## Supplementary File 5: Bliss parents’ perspective questionnaire

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| **Question** | **Select one of the following answers** |
| How many weeks through pregnancy was your baby born? | * Less than 28 weeks * 28 to 32 weeks * 33 to 37 weeks * Over 37 weeks |
| Was he/she diagnosed with respiratory distress syndrome (RDS)? | * Yes * No * I don’t know |
| While on the neonatal unit (NICU) what breathing support did your baby need? | * Breathing tube and ventilator * Breathing support – mask over their mouth or tubes in their nose |
| During my baby’s time in the hospital, I felt involved in my baby’s medical care | * Strongly agree * Agree * Neither agree nor disagree * Disagree * Strongly disagree |
| If a medical procedure needed to happen with my baby and it wasn’t urgent, the nurses and doctors spoke to me about it first | * Strongly agree * Agree * Neither agree nor disagree * Disagree * Strongly disagree |
| I would have liked to have been more involved in the medical decision-making process of caring for my baby | * Strongly agree * Agree * Neither agree nor disagree * Disagree * Strongly disagree |
| What would influence how involved you were with your baby’s medical care? Please rank the following in order of importance/relevance from 1 to 4 (1 being the most important/relevant) | * Level of information I had access to * Amount of time I had to consider the situation * Doctors’/nurses’ authority in making decisions * Opportunity to discuss the options |
| I trusted the doctors on the NICU to make decisions about the medication choices that were best for my baby | * Strongly agree * Agree * Neither agree nor disagree * Disagree * Strongly disagree |
| How involved would you have liked to be in the decision-making process around medication choices whilst your baby was on the NICU? | * Fully involved, with my input influencing the final decision * Fully informed, but final decision made by medical team * Informed (a complete overview of the options) * Not involved at all |
| I would have liked the doctors and nurses to discuss medication options with me | * Strongly agree * Agree * Neither agree nor disagree * Disagree * Strongly disagree |
| I would have liked to know about the side-effects and/or risks of medications when being involved in decisions about using them | * Strongly agree * Agree * Neither agree nor disagree * Disagree * Strongly disagree |
| I would rather not use any medication if using it made my baby more comfortable but meant a short but potentially uncomfortable procedure was less likely to be successful | * Strongly agree * Agree * Neither agree nor disagree * Disagree * Strongly disagree |
| Please consider a medical procedure that was short but potentially uncomfortable for your baby, including the options to use pain relieving medications that have potential side effects. What do you feel is the most important factor to consider in this situation? Please rank the following in order of importance/relevance from 1 to 4 (1 being the most important/relevant) | * Making my baby comfortable, while accepting risk of side effects * The possible side-effects of the medication * The success of the procedure * Making the procedure more easy to perform |