

DATA COLLECTION AND RESEARCH

– improving care for babies needing intensive care

The future health and wellbeing of babies treated in intensive care requires an understanding of the relationship between what we do in intensive care and how your baby develops later. We do this by collecting as much information as possible about your baby's stay in hospital and link it with information that we gather about your baby's growth and development later. A long-term follow-up programme is provided for many infants who are cared for in our intensive care and it is the information from these babies that we link with the information obtained when they were in intensive care. When we assess your baby in our follow-up clinic we measure your baby's skills in a range of areas of development – which we describe as “outcomes”.

The Centre for Newborn Care is one of ten NICU's in the ACT and NSW and one of 27 across Australia and New Zealand. Two important systems of co-operation and learning have been put in place to ensure the highest possible standards of care for babies requiring intensive care. These are called the NSW and ACT Neonatal Intensive Care Units Data Collection (NICUS) and the Australian New Zealand Neonatal Network. These systems collect data about babies who:

- Require assistance with breathing (mechanical ventilation or continuous positive airway pressure)
- Weigh less than or equal to 1500 grams at birth
- Are born more than 8 weeks premature i.e. at less than or equal to 32 weeks gestation
- Require a major operation

The information gathered is designed to provide as complete a picture as possible of your pregnancy and your infant's treatment and progress in the NICU. The database held in The Centre for Newborn Care contains information about your baby's problems and treatment. You will receive a discharge summary about your baby's treatment when you leave. This will have been produced by the database and contains accurate information that can be communicated to your family doctor and paediatrician. The database also links with our follow-up clinic and allows us to assess your baby's growth and development in relation to their treatment when in hospital. This database also provides information to the NICUS database detailed above. The information sent is completely anonymous and not linked to any other database. This prevents you or your baby from being identified in any reports or audits. This system helps us to measure our performance as a Neonatal Intensive Care Unit with other units in NSW and Australia. This is an important part of maintaining our standards of care.

For such systems to be accurate and reliable it is vital that every eligible baby in ACT and NSW is included. Information will automatically be collected unless you direct us that you do not wish this to occur. If you have any questions at all please contact any of the following people at any time:

- Lyn Barnes (Clinical Audit Officer – The Canberra Hospital)
Phone: (02) 6244 3129 Fax: (02) 6244 3112
Unit secretary: (02) 6244 4056
lyn.barnes@act.gov.au
- Barbara Bajuk (NICUS Co-ordinator)
Phone: (02) 9351 7750 Fax: (02) 9351 7742
Barbara.Bajuk@perinatal.usyd.edu.au
- Associate Professor Zsuzsoka Kecskes (Clinical Director)
Phone: (02) 6244 4056
Zsuzsoka.kecsek@act.gov.au

You may also be asked to involve your baby in one of the research projects that is currently being carried out in the unit. Research is integral to improve the treatments and outcomes for infants requiring intensive care. We greatly appreciate the generosity of parents who agree to involve their child in research, but understand that you may not consider this possible at the time you are approached. If you decline to be involved in a research study your child's care will not be affected in any way.

If you have any further questions please ask the medical and nursing staff.

Approved by Canberra Hospital Neonatal Intensive Care Unit, 2012
Revision Date 2015