INTRODUCTION
This is the second half year report of the Staffordshire, Shropshire and Black Country Newborn Network (SSBCNN) parent experience survey 2008. The National Neonatal Audit Programme recommends that Neonatal Units carry out a regular survey of the parents whose babies were cared for in the neonatal unit. The importance of obtaining feedback on the experiences of patients and carers has recently been re-emphasized in Lord Darzi's High Quality Care For All – NHS Next Stage Review Final Report, June 2008, where for the first time healthcare providers are required to systematically measure and publish information about the quality of care including patient's own view on the quality of their experiences. The first half year report was presented at the March 2009 network board meeting.

AIM
To collect and compare parents views on their experiences of the neonatal services across the network

OBJECTIVES
• To explore the ‘experiential’ aspect of quality
• To gain a parent’s perspective on their experience on the neonatal unit and provide a measure of ‘satisfaction’ levels
• To evaluate outcomes and compare responses between neonatal units and networks
• To raise awareness within neonatal units of parents experiences and needs
• To highlight good practice and make recommendations to improve support for parents and improve their experience on the neonatal units in Network

METHOD
All parents whose baby(s) were being discharged from the six neonatal units in the network were provided with the questionnaire and a stamped addressed envelope a couple of days prior to the intended discharge date. Parents were reassured about the anonymity and confidentiality of their answers. Completed questionnaires were sent to the Newborn Network office for collation and data input.

RESULTS
The overall number of responses was lower than the previous half year report only 96 parents (range 4 – 36 respondents per neonatal unit) completed the questionnaire compared with 136 parents in the previous report. The demographics of the respondents were similar to the previous report. Over three quarters of respondents were between 21 & 35 years old, 15% were between 36 & 45 and only 3% were less than 21 years old. Almost 80% of respondents were mothers, 9% fathers and 11% both parents. The majority of the respondents described themselves as White British (90%). The majority of respondents stated English (84%) is their first language, 14% did not respond. 1 respondent each stated Hungarian and Kurdish. No Asian languages were reported, this is dissimilar to the previous report where 5 respondents identified an Asian language as their first language.

As in the previous report the majority of responses in this report were positive, either agreeing or strongly agreeing to the statements in the survey. Below is a synopsis of the highest negative responses from parents, either disagreeing or strongly disagreeing with the statements. For details of the responses to all the statements please see the full report available on the network's website shortly.

www.newbornnetworks.org.uk/staffs/

ACCESS & FACILITIES:
82% of respondents stated their baby was born at the hospital where the pregnancy was booked. 17% of the respondents’ babies were not; 50% of these (8) were inappropriately transferred out and delivered in a hospital outside of the SSBCNN due to a lack of neonatal capacity at the time of delivery. The remaining 50% (8) were appropriate transfers to a hospital to receive specialist neonatal assessment & care.
11% of respondents (11) identified their baby had been moved to another hospital as part of their care. Nearly 75% appear to be appropriate transfers: 5 were back transfers closer to home, 2 for surgery and 1 was transferred to a nearby special care unit for step down care to create space in the level 3 unit. Only 1 appears to have been moved inappropriately due to a lack of neonatal cots.

Over half (56%) of parents’ travel time was less than 30 minutes. 36% travelled between ½ - 1 Hour, only 4 parents travelled 1-2 hours (3 at Shrewsbury and 1 at Russells Hall) and 2 parent in Shrewsbury travelled over 2 hours.

I was happy with the visiting arrangements on the NNU
Over 90% of parents agreed or strongly agreed they were happy with the visiting arrangements on the NNU, however 7% of parents disagreed or strongly disagreed with this, this is higher than the previous report (less than 1%). The comments received suggest a need to ensure a consistent visiting policy across the network which is communicated to the parents early on in their baby’s stay on the NNU and which is flexible in who the nominated visitors are. E.g. “An explanation for any exceptions to the rules would help prevent the moaners escalating it as an issue”. “Happy with visiting for parents but not for grandparents and would have liked close family i.e. sister to be able to visit”. “My husband was at work so I would have liked a family member with me”. “I couldn't bring my brother or sister-in-law, or brother-in-law to see my son”.

My baby's visitors and I were always asked to wash our hands
This statement received the highest number of negative responses (11) outside of the facilities questions. The majority of parents (82%) agreed or strongly agreed that their baby’s visitors and themselves were always asked to wash our hands, however 11% of parents disagreed or strongly disagreed with this. Comments indicated that there were washing facilities provided close to the entrance to the neonatal units and parents often washed their hands without being told to do so.

As in the previous report the facilities question received the highest number of negative responses with 25% (24) identifying car parking, 15% identifying play area and 11% identifying secure storage as poor or very poor.

COMMUNICATION
When staff discussed my baby with me, or each other, they did so in private so that other people could not over hear
The majority of parents (82%) agreed or strongly agreed that when staff discussed their baby with them, or each other, they did so in private so that other people could not overhear and commented on confidentiality. However 10% of parents disagreed or strongly disagreed with this; comments included; I had to ask for discussion to be in private”. “Some staff would discuss so others could hear”. This is comparable to the previous report.

I was encouraged to ask questions about my baby's care
The majority of parents agreed or strongly agreed that they were encouraged to ask questions about their babies care, however 5% disagreed, this is higher than the previous report (2%). Comments indicate that some parents felt able to ask even though they weren’t invited to e.g. “I wanted to know all about my baby, so didn’t need encouraging to ask questions”. Whilst other parents did not feel invited to ask and felt isolated e.g. “If we didn’t ask on arrival, felt left alone, in the end needed to ask for a private discussion”. “If you never asked you didn’t know”. “Nurses sometimes didn’t want to answer”.

The written information that I received about my baby's care was clear and easy to understand
Over 80% of parents agreed or strongly agreed that the written information they received about their baby’s care was clear and easy to understand, however this is 10% less than the previous report and 4% of parent disagreed with this, again this is higher than the previous report (1%).

The written information that I received, about my baby's care was helpful
Over 80% of parents agreed or strongly agreed that the written information they received about their baby’s care was helpful, again this is 10% lower than the previous report and this time 3% did not find the information useful compared to none in the previous report.
PARENTAL SUPPORT
Parent Support Group
Over 60% of parents felt there was a need for a parent support group in the area especially for first time parents e.g. “Mainly for first time mums/dads.” Almost 90% of those said they would use it if a group was available. Comments indicate parents feel there is value in peer support from other parents e.g. “People who have already been through the NICU can give advice and give new people hope! As you always look at the bad side of things, other people can reassure you.”

PARENTS SUGGESTIONS FOR IMPROVEMENTS TO THE NEONATAL UNIT
Several parents identified a need for more resources such as breast pumps, screens, better drinks and rooming in facilities and somewhere for siblings to play. More support for parents was identified including a suggestion for a parent liaison post to support them whilst they were on the neonatal unit. A few parents suggested that visiting hours for grandparents should be longer and more staff are required.

CONCLUSION
Despite the low response rate this survey adds valuable feedback from parents on the newborn services within the network. Overall the survey has revealed a high level of parental satisfaction in the newborn services with the majority of parents responding positively to the statements in all six neonatal units. The low response rate may be attributable to a number of causes including:
• The questionnaire itself;
  ➢ Only available in English. The majority of respondents described themselves as White British with English as their first language this probably does not reflect the ethnicity of the population served across the network.
  ➢ The length of the questionnaire being 4 pages long may put off parents from completing it.
• The process does not include a mechanism to chase up non responders.
There was a high degree of similarity in responses with the previous report however access & facilities and communication had a number of questions which received a higher proportion of negative responses in this report. There were two statements which received proportionately less negative responses in this report compared to the previous one. “All the staff that cared for my baby introduced themselves to me” 4% versus 8% and “The nurses always had sufficient time to provide good care for my baby” 6% versus 9%.

FURTHER ACTIONS
The network Research, Development and Audit group is reviewing the questionnaire in order to address the above issues in future editions of the survey. The continuous survey has been stopped since 1 October whilst the questionnaire is revised with an aim to restart with a shorter version in January 2010. Units are to be asked if the full report can identify the neonatal units rather than units being anonymous.

Although the responses are generally very good there are still a number of areas that can be improved in order to address areas of concern identified by some of the parents. Each unit is recommended to read the full report and reflect on the comments made in order to identify and prioritise appropriate actions to improve their unit for parents and their babies. In particular;
Communication:
“Staff discussed my baby with me in private” received the second highest number of negative responses from parents (9).
Parents perceive little or no written information is given out on the neonatal units.
Over 60% of parents felt there was a need for a parent support group whilst on the NNU, however none currently exist in the network
Access & Facilities:
Consistency and flexibility in visiting policy needs looking at across the network
Car parking costs for parents need reviewing with Trusts across the network
A higher number of parents than previously did not perceive they or their visitors were asked to wash their hands, although the majority said they did it any way.