

Evaluation of parental experience post-discharge and development of a parent focus group



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ARTICLE INFO

Article history:

Available online 18 December 2017

ABSTRACT

The aim of the Integrated Family Delivered Neonatal Care (IFDC) project is to improve parent-experience, parent-infant bonding, parental mental health, and infant health outcomes by pioneering a new care model at Imperial College Healthcare NHS Trust based on international evidence. It is particularly challenging to measure parent experience in neonatology, and there isn't a uniform internationally accepted tool for this. Understanding parents' experiences is vital to understand how quality of care can be improved. As parents are in a very vulnerable situation in the neonatal unit progressing on an often long, unpredictable and complicated journey, special approach and tools are needed to distill their overwhelming experience.

Within the expanse of the Quality Improvement project we hoped to focus and achieve the following objectives:

1. To develop a sustainable feedback model for parent experience to collect feedback on neonatal care using validated tools.
2. To establish a parent focus group to collect feedback about our care and to create an experience co-designed parent educational material for our project.

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1. Introduction

Neonatology is a challenging specialty in healthcare where not only the medical care but also the human and social aspects of care are particularly important. Neonatal intensive care can arouse deep emotions and anxiety in parents, and they often feel helpless at the cot side of their newborn and vulnerable baby. There has been a change in the last 5–10 years in the developed countries, shifting the focus from purely the care of the baby to putting the whole family at the center of care – called family centred or family integrated care (FIC) models. Beside the medical care of the often critically ill babies, the focus is also on forming, developing and bonding a family in the neonatal unit. This means that neonatal care is no longer only assessed on medical outcomes and survival, but also on parental experience, anxiety and stress, mental health and coping as important outcome measures.

There is growing evidence that educating and engaging parents in the care of their baby can reduce their anxiety, improve parent experience and improve bonding. Current evidence has also shown the feasibility of Family Integrated Care (FIC) in neonatal settings and clinical outcomes are better than in traditional healthcare settings (Levin; O'Brien et al., 2013; Bracht et al., 2013; Macdonell et al., 2013; Pineda et al., 2014; O'Brien et al., 2015). The overall aim of our Integrated Family Delivered Neonatal Care (IFDC) project (Imperial Neonatal Services, 2015) at Imperial Neonatal Service is to improve parent-experience and parent-infant bonding, parental mental health and infant health outcomes by pioneering a new care delivery model in the Imperial Neonatal Units (Queen Charlotte's and Chelsea and St Mary's Hospitals) based on the international evidence around FIC models, in line with the British Association of Perinatal Medicine (BAPM) clinical strategy (BAPM, 2014) and the developmental care ethos of the Imperial Neonatal Service.

The NHS England and the Department of Health has produced clear national guidance to focus on the family-centred approach in neonatal intensive care; "involving families in the care of their own children and helping parents understand their baby's needs" (NHS England, 2013; Department of Health, 2009). Quality of care and

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parent experience are important drivers for improvement in our services.

Bliss strongly advocates parent involvement in delivering high quality neonatal care as a national charity. Their Baby Charter and accreditation process (Bliss, 2011) enables hospitals to benchmark and provide the best possible family-centred care for premature and sick babies.

BAPM has identified family engagement in neonatal care as one of their agreed focus in their strategic plan in the next 3–5 years (BAPM, 2014). There is an increasing interest in the UK towards this new care model.

2. Parent experience and how to measure it

In general healthcare settings patient experience is limited to definite, short time procedure or care episodes. However neonatal care is different: critically ill babies may stay in the neonatal units for several weeks/months with their parents in a specialized environment. Therefore it is particularly challenging to measure parent experience and there isn't a uniform internationally available tool.

Assessing parents' experiences is crucial to understand how quality of care can be improved and special tools are needed to distill their overwhelming experience.

Written questionnaires are frequently used as well as semi-structured one-to-one interviews to understand weaknesses locally; however, it needs significant resources, and feedback is limited to a number of families and it is usually not suitable for wider benchmarking nationally or internationally. Timing of feedback is important. It can be done while on the unit or following discharge once the experience is more processed.

In UK settings two important projects were carried out to assess parent experience in neonatal care: the Parents of Premature babies (POPPY) Project and the Picker Surveys. The POPPY Project involved research on three aspects of neonatal care: parent experience, facilities and environment and communication (Redshaw ME et al., 2010). Participating units completed the neonatal unit survey, and interviews were held with 55 parents receiving neonatal care in England and Scotland post discharge. This survey was carried out by the National Perinatal Epidemiological Unit (University of Oxford) and RCN Research Institute.

The latest Picker Neonatal Survey, a nationally developed tool for parent experience in neonatal settings, was carried out in England in 2014–15 by the Picker Institute in collaboration with Bliss and NHS England. The purpose of the survey was to assist units in understanding areas of strengths and what could be improved, and understand parent experience in neonatal units (Picker Institute, 2014a, 2014b). The survey involved 88 neonatal units from 72 NHS Trusts in England. For each unit, 100 parents received the questionnaire following discharge. Responses were received from about 6000 parents, with an overall response rate of 37.6%. Picker Institute published Executive summary and individual reports to units. The Executive summary (Picker Institute, 2014b) highlighted areas where parents reported the most and least positive feedback. Themes of the least positive experience were around information received about neonatal care, communication and emotional support from staff. The survey also identified significant variation across neonatal networks in England, with London showing the greatest room for improvement. Limitations are the inclusion of all neonatal parents, the majority of whom only have short NICU stays.

3. Methodology

The aim of our parent experience survey was to develop a sustainable feedback model for parent experience incorporating

validated national or international tools, as our outcome measure following implementation of the IFDC care model, and achieving parent engagement via parent focus group sessions for more feedback. A cross-sectional survey (Appendix 1) was developed around parent experience, which enabled us to study the experience of a defined large population at defined time intervals.

The survey was sent out by post for individual anonymous completion accompanied by a stamped response envelope. As the survey was returned anonymously we did not send out reminder letters. Anticipated return rate was 20–30%. A cover letter, and invitation letter for our parent focus group with a written consent form were attached to the survey. The structured survey (Appendix 1) consisted of eight different topics and was based on a selection of validated tools used for neonatal parent experience with the option to provide open-ended feedback answering 'If there is anything else you would like to tell us about neonatal care received, then please do so here'. Picker questions were specifically selected for Sections 1–5 to measure effect of the IFDC project or similar QI initiative. Questions where our units previously achieved very high scores, and ones, which were not applicable to our settings, were not included. The responses were scored on a 10 point Likert scale with '1' being 'Not at all' and '10' being 'Yes, definitely' with an opt out option 'Unable to comment'. This was different from the original Picker survey, where fewer choices were available, but it enabled more detailed and contrasted feedback on our care. To assess support with lactation and feeding support received (both breastfeeding and bottle feeding), the UNICEF Baby Friendly Initiative international Audit Tool for Neonatal Services was used (Section 6) (UNICEF UK, 2013). This tool originally was designed to be used in short interviews, but our team converted it to a written questionnaire.

Following recommendations by our psychology team, we aimed to measure parental stress both in terms of potential anxiety and depressive symptoms the international Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) and Mothers Object Relations Scales (MORS-SF) (Milford and Oates, 2009) were selected and copyright was obtained to use them in our survey. Subsequently in 2017 we stopped using the HADS as mothers felt ambiguous about this test and often have not completed it, and only included the Mothers Object Relations Scales (MORS-SF) (Milford and Oates, 2009) test.

A parent focus group was established. Several focus group sessions were held between February 2016 and April 2017 in afternoons and evenings to enable participation for those with small children. These were informal meetings with refreshments provided lasting for about 2.0–2.5 h, facilitated by neonatal consultants, attended by veteran parents, core IFDC project team members, and representatives of the Trust's QI Hub. The aim was to obtain feedback on our care, co-design and develop the IFDC parent educational material. Topic, objectives and the material discussed at the meeting were sent to parents via email well in advance. Minutes of these meetings were recorded.

4. Data collection and analysis

Data collection was done according to the Data Protection Act (United Kingdom Acts of Parliament, 1998) the confidential data is kept securely and registered as service evaluation in our Trust. Access was obtained to parents' contact details and clinical details of infants receiving neonatal care in 2015 and 2016 via the Neonatal Electronic Patient Record System (BadgerNet). The parent experience survey was sent out in December 2015 and July 2017 to parents whose baby was born prematurely below 34 weeks gestation in 2015 and 2016 calendar years, who received care in Imperial Neonatal units for at least 14 days and were discharged home as

their final destination, short stay admissions and families with term babies were not included in the survey. The survey was sent out to 178 families in 2016 and 196 families in 2017 and 30 (17%) and 41 (21%) responses were received respectively. Results from this survey were compared to the national and local report of Picker survey (Picker Institute, 2014a,b) and will also be used as baseline data to assess improvement in parent experience following the implementation of the IFDC project.

The qualitative elements of the survey (free-text feedback, verbatim quotes) were analyzed for emerging themes. Additionally free-text feedback was presented as word cloud using Tagul web-based tool. Word clouds are a visualization of the verbatim comments received to the free text question. Word clouds perform a count of the frequency of word to produce an image. The more a word is mentioned, the larger it appears in the image. The HADS and My Baby psychological questionnaires were analyzed and scored by our psychology team. These results are not included in this publication and will be separately published elsewhere. The qualitative elements collected during parent focus group meetings were analyzed similarly for themes, verbatim quotes were used, and also word clouds were created similarly.

5. Findings and discussions

The detailed analysis of the results of the parent survey collected in 2016 and 2017 is beyond the scope of this article, but we aim to present the usefulness of the tool developed by our team.

5.1. Questions from the Picker survey

Responses were converted into scores on a scale of 0–100. The score of 100 represented the best possible response (10 on the Likert scale). The average score and percentage calculations excluded the responses that did not answer or ticked 'unable to comment' throughout the analysis. The overall score for each question is calculated as an average of the individual scores. These were compared to the national survey results published in 2015 (Picker Institute, 2014b), and also to our local scores from 2014.

Our aim was to achieve scores above 85 in each topic as minimum standard. Scores below 85 were highlighted in red as they represented need for improvement.

Tables 1–3 present the specific answers and the number of missing responses from both 2015 and 2016 together with national

Table 1
Section 1. Staff on the Neonatal Unit, Survey results.1

Section 1	STAFF ON THE NEONATAL UNIT	Picker national survey 2014			2015 Survey			2016 Survey			Comparisons	
		Average score in national survey	Threshold for the lowest scoring 20% units	Threshold for the highest scoring 20% units	Total specific responses	Missing responses	Average score	Total specific responses	Missing responses	Average score	Comparison 2015-16	Comparison 2014-2016
1.	Were you given enough information about the neonatal unit (such as protocols, procedures and alarms used in the neonatal unit clearly explained to you,	76	74	82	29	1	83	40	1	82	→	↑
2.	Were the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you,	73	67	78	29	1	76	40	1	82	↑	↑
3.	Were infection control practices explained to you, such as hand washing and procedures for visitors?	85	80	93	29	1	95	41	0	91	↓	↑
4.	Were you able to talk to staff on the unit about your worries and concerns?	88	83	93	30	0	86	41	0	90	↑	→
5.	Were you able to speak to a doctor about your baby as much as you wanted?	66	60	71	30	0	73	41	0	78	↑	↑
6.	Were the staffs on the unit sensitive to your emotions and feelings?	85	78	90	30	0	87	41	0	85	→	→
7.	Did staff give you conflicting information about your baby's condition or care?	67	61	73	30	0	46	41	0	50	↑	↓
8.	Overall, did you have confidence and trust in the staff caring for your baby?	92	91	95	28	2	90.0	41	0	89	→	→

Table 2
Section 2 Involvement in baby's care. Survey results.2

Section 2	INVOLVEMENT IN BABY'S CARE	Picker national survey 2014			2015 Survey			2016 Survey			Comparisons	
		Average score in national survey	Threshold for the lowest scoring 20% units	Threshold for the highest scoring 20% units	Total specific responses	Missing responses	Average score	Total specific responses	Missing responses	Average score	Comparison 2015-16	Comparison 2014-2016
1.	Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and	89	85	93	29	1	93	41	0	91	→	→
2.	Did you have as much skin-to-skin contact with your baby as you wanted?	72	63	80	30	0	82	41	0	88	↑	↑
3.	Did the neonatal staff include you in discussions about your baby's care and treatment?	78	74	83	29	1	86	41	0	85	→	↑
4.	Where possible, did staff arrange your baby's care (such as weighing, bathing, cares) to fit in with your usual	74	65	84	29	1	79	38	3	83	↑	↓
5.	If you wanted to express breast milk for your baby, were you given the support you needed from neonatal	84	83	91	30	0	89	39	2	91	→	↑
6.	If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff?	84	80	90	29	1	90.0	35	6	89	→	↑
7.	If you bottle fed your baby formula milk, were you given enough support to do this from neonatal staff?	85	81	90	14	16	86	18	23	81	↓	↓
8.	Overall, did staff help you feel confident in caring for your baby?	89	85	94	30	0	94	41	0	86	↓	→

scores (2015) for each question.

Section 1 contained questions around neonatal staff (Table 1). While scores generally were high and slightly higher than the national results, question 2, 5 and 7 highlighted some weaknesses. These topics appeared also in the free-text feedback: parents wished to have more conversations with the medical team and they experienced conflicting information about the same topic sometimes from different members of the team.

Section 2 assessed parents' involvement in their baby's care (Table 2). Scores were mostly above 85. But responses showed that the team was not always flexible to arrange tasks (cares, bath and feeds) around the time when parents were present. We also learned that more support was needed around bottle-feeding.

Section 3 contained questions around communication and information (Table 3). The scores were higher than the national average, but below the aimed standard (>85). Parents wished to have more written/supporting information and also felt that parent support groups and activities are not advertised well enough. We anticipate that the IFDC programme with the mobile app and parent education sessions will bring in a real change in this area.

In Section 4, around environment, the scores were all satisfactory >85, but of course there is ongoing work to further improve parent facilities for our IFDC programme as parents are spending more time in the unit in this new care model (Table 3).

Section 5 about discharge preparation did highlight weaknesses in discharge planning (Table 3). Parents did not always feel confident and prepared when leaving unit and needed more information about progress and expectation after discharge.

Despite some areas of weakness identified within our service using this tool, it was reassuring to see that a high proportion of the parents were generally satisfied with these aspects of the care.

5.2. Questions from Baby Friendly Initiative questionnaire

Section 5–6 contained the questions from the modified Baby Friendly Initiative Audit Tool for Neonatal Services (UNICEF UK, 2013) and referred to the feeding support (both breastfeeding and bottle feeding) received on the unit. For these questions, national data for benchmarking in similar format was not available.

In both annual cohorts nearly all (30, 100% and 35, 97%) parents said that it was explained to them why breast milk was important for their baby. Similarly a high proportion of parents answered that they were shown how to express by hand or pump during their stay in the neonatal unit.

All mothers received breastfeeding support, were shown how to position and attach their baby and were encouraged to do skin-to-skin (Fig. 1).

In the two cohorts 26/27 (96%) and 29/33 (88%) of the parents respectively felt that from feeding point of view they were prepared for discharge (Fig. 2), however there is room for improvement when looking at the different aspects in the question.

All but 2 mothers (93%) in 2015 and 33/41 mothers (80%) in 2016 managed to breastfeed or give breast milk to their baby to some degree (exclusively or partially) following discharge from the neonatal unit, which is significantly better when compared nationally or internationally. We also observed that a relatively high proportion of mothers 8/28 (28%) in 2015 and 12/33 (37%) in 2016 breastfeed her baby longer than 6 months after discharge. This is very encouraging information for our service and a testament to the ongoing support we provide (Fig. 3).

In 2015 12/30 (40%) and in 2016 27/41 (66%) of mothers were supported to know how to give their baby a bottle with either formula or expressed breast milk before discharge. Once breastfeeding is established, some parents opt to give supplements such

Table 3
Section 3, 4 and 5. Survey results.3

Section 3 INFORMATION AND SUPPORT	Average score in national survey	Threshold for the lowest scoring 20% units	Threshold for the highest scoring 20% units	Total specific responses	Missing responses	Average score	Total specific responses	Missing responses	Average score	Comparison 2015-16	Comparison 2014-2016
1. If you asked questions about your baby's condition and treatment, did you get answers you could	88	85	91	30	0	90.0	40	1	85	↓	→
2. Were you given enough written/supporting information to help you to understand your baby's	53	43	62	29	1	76	37	4	77	→	↑
3. Did staff give you any information about parent support groups?	53	46	61	30	0	73	40	1	75	→	↑
Section 4 ENVIRONMENT AND FACILITIES	Average score in national survey	Threshold for the lowest scoring 20% units	Threshold for the highest scoring 20% units	Total specific responses	Missing responses	Average score	Total specific responses	Missing responses	Average score	Comparison 2015-16	Comparison 2014-2016
1. Were you able to visit your baby on the unit as much as you wanted to? (please only think about unit-	95	93	98	30	0	97	41	0	95	→	→
2. Was there enough space for you to sit alongside your baby's cot in the unit?	82	76	90	30	0	91	41	0	90	→	→
3. Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?	84	80	89	30	0	92	40	1	88	↓	↑
Section 5 LEAVING THE NEONATAL UNIT	Average score in national survey	Threshold for the lowest scoring 20% units	Threshold for the highest scoring 20% units	Total specific responses	Missing responses	Average score	Total specific responses	Missing responses	Average score	Comparison 2015-16	Comparison 2014-2016
1. Did you feel prepared for your baby's discharge from neonatal care?	86	82	90	28	2	81	38	3	81	→	↓
2. How likely are you to recommend this neonatal unit to friends and family, if their baby needed similar care or	91	89	94	30	0	95	41	0	90	↓	→
3. Were you given enough information on what to expect in terms of your baby's progress and recovery?	76	72	81	29	1	81	41	0	81	→	↑

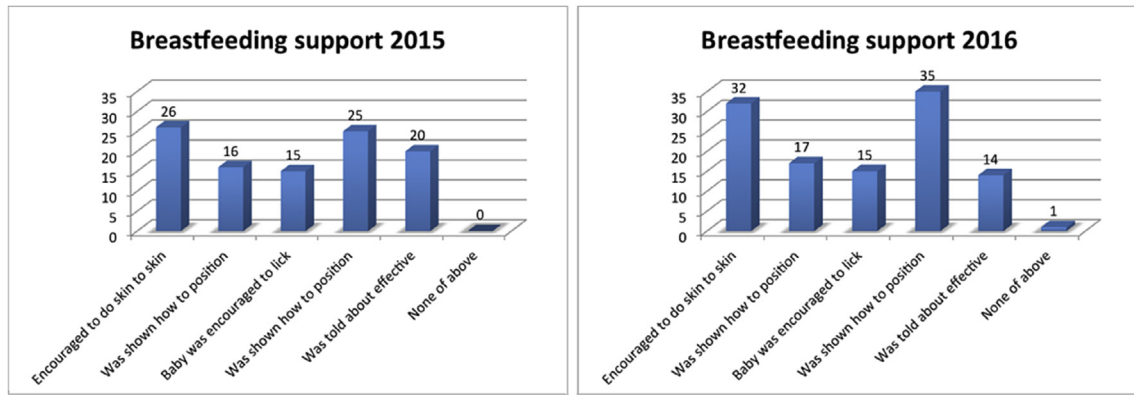


Fig. 1. Breastfeeding support.

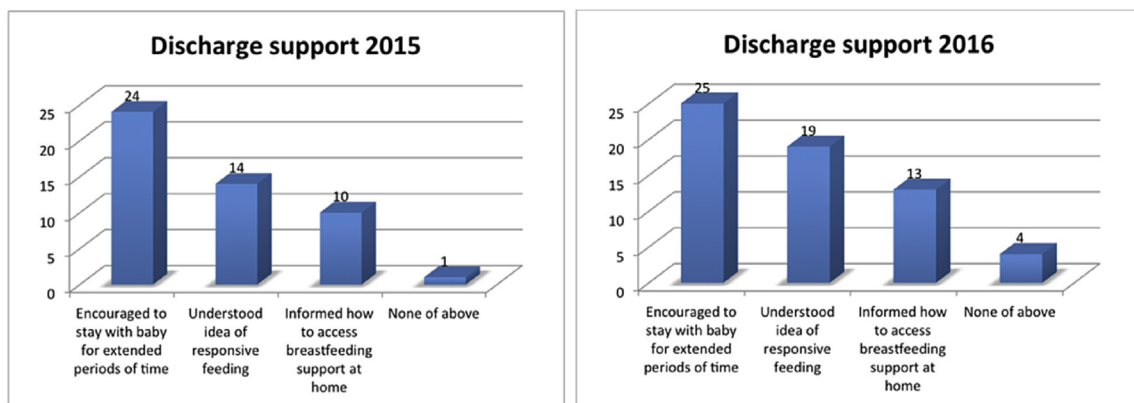


Fig. 2. Discharge preparation.

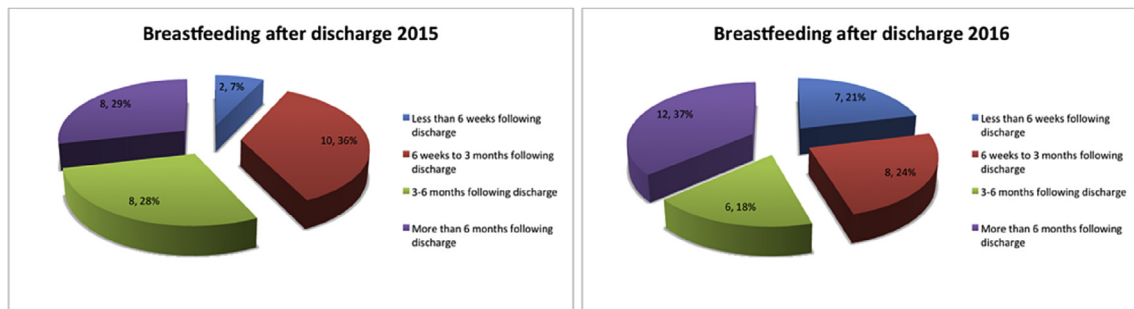


Fig. 3. Length of breastfeeding.

as breast milk fortifier and vitamins by bottle in <10 mls of milk. The support around bottle-feeding was significantly less compared to breastfeeding in both years, and could be improved (Fig. 4).

5.3. Free-text feedback

Section 7 was a free text feedback using the question 'if there is anything else you would like to tell us about neonatal care received; then please do so here'. 23/30 parents completed the free-text feedback in 2016 and 20/41 in 2017.

These qualitative elements of the survey were categorized as positive and negative and were also analyzed around themes

emerging from the data, and presented as a word cloud in Fig. 5. The most frequently mentioned words were 'care', 'nurse', 'baby', 'hospital', 'doctors', 'experience' and 'breastfeeding, milk'. Other positive words were 'support', 'thank' 'feel/felt', 'help', 'amazing', 'wonderful', 'fantastic', 'excellent'.

In the free-text feedback several very positive comments were received about our care.

'The overall experience we as absolutely amazing and we felt incredible lucky to be in the care of such wonderful hands.' (2015)

'The neonatal unit at Queen Charlotte's and Chelsea Hospital for me was world-class. I couldn't ask for more.' (2015)

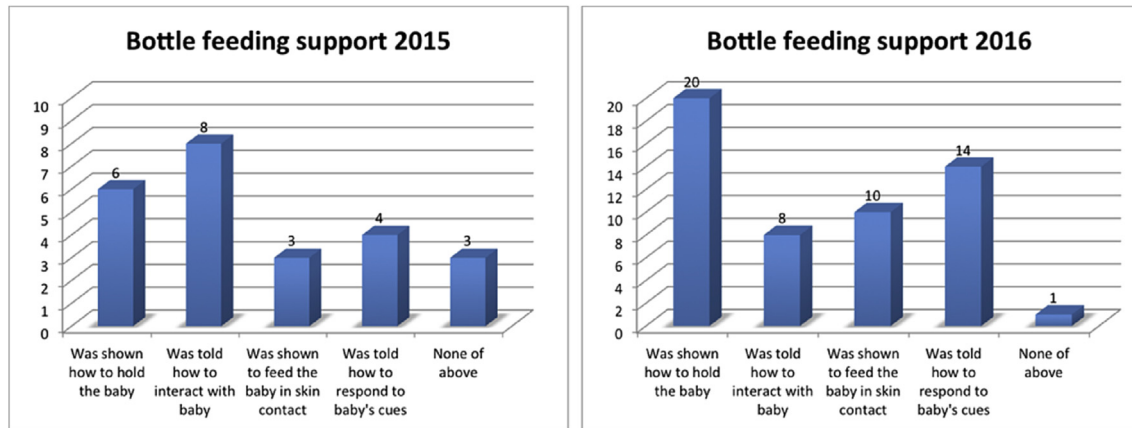


Fig. 4. Bottle feeding support.



Fig. 5. Word cloud from free-text feedback.

'I am so proud of the neonatal care which I received for both my children. The nurses and doctors did such a fantastic job in supporting me and my partner.' (2015)

'We are extremely grateful for the excellent care that our daughter received on the neonatal unit. Overall we were happy with all aspects of her care.' (2016)

'All the staff was great with my babies' care and was informed about every step of how he would be transferred to another unit closer to home.' (2016)

'My 8 weeks in your unit will be remembered as a very happy and peaceful time in my and my daughter's life. I couldn't fault anything and really credit the whole team with giving us such a supportive and positive beginning to our adventure together.' (2016)

As in Section 1 questions, parents did highlight that communication with the medical team was not always sufficient:

'Care was great and we always felt secure but doctors were never available: too busy ...' (2015)

'Would have liked to see doctors more often.' ... (2015)

'Information sometimes varied a lot by doctors and nurses, which made information given difficult to understand.' (2016)

It was rare to see negative comments; these were around staff, the difference between ITU/SCBU and transfer back to the local hospital. It is well known that the majority of complaints are around communication between neonatal staff and parents as reflected here:

'I felt a huge difference between HDU and SCBU. I was very confident in ITU that our baby was having full attention from staff, but I felt things were chaotic in SCBU and I was not confident leaving her there when we went home.' (2015)

'The transfer to my local hospital was very last minute and I did not feel it was communicated to me properly.' (2015)

'Agency staff always seemed to know very little about what was going on. We experienced two units during our child's treatment and in both units the only time we ever felt nervous about her treatment was when agency nurse was responsible for her care.'
(2016)

Parents gave some advice for improvement and optimisation of care. These were around: staff, expressing and lactation support, environment, visiting policy, and parent group.

'Some nurses pushed you to be more involved – all nurses should do this ...' (2015)

'Only thing that would make this place even better is to have only permanent staff. Temporary nurses sometimes were less caring and not always on track. But I understand that at very busy periods you have to get outside help ... ' (2015)

'Consultants rotating every week do not support long term care planning for babies currently. It hindered our experience. Care planning should be standardized for all babies, so any staff caring for any baby are clear what the objectives are.' (2015)

The expressing room was through a locked door. This was problematic at weekends and at nights as it could take a long time for it to be unlocked.' (2016)

'The staff clearly loves their job, and dedicated their lives to caring for tiny people born too soon. They need to be treasured and treated with kindness and respect. I am sure an occasional thank you from senior management would go a long way towards reassuring these amazing people they are highly valued and appreciated. I got the sense this might be an area currently neglected amongst all the change at Imperial ...'

Other comments referred to the journey in the neonatal unit in general:



'I had the problem of not being allowed to touch my baby, so this programme is good as gives back some control to parents ...' 'The idea of being signed off for procedures makes me feel able ...' 'You feel empowered to challenge a decision if you have training/ education ...'

6. Summary

Understanding parent experience is essential for any neonatal service, and vital to plan improvement and assess the effects of changes. Previously we relied on the feedback from the national Picker survey, but this is not carried out regularly, therefore additional work was needed to follow parent experience in a timely way.

In our unit general feedback is often obtained on an ad hoc basis by senior nurses or psychologists without standardized tools. Unfortunately it is difficult to identify themes and areas for improvement in this way; the information can be very limited or biased and it is not possible to reliably assess the effects of a change in the service.

We designed a parent experience tool using a combination of validated tools and option of free-text feedback. As it is a written questionnaire, it is possible to seek feedback from a large number of families post discharge anonymously.

Generally the feedback received was positive; highlighting several values about the care delivered in the Imperial neonatal units: general ethos and standard of care, caring staff, breastfeeding and lactation support, infection control.

The 'negative' comments followed the theme of communication: not sufficient conversation with the medical team, conflicting information, and insufficient communication before transfer to other hospitals. Advice and recommendations were received to improve and optimize our care. Many of these were in areas where it was obvious for our department that further development/improvement was needed, for example about environment and parent facilities or breastfeeding consultant support.

We also believe that the implementation of the IFDC project including the launch of the parent supporting mobile application (App) will be able to address and facilitate several aspects highlighted.

This project through education and empowerment should increase parental involvement and give parents back some degree of 'control' of their journey, improving parental experience. It was mentioned several times in the feedback, that the loss of this 'power' or 'control' results in the majority of their anxiety and stress. It is hoped that the introduction of the IFDC project will reduce the anxiety levels of families cared for on the neonatal unit.

We were able to obtain detailed, valuable feedback about our service with the designed tool. Repeating this survey regularly will enable us to assess the effect of changes in service delivery. We

recommend repeating this parent experience survey annually to detect and understand arising issues around our care.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jnn.2017.11.007>.

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