BUDS results report for ISRCTN

Stage 1: 'Proof of concept' (2 weeks—SCBU, lowest intensity area)

Parents: We randomly approached and recruited three parents on the Special Care Baby Unit (SCBU) of Chelsea and Westminster Hospital Neonatal Unit (CW NNU) over a 2-week period. All three parents were female, aged between 25-40 years old and their infant's gestational age at birth ranged between 27-32 weeks. Their ethnicities were Asian, White, and Mixed. One infant's duration of stay on the CW NNU was under 1 month; the two other infants had spent between 1-6 months on the unit. These parents received a sealed written *'My Baby's Summary Report'* (MBSR) daily for 7 weekdays. We asked parents to complete the PEC survey 3 times; at baseline, midweek and during the second week. One parent completed the PEC survey 3 times; the other two parents did not complete their third survey (one parent was discharged and one parent did not return the survey).

Staff members: Staff members working a clinical shift in the SCBU unit area completed staff surveys at the same time points as per PEC parent surveys. During this period, 12 staff surveys were completed. It was not possible to estimate the exact number of individual staff member participants, as the survey was conducted anonymously, and some staff members could have completed the survey more than once.

EPR data completeness and accuracy: During this period, we evaluated data completeness and accuracy in the Electronic Patient Record (EPR) every weekday.

For PEC surveys, staff surveys, EPR data accuracy and completeness, we focused on reviewing the piloting process rather than analysing quantitative results (very small sample numbers).

We conducted two PDSA (Plan-Do-Study-Act) cycles where we studied the implementation process in Stage 1 to improve the overall piloting process, in preparation for Stage 2 'Roll-out'. This included plotting the parent and staff survey data on run charts, to review the process. We utilised parent feedback from the MBSR-specific PEC survey questions (questions B15-B20) to develop the final MBSR template for use in Stage 2 'Roll-out'. This template contained information from 12 EPR data items.

Stage 2: 'Roll out' (6 weeks—SCBU 2 weeks—HDU 2 weeks—ITU 2 weeks)

Parents: During a 6-week baseline period of clinical service evaluation on the CW NNU (preceding Stage 2 'Roll out'), 43 parents completed a total of 107 PEC surveys. Survey completion times by parent ranged between 1-12 times, with a mean of 2.4 times. 43 parents completed the PEC survey at least once, of which 19 parents completed it twice. During the 'Roll out' intervention period of administering the MBSR, we randomly approached 26 parents across the 3 neonatal unit areas (SCBU, HDU, ITU), of which we recruited 24. During the intervention period, 90 PEC surveys were completed in total. Survey completion times by parent ranged between 1-10 times, with a mean of 2.4 times. 24 parents completed the PEC survey at least

once, of which 20 parents completed it twice. Parents ended their participation according to when their infants were discharged, or at the end of 6 weeks, whichever came first. Parent demographics in Table 1.

MBSR template improvement: During the 6-week intervention period, we utilised parent feedback from the MBSR-specific PEC survey questions (questions B15-B20) and conducted four PDSA cycles to further improve the MBSR template. The final MBSR template contained 14 EPR data items.

PEC surveys: We obtained a research ethics amendment approval for administration of the PEC survey to parents twice-weekly, instead of the originally planned once-weekly, to increase the number of PEC survey data points and optimise the use of run charts. The project's steering group chose 15 questions from the 35-question *'Parents' Experiences of Communication in neonatal care'* (PEC) survey for outcome evaluation and analysis (12 continuous and 3 categorical questions). These 15 questions were deemed to be the most specific for evaluating the impact of the communication tool.

Run chart analysis examining how PEC survey responses changed over time (baseline versus intervention period), demonstrated that during the period of introducing the MBSR on the CW NNU parents overall:

- Were *more satisfied* with the method of communication being 'written information' and more likely to recommend the CW NNU to friends and family *(Primary outcome).*

- Were *less satisfied* with the frequency of updates received by nurses and doctors and the method of communication being 'verbal updates' and 'telephone calls' *(Primary outcome).*

- Reported telephoning the unit 'more times in 24 hours' *(Secondary outcome: Parent-staff interactions).*

In evaluating the communication tool's specific impact on PEC survey responses, we compared mean responses from paired parent samples from the baseline period (second survey answered by parents) versus the intervention period (second survey answered by parents after receiving the MBSR), while adjusting for first survey responses. Statistically significant results indicated that:

- More parents in the intervention period reported they had 'received enough written information' compared to the baseline period *(Primary outcome).* This result is most likely a reflection of the MBSR's implementation. *Question: Have you been given enough written information?' (1. Yes definitely – 4. No, not at all).* The second survey mean response in the baseline period was 3.00 (SD 1.054), versus 2.06 (SD 1.181) in the intervention period (ANCOVA test, p=0.012).

- Parents reported asking their baby's nurse for a face-to-face update more frequently in a 24-hour period in the intervention period (mean 3 times) compared to the baseline period (mean 2 times) (ANCOVA test, p=0.034) *(Secondary outcome: Parent-staff interactions).*

In evaluating how satisfied parents were with the MBSR over time, satisfaction during the intervention period was high for both '*frequency of receiving the MBSR'* (median 4.5 out of 5, 5: Extremely satisfied*) and the 'MBSR overall'* (median 4 out of 5, 5: Extremely satisfied*).* There were not enough data points to conduct a formal analysis as per run chart rules; however, as a general pattern parents appeared more satisfied with the MBSR from the second week onwards and slightly less satisfied during the last 2 weeks (and from the 8th time of PEC survey completion per parent).

In comparing paired parent survey responses from the first and last time parents received the MBSR, satisfaction levels were generally high and were not statistically significantly different.

Staff members: During the 6-week baseline period of clinical service evaluation, 168 staff surveys were completed. Most staff members were nurses (79.8%), while the commonest unit area with completed staff surveys was ITU. During the intervention period, 70 staff surveys were completed. Most staff members were nurses (94.3%), while the commonest unit area with completed staff surveys was HDU (44.3%).

In evaluating staff survey responses (baseline versus intervention period), results were statistically significant for the question '*In the last 24 hours, have you updated parents during a ward round?'.* The odds of staff members replying *'1.Yes'* in the intervention period were 2.15 times higher than in the baseline period (logistic regression while correcting for job role and unit area, p=0.036).

Data completeness: The final MBSR template included 14 EPR data items.
The first 2 data items (age and corrected gestational age) are always fully recorded, as a counter automatically updates them daily. Of the remaining 12 items, the NNRD holds available completeness values for the 11 items only.

On comparing the *'baseline period NNRD population completeness proportion'* to the '*intervention period EPR parent sample completeness proportion'* for each of the NNRD data items using the binomial test, completeness in the intervention period was generally high (10/12 items >90% completeness). Completeness in the baseline period was seen to be lower (>80% for 7/11 items).

For 6/11 data items completeness significantly increased in the intervention period (by at least 10% for each item); for 5 of these items this was statistically significant (*Daily weight; Method of feeding today; Volume of milk given in 24 hours, Mode of non-invasive respiratory support; Blood/cerebrospinal fluid culture performed today: P<0.001 for all)* and for 1 item not statistically significant *(Medication given today, p=0.058*).

One data item's completeness reduced during the intervention period (*Type of enteral feeds given today*) and this was statistically significant (p<0.001). For the 4/11 remaining items (*Intravenous glucose and electrolyte solutions; Total parenteral nutrition; Respiratory support today; Added oxygen today*) the comparison was not possible as completeness in the NNRD was 100% (and >95% in the intervention period).

Data accuracy: There were no available pre-intervention NNRD data accuracy comparators as data accuracy is not routinely recorded in the NNRD. We arbitrarily defined low accuracy as <80%, intermediate accuracy as 80-89.9% and high accuracy as 90-100%. Over the whole intervention period 9/12 items had a high accuracy proportion (defined as 'accurately completed data fields / total completed data fields'), 1/12 had intermediate accuracy (Medication today) and 2/12 had low accuracy (Milk volume; Weight).

Interviews: In both the baseline and intervention period, we recruited 6 parents (two from each unit area, SCBU; HDU; ITU) and 5 neonatal staff members: one nurse from each NICU area (SCBU, HDU and ITU) and 2 doctors (one consultant and one registrar). In individual interviews, issues highlighted included parental views on stress (and its inevitable nature under these circumstances) and how the way neonatal staff members approach communication with parents can further negatively or positively influence this. Parents and staff agreed that regular sharing of concise, jargon-free information can help alleviate this stress. The MBSR is a way to provide this daily information to parents. Parents reported always needing the face-to-face update; the MBSR could therefore serve as an adjunct to parent communication, rather than replacing in person discussions.

Parents were overall very happy with receiving the MBSR and reported feeling more informed. Key MBSR benefits identified by parents included: being actively offered daily updates, having more time to absorb and process information, being able to track their baby's progress and feeling better prepared to have conversations with staff. Parents used the MBSR as a written record, reminder, memento and way of sharing their baby's progress with their loved ones (by sending a photo of it). Staff members reported that the MBSR appeared to empower parents, serving as a reference to ask questions during the ward round, with parents appearing more informed and involved. In terms of the MBSR's impact on the frequency of parents asking questions and type of information asked, staff felt it was challenging to assess as different parents visited at different times, but this was generally unchanged. Since the MBSR is being proposed as an adjunct to parent communication, it is anticipated that the MBSR can help better focus the verbal discussions, rather than replace or reduce them. In terms of data flow processes, the MBSR created an increased motivation and accountability for nurses to record data on EPR correctly, since parents would question the accuracy/completeness of information in the MBSR. Parents had many requests for expanding the MBSR, namely in terms of including more types of information and making the information 'real time'. Suggestions have been incorporated as much as possible in the development of an app prototype, within the current constraints of the Hospital trust's information systems. Following the creation of a BUDS mobile application prototype we have signed a contract for a live app for use by parents on the CW NNU (development in progress). A live app would have the potential to be applied to any other NNU, as long as EPR data can be appropriately extracted for use by the app.

No adverse events reported.

Table 1: Demographic details from parents that completed at least one PEC survey in baseline versus intervention period

	Baseline period (n=43 parents)	**Intervention period (n=24 parents)**
Parent gender	**Female, 28 (65%)** Male, 15 (35%)	**Female, 18 (75%)** Male, 6 (25%)
Age in years	**Over 35, 15 (35%)** 30-35, 13 (30%) 25-29, 12 (28%) 18-24, 3 (7%)	Over 35, 10 (42%) **30-35, 11 (46%)** 25-29, 3 (12%) 18-24, 0 (0%)
Ethnicity	**White, 25 (58%)** Mixed, 3 (7%) Asian/Asian British, 9 (21%) Black/Black British, 3 (7%) Other, 3 (7%) (Asian; Arab/Middle Eastern)	**White, 10 (42%)** Mixed, 1 (4%) Asian/Asian British, 7 (29%) Black/Black British, 2 (8%) Other, 4 (17%) (Indian; African; White/Black Caribbean)
Gestation in weeks	< 24, 2 (5%) **24-28, 10 (25%)** 28+1-32, 8 (20%) 32+1-36, 8 (20%) **36+1-40, 10 (25%)** >40, 2 (5%)	< 24, 1 (4%) 24-28, 6 (25%) **28+1-32, 10 (42%)** 32+1-36, 3 (12%) 36+1-40, 4 (17%) >40, 0 (0%)
Length of stay	**<1 week, 22 (51%)** 1-2 weeks, 4 (10%) 2-4 weeks, 8 (17%) 1-2 months, 5 (12%) 2-4 months, 3 (7%) 4-6 months, 0 (0%) >6 months , 1 (3%)	**<1 week, 7 (29%)** 1-2 weeks, 5 (21%) **2-4 weeks, 7 (29%)** 1-2 months, 4 (17%) 2-4 months , 1 (4%) 4-6 months, 0 (0%) >6 months, 0 (0%)

Table 1: Demographic details for parents: the groups with highest percentages are in BOLD.