

Family Experiences of Neonatal Care: Co-design and piloting of resources to promote positive family experiences.

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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 families and staff in exploring potential service improvements through co-design approaches.
- It responds to policy drivers from 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



Co-design process

Process

Initial exploratory workshops with the Neonatal Service's staff teams took place at Newcastle's Royal Victoria Hospital.

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. (Whatsapp records) Further insight and interpretation has been provided by one parent-representative (Rachel Collum) who has supported 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.




Family Profiles

were constructed by a cross section of staff and our parent-representative. Parent Interviews and Secondary Research (inc. walk-through of the unit - TLT Parents' Survey – HV Survey – Bubbles Group research)

Tiny Lives Trust - Workshop 2 - Family Profiles

1



Characteristics Based on Workshop 1 outputs

Family Circumstances
Flo and Anthony currently live in Forest Hall and met through their work at the building safety executive, a government standards agency. They still work for the same organisation but have recently transferred from Darlington to the new offices at Longbenton.

For a long time, Flo and Anthony thought they wouldn't be able to have children, but 5 years ago they had a daughter Ellie after two rounds of IVF. Then, last year, they got pregnant without help, which came as the nicest sort of surprise but a surprise nonetheless.

When Flo was 5 months pregnant she started to have difficulty with pre-eclampsia and they were fearful they might lose the baby, but their daughter, Joy, actually arrived by c-section at just 25 weeks.

Experiences of the Neonatal Service
They remember having had a mainly positive experience in terms of their relationships with staff on the unit at the RVI. They tried to share responsibilities with staff and always tried to make sure they understood exactly what was happening and felt they were quite expert, because they could visit every day. Work were very good about that.

Their first child had arrived early too (nowhere near as early as Joy though). That was when they were based in Darlington and they had a very good experience with the James Cook Hospital, in Middlesbrough. By comparison, the Neonatal Ward at Newcastle just seemed a lot busier – Flo remembers that sometimes staff didn't have much time for you unless you were quite pushy.


Moving back home
Planning to leave the ward was a bit confusing. It wasn't as simple as setting a date and sticking to it, as they'd imagined, because there were some fluctuations in Joy's health but also a squeeze on capacity in the ward. When the week came, there was a flurry of activity – checklists – discharge letters – and a practice night in the special flat.

At home they were both relieved to feel back in control but also anxious about establishing a routine – especially feeding and sleeping. If Joy didn't seem herself, Flo would sometimes ring the ward, but the advice was usually wait and see and thankfully, Joy, did pick-up each time. Oxygen weaning was frustratingly slow and it trapped them in the house, but eventually Joy joined the Bubbles group which reassured her that this was very common. At least they understood pre-term babies better – their Health Visitor had been a bit too focussed on babies growth rates.

Your Thoughts

Tiny Lives Trust - Workshop 2 - Family Profiles

2



Characteristics Based on Workshop 1 outputs

Family Circumstances
Amber is almost 18 and currently lives with her parents in High Fell, Gateshead. She has been doing an apprenticeship programme in Hospitality and Catering through Gateshead College. Even though she's determined to do well, Amber has missed lots of college sessions through her pregnancy and has had to defer her final year.


Experiences of the Neonatal Service
Amber was in hospital for the first 10 weeks with the newborn. She was in the NICU for 10 weeks. It was clear that Erin would need to stay in the hospital for some time, so Amber

Moving back home

Your Thoughts

Tiny Lives Trust - Workshop 2 - Family Profiles

3



Characteristics Based on Workshop 1 outputs

Family Circumstances
Soyeon (Joyce) and Ji-hun Park are both in their late 30's. They moved from South Korea to the UK 5 years ago when they had their first child. They still speak Korean at home and, as yet, their English is not great.

They rent a house in Fenham, Newcastle and earn enough to live comfortably, but not enough to save. This means Ji-hun can't afford to take much time off work. Joyce currently stays at home to look after their two other children.

Joyce and Ji-hun live very near to the family of their Cousins, who moved to the UK over 5 years ago. They have found the local community around them and their nearby family members being and supportive.

Their children are aged 3 and 5 so this means they already have significant care responsibilities at home and Joyce worries she won't be able to devote as much time to their new baby because of the demands of his siblings.

Experiences of the Neonatal Service
Their son Ho-jan (Eric) was born at 29 weeks.

Throughout their long relationship with the Neonatal Ward, Joyce and Ji-hun experienced difficulties with the staff, this was because when the language barrier caused problems staff took control, rather than spending longer explaining things to them. Joyce started doing some extra English lessons but is still finding it hard.

Due to their lack of involvement in the care process during their time on Ward 35, when they were discharged, Joyce and Ji-hun both felt a lot of anxiety. They weren't confident about the care of their son. Using the flat to practice with the oxygen helped right at the end, much to take in all at once – sleeping, feeding, infection risks, oxygen – all in a more discharge.

Moving back home
Joyce and Ji-hun took Eric home and had help getting their bedroom set up properly with the oxygen supply. The oxygen weaning had some technical terms, so Joyce was able to access some online information in Korean, which helped her work out the English equivalents.

It was the hardest thing – the oxygen weaning – it felt so important to get right and Joyce was nervous because of the anxiety and the feeding in the night. She did call 111 one night, and was told to attend A&E with Eric, but it wasn't serious so she felt she'd wasted people's time going back to working long hours, so Joyce had long days and nights and felt low. She was the same for all mums or if she needed some sort of help. She'd been offered support on the ward but didn't think it was something she should need.

Over the few months or, most of the anxiety has gone, but Joyce feels she has to be very strict with her children to take enough care around Eric – especially when he is having his oxygen.

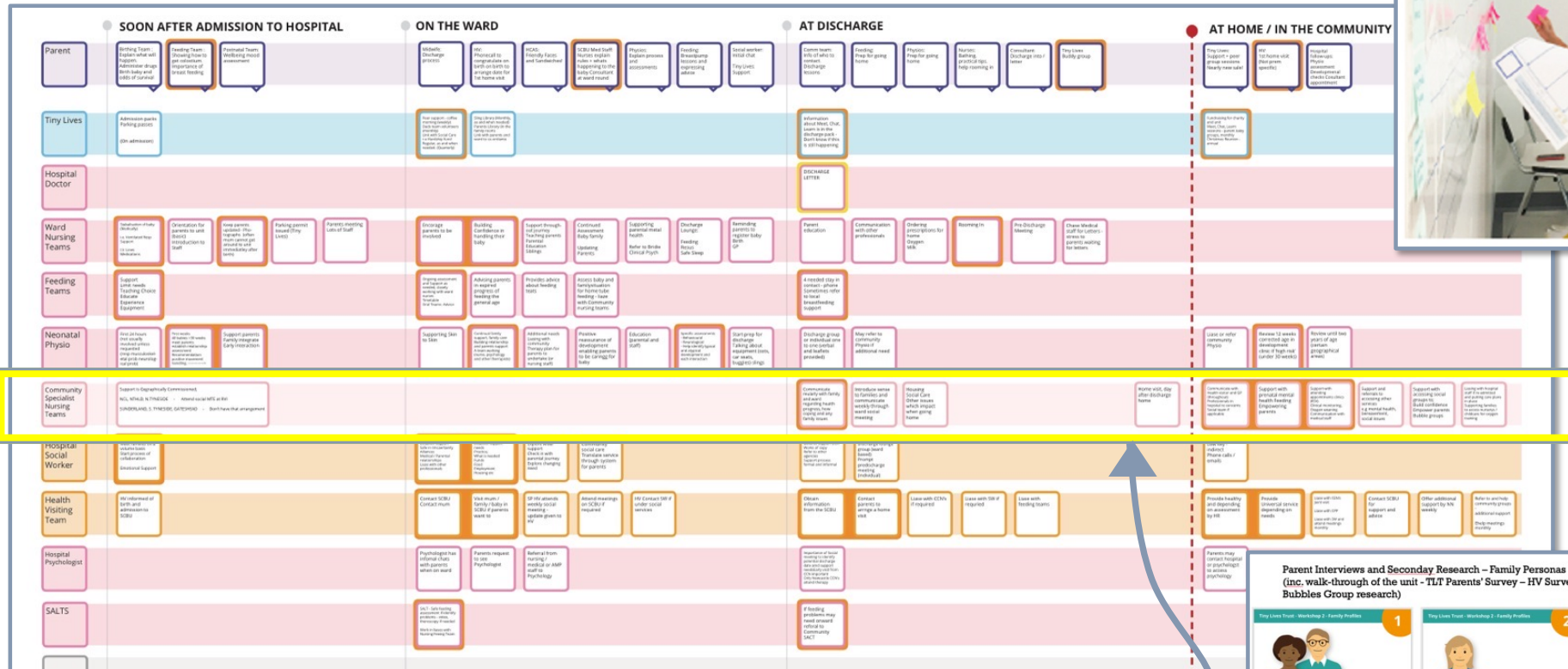
Your Thoughts

Family Circumstances

Experiences of the Neonatal Service

Experiences of Moving Back Home

Workshop Outputs – Mapping of Current Provision and Family Profiles



Workshop Constituency: Parent Representative, TinyLives project lead, Ward Nursing team, Feeding team, Neonatal Physio, **Community Specialist Nursing**, Hospital Social Worker, Health Visiting team, Health Psychologist, SALTs

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

1

Tiny Lives Trust - Workshop 2 - Family Profiles

Characteristics based on Secondary Evidence

Key Thoughts

2

Tiny Lives Trust - Workshop 2 - Family Profiles

Characteristics based on Primary Evidence

Key Thoughts

3

Tiny Lives Trust - Workshop 2 - Family Profiles

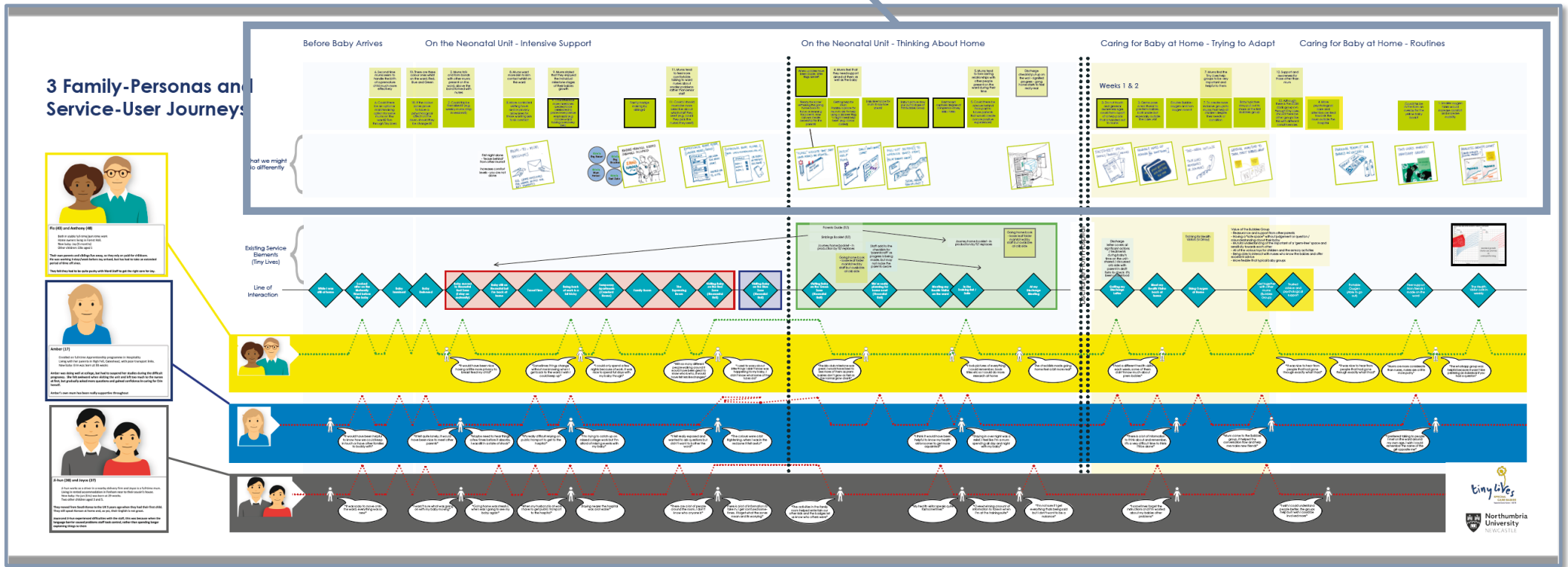
Characteristics based on Primary Evidence

Key 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



Translating 'insights' from the research into sketch ideas (zoomed-in)

On the Neonatal Unit - Thinking About Home

11. Mums tend to feel more comfortable talking to ward nurses about smaller problems rather than senior staff

11. Could / should mums be more selective about which staff they see? (e.g. could they pick the nurses they see?)

The expressing room is an opportunity for reflection - could be used for sharing positive stories etc - providing hopeful outlook

When updates have been made - little flags are left

'Ready for Home' rethinking this going home book to focus on learning for parents. How can we create ownership for the parent?

4. Mums feel that they need support aimed at them as well as the baby

Getting help for mum
Possibly a place for mum to ask for help using a discreet flag 'i might need help here' (e.g. colour coded)

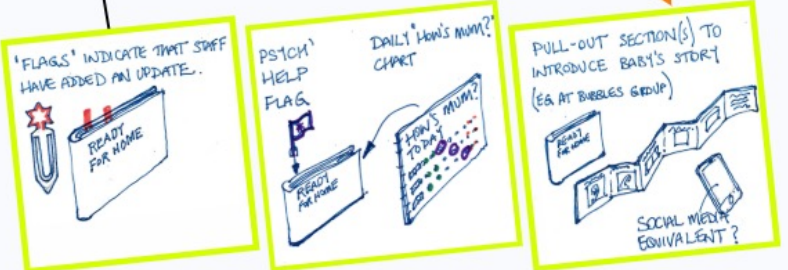
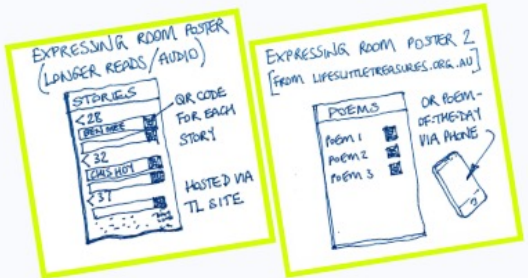
Daily likert scale for mum to say how she is?

Baby's picture story pull out to share at first Bubbles Group

5. Mums find it difficult to form relationship with other people present on ward during time

5. Could there be a leave book from past future patients that would give a more positive experience

Family badge making by siblings?



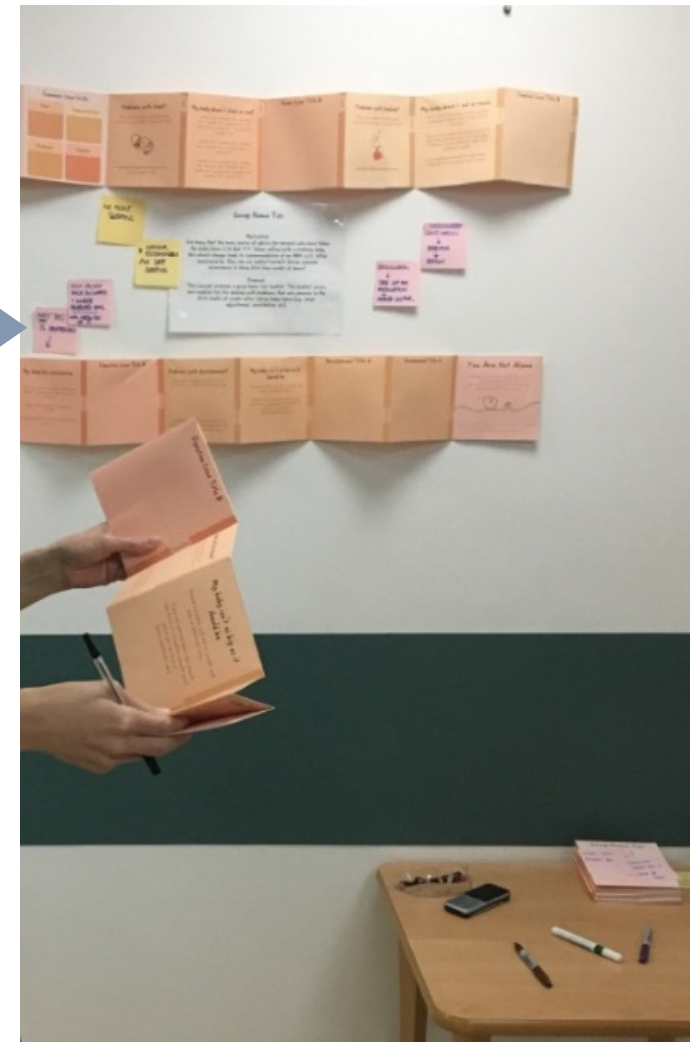
Engaging parents and staff with possible improvements – using mock-ups

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.

Going Home Tips



On the Ward (four elements shared at the RVI feedback event)

Family Badges

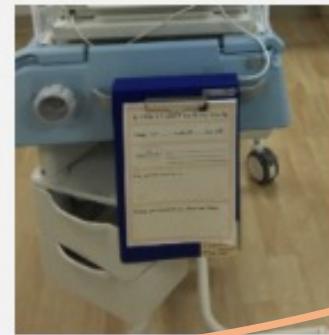
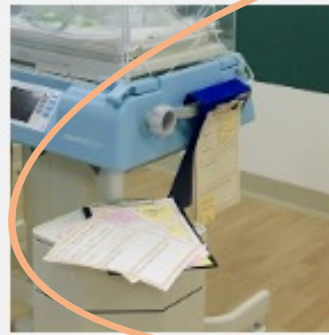
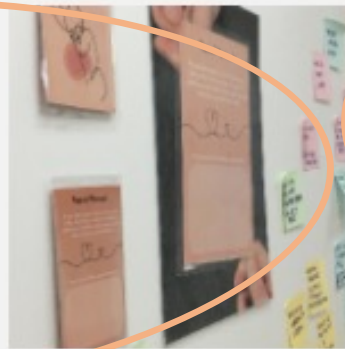


Chart Cover Sheet

Parent Permission Cards



Posters



RVI Feedback Workshop

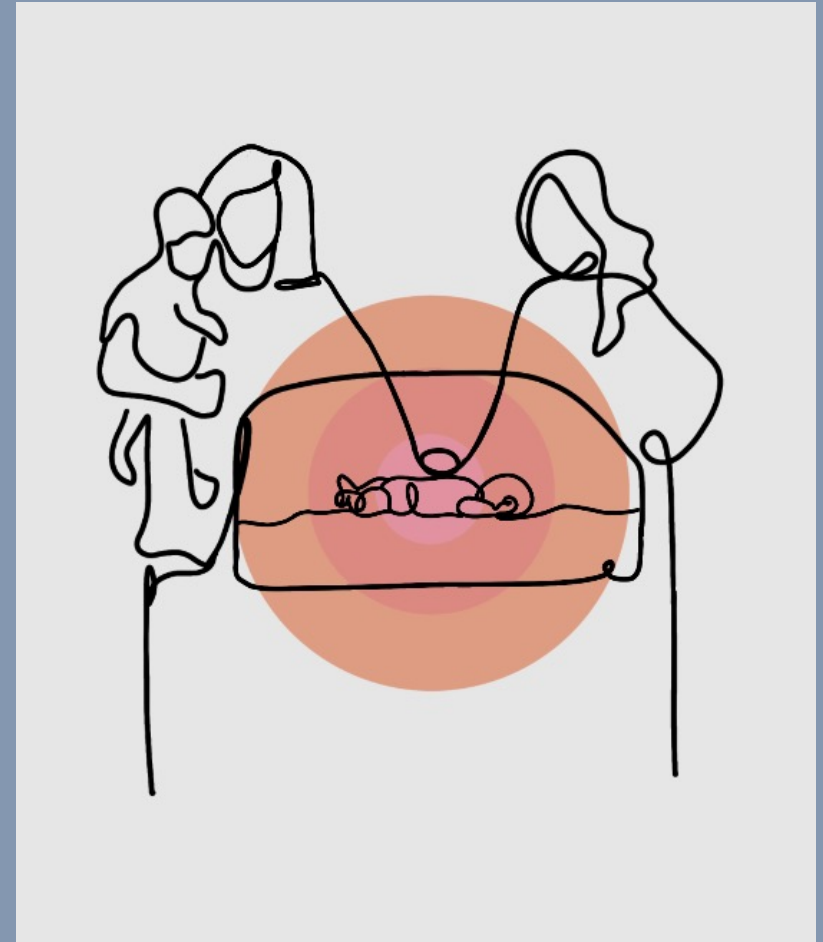


Prototypes were displayed in the training room in the RVI. Staff and parents associated with Ward 35 attended, to review the initial prototypes and provide their feedback.

These 'prototypes' are incomplete and the workshop participants – parents and staff – suggest what content would be valuable.

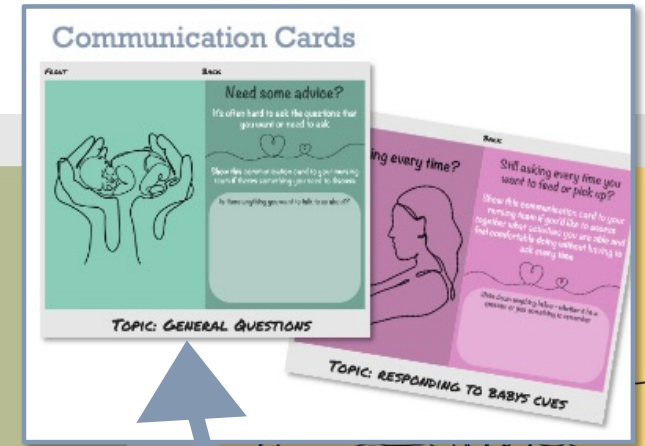
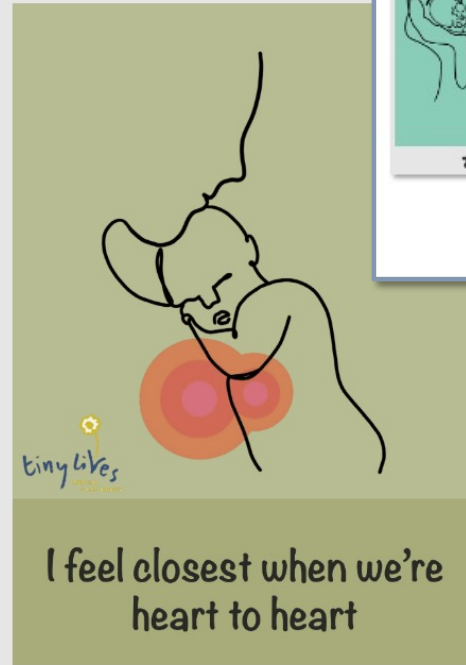
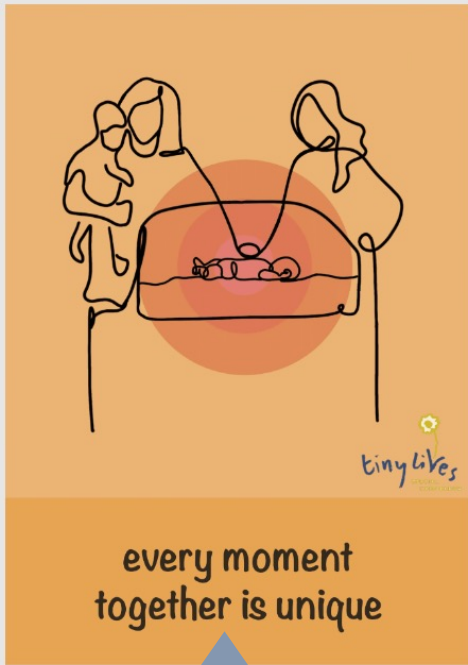
A parent's perspective: on the process

- ▶ Being invited to co-produce a project like this, which can make a real difference on the neonatal unit, is a wonderful way to value and acknowledge a parent's experience.
- ▶ The collaborative and iterative nature of the project meant that there were less power hierarchies – so the parent voice was (eventually!) seen as just another expert in the room.
- ▶ Sometimes, careless language can be a barrier to working together. “difficult parent” is one example, but if we create a safe space to call out these terms, we make good progress!
- ▶ Conflicting priorities/different perspectives of what's important can be a big barrier.



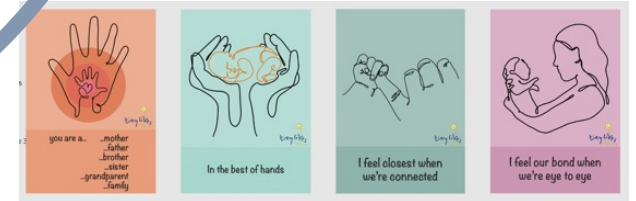
Example intervention components

Example intervention components (on the ward)

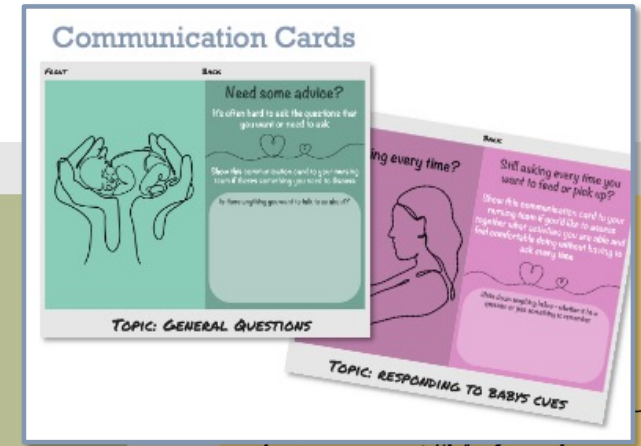
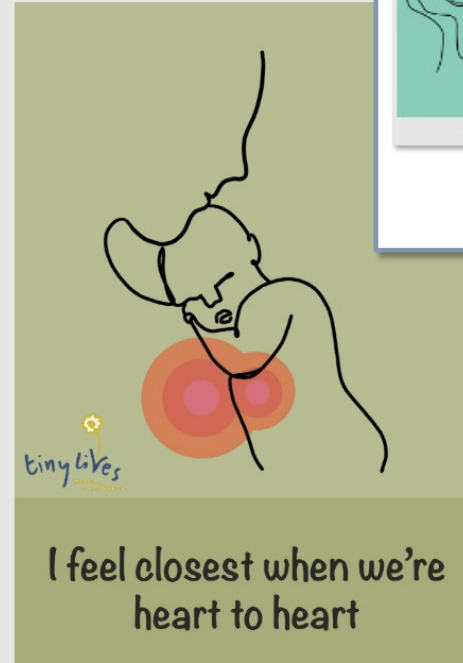
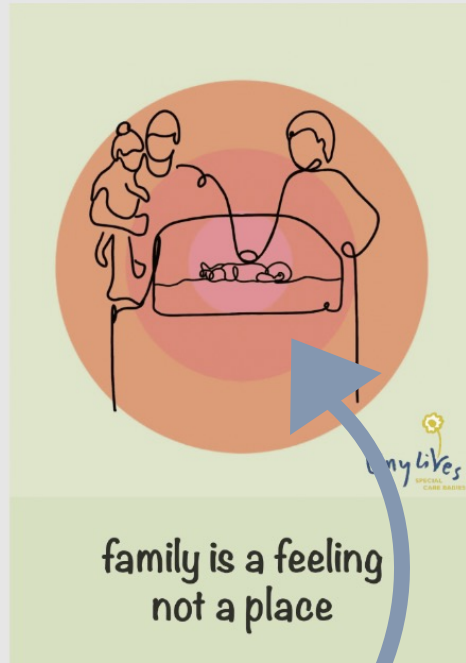
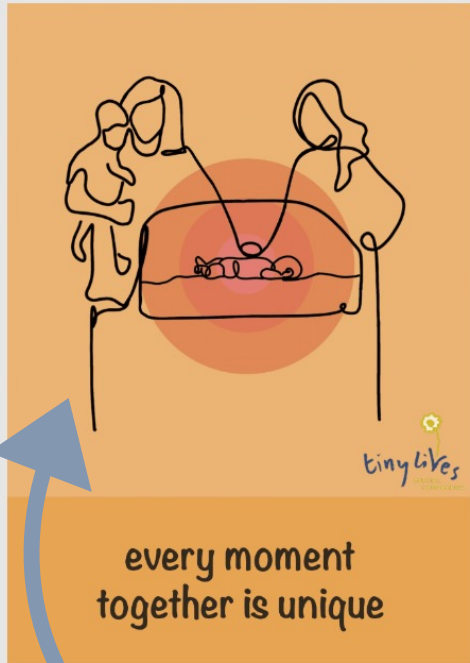


Poster messages promote the importance of family (in what can be a disempowering environment). They're also a 'nudge' to staff.

Communication Cards give positive messaging to parents to encourage them to 'set the agenda' for what happens on the ward.



Example intervention components (on the ward)



The illustration style leaves gender and ethnicity unspecified. Family structure can then also be ambiguous – i.e are parent and grandparent represented or is it mum and dad?



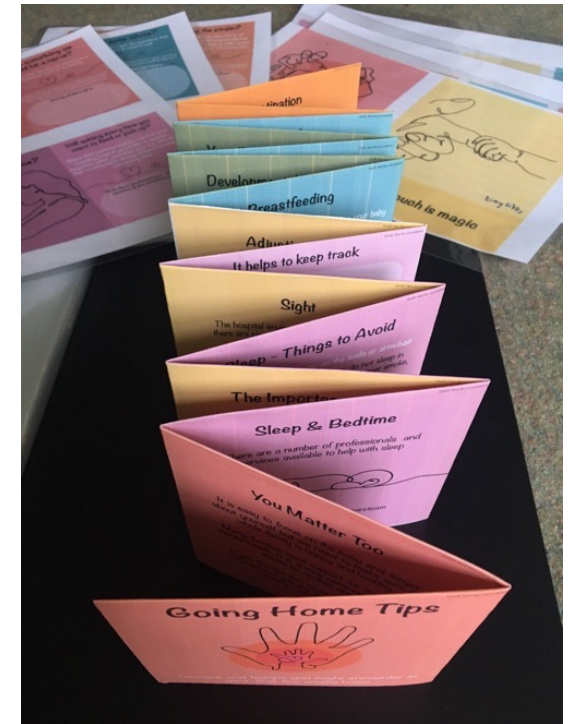
Example intervention components (at home)

'Going Home Tips'

Playful, tactile format aims to encourage families to treat this little book of tips as something precious and worth keeping.

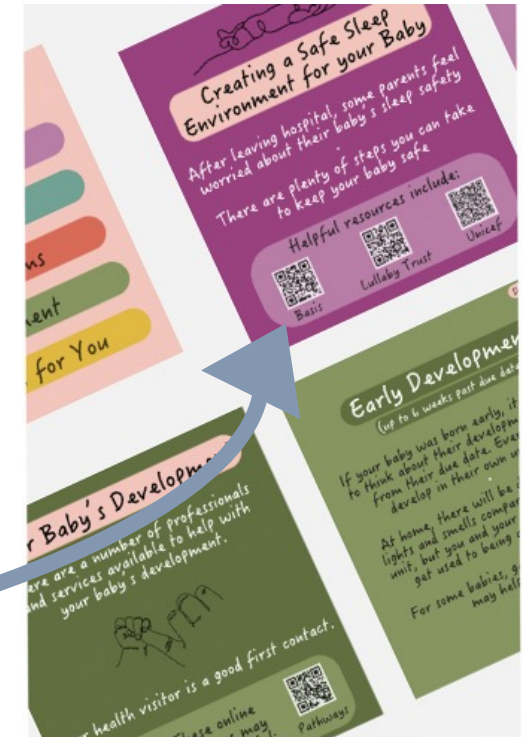
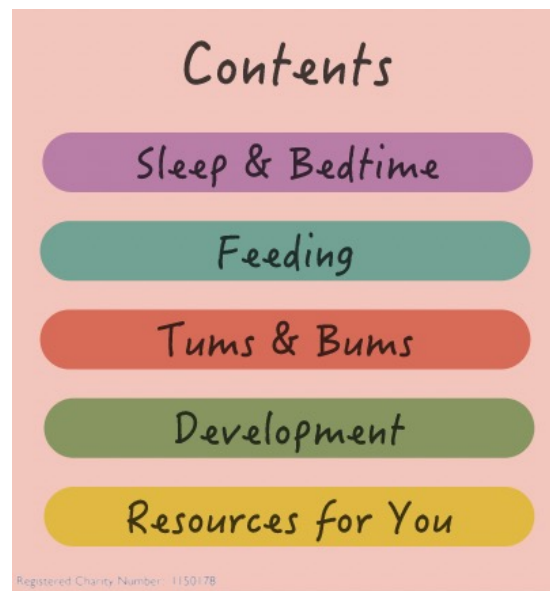
The format will easily tuck into a pocket on the parents' baby-bag for example.

Meets W3C 'AA' colour contrast standards - for easier reading with visually impairments



Example intervention components (at home)

'Going Home Tips'



QR codes link parents to more in depth information on each topic – from a range of reputable sources.



**Piloting the
intervention components.**

Where we are today – scope of the pilot

Running a pilot of the resources in the Newcastle Neonatal Service. (May 2022 – Oct 2022)

- The walls of the unit were stripped of cluttered older-information and the new family-centric messaging and imagery introduced in their place as a set of *Posters*.
- 15 *Communication-Card Packs* have been issued to families on Ward 35
- 8 *Going Home Tips* booklets have been issued to families leaving Ward 35 to return home

- 8 families contacted after discharge for feedback (interviewed by parent researcher, Rachel Collum)
- 9 parents provided feedback during attendance at Stay and Play session (Jacqui Adams, Tiny Lives Trust)
- Staff feedback on the neonatal unit being collected (Claire Marcroft, Neonatal Physiotherapist)

- Staff requests to use the same look-and-feel (images and messaging) on upcoming leaflets have been supported where possible – illustrating growing ownership across the team.

Ethics: Recognised by the host NHS Trust as a Service Evaluation and Development project.

Limitations: Small scale pilot with recruitment limited by increased movement of babies within the network, as many families move to another unit before home (unique network as only have level 3 and 1 units).

Where we are today – early potential themes

Developing themes (from the early data collection).

▶ Authority and Belonging on the Ward

- Underlying *messaging* to parents that ‘their baby belonged to them’. (images and text)
- *Communication Cards* helped to “find our voices more easily” and acted as a prompt – i.e. overcomes the idea that they are bothering staff by asking questions – it clearly gives permission to ask.

▶ Positive Messages, Positive Memories

- The *Poster* ‘family is a feeling, not a place’ at the entrance was important to parents. Sets positive tone.
- Parents liked to keep the *Communication Cards*, to “remember the positive experiences on the unit”
- Parents do take time to look and read things on the wall in corridors or bays and positive *messaging* is important. Staff do not see info on walls as having particularly high importance.
- Branding – in a positive way (use line drawings on unit leaflets and letters)

▶ Getting just the right Information, in just the right place, at just the right time

- Timing to give the *Going Home Tips* booklet – would like to read before discharge but then some parents didn’t want it to ‘jinx’ actually going home.
- Reassuring to have booklet with QR codes, and ‘could there be a poster . . .’ e.g. in the home bay?
- Information about bottle feeding (expressed milk)

A parent's perspective: (early) learning points

- ▶ The tone and ethos of the resources that parents on the working group loved, has also been welcomed by parents on the unit – which shows how some 'core' experiences are shared.
- ▶ Some aspects of the resources haven't been as used in practice, as we'd originally envisioned as parents on the working group: It shows the individual and changing nature of a NICU stay!
- ▶ Differences in what staff and parents value is a helpful pointer to where the gaps are that we need to work on as part of embedding FI Care.





Acknowledgements:

*Thank you to our fantastic partners: at **Newcastle Hospitals Trust**, the wider project team members (especially our project-lead at **Tiny Lives Trust**, Jacqui Adams), all the parents involved in the co-designing process, and our project funders: the **Tiny Lives Trust**.*



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Thankyou + Your questions

