

Perinatal care at the borderlines of viability: a consensus statement based on a NSW and ACT consensus workshop

Kei Lui, Barbara Bajuk, Kirsty Foster, Arnolda Gaston, Alison Kent, John Sinn, Kaye Spence, Wendy Fischer and David Henderson-Smart

Perinatal care of the extremely low gestation and extremely low birthweight infant has improved. Although the boundary of viability has been challenged and has shifted over the past two decades,¹⁻⁴ there is substantial risk of long-term neurodevelopmental disabilities in very premature babies who survive.⁵⁻⁹ A number of international guidelines on managing premature babies at the threshold of viability, formulated predominantly by physician expert panels, have been published. These guidelines acknowledge that, within boundaries set by birthweight and gestational age, there is a discretionary zone (a “grey zone”) in which attitudes of parents and clinicians play an important role (Box 1).¹⁰⁻¹⁴

The debate on management of neonates at the threshold of viability is an emotive and complex issue that involves families, clinicians and other health care professionals.¹⁵⁻¹⁹ In view of this, and in contrast with previously published guidelines prepared by expert panels, it was considered desirable to conduct a consensus workshop to bring together the views of multiple stakeholders, including consumers. The workshop, with participants from New South Wales and the Australian Capital Territory, had two aims:

- To produce consensus statements to support clinicians and parents in dealing with the challenging scenarios encountered at the borderlines of viability; and
- To agree on accurate, meaningful and consistent information across NSW and the ACT for clinicians, parents and prospective parents of extremely premature infants.

The limits of viability have until recently been addressed in terms of gestational age or birthweight in relation to mortality and long-term outcome. The concept of a gestational “grey zone” was acknowledged by workshop participants as clinically more practical and relevant to perinatal care, as varying biological and clinical situations can render “cut-off” limits impractical and conflict-provoking.

Process

In planning the workshop, the organising group was cognisant of adult learning principles.²⁰ All participants would be actively involved and have experience of the dilemma in practice. It was crucial to achieve meaningful consensus by involving as many well informed stakeholders as possible, with a spread of urban and rural professionals as well as parents. Each of the 10 tertiary neonatal intensive care units in NSW and the ACT were invited to send professional delegates from five disciplinary groups (feto-maternal obstetrics, midwifery, neonatology, neonatal nursing, and developmental teams/other allied health professionals). Representation was also invited from parental groups, professional associations, medical and nursing colleges, and rural or regional clinical practices.

The workshop was held in February 2005 over one and a half days. The program included presentation of outcome data for very premature births along with ethical, parental and medicolegal viewpoints to stimulate discussion and to identify a preliminary grey zone.

ABSTRACT

- Perinatal care at the borderlines of viability demands a delicate balance between parents’ wishes and autonomy, biological feasibility, clinicians’ responsibilities and expectations, and the prospects of an acceptable long-term outcome — coupled with a tolerable margin of uncertainty.
- A multi-professional workshop with consumer involvement was held in February 2005 to agree on management of this issue in New South Wales and the Australian Capital Territory. Participants discussed and formulated consensus statements after an extensive consultation process.
- Consensus was reached that the “grey zone” is between 23 weeks’ and 25 weeks and 6 days’ gestation. While there is an increasing obligation to treat with increasing length of gestation, it is acceptable medical practice not to initiate intensive care during this period if parents so wish, after appropriate counselling.
- Poor condition at birth and the presence of serious congenital anomalies have an important influence on any decision not to initiate intensive care within the grey zone.
- Women at high risk of imminent delivery within the grey zone should receive appropriate and skilled counselling with the most relevant up-to-date outcome information. Management plans can thus be made before birth. Information should be simple, factual and consistent.
- The consensus statements developed will provide a framework to assist parents and clinicians in communication, decision making and managing these challenging situations.

MJA 2006; 185: 495-500

For editorial comment, see page 477

Collection and analysis of NSW and ACT outcome data

It was agreed that the most relevant and up-to-date NSW and ACT survival and outcome data should form the basis for consensus discussions. The analysis included 897 births of premature infants between 22 weeks’ gestation (22⁰) and 25 weeks and 6 days’ gestation (25⁶) to NSW and ACT resident mothers between 1 January 1998 and 31 December 2000.

Follow-up assessments of the surviving children were performed at 2–3 years of age, corrected for prematurity. Most children were assessed at a tertiary centre, but about 10% who lived too far from a major hospital were assessed by their paediatrician or general practitioner. Assessments consisted of a neurological examination and a standardised psychological assessment (the Griffiths Mental Development Scales²¹ and the Bayley Scales of Infant Development, second edition²²).

Categories of functional disability²³ were defined as:

1. None/minimal: developmental quotient above 1 SD below the mean;

CONSENSUS STATEMENT

1 Summary of published guidelines on managing premature infants at the threshold of viability (ie, in the “grey zone”)

| Country | Year | Authors | Grey zone |
|-----------------------------|------|--|--|
| International ¹⁰ | 1993 | World Health Organization; International Federation of Gynecology and Obstetrics | 22–28 weeks or 500–1000 g birthweight as “threshold viability” |
| Canada ¹¹ | 1994 | Fetus and Newborn Committee, Canadian Paediatric Society; Maternal–Fetal Medicine Committee, Society of Obstetricians and Gynaecologists of Canada | 23–25 weeks |
| UK ¹² | 2000 | British Association of Perinatal Medicine | < 26 weeks as “threshold viability” |
| USA ^{13,14} | 2002 | American Academy of Pediatrics; American College of Obstetricians and Gynecologists | 22–25 weeks |

2. Mild: developmental delay (developmental quotient between 1 SD and 2 SD below the mean), or mild cerebral palsy;
3. Moderate: developmental delay (developmental quotient between 2 SD and 3 SD below the mean), moderate cerebral palsy (able to walk with the assistance of aids), or sensorineural or conductive deafness requiring amplification with bilateral hearing aids or unilateral/bilateral cochlear implant;
4. Severe: developmental delay (developmental quotient more than 3 SD below the mean), bilateral blindness with visual acuity < 6/60 in the better eye, or severe cerebral palsy (unable to walk with the assistance of aids).

Identifying key issues for the consensus statements

Two interactive large-group sessions — panel discussion and discussion of hypothetical case scenarios — were held to identify key issues pertinent to care around the borderlines of viability. Both sessions were facilitated by an external facilitator.

Panel discussion teased out the most important issues from the clinical scenarios, forming the basis of questions for the subsequent small-group work in developing consensus proposals.

Hypothetical case scenarios (compiled by the workshop organizing committee) highlighted common practical issues and forced participants to confront the way in which decisions have to be made in the clinical area. An electronic multigrade response system (hand-held Digivote [Bramshaw ICS Conference Communications, Melbourne, Australia]) was used by participants to help compile responses. The tracking of each participant's discipline was based on the delegate's first answer in identifying his or her discipline or group.

Development of consensus proposals

After the large-group discussions, delegates were split into multi-professional groups of 10, each of which was allocated a question or issue developed during the panel session and asked to formulate a response suitable for inclusion in a consensus document. Each group's consensus statement was presented to the main group for refinement and approval, with the Digivote device used to record each participant's response on a five-point Likert scale: 1, strongly agree; 2, agree; 3, disagree; 4, strongly disagree; or 5, unable/don't wish to comment.

Post-workshop refinement of consensus statements, and consultation with other groups

Consensus was considered to be unequivocally reached if the combined “agree” and “strongly agree” votes were over 90%, while

agreement of 75% was a minimum criterion for consensus, given that statements varied in their degree of gravity.

The proposed consensus statements were grouped according to similarity of themes and content. Statements with higher voting scores formed the principal statement and incorporated any similar statements. The report was circulated for consultation within the committees of the Pregnancy and Newborn Services Network, along with various consumer and professional groups (see Acknowledgements). It was also reviewed by the NSW Health Clinical Ethics Advisory Panel. The process was completed in November 2005.

Outcomes

Participants

The workshop was attended by 112 delegates. Participants, according to discipline, were as follows: obstetricians, 10 (9%); midwives, 19 (17%); neonatologists, 28 (25%); neonatal nurses, 29 (26%); allied health professionals or members of a developmental team, 11 (10%); perinatal care administrators (non-clinical), 8 (7%); and parent and community advocates, 7 (6%). Consumers who attended the workshop were offered, and accepted, the opportunity to debrief with a skilled social worker after the workshop.

NSW and ACT outcome data

Statistics on births at 22⁰ to 25⁶ weeks' gestation in NSW and the ACT are shown in Box 2. Infants born between these gestational ages who were not admitted to a neonatal intensive care unit (NICU) did not survive. With increasing gestational age, an increasing number of infants were born alive and admitted to an NICU.

Of 342 infants admitted to an NICU, 183 survived to hospital discharge. One infant died at 5 months of age, leaving 182 infants available for follow-up, of which 166 (91%) were assessed at 2–3 years (the remainder being lost to follow-up). The average birthweight for children assessed was 750 grams, compared with 713 grams for those lost to follow-up. The average gestational age at birth for both groups was 24.5 weeks.

With increasing gestational age, the proportion of infants diagnosed with mild, moderate or severe functional disability decreased. A comparison was made to a control group of 460 singleton term infants without a major congenital anomaly assessed at 3 years of age using the same assessment methods.²⁴ Extremely premature infants were more likely than term infants to have a mild (13% v 2%), moderate (10% v 1%) or severe (16% v 0.5%) functional disability.

CONSENSUS STATEMENT

| | Gestational age at birth (weeks) | | | | Total |
|---|----------------------------------|-----------|-----------|-----------|-----------|
| | 22 | 23 | 24 | 25 | |
| Total births in NSW and the ACT at gestational ages of 22–25 weeks | 215 | 203 | 233 | 246 | 897 |
| Live births (% of total births) | 77 (36%) | 89 (44%) | 139 (60%) | 176 (72%) | 481 (54%) |
| NICU admissions (% of live births) | 3 (4%) | 48 (54%) | 133 (96%) | 158 (90%) | 342 (71%) |
| Survival to hospital discharge (% of NICU admissions) | 0 | 14 (29%) | 66 (50%) | 103 (65%) | 183 (54%) |
| Median age at death, in days (range) | 1 (0–4) | 3 (0–134) | 4 (0–163) | 3 (0–54) | 3 (0–163) |
| Infants with ROP requiring laser surgery (% discharged) | na | 9 (64%) | 18 (27%) | 16 (15%) | 43 (23%) |
| Infants with IVH Grade III or IV or parenchymal cysts at 6 weeks (% discharged) | na | 1 (7%) | 9 (14%) | 11 (11%) | 21 (11%) |
| Infants requiring home oxygen (% discharged) | na | 8 (57%) | 19 (29%) | 32 (31%) | 59 (32%) |
| Infants assessed at 2–3 years (% discharged) | na | 12 (92%) | 58 (88%) | 96 (93%) | 166 (91%) |
| No apparent functional disability (% assessed) | na | 4 (33%) | 33 (61%) | 64 (67%) | 104 (63%) |
| Mild functional disability (% assessed) | na | 2 (17%) | 6 (10%) | 14 (15%) | 22 (13%) |
| Moderate functional disability (% assessed) | na | 2 (17%) | 8 (14%) | 6 (6%) | 16 (10%) |
| Severe functional disability (% assessed) | na | 4 (33%) | 11 (19%) | 12 (13%) | 27 (16%) |

IVH = intraventricular haemorrhage. na = not applicable. NICU = neonatal intensive care unit. ROP = retinopathy of prematurity.

* Births at between 22 weeks' and 25 weeks and 6 days' gestation. ◆

Workshop consensus statements

From 10 questions debated by 12 groups, a total of 40 draft statements were proposed, refined and voted on. Acceptance of over 90% was achieved for 26 proposed statements, with 17 receiving acceptance of over 90% across all discipline groups.

Final consensus statements derived from the workshop are shown in Box 3, Box 4 and Box 5. It was established early (voting results not shown) that factors including planned pregnancy, assisted conception, maternal age, maternal illness, antenatal complications and fetal conditions or compromise carried significant weight in the decision-making process. It was acknowledged that unexpected births outside tertiary perinatal centres are even more complex than births in major centres. The local team's skills, time factors and transport logistical issues have a pivotal impact on the likelihood of a favourable outcome.

Defining the grey zone and implications for clinical practice

The case scenarios developed the most common presentations of premature labour in an *otherwise uncomplicated pregnancy*. Gestation was assumed to be known with *reasonable accuracy*.

Non-initiation of treatment if requested by parents

Participants were asked the highest gestational age at which they would agree, if requested by parents, not to initiate resuscitation: 100% would agree at 23^{0–6} weeks; 72% at 25^{0–6} weeks; and 36% at 26^{0–6} weeks. The break-even point appears to be between 25⁰ and 26⁶ weeks' gestation, below which there was a majority trend towards agreeing not to resuscitate (Box 6).

Non-initiation of treatment if no parental influence

An alternative scenario attempted to remove the influence of parental request (by hypothesising a situation prior to meeting the parents). Over 90% of participants said they would not wish to initiate resuscitation at 23^{0–6} weeks. This fell to 40% at 24⁵ weeks,

and only 20% said they would not wish to offer active treatment at 25^{0–6} weeks (Box 7).

Influence of certain factors on life-support decision making within the grey zone

Participants were asked to rank the influence of certain factors on making a decision about whether to resuscitate an infant born with a known gestation of 23⁴ weeks. Parental wishes and condition at birth were ranked as the most important issues (Box 3). Other factors included birthweight and absence of congenital abnormality. The availability of resources was ranked the least important factor. Neonatal events that would influence the offering of withdrawal of intensive care included Grade III and Grade IV brain haemorrhage (ie, major intraventricular and/or parenchymal haemorrhage) (ranked highest), ventilator dependence at 36 weeks, and the presence of necrotising enterocolitis requiring surgery.

Antenatal communication

The incidence of prematurity is currently 6.7% in NSW and the ACT.²⁵ The risk of birth within the gestational grey zone defined in the workshop is 1 in 100, which is higher than the risk for Down syndrome, about which mothers are more likely to receive counselling. The workshop participants overwhelmingly endorsed an effort for general education in the community regarding premature births (Box 4).

Managing the grey zone in clinical practice

The agreed grey zone was identified as between 23⁰ and 25⁶ weeks. The fact that gestational age assessment is not always accurate may confound management decisions. When other serious fetal conditions exist, the management principles recommended here could apply beyond this gestational range. Counselling on the options of active resuscitation and treatment within the grey zone should take into account the infant's condition at birth, serious anomalies and other relevant factors. It is *not* appropriate to discuss health care resource implications during

3 Consensus statement: gestational “grey zone”

- Notwithstanding the complexity of maternal, obstetric and other clinical factors, the grey zone identified using hypothetical cases appears to be between 23⁰ and 25⁶
- Parental wishes and on-site assessments such as condition at birth, place of birth (eg, non-tertiary hospital) and presence of anomalies would influence the decision whether to offer resuscitation and intensive care.
- Withdrawal of intensive care from infants born within the grey zone is influenced primarily by the occurrence of neurological complications, in comparison with illnesses for which prognoses are less clear. ◆

4 Consensus statement: all pregnancies

- Women in the low-risk population should routinely be given information between 18 and 22 weeks’ gestation about the possibility of preterm delivery.
- This information should principally include signs and symptoms of preterm labour, with limited information provided on potential outcomes of preterm birth based on relevant state-wide data.
- Women who are more likely to experience preterm birth (eg, those with multiple pregnancies or assisted conception) should be provided with more specific information and an opportunity to discuss the likelihood and implications of preterm birth. ◆

counselling. Institutions should develop decision-support management policies and procedures that are culturally sensitive and appropriate for the family and local community (Box 5).

Discussion

The perinatal care of women and their babies at the borderlines of viability is a complex issue that deserves much ethical debate and consideration.²⁴⁻²⁹ The risk of infant death or survival with long-term sequelae increases acutely with each weekly (and even daily) reduction in gestational age at birth.⁷⁻⁹ In contrast to guidelines developed by expert panels,¹⁰⁻¹⁴ our consensus workshop was conducted as an interactive forum involving well informed members of multidisciplinary perinatal care teams as well as community representatives and parent advocates.

In our workshop, the debate focused on perinatal scenarios and was based on the best antenatal estimation of gestational age rather

than birthweight. While it is accepted that female premature infants generally have better outcomes, this factor was not included in discussions, as sex is not usually known before birth. Poor condition at birth correlates with early mortality and morbidity.^{30,31} Given the uncertainties surrounding very premature births, workshop participants stressed the importance of appropriate counselling in clinical practice and developing management plans before birth.

We took the approach of establishing a grey zone of borderline viability. The grey zones defined in previous guidelines (ranging from 22 to 28 weeks) are summarised in Box 1. Common to all guidelines, parental involvement was emphasised. Each suggested the use of institutional or local outcome data to establish more precise management guidelines within the grey zone. There are inherent pitfalls in generalisation using non-local NICU outcome data, as unique local factors may influence survival and long-term outcome. For example, a US study showed that non-white infants were more likely to survive

5 Consensus statement: clinical approach within the “grey zone”

Within the gestational age range 23⁰ to 25⁶ weeks, when gestation is known with reasonable certainty, parents’ involvement in the decision-making process during prebirth counselling or subsequent management is mandatory.

Offer of active resuscitation and treatment at varying gestational ages

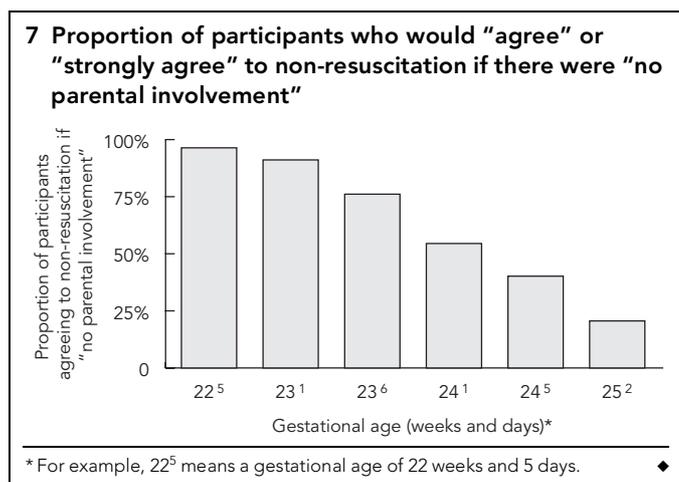
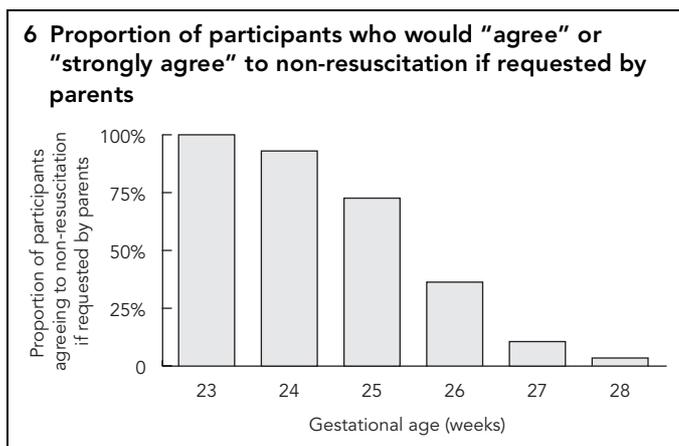
- In an otherwise normal infant born before 23 weeks, the prospect of survival is minimal and the risk of major morbidity is so high that initiation of resuscitation is not appropriate. Maternal transfer to a tertiary centre for fetal reasons may not be justified.
- At 23 weeks, active treatment may be discussed, but would be discouraged in NSW/ACT neonatal intensive care units.
- In an otherwise normal infant born between 23⁰ and 25⁶ weeks’ gestation, there is an increasing obligation to treat. However, it is acceptable medical practice not to initiate intensive care if parents so wish, following appropriate counselling.
- At 24⁰⁻⁶ weeks, antenatal transfer to a tertiary centre for fetal reasons is indicated. The option of non-initiation of intensive care/resuscitation should be offered.
- At 25⁰⁻⁶ weeks, active treatment is usually offered, but the option of non-initiation of intensive care/resuscitation — particularly in the presence of adverse fetal factors such as twin-to-twin transfusion, intrauterine growth restriction or chorioamnionitis — should also be discussed.
- In an otherwise normal infant born at 26 weeks and above, the obligation to treat is very high, and treatment should generally be initiated unless there are exceptional circumstances.

Where the family has opted for non-intervention at 23–25 weeks’ gestation

- All hospitals should have guidelines for communication with parents in situations in which the family has opted for non-intervention.
- Counselling should be done by, or at least in consultation with, senior clinical staff.
- If the birth occurs in a non-tertiary centre, access to senior staff in a tertiary centre for consultation should be available and should take place prior to delivery.
- Clinical staff should be well versed in preparing parents for palliative care of their infant. This may include information for parents regarding the likely appearance of the infant, and the likelihood that the baby may breathe and gasp after birth.
- Appropriate support for the grieving process should be made available and coordinated, including appropriate infant dressing, cuddles by parents, preparation of mementos and discussion of post-death arrangements.

Where the family has opted for active intervention

- If, at 23⁰ to 25⁶ weeks’ gestation, treatment is initiated, meetings with families should be held at appropriate intervals during the first week, or after any major complications, to discuss whether ongoing intensive care is appropriate.
- Clinical staff should be aware of the possibility of parents’ decision uncertainty at the time of a live birth and the need to individualise a management plan to deal with changes of decision. ◆



than white infants, although they did not have a better developmental outcome.⁷ Furthermore, NICU collaborative networks that receive data contributions from multiple geographically distant centres show differences in outcome between centres.³²

Our consensus workshop used regional outcome data that included all births, live births, NICU admissions, survivors and follow-up assessments. Participants' responses to the case scenarios clearly showed a gradual increase in the acceptance of active intervention with increase in gestational age. Results supported the approach of defining a grey zone rather than a specific cut-off limit. Nonetheless, it was established that the vast majority (> 90%) of workshop participants would not wish to initiate active treatment before 24 weeks, and 100% would agree with parents if non-intervention was requested at this stage.

The hypothetical scenario of "no parental influence" explored the clinician's own perception of or inclination for intervention. In reality, this scenario does not exist. Nevertheless, clinicians may encounter situations in which there has been limited opportunity for discussion, counselling or preparation of parents.

A complicating factor in the debate about management of extremely premature infants is that clinicians, nurses and parents tend to have differing views about the advisability of active intervention and the health-related quality of life of surviving children. Studies surveying parents of very premature infants and surviving teenage children who had themselves been extremely low birthweight infants (less than 1000 g) have shown that

consumers (parents and teenagers) are more likely than health professionals to believe that treatment was worthwhile.³³⁻³⁷ Australian surveys³⁸⁻⁴¹ indicate that neonatologists, neonatal nurses and obstetricians tend to underestimate survival and overestimate likely disabilities. Of the three, neonatologists' estimates of outcomes are closest to the true picture.

Another issue is the degree to which outcomes are influenced by clinicians' attitudes. It has been shown in a population-based comparison of two perinatal management strategies that proactive management is associated with better survival of infants born in the grey zone gestational age range.⁴² The workshop participants considered ongoing audit of outcomes and regular updates of information as essential.

The principle of non-directive counselling (and the difficulty of achieving it) was discussed during the workshop. In a recent survey regarding counselling of parents within the grey zone, substantial differences were noted between clinicians' and parents' perceptions.⁴³ Although clinicians aimed to conduct counselling sessions in a non-directive way and believed they had done so, most parents perceived the experience as directive counselling.

Workshop participants agreed that consistent, transparent information should be shared between parents and members of the perinatal team. Information on survival and long-term outcomes of very premature infants was best provided in a written form available to parents. One outcome of the workshop was to update and revise — with substantial consumer input — the NSW and ACT parent information booklet for extremely premature births.⁴⁴ The objective of the booklet is to provide simple and factual information written in appropriate language for parents. It is envisaged that these efforts will be of great benefit to the counselling process.

Participants also discussed whether all pregnant women should be given information about the risks associated with very premature birth. The incidence of premature birth at the borderlines of viability (1 in 100) is higher than that of aneuploidy. While it appears logical to provide consumer information on premature birth, its presumed benefits need to be evaluated. In contrast to aneuploidy, for which early detection and intervention are possible, there is no effective prevention or treatment for extremely premature birth. Participants suggested that all pregnant women should be given some idea of premature birth rates and information about symptoms of premature labour and other antenatal complications. Early medical attention may then be sought if these symptoms occur.

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Competing interests

None identified.

Author details

Kei Lui, MB BS, MD, FRACP, Director,¹ Senior Lecturer²
 Barbara Bajuk, MPH, NICUS Coordinator³
 Kirsty Foster, MB ChB, DRCOG, MEd, Postgraduate Medical Educator⁴
 Arnolda Gaston, MPH, Epidemiologist³
 Alison Kent, BM BS, FRACP, Neonatologist⁵
 John Sinn, MB BS, FRACP, MMed(Epi), Neonatologist⁶
 Kaye Spence, RN, BEd(N), MN, FCN, Clinical Nurse Consultant⁷
 Wendy Fischer, BA(Hons), RN, CM, Policy and Research Officer³
 David Henderson-Smart, MB BS, PhD, FRACP, Director³

- 1 Department of Newborn Care, Royal Hospital for Women, Sydney, NSW.
- 2 School of Women's and Children's Health, University of NSW, Sydney, NSW.
- 3 NSW Pregnancy and Newborn Services Network, Sydney, NSW.
- 4 RPA Women's and Babies, Royal Prince Alfred Hospital, Sydney, NSW.
- 5 Centre for Newborn Care, Canberra Hospital, Canberra, ACT.
- 6 Department of Neonatology, Westmead Hospital, Sydney, NSW.
- 7 Department of Neonatology, The Children's Hospital at Westmead, Sydney, NSW.

Correspondence: kei.lui@sesiahs.health.nsw.gov.au

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