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Support for families beyond discharge from the NICU

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ABSTRACT

Preparing parents for taking their baby home is a process that should begin at admission to the neonatal unit. When parents are involved in their baby's care, feel confident that they know their baby and their baby is well enough to be better care for at home their discharge can be an easy transition. This process requires time, planning, support and education to be successful as well as a range of resources and staff to enable this success. Support continues after discharge to address the specific needs and concerns that a family of a preterm baby may have. Babies who have been born preterm require specialist neuro-developmental monitoring and follow up and may need onward referrals to address developmental or feeding concerns identified.

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1. Introduction

Nurturing families and supporting parenthood needs to start at the beginning of the neonatal journey especially for those with small, vulnerable or sick babies who have had a frightening start. Neonatal care can present barriers to this bonding and sense of autonomy as parents. The preparation for discharge needs to be considered from admission so that by the time a family leaves they feel confident in their abilities as a parent to be their baby's main caregiver and advocate. It is a gradual process but needs to start early, so that going home doesn't come as a shock to parents. Parents can feel insufficiently prepared and have unanswered question on leaving the NICU (Sneath, 2009) with anxiety about their baby's safety, not feeling practically or mentally prepared (Larsson et al., 2015), resulting in increased anxiety and an increase in parents accessing medical care and advice for their baby post discharge (Smith et al., 2013). Parents will often describe a mixed emotion of fear and joy upon discharge home (Osorio et al., 2017). A meta-analysis of the literature on parents' experiences of caring for preterm infants after discharge from neonatal intensive care (Adama et al., 2016) highlighted the anxiety and fear of leaving the safety net of the NICU. Fear and anxiety of not being able to care for their baby persisted in some parents up to six months and up to 18

months post discharge. These fears and anxieties are well managed if parental support is provided to parents while on the NICU and after discharge.

Relationships with their baby need to be strengthened and encouraged from the beginning and parents confidence needs to be gradually increased so that they feel independent of the medical care and ready to take their baby home. Parents who are closely involved in their baby's care and who stay with their baby are better prepared for the transition home (Larsson et al., 2015; Osorio et al., 2017). Effective and well-planned discharge planning can facilitate timely discharges before 36 weeks corrected age, and shorten the length of stay. There are a number of things that can help start this journey in hospital and make transfer into community more seamless. Evidence shows that consistent use of resources including a discharge planning tool, scheduled discharge plans and promoting communication between parents and staff promotes a smooth transition to home (Sims et al., 2006). In our neonatal unit, we do not have fixed criteria for discharge in terms of weight or gestational age; they need to be able to maintain their temperature, feed independently and be putting on sufficient weight. Our average gestational age at discharge is 35 weeks. Parent need to feel confident in the neonatal team's assessment that their baby is medically healthy and developmentally ready to be better cared for at home. Discharge needs to be part of the process of our partnership with the parents. Ultimately, with optimal care, the baby will determine when they are "ready" and no longer require hospitalisation; but with effective support and preparation the parents will also be able to tell us when they feel ready to

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take their baby home. For our Integrated Family Delivered Care (IFDC) project we used many existing resources from our service.

1.1. Steps to home passport

Along with other neonatal discharge planning packages, such as the “Train to Home” developed in Bristol, UK (Ingram et al., 2015), we have noticed that supporting the process with a visual tool has been helpful. North West London Perinatal Network designed valuable material for discharge planning, including the “Steps to home passport, “Early days” and” Getting ready for home” posters.

The “Steps to home passport” (Fig. 1) enables parents to see the anticipated neonatal journey, including where they were on that journey and what to expect in terms of the next steps. This enables conversations about steps towards discharge to happen from the beginning of their time in neonatal care and for the family to feel informed and prepared from the start. The passport provided something parents and staff could refer and orientate to during their journey and would accompany them to another unit if transferred.

The early days stage includes three sections (Fig. 2):

- Welcome and what to expect on the neonatal unit; Orientation to the environment, staff and equipment, hand washing, their baby’s care needs and what they could do to be involved.
- Providing breastmilk and learning to feed; Expressing, non-nutritive sucking and the importance of skin to skin.

- Spending time with your baby; Learning their cues, how to be involved in cares and the importance of closeness, skin-to-skin, singing, talking and touching their baby

The next stage of getting ready for home also has three sections (Fig. 3):

- Establishing suck feeds.
- Making progress.
- Preparing for home

1.2. Discharge planning

Once a baby moves into the low dependency unit or special care the focus moves towards preparing for home; parents feeling confident in being involved in the baby’s care, their baby being more stable, needing less medical care, feeding, growing, maintaining their temperature and getting ready for home.

The weekly special care multidisciplinary team (MDT) ward rounds in our service are a chance to discuss and update current progress and plan the next steps to home. Parents are encouraged to present their baby and be an active member in the decision making. This promotes parental confidence, as parents know their baby best and can be part of the decision making process for their baby’s care needs.

Discharge planning begins at admission and the discharge coordinators will oversee this ensuring that parents are supported while preparing for discharge and once they are at home. Parents

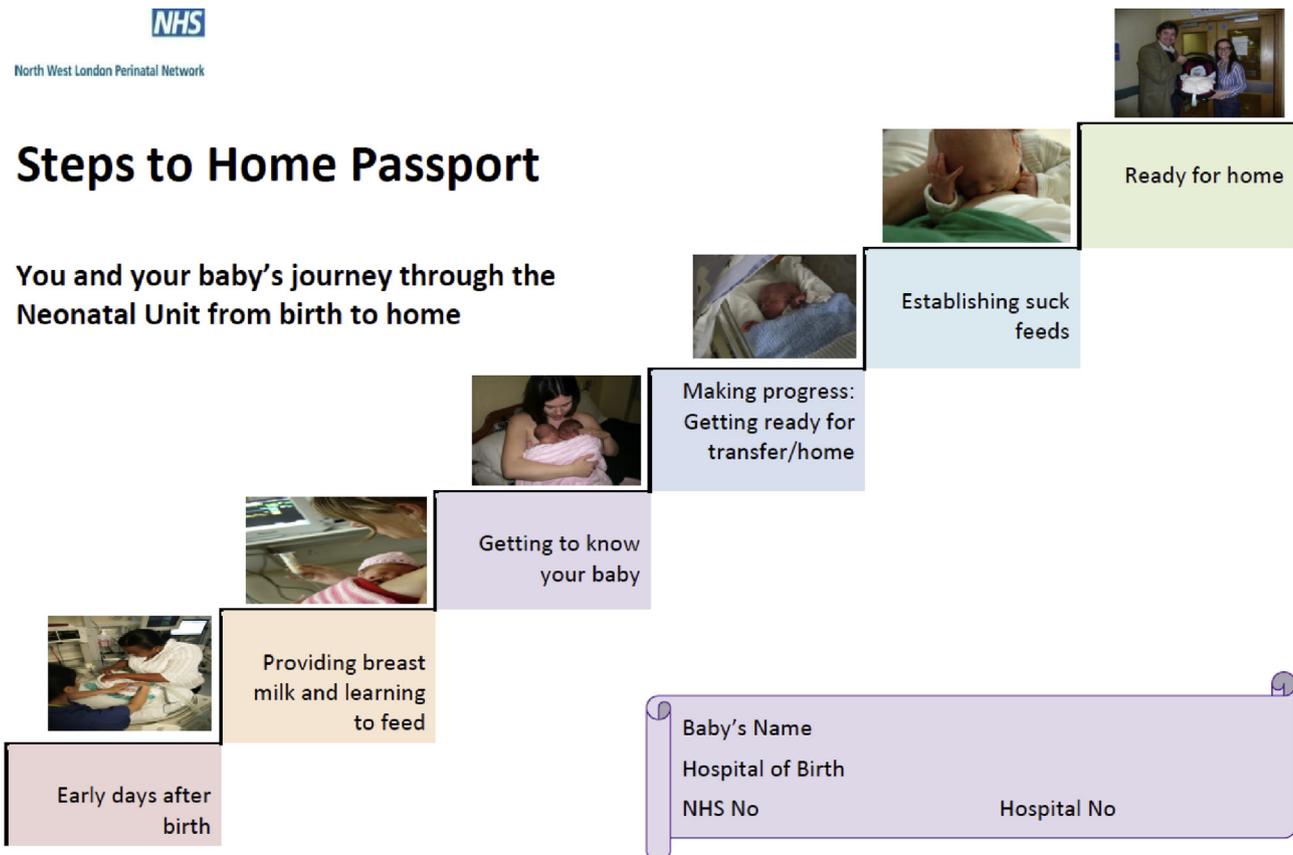


Fig. 1. Steps to home passport.

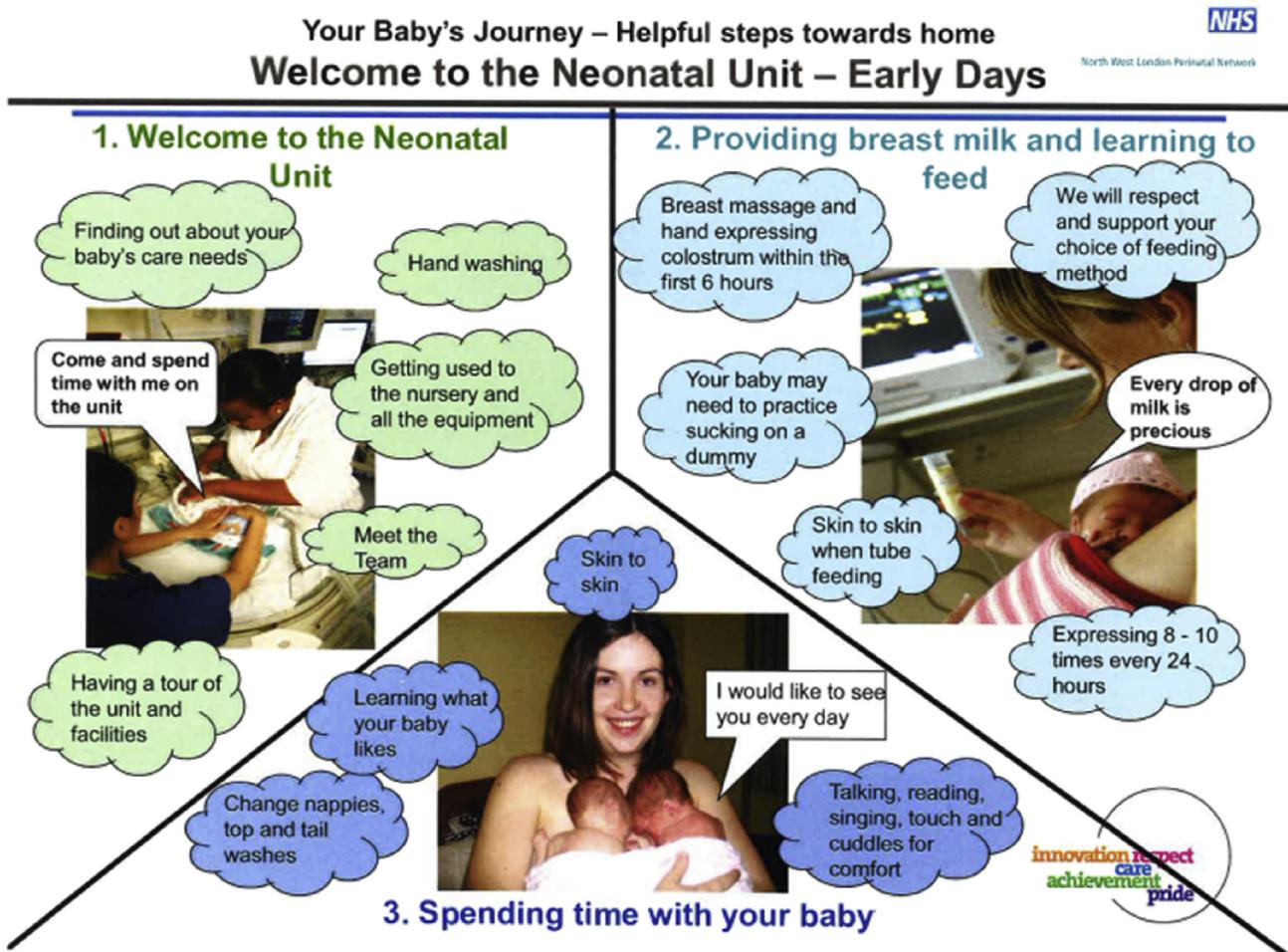


Fig. 2. Welcome to the unit – Early days poster.

are introduced to the discharge co-ordinator who will support the family preparing for home and follow them up once at home. They make sure the discharge planning checklist is being completed including; basic life support training, safe sleep advice, screening and immunisations are up to date, baby and family are registered with local healthcare providers, that parents have everything ready at home and act as liaison between parent and their health visitor and GP so they are prepared for home with any prescriptions and follow up appointments in place.

A discharge planning meeting can be held with the hospital MDT and community health care providers, social services etc as required. This often occurs when a baby is going home with complex needs for example; on oxygen or needing tube feeding or other medical support and is a chance for all to feel confident that everything is in place for the baby to be at home. Regular MDT case conference meetings starting from the first two weeks of a baby's stay in NICU have been shown to improve family satisfaction in their involvement in care and experience of the NICU (Trujillo et al., 2016).

Around discharge families would be given the opportunity to room in to establish feeding and once Basic Life Support (BLS) training has been completed can room-in with baby before discharge. This gives the family the opportunity to build confidence in caring for their baby but with the support of staff in the NNU. Once BLS training is complete they are able to room in with their baby and just return to the unit as required for support and monitoring. This gradual transition of being responsible for all of

their baby's care and the increasing withdrawal of a dependence on medical care, particularly getting used to the absence of monitors and feeling confident instead in their knowledge of their baby's cues, aids a smoother discharge process.

Feeding can cause a significant amount of anxiety around discharge; it is often the last skill a baby needs to master before going home but can be an uncertain time for a family as they have to rely on their knowledge of their baby's abilities and cues rather than charts and measures. This may include specific concerns that they do not know how much milk their baby is getting at the breast, as they no longer are supplementing with NGT. Time is spent supporting them with feeding readiness cues, good positioning and attachment and signs of milk transfer. Feeding schedules are treated less medically with a move away from a prescribed mls/kg, 3 hourly volume; and instead considered in response to the baby's cues, thinking about a 24 h period of feeding and that time at the breast may also be in response to a need for comfort and closeness for mother and baby. Families are signposted to their local community breastfeeding support and what the expectations will be in terms of weighing and measuring growth in community.

Discharge dates are set collaboratively and should never feel like a surprise or shock for parents. The discharge coordinator gives a contact number to the parent if parent needs to liaise before the first home visit. Once at home, the discharge co-ordinator will arrange a joint visit with the Health Visitor (HV) to handover and discuss the neonatal journey and make a plan for support at home

Your Baby's Journey – Helpful steps towards home

Getting Ready for Home

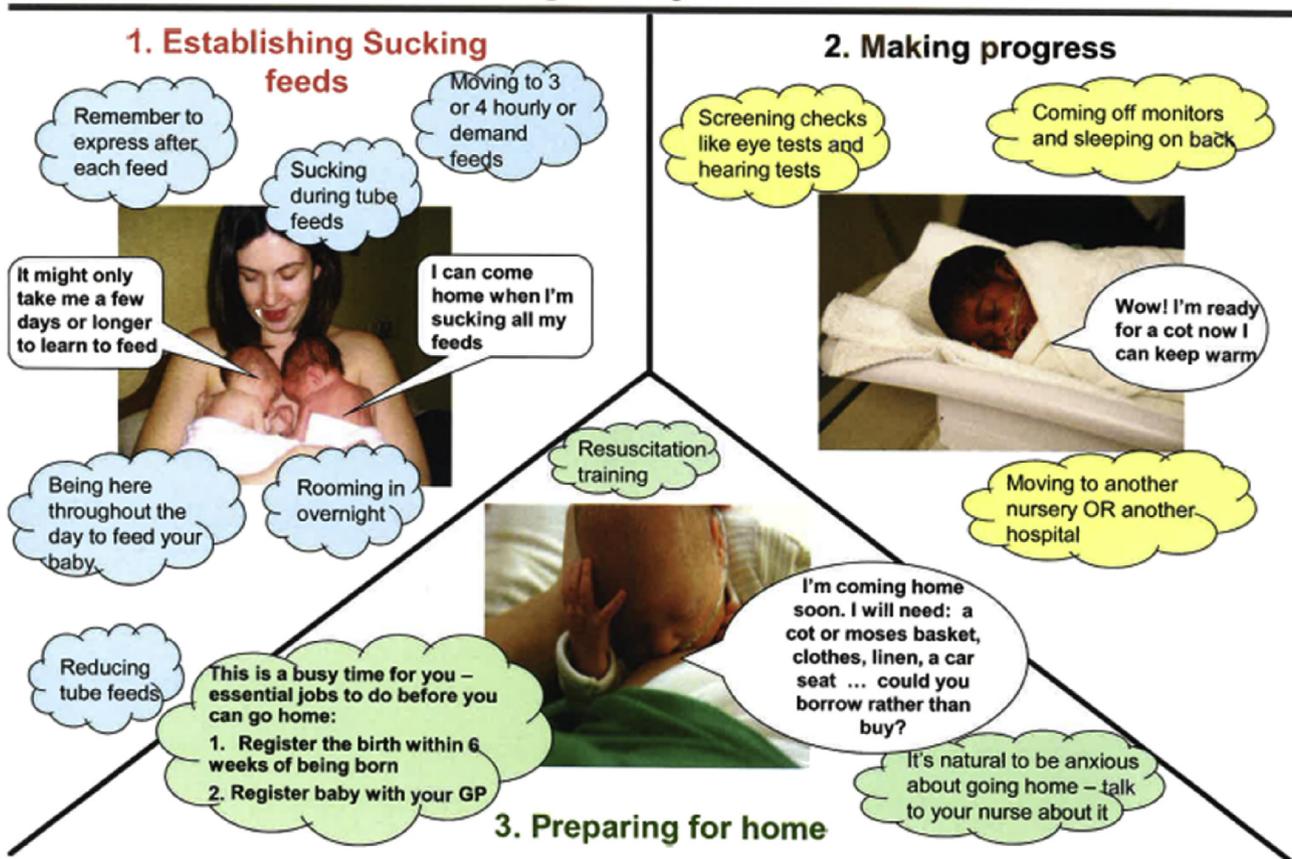


Fig. 3. Getting ready for home poster.

which could include weekly visits for weighing. For complex babies this could also involve the children's community nurses and social workers. Parents are encouraged to liaise by telephone if they have any concerns once handover to the HV is done especially if awaiting appointments for further investigations. The discharge coordinator remains the link with the neonatal team post-discharge. The opportunity for telephone contact with neonatal nurses post discharge has been reported to facilitate a positive discharge experience (Osorio et al., 2017).

1.3. Next steps post discharge group

While taking a baby home for the first time can be an exciting time, it is also a time of adjustment. Instead of being surrounded by staff and equipment, the family has to draw on their own skills, strengths and confidence in taking care of their baby alone. Having an early baby may mean other people in their antenatal classes have not yet had their baby and those early postnatal friendships, which are often helpful for support, may not be there. Whilst social media can help sustain friendships and support mechanisms which were made between parents in the neonatal care environments many parents live far from each other once they are discharged which reduces their opportunities to access this peer network. Parents often find that staff in children's centres and parent groups are not familiar or confident in giving support and advice for small babies and they have less in common with other parents who have not been through the neonatal journey. This can leave them feeling isolated

and unable to access the appropriate advice and support they need. Support groups that provide space for interaction with other parents with similar experience can provide perspective and are seen as a facilitator to positive discharge experience (Osorio et al., 2017).

In response to these challenges and to continue to offer appropriate support to families after they leave the hospital we developed a multidisciplinary follow up group called the "Next Steps Group". The group aims to bridge the gap between the neonatal unit and home, help reduce parental isolation, help promote parental confidence, help build parents skills with their baby and maintain links with the NICU and other neonatal parents. The group is offered to all parents when leaving the unit and is co-ordinated by our clinical psychology team and the neonatal discharge co-ordinators. It runs every other week and has a rolling programme of seven topics and a party at the end of each block. It is held in the middle of the day to ensure it remains accessible to parents with other children, and each session lasts an hour with some time before and after to set up and socialise. It is an informal setting, where we provide mats, baby toys, and parent refreshments.

Next Steps topics:

Sleep and Soothing – Clinical Psychology.

Weaning – Dietetics and Speech and Language Therapy.

Play and Development in the First Year/Baby Wearing – Occupational Therapy.

Physical Development in the First Year – Physiotherapy.

Winter Illness – Discharge Co-ordinator and Pharmacist.

Early Communication – Speech and Language Therapy. Transitions - Clinical Psychology.

Parents are welcome to attend up to two rotations of the group, as some topics may not be useful to them in where they are in their journey, or others may wish to hear the information again for a second time. Following this, it is thought that parents will feel equipped to make more use of parent and baby support in their local community. Next Steps Group also allows parents to make links with other neonatal families and this may service as an additional ongoing informal support mechanism.

The group has been running since 2012, and the number of parents attending varies between 2 and 12 families attending each session. A questionnaire is distributed to parents after each session to gather feedback. This has demonstrated that parents attend for a multitude of reasons, including an interest in the topic covered, meeting other parents, sharing their experiences, and being encouraged to attend by other parents, staff or email. All parents report that their initial goals for attending were achieved and they would recommend the group to other neonatal families. Nearly all the families that completed evaluations reported that the group is supportive, informative and comfortable for both parents and babies. Evaluation has shown that some parents felt they would like the group to be longer, and there have been suggestions of offering a fathers group. Parents report that the group provides “*useful knowledge, builds confidence, gets you out of the house, information provided was helpful, meet similar babies and parents, refreshing and fun, keeping in touch*”.

The word cloud (Fig. 4) describes parent's knowledge and usefulness of the Next Steps Group. The size of the words represents the frequency of the use of words.

1.4. Neonatal neurodevelopmental follow up

Preterm birth is associated with an increased risk of developmental problems and disorders. These include developmental challenges, physical, sensory, cognitive and learning disorders, and emotional and behavioural problems. These may extend into adolescence and, in some cases can be lifelong. In particular, the risk and prevalence of impairments that affect educational attainment rise sharply in children born before 28 weeks' gestation. Although most major disorders are detectable in the first 2 years of life, several developmental disorders and problems, particularly those that have an impact on the child's ability to participate and on their educational attainment, may not be apparent until they are older.

The NICE guideline on Developmental Follow up of Children and Young People Born Preterm (National Institute for Health and Care Excellence (NICE)) aims to improve the identification of developmental problems and disorders in children born preterm by setting standards for follow-up. This is expected to improve outcomes for these children by reducing variation in follow-up and enabling benchmarking of neonatal care. Follow up data is inputted into the National Neonatal Research Database as part of neonatal audit requirements.

Babies <30weeks gestation or those <37 weeks who have neurodevelopmental risk factors will have enhanced

developmental support and surveillance up to and at 2 years (corrected age) to identify major problems and disorders. The medical team will see them twice in the first year of life and have a full multidisciplinary developmental assessment at 2 years corrected age including a formal neurodevelopmental assessment. A later developmental assessment at 4 years is recommended for children at high risk (<28 weeks gestational age). It aims to identify problems that are more apparent at school age, with a view to supporting education plans for the child.

1.5. Multidisciplinary feeding clinic

Feeding can be an area of ongoing anxiety for families in the pre-school years. Estimates of feeding problems in the early years in the normal population vary widely from 5 to 60% and can be higher in at risk groups including preterm babies and those who have spent time in Special Care (Michaelsen et al., 2003). Issues with feeding can cause significant stress and worry particularly for parents of small babies; they remain with a heightened vigilance and concern about weight gain and growth. Preterm babies have a higher incidence of sensory based feeding issues in particular progressing onto lumps and textured foods which can result in gagging and concerns that they may choke. The beginning of independent self-feeding with weaning and the shift in the relationship of control over feeding and intake can be an anxious time. Parents frequently seek multiple health professionals' advice to support feeding difficulties. Recognising the frequency of these issues and the anxiety it causes parents, we have a weekly multidisciplinary feeding clinic with psychology, dietitian and speech and language therapist. Referrals are taken from Neonatologists. We meet as a team with the family for a 90 min initial appointment to take a full case history, observe a mealtime and discuss a management plan with the family. Many times the information shared acts to reduce anxiety by reassuring about growth in preterm infants, discuss how normal pre-school eating skills develop and what feeding looks like. The behaviours and communication around mealtimes can be considered and the environment and routines of eating discussed. Often this acts as reassuring context and we will just see the parents once or twice again to support the adjustments they have made to mealtimes, assess they are happy with progress and reassure them about growth and development.

1.6. Veteran parents involvement

As part of the IFDC Project, we are keen to involve parents in neonatal service delivery and encourage their feedback. Listening to parent experience enables us to reflect and improve on the services we offer.

Current and veteran parents have been essential in planning the IFDC project including co-designing the parent App, training materials and providing helpful insight into our services.

We have set up a forum where staff and parents can meet on a regular basis to discuss the service and consider things that could make the experience better. The group works in partnership to listen to feedback, reflect on how things could be different and come up with shared action plans for change. We chose the acronym “NIGL” as we wanted the forum to be an opportunity to discuss the “niggles” staff and parents have with how the service is working for them. It is not the forum for complaints, but a place to share “niggles” and discuss ideas and solutions. The group has agreed boundaries of confidentiality, mutual respect and trust to enable true listening and partnership working and make the collaboration productive. The group meeting is open to all staff; medical, nursing, AHP and admin staff and all parents – current and veteran. The group meets every 8 weeks on each site and twice a



Fig. 4. Feedback word cloud about Next Steps group.

year as a whole neonatal service. This model of partnership working fosters the ongoing essential relationship between parents and staff of open and honest communication to ensure ongoing reflection and improvements in the neonatal care we offer.

1.7. Peer support

Other FIC projects have drawn heavily on veteran parent peer supporters to provide some of the parent education and support to current NICU families (Hall et al., 2015). This is an area of future development for our project.

2. Summary

Bonding and “future proofing” by building coping strategies and resilience is even more important for families who may have a complex journey ahead with their child. Many babies who leave neonatal care continue to be followed up by medical professionals over the first two years and some will go on to have longer term healthcare needs resulting in re-admission to hospital or requiring more regular intervention. These families need to feel confident in their parenting abilities, in how to interact and work with alongside healthcare professionals to best care for their baby. Parents are there for life, as professionals we are there to support and equip them for that journey. Families who have had this model of care access healthcare services less post discharge hypothesised to be due to an increase in caregiver confidence and a reduction in anxiety. We hope that the support that parents receive during and after their hospital stay will equip them with the skills they need as

parents in the future.

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