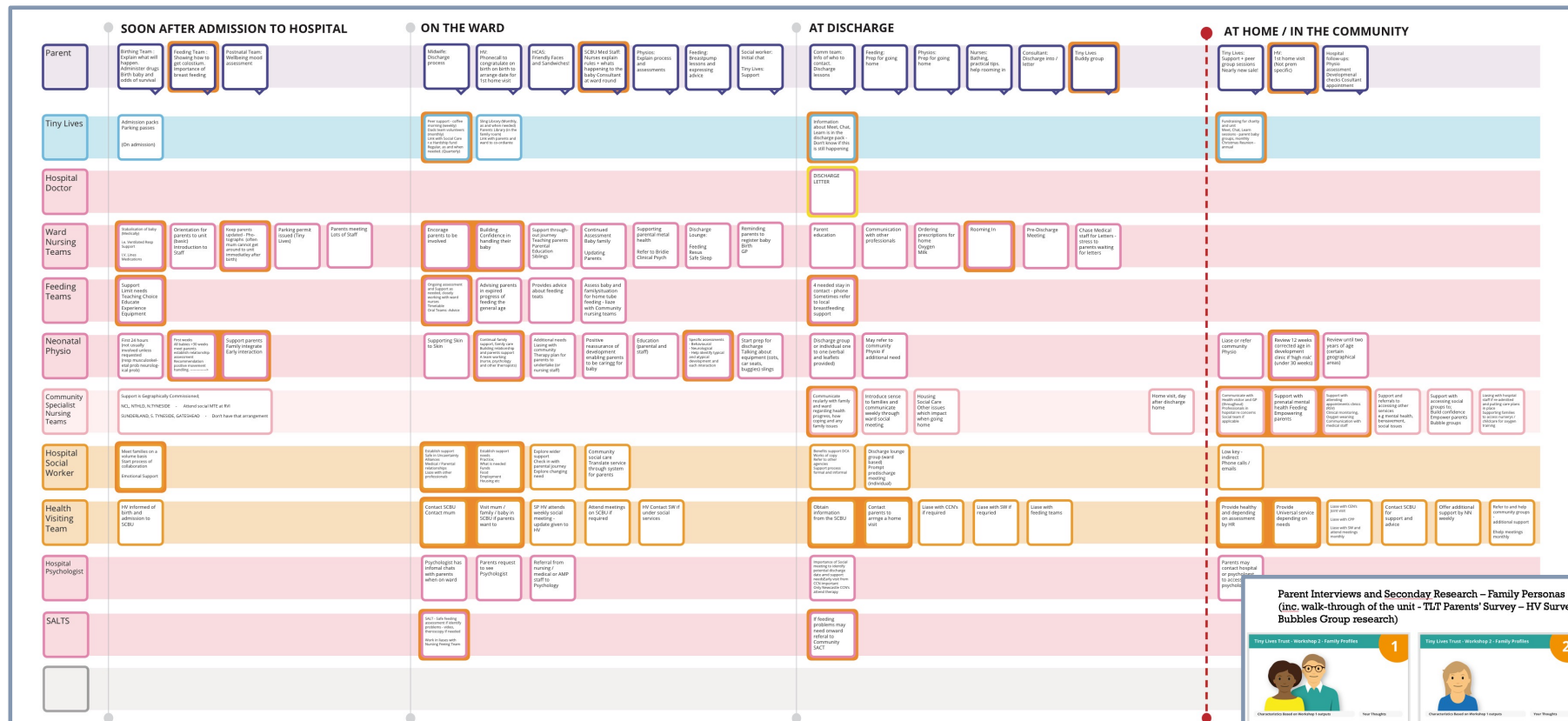
The outcomes were a set of collectively-generated family profiles, a timeline of current (cross-functional) service provision and early ideas around potential improvements.

Interviews with three families who have been supported through the service were conducted. Further insight and interpretation has been provided by one parent who was recruited to support the project team throughout, and also from the Tiny Lives Trust's own Parent Surveys.

During Covid, Miro whiteboards were used to facilitate co-design progress and reviews.



Workshop Outputs – Mapping of Current Provision and Family Profiles



Parent Interviews and Secondary Research – Family Personas (inc. walk-through of the unit - TLT/ Parents' Survey – HV Survey – Bubbles Group research)

Tiny Lives Trust - Workshop 1 - Family Profiles 1

Observations based on Workshop 1 Output

Their Thoughts

Tiny Lives Trust - Workshop 2 - Family Profiles 2

Observations based on Workshop 2 Output

Their Thoughts

Tiny Lives Trust - Workshop 3 - Family Profiles 3

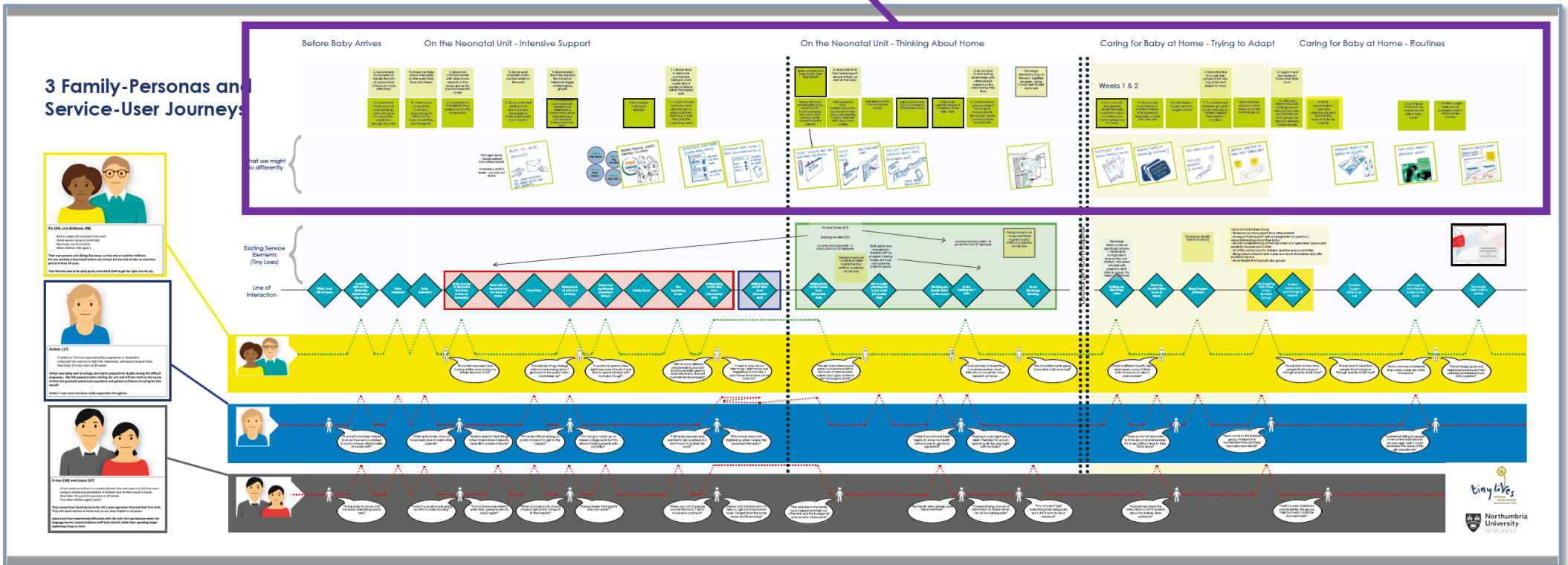
Observations based on Workshop 3 Output

Their Thoughts

Combining Data – [Staff Workshops] + [Secondary Sources] + [3 Parent Interviews]

3 Family-Personas and Service-User Journeys (original data redacted)

Existing provision and potential areas for changes were mapped along the top section of the timeline



Example intervention components (at home)

Seventeen proposed elements of the intervention were considered by the project team. The five shortlisted, were then developed as mock-ups and shared with stakeholders in a simulated ward.

The half-day co-design and feedback event enabled staff and families to interact with the mock-ups, identify changes and improvements and feed back on the project's direction and progress. Prototypes were revised and implementation plans agreed.




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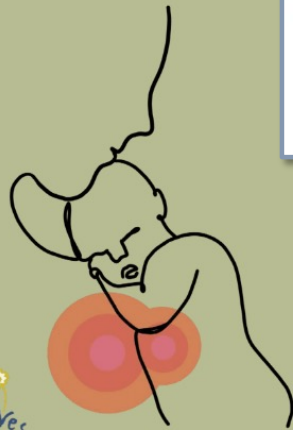
Example intervention components (on the ward)



every moment together is unique



family is a feeling not a place



I feel closest when we're heart to heart



your touch is magic

Communication Cards

FRONT **BACK**

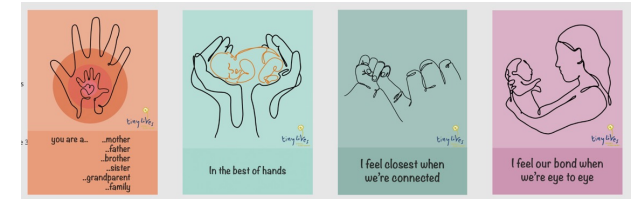
Need some advice?
It's often hard to ask the questions that you want or need to ask.

TOPIC: GENERAL QUESTIONS

FRONT **BACK**

Still asking every time you want to feed or pick up?

TOPIC: RESPONDING TO BABY'S CUES



Early learnings (from this context) for DESIS

Do all you can, to keep service-users' voices evident in the project.

Act through the in-hospital phase, to drive positive experiences of transition to home.

Geographical power

Acknowledgements: Thank you to our fantastic partners: at Newcastle Hospitals Trust, my colleagues Sophie Coombs and Charlie Richardson, and our project funder the Tiny Lives Trust. matthew.lievesley@northumbria.ac.uk

