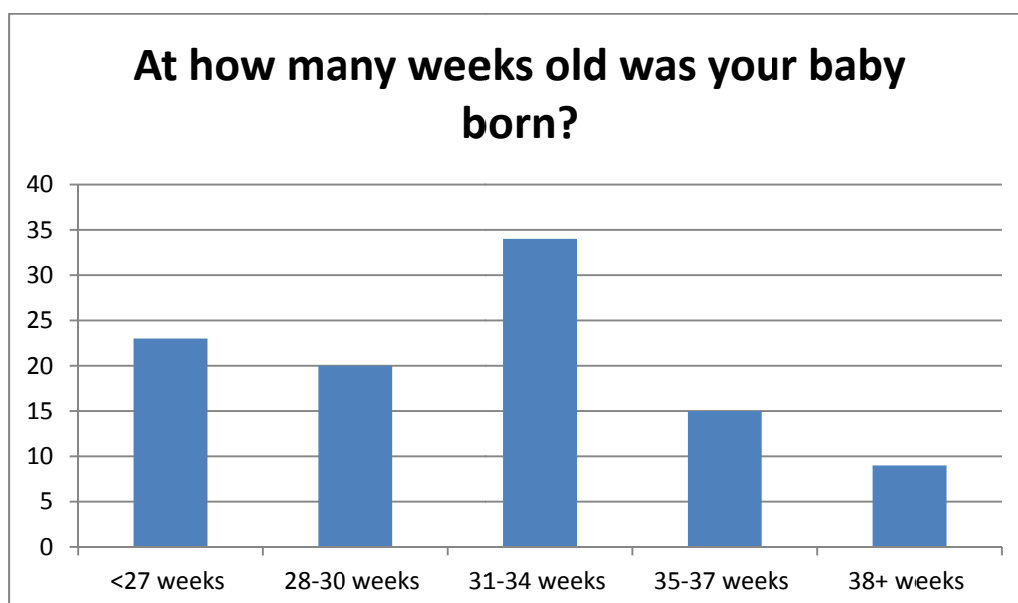
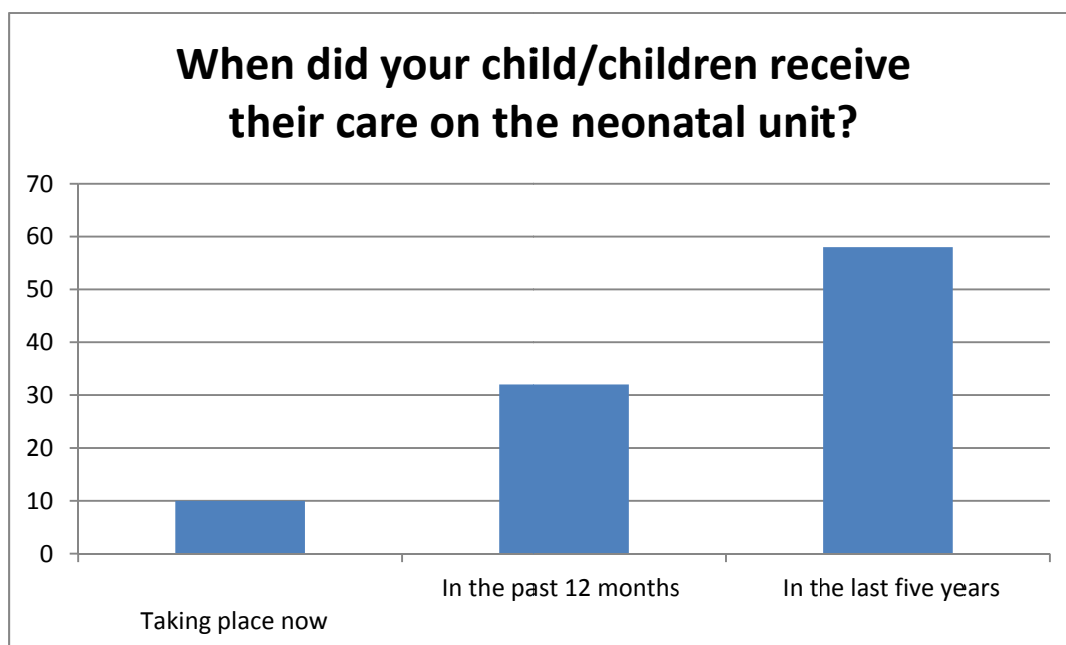
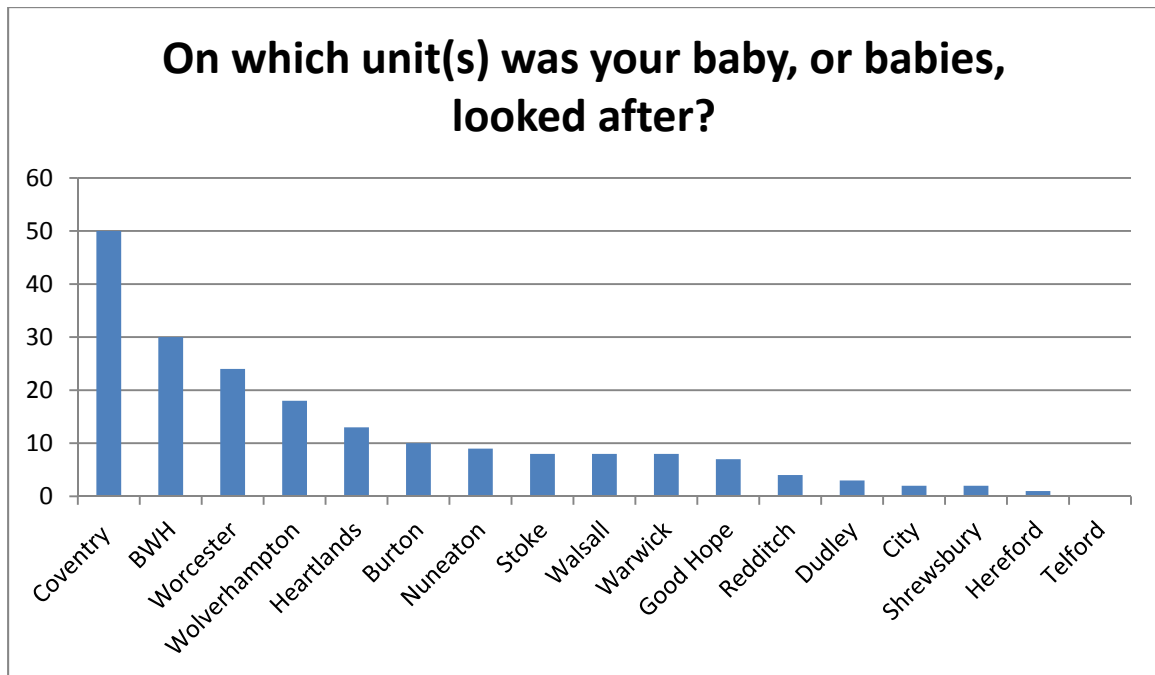


## West Midlands neonatal review questionnaire for parents – summary of results

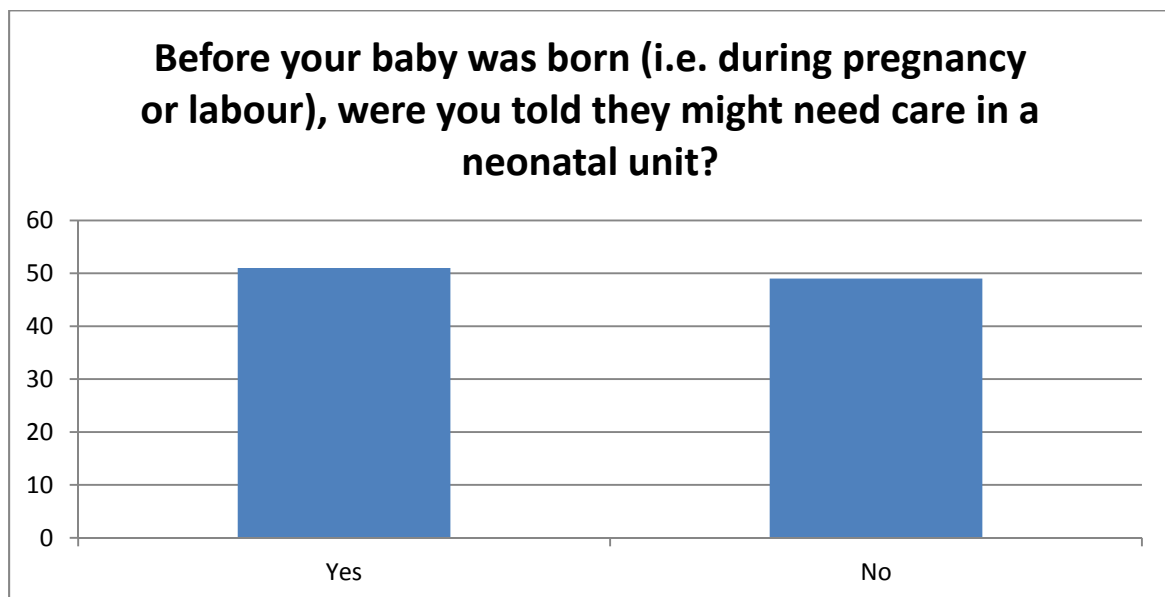
The survey was available online for four weeks from Monday, 18<sup>th</sup> April, until Sunday 15<sup>th</sup> May. In total we had 168 responses.





Note: 35 of 166 (21%) received care on more than one unit. 11 spent time on units outside the region, the most common of those being Leicester.

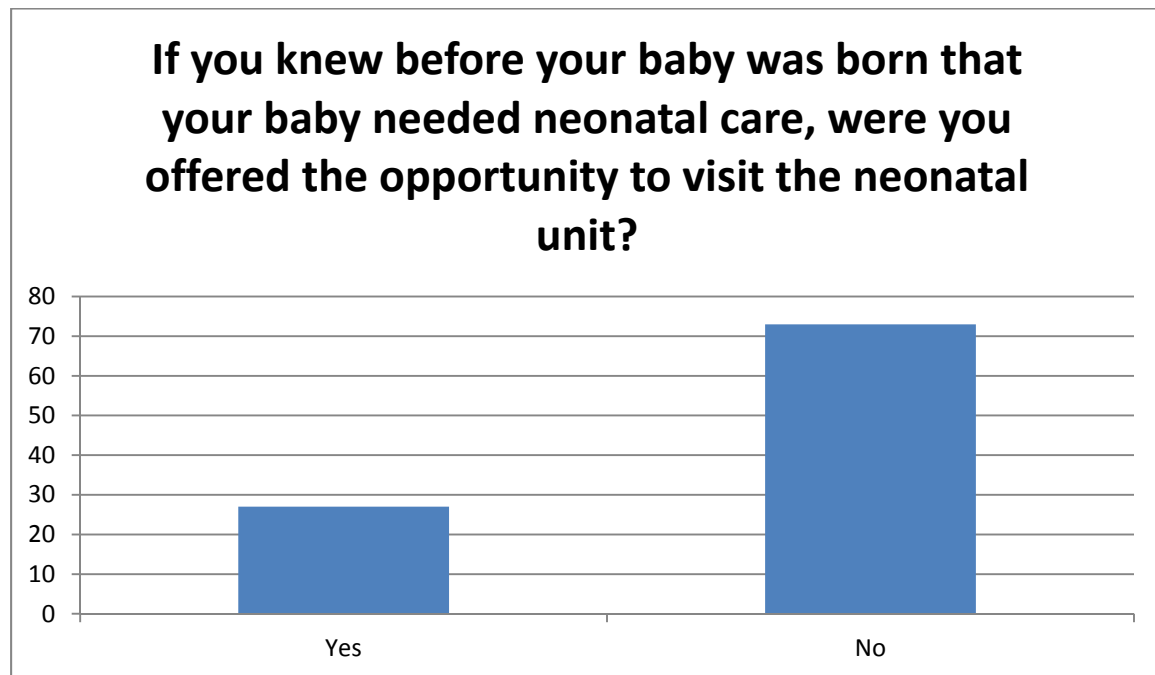
#### Before the birth



“Think this was really poor as I was expecting twins. It was only after I had them I realised how common it was for multiples to end up in neonatal.”

“My baby measured small at 20 weeks so we were referred to Fetal Medicine and were monitored fortnightly then weekly. We were aware from our first FMU appointment that premature birth was very likely but we weren't given any information about the neonatal unit.”

“I was told this when I was in labour, however I had false labour/early labour signs from 26 weeks and spent 4 nights in hospital and the neonatal unit was not discussed. The only information I had was what I gathered myself during frantic midnight googling sessions.”



Around three quarters of parents said the opportunity to visit the neonatal unit in advance either did help them, or they believe it would have done. Others said that either there was no time, or they would have found it too scary.

“It would have helped to understand it better. When I first saw him I didn't understand why my baby was in a box.”

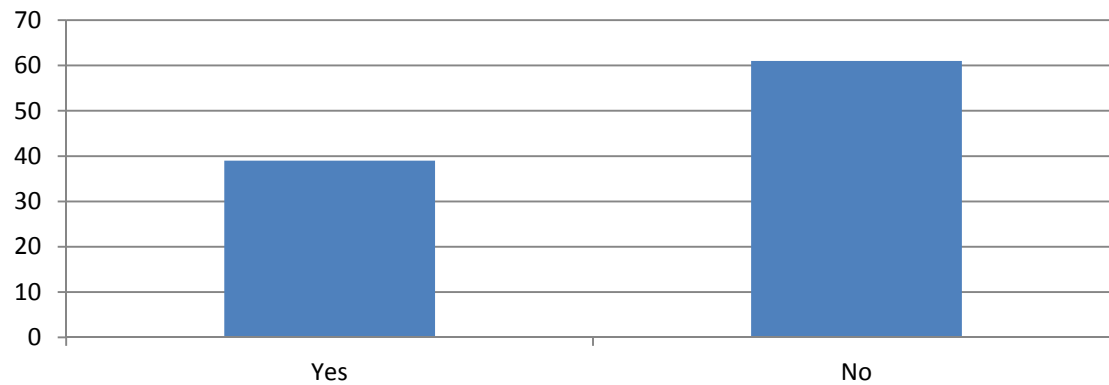
“Although it was a frightening experience and made the reality hit home, I believe it was helpful to have the visit to help me prepare mentally.”

“Yes, we wouldn't have been so terrified about it all.”

“We asked to, but were told it would not be possible. It would have helped us to know where our daughter would be cared for.

“We were offered the opportunity and gratefully accepted the offer, however the tour never happened despite us chasing it up on numerous occasions. Visiting the unit beforehand would have been incredibly beneficial.”

**Before your baby was born (i.e. during pregnancy or labour), did a member of staff from the neonatal unit talk to you about what to expect on the unit after the birth?**



“Is there anything that could be given to parents to be who know they will need neonatal care, whether it's a booklet with pictures of a standard incubator and basic machinery so it's one less thing to be frightened about, or a short DVD for them to take home, or even to watch somewhere within the hospital”

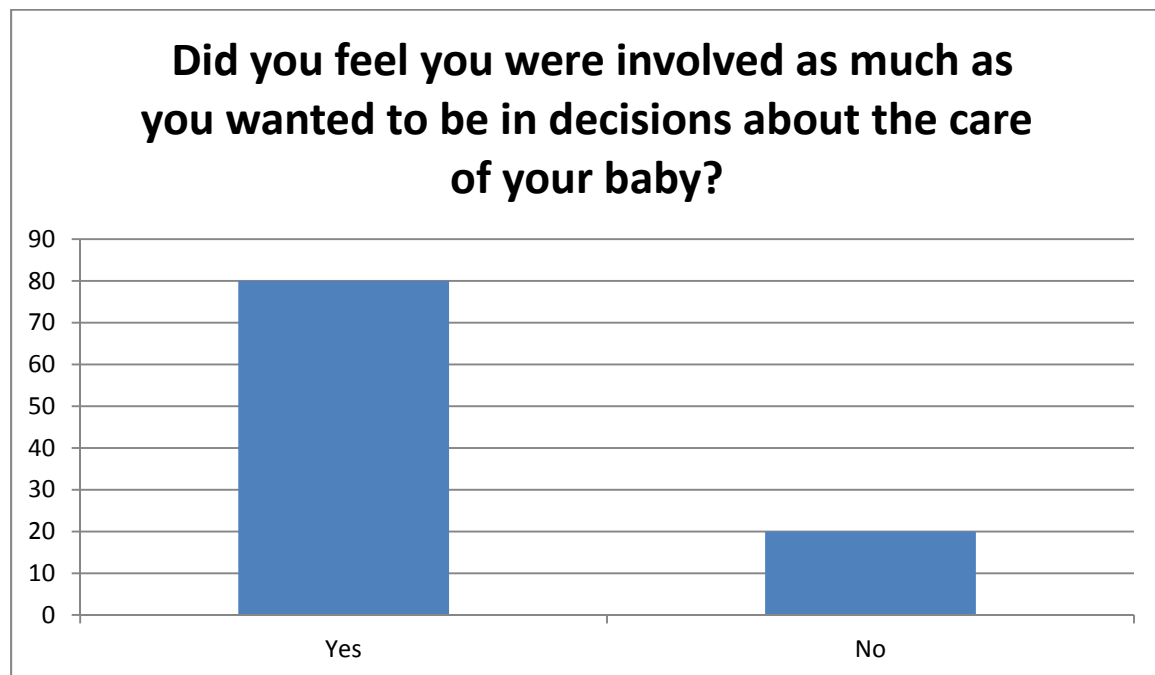
“I am from BME and I think it would be good to increase training and awareness about this amongst my community. I felt like I was in a different world. I felt useless because the clinicians did not like to hear what I say. They did not have enough time even to simply talk to me. My expectations were high but I did not know how to manage them because of lack of communication.”

“I think mums to be should be made aware of how the neonatal system works as many I spoke to had been moved to and from different hospitals. While I now understand why there are different levels at each unit and it makes complete sense, it would have been good if this had been mentioned at some point during my pregnancy”

“I do think the neonate doctor spent too much time telling me the risk. When you have no choice to give birth at 28 weeks, you don't need to know the risk of cerebral palsy or chance of death. I think he should have been telling me things like 'we will do everything we can for him'.”

“Less pessimistic prognosis. The doctors always told you the worst case scenario to the point that I thought my daughter was going to die, be deaf, have learning difficulties etc. My daughter is now a healthy 3 year old with very little that would identify her as prem.”

## Care on the neonatal unit



### Need for a support worker / change in skill mix

“I propose if possible the hospital recruit a support worker with a specific role to communicate with parents, because nurses don't have time.”

“I believe that all neonatal units should have some sort of councillor. It's such a hard process that having someone to talk to about your emotions would have helped. And they should all be equipped with cameras. There are lots of milestones that a mother misses. So taking photos is so thoughtful.”

“One unit had a separate support worker for families. I found this helpful having someone else to talk with who were not staff involved in my child's care. The nurses were always willing to chat but sometimes very busy. There were times I did not feel able to 'burden' them with my feelings, worries or needs. As a parent you also have to try and keep positive relationships with the staff looking after your child, who can change at least twice a day and are usually different one day to the next, that can sometimes be tiring and stressful. So having a conversation with a separate person, the same person, who had plenty of time to talk and listen and not worry about anything affecting the relationship between us and the care providers was so very welcome and helpful.”

### Continuity of care

“Having a nurse stay with the same child for a couple of days would help rather than rotating every day. They know the child better, there is more continuity of care and can be helpful to parents. Having the same consultant for a few days at a time would also be helpful, this was not always the case on SCBU, where it could vary day to day. We experienced some issues with poor continuity of care due to this, different plans made each day and not follow up of the previous day unless prompted by myself.”

## **Actively involving parents**

“I think there should be a section on obs sheets that parents can note concerns or questions or any of their own observations which the consultants can see on ward round.”

“Some nurses did involve me. Others made me feel like I was an inconvenience when I was in the room. I felt I had to ask permission before caring for my son. This was the hardest part about being in special care.”

“We were not told that we could touch our baby until about three days after she was born. We felt like we were in the way and that the staff found us to be a nuisance. When they asked us to change the nappy for the first time, before we even knew that we could touch our baby, it was done in an irritated way as though we were being lazy and disinterested.”

“It felt like it wasn't our baby, although the staff never intended us to feel this way.”

## **Impact of moving babies without telling parents**

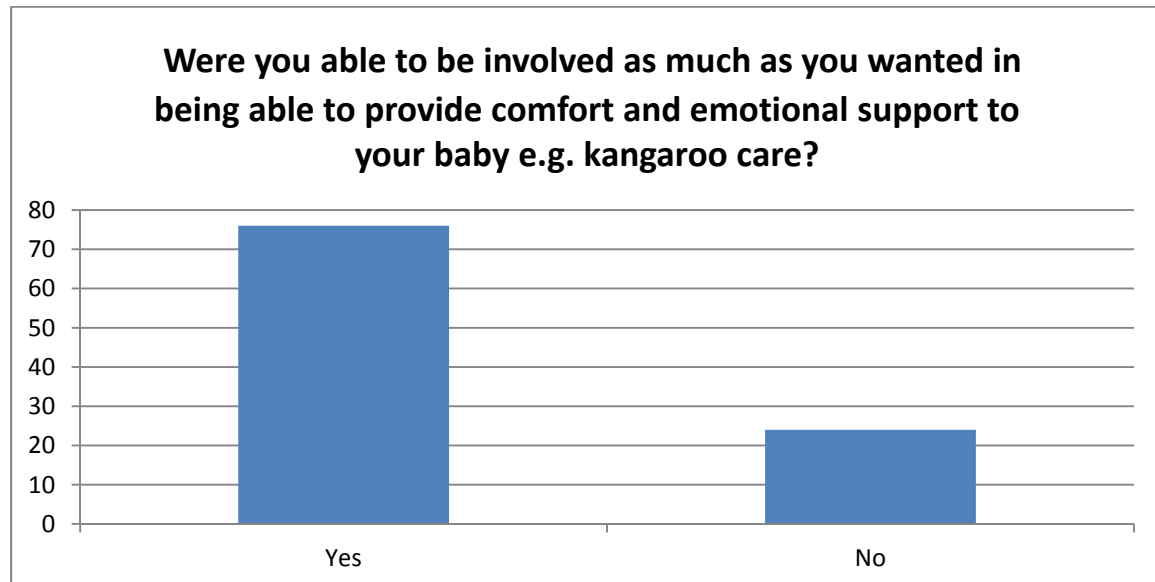
“One morning I went to visit my son in special care. I walked up to his cot but a different baby was asleep in the cot. I then approached a nurse and asked where my son was. I was then informed my son had been moved to a side room as he had become poorly in the early hours of that morning. It was such a shock as he was doing so well but also because no one had called me to inform me that my son became very poorly. I started to suffer with anxiety and panic attacks to the point I was too scared to leave him. Months afterwards I cried just talking about it all. I can remember was seeing a different baby in my son's place. I discussed my concerns with the ward sister who told me I wasn't informed as they knew I would be in to visit, plus it is something they see most days with prem babies so it wasn't classed as a concern. I told the sister that the slightest change in my son's condition was a concern to me and I would of expected them to call me. I just didn't want any other parents to go through what I went through.”

## **Benefits of involving parents**

“We were kept fully and well informed and usually involved in decision-making where appropriate. This made us feel valued, respected, empowered and part of the team caring for our son. However, there were occasions in other hospitals where we were not listened to or able to be part of the decision-making process. This was incredibly frustrating, particularly when staff were 'following standard procedure' without thinking about the needs of the individual patient or willing to engage in conversation about it.”

“I was fully involved in decision-making. One example is when the medical staff wanted to take one course of action which I knew in my heart wasn't the right one for my child. I raised my concern and after a discussion with the consultant it was agreed a weekend trial for my preferred course of action would take place. After the trial ended it was unanimously agreed by the medical staff that my course of action was the right one. As the parents of a sick child you feel helpless when you cannot do the 'norm' and completely look after your child. So being involved in decision-making is extremely important as it feels like you are contributing in some way when you are limited with what you can do.”

“I'd like to give a mention to the staff who go the extra mile with special touches which make the whole experience a little more personal e.g. one NICU nurse made a lovely name card for our daughter's incubator, the staff kept things for us like her first dummy, eye mask etc. and the transport team even gave her a certificate for her first trip in an ambulance. They're all special mementos to treasure.”



### **More promotion of kangaroo care**

“At the first hospital it was actively encouraged. At the second, not so much. In fact I overheard the nurse in charge saying 'that mum has had an hour with her baby that is more than enough.' This is not what the evidence suggests.”

“I didn't have as many opportunities to do kangaroo care as I now know I should have had. Sometimes I was made to feel that it was a hassle getting my son out of the incubator.”

“I wish I'd been encouraged more as in the early days I was so afraid of taking her out of her incubator.”

“My daughter was two weeks old before I could have a cuddle. I really struggled to bond and think if this had been offered earlier it wouldn't of been an issue.”

“Had to ask a lot of the time for the nurses to get my baby out of the incubator as they never seemed to offer.”

“I didn't feel that kangaroo care was something that was promoted on the unit and it sometimes felt like I was being a burden to the nurse when requesting my son be taken out for skin to skin. I didn't realise the importance of it then but understand now that I should have been given the opportunity on a daily basis when my son was well enough for it.”

“Several times I was told I couldn't hold my son. It was heartbreaking when they didn't give a reason. A few times they fed him before he was due so I would just miss it then tell me I had to wait 30 mins to hold him. I ended up not leaving the side of his cot so that I could be there if they fed him early.”

“Very experienced staff tended to offer and encourage kangaroo care, whereas newly qualified and less experienced staff would not routinely offer and could be reluctant to provide it when asked.”

### **Benefits of kangaroo care**

“Kangaroo care was great once he was well enough to be touched. A real highlight. I wish I'd known I could take photos of him. The first night on the postnatal ward at the other end of the hospital without him, and without a photo were truly awful.”

“The neonatal staff were amazing. I had never heard of kangaroo care before the staff mentioned it, but it made me feel close to my son.”

“The midwives helped both me and my husband do kangaroo care with our little girl - I thought this was particularly good for my husband as it really helped them bond.”

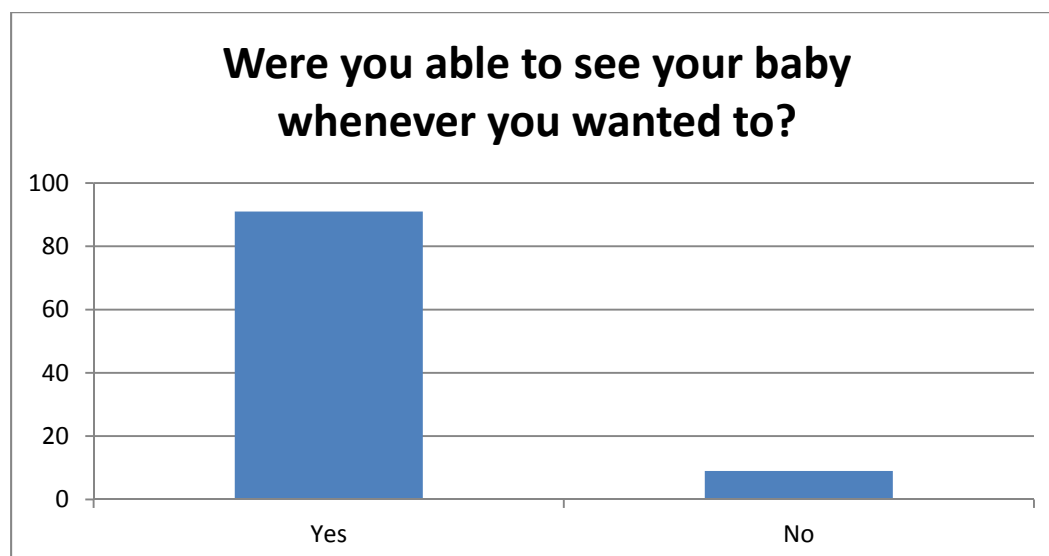
“This is where I think the neonatal / SCBU nurses excel. They are always willing to support parents to hold their babies and get involved in their care as much as possible. As soon as it was possible to hold our daughter the staff showed us how to take her out the incubator with all the wires etc,”

“I was always asked if I wanted to do skin to skin, or just to have normal cuddles which made me actually feel like a parent, when they have wires coming out of them you forget you can touch and hold them. So the encouragement helped a lot.”

“Doing kangaroo care was the best it made me fill like I was doing something to help with her progress.”

### **More support for breastfeeding**

“I didn't feel like breastfeeding was encouraged. I was feeding the twins and one nurse told me I had to have screens around me because of other visitors. This really upset me and to be honest still does - I occasionally see this nurse at the gym. If you can't breastfeed on a neonatal unit as you wish, where can you! Also towards the end I felt like it was implied that if I was bottle feeding we would get out sooner.”





## **Impact of different policies**

“I was once asked to leave special care when ward round was taking place. I had seen my baby for 1 minute and was then asked to leave for over an hour.”

“We were told to leave at shift changes which was an inconvenience when we were only able to travel over at certain times due to work, other children etc.”

“On the changeovers, I felt it wasn't necessary to be asked to leave the room. Surely just stepping away would be sufficient. Being asked to leave your baby even for this short while felt horrendous.”

“We were asked to leave the room during ward rounds at the second hospital, whereas this was not what happened at the first. We were left to stand in the corridor, sometimes for a long period of time, as there was not a parent's room at that unit.”

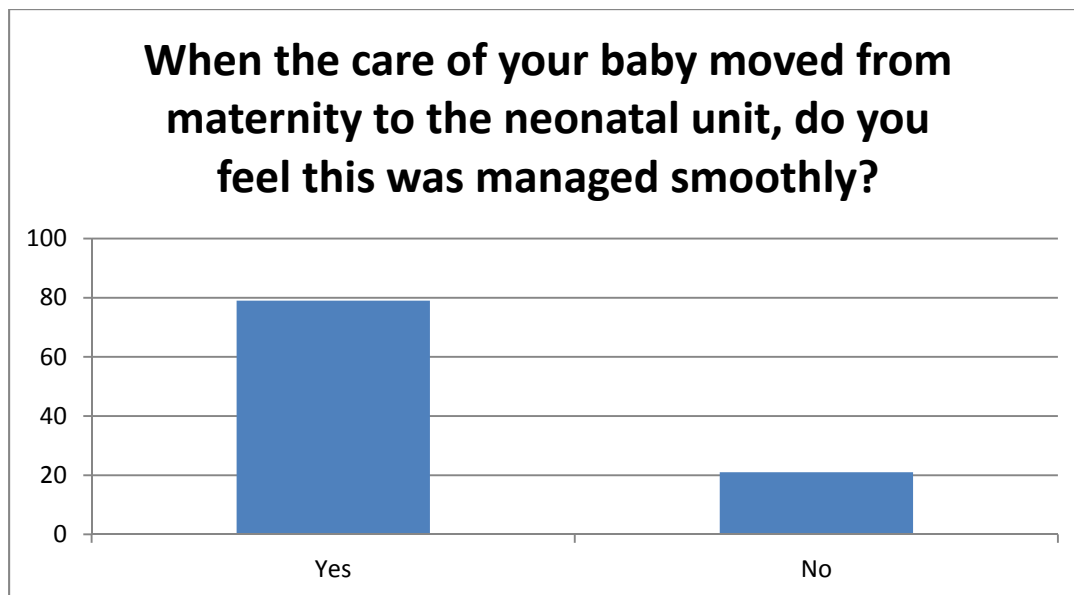
## **Visiting rules**

“We had issues with transitional care as fathers were only allowed to visit between 8am and 7pm. I found this very isolating being a new parent having to do the all care of my children by myself when this had not been a problem before and wouldn't be at home when they were discharged but also very isolating.”

“It would have been absolutely brilliant if grandparents had been allowed the same ease of access as I was without my husband for three days and could really have done with the support.”

“When I was acutely unwell my sisters and mother were present at hospital to support me. When the baby was born only father and my mother were able to visit. I understand rules to be father and grandparents but my sisters were devastated they never got to meet her alive. I think the rules should be in place to limit visitors and allow staff to do job but maybe it can be up to parents on those 'most important' to visit.”

“We even visited after midnight a few times when my partner finished work, which made a big difference to his mental health being able to just go and see him when he had been at work all evening and had only seen him for a couple of hours before work.”



#### Variable experience in delivery room

“Emotionally it wasn't smooth. I was distraught and my baby was taken straight away which was very traumatic.”

“Once he was in the transport pod ready to be taken from theatre to neonatal, the anaesthetist stopped the surgeons and lowered the theatre table so I could see him before he left. I had thought he would just be whisked off so that was a really nice touch.”

#### Long waits for information

“We did have to wait 4 hours to get someone to tell us how it was going and it would have been nice to have had an update, but on the other hand we were told if they came back in less than a couple of hours it was likely to be bad news and I wouldn't have wanted to pull anyone away from stabilising her!”

“I was told he would be gone an hour and even given a room with a cot. Upon seeing the consultant they told me this would never have been the case. We were then left in a room with no idea if our son was okay for at least 3 hours.”

“After the caeseran section my baby was taken straight away as she needed adrenaline and resuscitation for 30 minutes. I was not allowed to see my baby until the next day. We were given a photograph of her but there was no explanation given to us of all the wires and tubes coming out of her.”

“My husband was left waiting in a room on his own for hours not knowing if either of us were ok as I was rushed into theatre and our son taken to the unit, no one came back to tell him we were both stable.”

“I had emergency c section and was not very aware of what was happening. My partner was not happy as babies were taken within 5 mins of being born and no one told him for about 3 hours what was going on. I think sometimes the father gets forgotten.”

## **Need for more support on post natal ward**

“The NICU team were exceptional and brought me photos and updates constantly. However, the obstetric and midwifery team put up unnecessary obstacles to me visiting my son. I understood the clinical need to stabilise me as a mother but in the time they restricted me visiting my son, they did observations once in 6-8 hours.”

“I stayed on the antenatal ward so I wasn't surrounded by mums with their babies, which was a relief. However, I felt that I was a low priority for the midwives. They did regular observations but didn't offer to get a wheelchair so I could visit my baby and I didn't get any advice on hand expressing colostrum until a day and a half after my baby was born. I understand the reasons for not putting mums of premature babies on the postnatal ward but some thought could go into how care is maintained with that disconnect.”

“I felt like after I had my baby and she was taken away. I was left in a family room on the post natal ward, and sometimes it was hours before someone would come and check if I was ok or before giving me pain killers. I think a little more time with the parents that have had babies early would be amazing.”

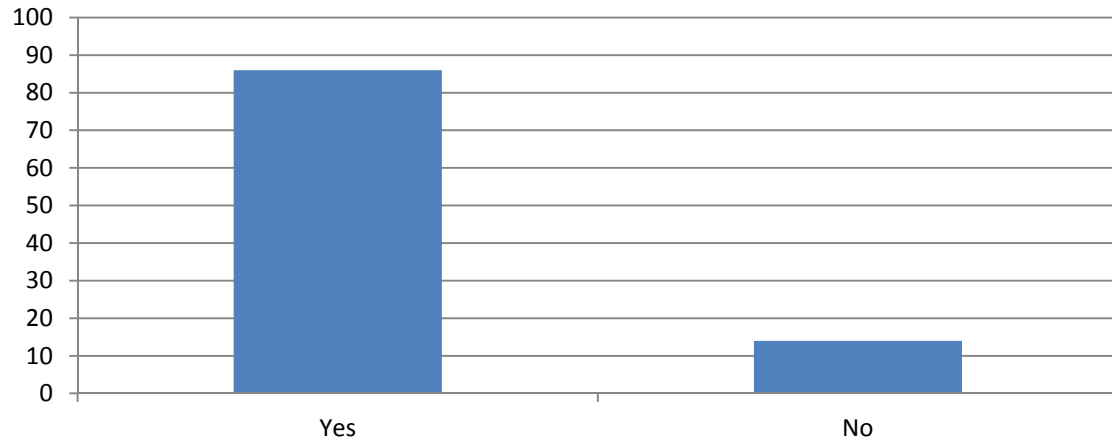
“On the post natal ward some nurses were less sympathetic and friendly than others. I did feel lonely at times. Sometimes it's nice just to be able to talk to someone. The cleaners came in at 6am and woke me and as I was expressing every three hours I wasn't getting much sleep, which was difficult.”

“Despite being born prem to an insulin using diabetic mother and him not feeding in the delivery room... I felt we were sent to postnatal ward, where we were forgotten about. Although he was being treated for IV antibiotics on the ward, there was no monitoring of him. By the time he was admitted to neonatal, he was very sick.”

“I think there needs to be more understanding on the maternity ward of the situation that they are in and how distressing it can be to be surrounded by women with their babies. For instance, I think it was unacceptable the number of times staff came to check my baby over and I had to explain that he wasn't there. Also that I had to wait for the doctor to check me over, which took until midday on the day following his birth, and therefore I couldn't see him until they'd been round. Simple things like that and helping transport expressed milk when I could barely walk would've made a huge difference.”

“It would have been nice to be able to receive postnatal care on the unit. I wasn't well myself but wasn't able to be checked by postnatal ward staff once I had been "discharged" to the parent room on NICU. Was told I'd have to travel home (20 miles each way) to see the community midwife!”

### On the neonatal Unit, did you feel that a nurse was always available when you or your baby needed them?

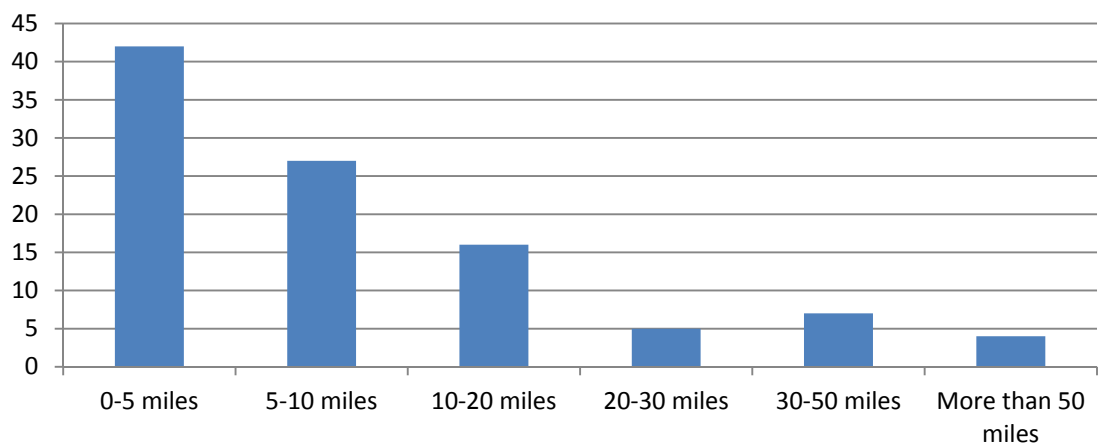


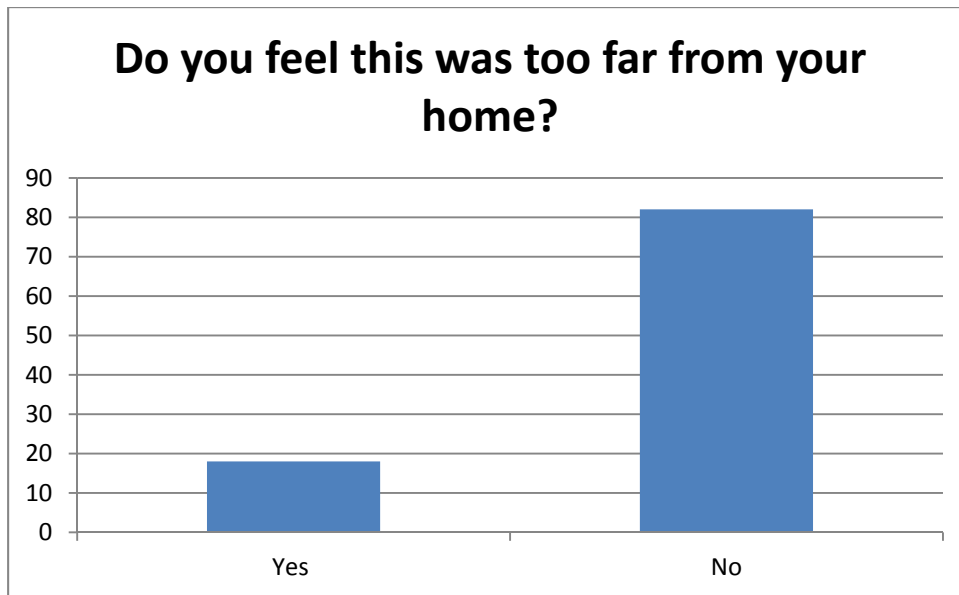
“They were always moaning about being short staffed and when you needed something they were always busy with other babies. Just felt in the way.”

“They were so busy and staff were stretched. Was very lucky to have a very supportive student on the unit who was able to help when the nurses couldn't.”

“Always there for the babies but not for me, any questions I asked where short answers and felt they didn't have the time to answer them.”

### How far away from your home was the neonatal unit where your baby was first cared for?





### Support with travel and parking costs

“I would travel the earth to have been with my baby. But as a single parent the financial side of the traveling was difficult. My baby spent 10 weeks in hospital, that's nearly 40 miles a day traveling, plus car park fees. I feel that parents should be able to claim money back for these fees.”

“As I had had a c section and my husband did not drive I had to get 2 buses every day and had to walk quite far to get to the unit. The nurses made you feel really guilty if you spent anything less than 18 hours a day there.”

“I was booked into this hospital so knew how far it was but didn't anticipate having a premature baby. When you have a C section and can't drive it is quite far away.”

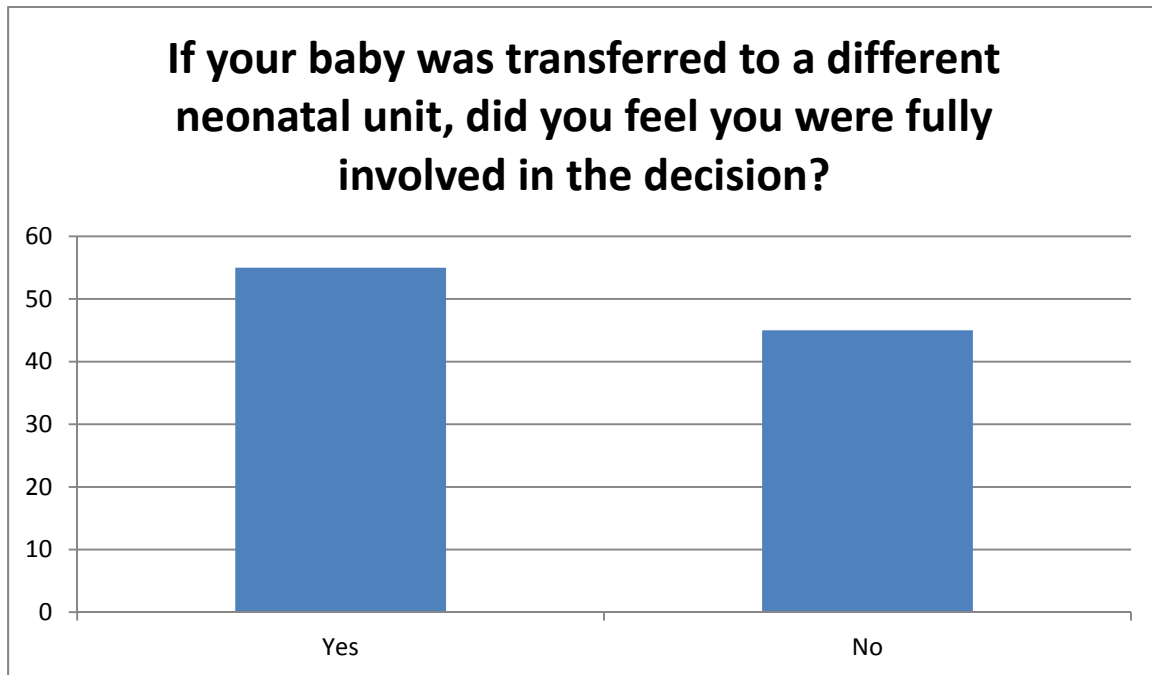
“I do think that there should be something available for parents who maybe do not drive and have to travel on public transport to be with their baby, maybe some room available for them to stay over. I didn't have this problem but I know of some parents while my son was there who had to rely on public transport and found it difficult, especially on a Sunday.”

“Getting into the hospital car park can be very traumatic at times. Lately you can wait up to 40 minutes in the line to park the car. If you have a sick child this can add a lot of stress and worry.”

“One of my main negative memories of our experience was the laughable parking charges.. During our time on the unit, I spent nearly £700 in parking at £8.50 per day. This added a lot of financial pressure to our situation.”

“For ICU level care it is acceptable to have to travel up to 45 mins, but less for SCBU.”

**If your baby was transferred to a different neonatal unit**

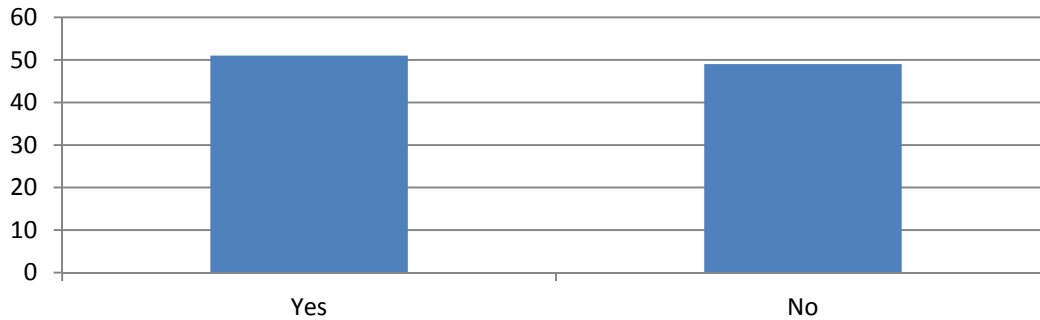


“We wanted the twins to be transferred back from Northampton to Walsall together. We'd said no but 15 minutes later they came back to tell us the transport was on the way and one of our daughters was being transferred. They paid for a taxi for us to go, otherwise we were told we'd have to make our own way the next day. It was all split second decision-making, and we felt very rushed. Our other daughter was transferred the next day.”

“Our daughter was transferred 4 times in 3 months and we always felt like she was safe. The transfer teams were always fantastic and put us at ease. The local teams were always clearly fully briefed and knew the process.”

“The transport team were amazing and told us exactly what was going to happen. We arrived at 4am at Coventry, but they were expecting us and made us a cup of tea in the family room. The little things make a real difference.”

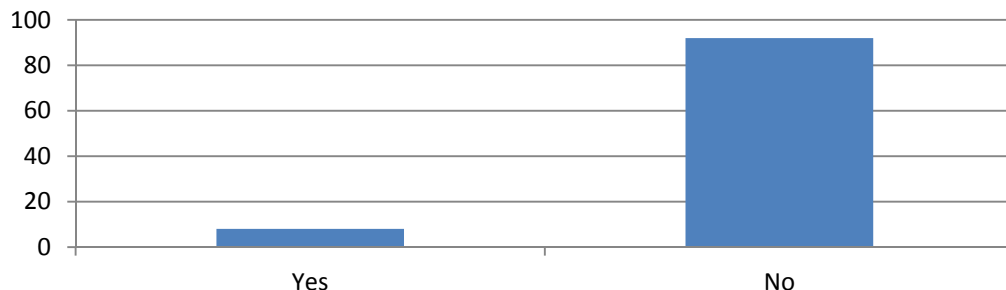
**If your baby was transferred to a different neonatal unit, were you given the information you needed about the new unit?**



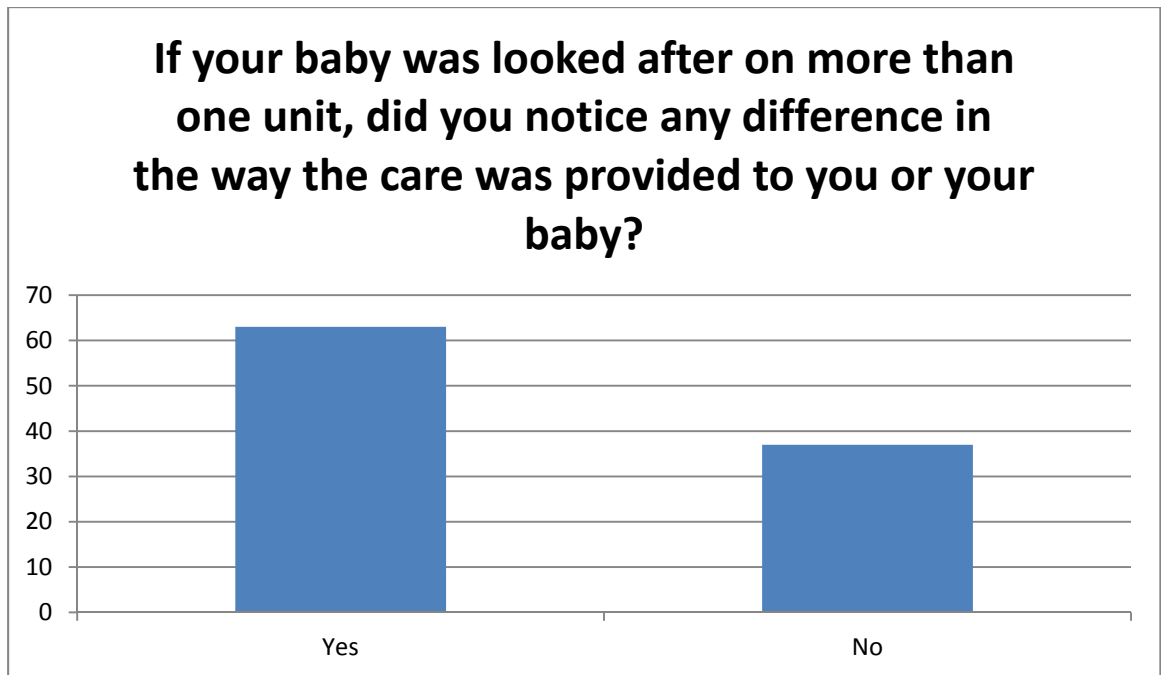
“It would have been useful to know about the different visiting rules as I'd got people lined up to visit based on the restrictions at the NICU then when we were transferred to SCBU, I found that people weren't going to be able to visit as they were stricter even though they were a lower level facility.”

“Staff tried to brief us but because the transfer was between networks, hospitals couldn't offer much detail. A national database with key information of the centres would be beneficial so a nurse can print off a 1/2 page fact sheet to give to parents to contain items such as: location, contact details, parking arrangements, cafe/restaurant details and accommodation arrangements.”

**If your baby was transferred to a different neonatal unit, were you encouraged to visit this unit prior to transfer?**



“I asked if this could be arranged and told no as they don't let visitors in - 24 hours later I was a visitor anyway!”



### **Lack of standardisation**

“Every unit had different policies re: feeding, visiting times and who could visit. Over a total stay of 11 weeks in hospital this made life very stressful.”

“Everything was different, but the one thing I got very upset about was how expressed breast milk was stored. At one unit it was for three days, but at the next it was only 24 hours, so for nearly two weeks several pots were being thrown away every day as nobody thought to freeze it or tell me to freeze it. Instead I was panicking that I wasn't able to make enough milk to keep up with his needs as I thought he was drinking it all.”

“Lots of differences, too many to write them all down, free parking, free meals, what I was allowed to do, feeding milk, one unit was all for cotton wool and water and the other baby wipes.”

“Some basic things such as one hospital encourage parents to bring in wipes for babies, whereas another insisted on cotton wool and water. Different expectations at each hospital just led to extra unnecessary stress.”

“Certain procedures were carried out slightly differently but with the same end result, the logging sheets with all his stats were different.”

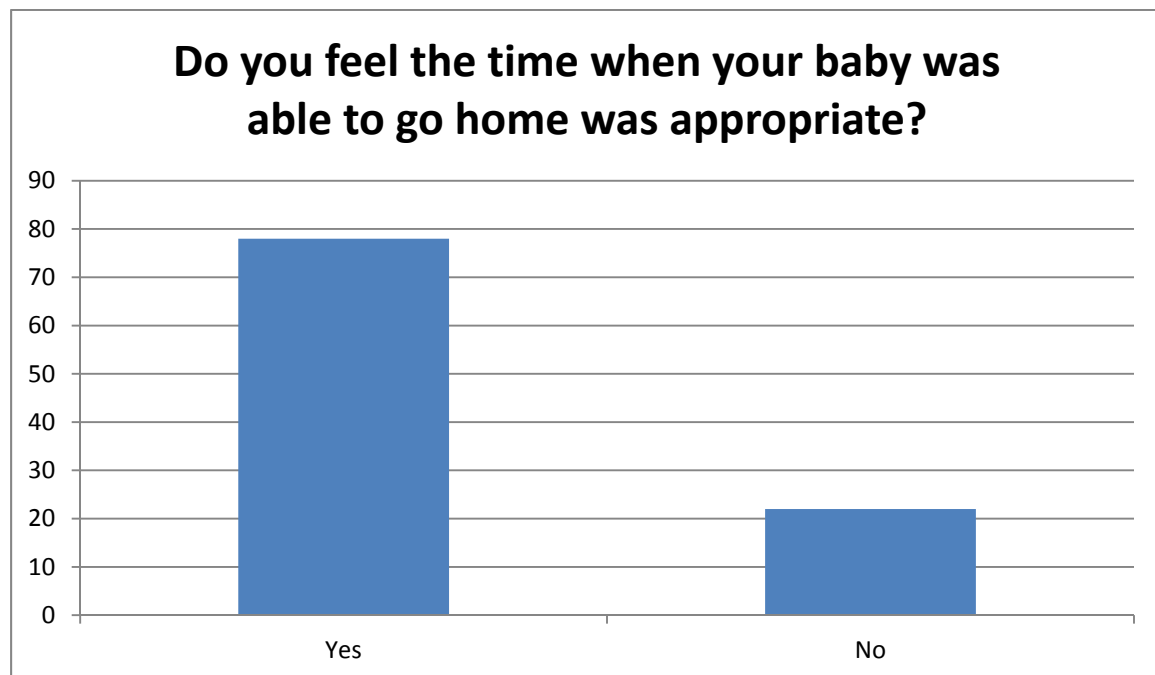
### **Value of SCUBUs**

“The Level 1 unit has helped to prepare us as parents to get ready to take her home. Having been through such a traumatic experience, you need to be in a calmer environment before you go home to help you to get over it.”

“There is the same level of professionalism, but it's more friendly here. At Leicester, you never saw the same nurse twice. Here they are familiar with your baby, which puts you at ease. You have access to the notes. It's like baby boot camp, they give you lots of support to learn to look after your baby.”



## Going home



### Discharge too early

“Due to the breathing difficulties I feel discharge was too soon. I feel an extra 2-3 days would have reduced my anxiety and fear and would have possibly reduced my risk of getting postnatal depression as I had such an unhappy baby I felt like I was being a terrible mum as nothing I did resolved his upset.”

“Too early. He was re admitted the following day.”

### Discharge unplanned / capacity driven?

“I was very upset as I had pleaded with the staff if my baby could go home on my birthday. I was told he would be in for a few more days. The very next day after my birthday whilst my partner and I had gone out for the day, and the hospital was aware we had gone out for the day, they phoned to say he could be discharged that day and gave me three hours notice, which meant I had to get all the baby's things ready at home and quickly do a food shop - it was chaos.”

“The main issue was not really getting any guidance or idea when they thought you would be able to go home until the day before.”

“One day we were told we could be in for a couple more weeks, the next that we were going home the next day. It was probably the right time, even though we didn't really know the criteria they judged by.”

“At one point we got told on the day of discharge they were short on beds and needed space. Well hold on a minute, we've been coming here every day for 118 days and it feels like your trying to get us out quick. One of the nursery nurses was rushing me to get their belongings out their cot cupboard, which made me very mad.”

“On the day of discharge the nurses working were some that had not looked after us before and they didn't seem interested in us. We were not shown any cpr DVDs like we saw other parents being shown, and I had asked if I could bath him before we left as he hadn't had a bath, and they didn't offer to help so he didn't have one. We just got given our paperwork in the flat and told we could go. After 9 weeks in the unit and seeing the fuss that was made of other babies when they had left, it was a little disappointing.”

### **Discharge late in the day**

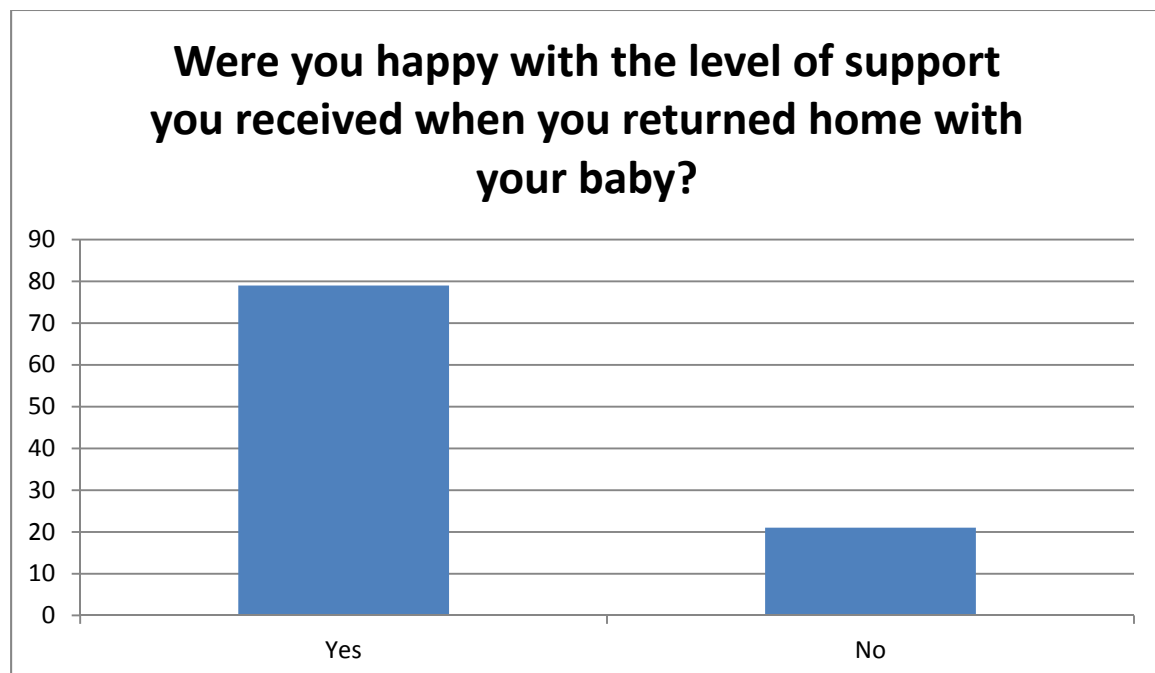
“Discharge took forever. We left at 20.00 at night in the pitch black.”

“Was unacceptable, we were discharged at 11.30 at night in the freezing cold.”

“We were very involved in the discharge of our daughter. Mum roomed in for two nights with our daughter to get used to caring for her (not so) newborn whilst still in the nursing environment. This was a fantastic and valued process because it gave us the confidence to be parents in the chaos of the preceding 3 months.”

“I went to the transitional care ward with my son for about a week to establish breast feeding. This was essential as I got dedicated one on one time with my son and breastfeeding support.”

“She came home when she was ready. They made it clear they do not rush the babies progress and that we should be patient and the babies will let us know when they are ready. Which in hindsight was the right thing to tell parents as we can start to become impatient.”



“We were not prepared for the emotional impact of looking after a baby that had almost died. We thought everything would be wonderful when we got him home but we really

struggled without the nurses and doctors on hand 24/7, it really was terrifying those first couple of weeks.”

“I saw my midwife once and they missed my six week check. I've seen my health visitor twice and my baby is now 16 weeks (6 weeks prem) I believe the support disappears and they seem too busy or distracted to actually listen to what you are trying to tell them!”

“I have to say I much preferred the midwives in the hospital than the home visit ones I had. They had a lot more time for our needs there.”

“I had no follow up visits from anyone. When I took my babies to be weighed (age 5 weeks, but still 3 weeks before due date) being breast fed and weighing 1.75 and 1.9 kilos I was told to bring them back in 6 weeks!”

“Health visitor very good with babies but no support of postnatal care from community midwife at all. Babies were in hospital 12 miles away and I couldn't sit at home waiting for her visits which could have been any time of the day. Also community midwife wasn't informed of birth due to it being out of area.”

“I didn't get any support whatsoever and when I went to register her with the GP they hadn't received and paperwork to say she had been born.”

“When I went home my twins were on a medicine only able to be prescribed by the hospital pharmacy, which I had to collect weekly for 11 months. This was very hard to have to come to the hospital weekly for so long. Only after 11 months did the pharmacy offer to do this monthly for me.”

“We received no support really after coming home. We were given a dvd on CPR instead of somebody showing us as they were too busy. When we had concerns about our son's breathing a few days after discharge they didn't want to know. Told us to go to A+E if we were that concerned.”

“I had no support when I took her home. I cried so much as she wouldn't stop crying. When I finally went to see a health visitor I just broke down and asked for help. A lovely lady who worked with neonates offered to come and teach me baby massage. And told me about positive touch. It was amazing.”

“The other support which is offered and which we still, almost two years later, access is the parent support group. The fact that this is led by NNU staff provides a link back to the unit and the sessions are often attended by a health visitor, physios, etc. The support of the staff alongside the fact that we have a shared experience among the parents provides a very good support network.”

“Our health visitor has been fantastic and contact with the NICU has been good, especially the Facebook support group.”