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## NEWBORN BLOODSPOT SCREENING POLICY (PD2016\_015)

## PD2016\_015 rescinds PD2006\_099.

#### PURPOSE

This Policy Directive provides direction to maternity services in NSW regarding the requirements of the Newborn Bloodspot Screening Program. This includes the following information: parents / guardians must be provided with information about conditions that are screened for by the Newborn Bloodspot Screening Program; the consent and documentation that must be obtained and recorded; and the requirements in relation to the privacy, storage and security of the information collected.

#### MANDATORY REQUIREMENTS

All parents / guardians must be provided with the consumer brochure *Newborn Bloodspot Screening* in the last four to six weeks of pregnancy.

All parents / guardians must be told about:

- What information is collected
- Storage of the blood sample
- The potential uses of the information collected
- The potential future uses of the blood sample
- The privacy and protection processes.

All parents / guardians must be provided an opportunity to ask questions about the Newborn Bloodspot Screening program.

All parents / guardians must sign the written consent component of the newborn screening card prior to the blood sample being collected.

All parents / guardians must be offered Newborn Bloodspot Screening for their baby within 48–72 hours of the baby's birth.

A newborn bloodspot screening card must be sent to the Newborn Bloodspot Screening laboratory for every baby born in NSW, even in the event that the parents/guardians have refused the screening test.

#### **IMPLEMENTATION**

The Chief Executives of NSW Local Health Districts are ultimately responsible for the implementation of this Policy Directive within their services / facilities.

## 1 BACKGROUND

#### 1.1 Introduction

Newborn bloodspot screening (NBS) detects babies at risk of serious disorders including phenylketonuria, primary congenital hypothyroidism, cystic fibrosis, galactosaemia and rare metabolic disorders of amino acids, organic acids and fatty acid oxidation defects. Early diagnosis and treatment by medication or diet can prevent death or serious complications and can lead to significantly improved outcomes. Among the 100,000 babies born each year in NSW and ACT, over 100 babies are diagnosed with one of these conditions.

A checklist (<u>Appendix 1</u>) has been developed for health professionals to ensure that parents have been provided the information at the most appropriate time about the:

- Screening tests and benefits
- Storage and potential uses of bloodspots
- Consent processes
- Legally enforceable privacy safeguards.

## 1.2 Key definitions

Must - Indicates a mandatory action requiring compliance.

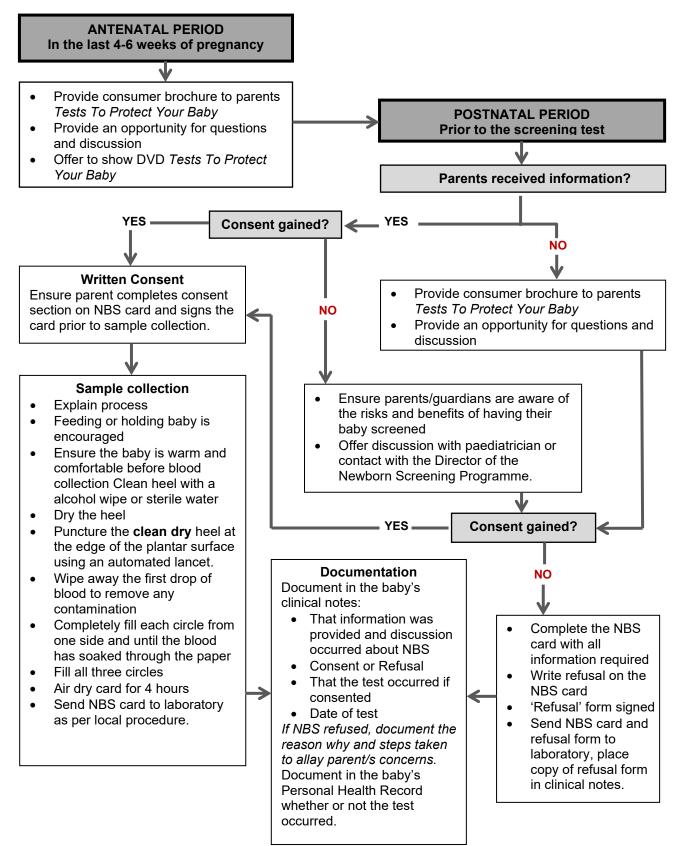
**Should** - Indicates a recommended action that should be followed unless there are sound reasons for taking a different course of action.

#### 1.3 Abbreviations

CF	Cystic Fibrosis
DNA	Deoxyribonucleic acid
LHD	Local Health District
MCAD	Medium chain acyl coenzyme A dehydrogenase
MOU	Memorandum of Understanding
NBS	Newborn Bloodspot Screening
РНО	Public Health Organisation
РКИ	Phenylketonuria
PPM	Privately practising midwife

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#### FLOWCHART: NEWBORN BLOODSPOT SCREENING PROCESS



## 2 INFORMATION FOR PARENTS / GUARDIANS

All information as outlined below must be provided to parents / guardians prior to the blood sample being collected.

- Parents / guardians:
  - Must be given a copy of the consumer brochure <u>Newborn Bloodspot Screening</u> in an appropriate language where possible
  - Should be offered the opportunity to watch the <u>NSW & ACT Newborn Screening Tests</u> <u>Education Video For Parents</u>
  - Must be told:
    - What information is collected <u>Section 8.1</u>
    - Storage of the blood sample <u>Section 8.2</u>
    - The potential uses of the health information collected Section 8.3
    - Potential future use of the blood sample Section 8.4
    - The privacy and protection processes <u>Section 8.2</u>
  - Must be provided with the opportunity to ask questions (discussion and questions may occur either in a group situation such as antenatal classes and / or on a one to one basis). An interpreter must be present for this discussion if required.

**NOTE:** The consumer brochure must not be distributed without discussion.

#### **3** BLOODSPOT SCREENING

Newborn bloodspot screening is highly recommended for all babies. Among the 100,000 babies born each year in NSW and ACT, over 100 babies are diagnosed with one of the conditions tested for. Early diagnosis and immediate treatment by medication or diet can prevent death or serious complications including intellectual disability, and lead to significantly improved outcomes.

Therefore:

- Newborn bloodspot screening must be offered to all babies.
- Parents / guardians should be informed about newborn bloodspot screening during the last four to six weeks of their pregnancy to allow sufficient time for consideration, clarification and informed decision-making
- Prior to the blood sample being collected, the person taking the sample must:
  - Check that parents / guardians have received a copy of the consumer brochure <u>Newborn</u> <u>Bloodspot Screening</u>
  - That they have had opportunity for discussion and clarification
  - That they consent to the screening test
  - Cross check patient identification.

## **4 CONDITIONS SCREENED**

The Newborn Bloodspot Screening program screens for approximately 25 medical conditions. Only a small number of babies will be diagnosed with one of the medical conditions of which the following are the more common conditions detected.

ons screened for					
Incidence	Caused by	If left untreated	Treatment		
1 in 2,600 live births (about 40 babies per year).	Absence or abnormal formation or function of the thyroid gland.	Causes growth and intellectual disability if not treated.	Medication with thyroid hormone started early results in normal growth and development.		
1 in 3,700 live births (about 30 babies per year).	A dysfunctional gene results in thick mucus in different organs throughout the body in particular the lungs and gastrointestinal tract.	Without treatment severe chest infections occur and often very serious failure to thrive leading to early death.	Early commencement of treatment greatly improves the health of individuals with CF.		
will also detect some	<b>NOTE:</b> Newborn bloodspot screening detects about 95% of babies with CF. Screening will also detect some babies who may only be healthy carriers. For these babies a sweat test at about six weeks of age determines whether the baby has CF or is a healthy carrier.				
1 in 10,000 live births (about 10 babies per year).	Inability of the body to break down the essential amino acid phenylalanine.	High blood levels of phenylalanine cause severe intellectual disability if left untreated.	A carefully managed diet low in phenylalanine, started in the first two to three weeks prevents this damage.		
1 in 15,000 births (about 6-8 babies a year).	Inability of the body to completely break down fat.	May be life- threatening or cause severe disability during times of common childhood illnesses.	Extra precautions are taken to ensure adequate energy intake during illnesses.		
1 in 40,000 births (about 1-3 babies per year).	Inability of the body to process galactose, a component of lactose found in milk and other foods.	Life-threatening liver failure and infections can occur.	A galactose-free diet commenced before 2 weeks of age is lifesaving.		
Rarer disorders that in total affect approximately 20 babies a year.	Some disorders of the metabolism of amino acids, urea cycle, organic acids and fatty acid oxidation can be	Without appropriate management they can have severe disability or death.	Early detection is important as diet and medications can treat most of these disorders.		
	Incidence1 in 2,600 live births (about 40 babies per year).1 in 3,700 live births (about 30 babies per year).NOTE: Newborn blow will also detect some test at about six week 1 in 10,000 live births (about 10 babies per year).1 in 15,000 births (about 6-8 babies a year).1 in 40,000 births (about 1-3 babies per year).1 in 40,000 births (about 1-3 babies per year).Rarer disorders that in total affect approximately 20	IncidenceCaused by1 in 2,600 live births (about 40 babies per year).Absence or abnormal formation or function of the thyroid gland.1 in 3,700 live births (about 30 babies per year).A dysfunctional gene results in thick mucus in different organs throughout the body in particular the lungs and gastrointestinal tract.NOTE: Newborn blootspot screening detect will also detect some babies per year).Inability of the body to break down the essential amino acid phenylalanine.1 in 10,000 live births (about 10 babies per year).Inability of the body to break down the essential amino acid phenylalanine.1 in 15,000 births (about 6-8 babies a year).Inability of the body to completely break down fat.1 in 40,000 births (about 1-3 babies per year).Inability of the body to process galactose, a component of lactose found in milk and other foods.Rarer disorders that in total affect approximately 20 babies a year.Some disorders of the metabolism of amino acids, urea cycle, organic acids and fatty acid	IncidenceCaused byIf left untreated1 in 2,600 live births (about 40 babies per year).Absence or abnormal formation or function of the thyroid gland.Causes growth and intellectual disability if not treated.1 in 3,700 live births (about 30 babies per year).A dysfunctional gene results in thick mucus in different organs throughout the body in particular the lody in particular the lungs and gastrointestinal tract.Without treatment severe chest infections occur and often very serious failure to thrive leading to early death.NOTE: Newborn bloodspot screening detects about 10 babies per year).Inability of the body to break down the essential amino acid phenylalanine.High blood levels of phenylalanine cause severe intellectual disability if left untreated.1 in 15,000 births (about 6-8 babies a year).Inability of the body to completely break down fat.May be life- threatening or cause severe disability during times of common childhood illnesses.1 in 40,000 births (about 1-3 babies per year).Inability of the body to process galactose, a component of lactose found in milk and other foods.Life-threatening infections can occur.Rarer disorders that in total affect abproximately 20 babies a year.Some disorders of the metabolism of amino acids, urea cycle, organic acids and fatty acidWithout appropriate and fatty acid		

http://www.schn.health.nsw.gov.au/health-professionals/statewide-laboratory-services/nsw-newborn-

## 5 OBTAINING AND RECORDING OF CONSENT OR REFUSAL

## 5.1 Consent

Offering the screening test and obtaining consent should comply with PD2005\_406 <u>Consent to</u> <u>Medical Treatment – Patient Information</u>. As the baby is a patient under the age of 14 the consent of a parent or guardian is necessary.

The following are the levels of consent required by NSW Health for the Newborn Bloodspot Screen.

Table 3: Consent			
Procedure	Level of consent and documentation		
Obtaining newborn blood sample for screening	Verbal consent required and to be documented in the baby's clinical notes.		
	Written consent by parent / guardian is documented on the NBS card at the time of taking the sample.		
Storage of the sample for longer than 2 years	Written consent by parent / guardian is documented on the NBS card at the time of taking the sample.		
Use of the sample for de-identified research	Parent / guardian indicates yes / no on NBS card at the time of taking the sample.		
	NOTE: Cards without consent for de-identified research will not be used for de-identified research.		
Use of the sample for identified research	Written consent from either the parent or the child (dependent on the age of the child at the time of the research) will be required prior to the research being commenced.		

#### 5.2 Processes for obtaining consent to newborn bloodspot screening

In newborn bloodspot screening, valid consent requires provision of full information about the test including information about what happens to the bloodspot sample after testing as outlined in Section 7. Any NSW Public Health Organisation (PHO) caring for babies must ensure the following:

- Both sections on the newborn bloodspot screening card *Consent for the collection and testing of sample* and *Storage >2 years* must be completed by the parent/guardian
- The newborn bloodspot screening card must be signed by the parent /guardian
- Documentation in the baby's clinical record includes the following:
  - That discussion about the newborn bloodspot screening test has occurred
  - That the parent / guardian has consented
  - That the newborn screening test has occurred. Use of a pre-inked stamp similar to the example below is recommended.
- Documentation in the baby's Personal Health Record (PHR) "Blue Book" whether or not the newborn bloodspot screen occurred.

Baby's name:	
Signature (Health	Professional)
Provision of the NBS pamphlet:	Date:
Discussion of NBS information:	Date:
Verbal/written consent:	Date:
Completion of sample collection:	Date:
	2(5(10)5(10))

## 5.3 Refusals

Parents / guardians may refuse the newborn bloodspot screening test on behalf of the baby. In this circumstance, it is suggested that parents/guardians:

- Are provided an opportunity to discuss their concerns with a paediatrician or specified health professional who is aware of all the implications of not screening
- Are offered the option of telephoning the Director of the Newborn Screening Programme to answer any further questions they may have Telephone (02) 9845 3659
- Are advised to notify their health care worker, in the event of the child requiring medical attention, that the child has not been screened.

Clinicians should undertake the following:

- Document the reason for refusal in the baby's medical record
- Complete a newborn bloodspot screening sample card, with all information completed on both sides, and write "refusal" on the card
- Send the card and the completed refusal form to the laboratory
- Retain a copy of the refusal form in the baby's clinical notes.

**NOTE:** <u>PD2005\_406 Consent to Medical Treatment – Patient Information</u> provides guidance concerning refusals and care and protection of minors based on the Children and Young Persons (Care and Protection) Act 19981.

**NOTE:** A refusal form is available for use by hospitals in the NSW Newborn Screening Programme Sampling Information and Guidelines (see <u>Section 9</u>).

## 6 COLLECTING THE BLOODSPOT SAMPLE

- The process for collecting the bloodspot must be explained to parents
- A blood sample is obtained by heel prick ideally when the baby is 48 to 72 hours old
- The blood sample is placed on a special pre-printed filter paper card
  - Do not use the card if damaged
  - Do not touch the sample area.
- The heel is the preferred site to obtain the sample. In the event that a sample cannot be obtained at the heel and a venepuncture is being undertaken for other tests, this blood can be used for Newborn Bloodspot Screening. In this case clinicians should ensure that the blood obtained is not mixed with other solutions or taken from a tube containing preservative prior to placing the sample on the card. Any blood sample obtained should be placed directly onto the card before being used for other testing purposes
- Mothers / parents / guardians are encouraged to be present and hold the baby during the procedure
- To relieve discomfort for the baby, breast-feeding is encouraged or alternatively comfort measures should be provided
- Should an adverse reaction or injury occur when obtaining the blood sample, a notification should be made through the NSW Health Incident Information Management System (IIMS).

<sup>1</sup> NSW Children and Young Persons (Care and Protection) Act, 1998

Table	Table 4: Sample collection			
Step	Action			
1	Ensure the baby is warm and comfortable before blood collection			
2	Puncture the clean $\underline{dry}$ heel at the edge of the plantar surface using an automated disposable lancet (Point < 2mm)			
3	Wipe away first drop of blood			
4	Completely fill each circle from one side and until the blood has soaked through the paper Do NOT layer blood			
5	Allow spots to dry before mailing (4 hours)			
6	Return completed card without delay			
	To: NSW Newborn Screening Programme			
	Locked Bag 2012, WENTWORTHVILLE NSW 2145			

## 6.1 Discharge prior to 48 hours of age

Arrangements must be made for the blood sample to be collected between 48 and 72 hours for all babies discharged prior to 48 hours of age.

The bloodspot sample should only be collected prior to 48 hours of age if:

- The baby is being discharged prior to 48 hours of age, and
- Availability for sample collection post discharge is compromised.

## 7 **RESULTS**

The receipt of each baby's bloodspot card is confirmed with the hospital of birth. Results are usually available within two working days after receipt of the sample. In most cases the results are normal and no further notification is made. Hospitals are only advised of individual results when retesting is necessary.

#### 7.1 Repeat blood test

A few babies will need to have a second blood test usually because the first test did not give a clear result or the sample was unsuitable for testing. The reason for retesting should be explained to parents / guardians and most second tests will give normal results.

Routine repeat tests are required for babies with special circumstances such as those with very low birth weight and those who have received blood products as specified in the <u>NSW and ACT Newborn</u> <u>Screening Programme: Sampling Information and Guideline</u> (section 10).

#### 7.2 Abnormal results

The paediatrician / doctor / privately practising midwife (PPM) identified on the newborn bloodspot screening card is notified of test results which are abnormal, the disorder being considered and any appropriate further samples required. It is the responsibility of this person to ensure that the baby is promptly referred for further investigation and treatment. The name of the person responsible must be filled in on the test card. Where there is uncertainty regarding whose name is to be written, it is recommended that the name be that of the paediatrician of the day.

#### NSW NEWBORN SCREENING PROGRAMME NSW NEWBORN SCREENING PROGRAMME ion and Testing of Sample understood the information in the NSW N Mother's information Full name No f Baby's information itorage of screening card for greater than 2 years consent to the storage of the screening card for lo last na Yes [ ] Last name: / / Date of birth: / / Birth weight: \_\_\_\_\_\_ Gender: M F Not determined Time of birth: Gestation: \_\_\_\_\_\_\_ Test < 24 hours of age: \_\_\_\_\_\_ Darante cignatura Date of sample: 1 1 Time of sample Feeds: Breastmilk Formula Soy based TPN Other: (Circle all that apply) Collect from ALL newborns between 48 and 72 hours Place of birth: (E.g. home or name of 1 A from ALL free before blood collection. Puncture clean dry heel with a disposable lancet Wipe away first drop of blood. Do NOT layer blood. Only fill spot from one side Allow spots to dry plotfore mailing (4 hours). Return complete deard without delay. Sample collected at: (E.g. home or name of home oital) liatrician/doctor/midwife in charge: Relevant clinical information: Baby's medical record number: [] Repeat test: [ Do not touch sample area. Do not use card if damaged. COMPLETELY FILL EACH CIRCLE - BLOOD MUST SOAK RIGHT THROUGH PAPER COMPLETE ALL DETAILS ON BOTH SIDES OF CARD If available apply Baby's hospital label on top of dotted b Ensure that all of the CONSENT remains visible.

## 8 NEWBORN BLOODSPOT SCREENING CARD

Newborn bloodspot screening cards are provided by the NSW Newborn Screening Programme, and used in accordance with the NSW Newborn Screening Programme Sampling Information and Guidelines. Contact details are provided in <u>Section 9</u>.

## 8.1 Information collection and process

The newborn bloodspot screening card collects written information and three bloodspots.

ALL INFORMATION must be completed on the card as each field has been included for a specific purpose.

Once the heel prick process has occurred the newborn bloodspot screening card is sent to the laboratory at the NSW Newborn Screening Programme at The Children's Hospital at Westmead. The laboratory:

- Transfers the written information to an electronic record
- Tests the blood
- Retains the card containing the unused portion of the three bloodspots for a minimum of two years.

NOTE: All results are recorded in the electronic record, not on the card.

#### 8.2 Privacy, storage, security and retention periods

#### 8.2.1 Privacy, storage and security

The NSW Newborn Screening Programme as a NSW Health facility, is the custodian of the bloodspot cards and records. Both the electronic record and the bloodspot card are subject to the privacy protection requirements of NSW privacy legislation2<sup>·3·4</sup>. The bloodspot cards are stored in a secured locked area with appropriate safeguards to prevent unauthorised use, disclosure, loss or other misuse.

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<sup>2</sup> NSW Health Privacy Manual for Health Information as at March 2015: <a href="http://www.health.nsw.gov.au/policies/manuals/Documents/privacy-manual-for-health-information.pdf">http://www.health.nsw.gov.au/policies/manuals/Documents/privacy-manual-for-health-information.pdf</a>

<sup>3</sup> Privacy and Personal Information Protection Act, 1998

<sup>4</sup> Health Records and Information Privacy Act, 2002

## 8.2.2 Retention of cards and data

Cards

- In accordance with National Pathology Accreditation Advisory Council requirements the laboratory must retain the cards for a minimum of 2 years for quality assurance and audit purposes
- In general the cards are retained for 18 years (age a child can legally consent for themselves)
- After this time the cards are destroyed.

Data

• In accordance with National Pathology Accreditation Advisory Council requirements the data is stored for 100 years.

## 8.2.3 Deoxyribonucleic acid (DNA) testing and data

Newborn bloodspot screening involves biochemical testing. Approximately 1% of the samples show an increased risk for cystic fibrosis and MCAD deficiency (a fatty acid oxidation disorder) from the biochemical testing. As part of routine testing these samples are then retested for the most common mutations in the DNA associated with each disorder. No DNA tests are done on any other samples and no other DNA records are held.

## 8.3 **Potential uses of bloodspots**

Stored bloodspots have a number of potential uses (<u>Table 5</u>). Any further use must be in compliance with privacy law, NSW Human Tissue Act5 and the NSW Human Tissue Legislation Amendment Act 20126. Potential benefits from stored bloodspots include obtaining clinical information for the child and/or the family. Whilst requests for use for this purpose are rare, the information potentially available to families is extremely valuable. Bloodspots may also be used for research to improve newborn screening techniques or develop new tests. Individual consent will be sought before research on any identified sample. However, de-identified samples may be used for ethics committee approved research with the approval of the NSW Newborn Screening Advisory Committee.

Table 5: Potential uses of bloodspot samples			
Consent given on the card covers the following:	<b>SEPARATE</b> consent other than on the card is required for the following:		
Directly related clinical purposes	Clinical use for the individual and family		
<ul> <li>Retesting to confirm result</li> <li>Provide information to a person or organisation providing ongoing care to the baby.</li> </ul>	<ul> <li>Further testing at the request of the parents or guardians that may provide medical information for the benefit of the child or family e.g. was an infection present at birth such as cytomegalovirus</li> <li>Diagnostic information for future reproductive decisions.</li> </ul>		
<ul> <li><i>Research using non-identifiable</i> <i>bloodspot samples</i></li> <li>Samples may be released only with approval by the appropriate health research ethics committee and the NSW Newborn Screening Advisory Committee</li> </ul>	<ul> <li><i>Research using identified bloodspot samples</i></li> <li>Research requires approval from the parent/guardian, the appropriate health research ethics committee and the NSW Newborn Screening Advisory Committee.</li> </ul>		

## 8.3.1 Table 5: Potential uses of bloodspot samples

<sup>5</sup> NSW Human Tissue Act, 1983

<sup>6</sup> NSW Human Tissue Amendment Act, 2012

Table 5: Potential uses of bloodspot samples			
Consent given on the card covers the following:	SEPARATE consent other than on the card is required for the following:		
Laboratory quality control	Third party access		
	• Access to stored samples or information by employers, insurers, police, legal representatives, other relatives or medical practitioners requires written consent of the parent/guardian (or child if of age of consent) or by court order.		
Patient access	Coronial purposes		
• Parents/guardians on behalf of the child or the patient at adulthood have the right to access personal information held about them	• A memorandum of understanding (MOU) between NSW Health and NSW police 2002 <sup>14</sup> sets out parameters and processes for requests for access to newborn bloodspot screening cards.		
	Access for law enforcement purposes and access and disclosure authorised by law		
	• It is possible that access to samples and disclosure of information may be required by court order.		

## 8.4 Transfer of cards to parents / guardians

The laboratory must retain the bloodspot cards for a minimum of 2 years for quality assurance and audit purposes in accordance with National Pathology Accreditation Advisory Council requirements. Any requests from parents/guardians for the destruction or transfer of the screening cards must be made in writing and must be supported with identification.

**NOTE:** Destruction or transfer of a screening card can only occur after the 2 year retention period is complete.

NOTE: For further information on sample storage and laboratory practice, please see:

http://www.schn.health.nsw.gov.au/health-professionals/statewide-laboratory-services/nsw-newborn-screening-programme

## 9 SAMPLING INFORMATION AND GUIDELINES

The NSW and ACT Newborn Screening Programme provide a guideline: *Sampling Information and Guidelines* which details procedures for:

- Storage of blank NBS cards
- Refusal of screening tests
- Collection of the blood sample for NBS
- Drying and storage of NBS cards prior to sending to laboratory
- Hospital
- o Community
- Sending of NBS cards to laboratory
- When to take the sample if the baby needs a blood transfusion
- Low birth weight babies
- Stillbirths and neonatal deaths.

These are updated as required to incorporate new information and procedures and are supplied to hospitals / maternity units and privately practising midwives.

## The Guideline is available either online at

http://www.schn.health.nsw.gov.au/files/attachments/newborn\_screening\_guidlines\_2015.pdf or from: The NSW Newborn Screening Programme

Locked Bag 2012, WENTWORTHVILLE NSW 2145

Telephone: (02) 9845 3255 / 3659, Facsimile: (02) 9845 3800, Email: newborns@chw.edu.au

## 10 QUALITY ASSURANCE AND MONITORING

#### 10.1 Role of the hospital/Local Health District (LHD)

The hospital of birth is responsible for ensuring all babies are offered the newborn screening test and arranging for any repeat samples, including those babies who have been transferred to another hospital and require a repeat sample.

Hospitals with maternity units and those who care for babies must nominate a liaison person (e.g. community liaison midwife or midwifery unit manager) to be responsible for newborn bloodspot screening. The name and position of the nominated (and relief person) should be notified in writing to *The NSW Newborn Screening Programme* (see Section 9). Responsibilities of the nominated newborn screening liaison person are detailed in <u>The NSW and ACT Newborn Screening Programme Sampling Information and Guidelines</u> and include the following:

- Ensuring that all parents / guardians are provided information on newborn bloodspot
- Ensuring that all babies have newborn bloodspot screening cards sent to the laboratory irrespective of whether the sample has been collected (<u>Section 5.3</u>)
- Ensuring that when a repeat or extra sample is requested by the laboratory that it happens in a timely manner
- Ensuring that staff are kept up to date with changes to the NSW Newborn Screening Programme Sampling Information and Guidelines.

Reports from the NSW Newborn Screening Programme are regularly provided to hospitals regarding screening samples and quality issues related to screening activities. LHDs are encouraged to ensure these reports are monitored locally to identify trends in relation to quality and compliance with this policy. Timely action must be taken when issues are identified that may adversely affect the efficacy of the screening test.

The Implementation Checklist for LHDs in relation to Newborn Bloodspot Screening is at Section 15

#### 11 CONSUMER INFORMATION

#### Newborn Bloodspot Screening Consumer Brochure

A printable version of the consumer brochure *Newborn Bloodspot Screening* is provided at Attachment 1.<u>For information on ordering hard copies of the consumer brochure (English only) please visit http://www.kidsfamilies.health.nsw.gov.au/publications/</u>

The consumer brochure can also be downloaded from the Office of Kids and Families website http://www.kidsfamilies.health.nsw.gov.au/publications/tests-to-protect-your-baby-newbornbloodspot-screening/

The consumer brochure is also available for download in Arabic, Traditional Chinese, Indonesian, Japanese, Khmer, Korean, Serbian, Turkish and Vietnamese, Thai, Bengali, Nepali, Tamil and Hindi at <u>http://www.kidsfamilies.health.nsw.gov.au/publications/tests-to-protect-your-baby-newborn-bloodspot-screening/</u>

#### NSW & ACT Newborn Screening Tests Education Video for Parents

Available to view online at <u>http://www.schn.health.nsw.gov.au/health-professionals/statewide-laboratory-services/nsw-newborn-screening-programme</u>

## 12 APPENDIX 1: CHECKLIST FOR HEALTH PROFESSIONALS

Table 3 Ch	ecklist for health professionals			
During pregnancy	Provide the consumer brochure <u>Newborn Bloodspot Screening</u> to parents preferably in the last four to six weeks of pregnancy. Provide an opportunity for discussion and guestions and offer to show the DVD <u>NSW</u> &			
	Provide an opportunity for discussion and questions and offer to show the DVD <u>NSW &amp;</u> <u>ACT Newborn Screening Tests Education Video for Parents</u> .			
After birth	Make sure that parents / guardians have been provided the consumer brochure <u>Tests to</u> <u>protect your baby</u> . Make sure that parents/guardians have been provided with an opportunity for discussion and questions.			
Inform parents/ guardians	<ol> <li>Conditions tested – phenylketonuria, galactosaemia, hypothyroidism, cystic fibrosis and rare metabolic disorders.</li> <li>Benefits of testing - diagnosis and treatment can prevent death or serious</li> </ol>			
about:	<ul> <li>disability.</li> <li>3. Collection of blood sample – encourage mothers to be present and breastfeed or offer alternative comfort measures.</li> </ul>			
	<ol> <li>Information collected – name, date of birth, hospital, etc.</li> <li>Bloodspot storage - minimum of 2 years and in general are stored for up to 18 years – written consent on the back of the card.</li> </ol>			
	6. Bloodspots and record security – governed by privacy and human tissue legislation and Health Department policy.			
	7. Potential uses of, access to, and storage of bloodspot cards:			
	• Identified cards may be used for family benefit or research and only with separate consent obtained before testing			
	<ul> <li>Non-identifiable cards, i.e. with identifiers permanently removed may be used for research approved by a health research ethics committee and with the approval of the NSW Newborn Screening Advisory Committee – consent on the back of the card</li> </ul>			
	• Parents have a right to access their child's information. Other access requires parental consent except where there is a court order.			
	8. Inform the parents about how results are conveyed			
	Normal results			
	• Retesting			
	Abnormal results.			
After all the above	1. Record in the mother's / baby's medical record that information has been provided and discussed.			
informatio	2. Obtain and document parent / guardian consent in the baby's clinical record.			
n has been provided and	3. Hospital staff are required to complete the relevant section of the baby's Personal Health Record (Blue Book).			
discussed:	4. If parents refuse testing, see Section 5.3 of this Policy for further guidance			
	<ol> <li>Conduct the test following sampling guidelines provided by the NSW Newborn Screening Programme.</li> </ol>			
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## **13** APPENDIX 2: RELEVANT DOCUMENTS

Туре	Published by	Publication
Policy	NSW Health	PD2005 406 Consent to Medical Treatment – Patient Information
Directive		
Policy	NSW Health	NSW Health Privacy Manual for Health Information as at March
Directive		2015:
		http://www.health.nsw.gov.au/policies/manuals/Documents/privacy-
		manual-for-health-information.pdf
Informatio	NSW Health	General Retention and Disposal Authority – Public Health Services:
n Bulletin		Patient/ Client
		Records (GDA 17), NSW Department of Health Information Bulletin
		No 2004/20,
		http://www.health.nsw.gov.au/archive/cib/information-
D 11		bulletins/2004/ib2004-20.pdf
Policy	NSW Health	Health Care Records - Documentation and Management
Directive		http://www0.health.nsw.gov.au/policies/pd/2012/pdf/PD2012_069.pdf
Legislation	NSW Act	Human Tissue ACT 1983
Legislation	NSW Act	Health Records and Information Privacy Act, 2002
Legislation	NSW Act	NSW State Records Act, 1998
Legislation	NSW Act	Privacy and Personal Information Protection Act, 1998
Legislation	NSW Act	NSW Children and Young Persons (Care and Protection) Act, 1998
Resource	Office of Kids and	Consumer brochure: Newborn Bloodspot Screening
110000100	Families	
Resource	Sydney Children's	Consumer video: NSW & ACT Newborn Screening Tests Education
	Hospital Network	Video for Parents
Other	National	National Statement on Ethical Conduct in Research Involving
Guidelines	Health and Medical	Humans, 2007
	Research Council	http://www.nhmrc.gov.au/guidelines/publications/e72
Other	Australian	National Pathology Accreditation Advisory Council, Retention of
Guidelines	Government,	laboratory records and diagnostic material.
	Department of	
	Health	

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## 14 IMPLEMENTATION CHECKLIST

LHD/Facility:			
Assessed by:		Date of Assessment:	
IMPLEMENTATION REQUIREMENTS	Not commenced	Partial compliance	Full compliance
1. Ensure all clinical staff working in maternity			
services are updated on the changes to the policy	Notes:		
2. Ensure all women are provided with the			
Consumer Brochure Newborn Bloodspot Screening	Notes:		
3. Ensure that written consent is provided by a			
parent/guardian prior to collection of the blood sample	Notes:		
4. Ensure that the name and position of the			
hospital-nominated newborn screening liaison person is notified in writing to the NSW Newborn Screening Programme	Notes:		
5. Ensure that Executive oversight for newborn			
screening activites occurs at facility level to ensure regular monitoring of the NSW Newborn Screening Programme reports	Notes:		

## **15** ATTACHMENT 1: CONSUMER BROCHURE

Consumer Brochure – Newborn Bloodspot Screening. Available on <u>health.nsw.gov.au/policies/PD2016\_015.pdf</u> is a printable version of the Consumer Brochure

## **BREASTFEEDING IN NSW: PROMOTION PROTECTION AND SUPPORT** (PD2018\_034)

## PD2018\_034 rescinds PD2011\_042.

## PURPOSE

The policy supports NSW Health's commitment to best practice in the promotion, protection and support of breastfeeding; to increase the initiation and duration rates of breastfeeding and to ensure the Health workforce have the knowledge and skills to implement this policy.

## MANDATORY REQUIREMENTS

NSW Health organisations must implement the strategies, appropriate to their organisation, identified in Section 4, The Practice Guide.

NSW Health organisations are required to comply with responsibilities under the WHO International Code of Marketing of Breastmilk Substitutes and the Marketing in Australia of Infant Formula: Manufacturers and Importers Agreement (MAIF).

NSW Health organisations must ensure midwives, child and family health and paediatric nurses complete the HETI eLearning module Breastfeeding Promotion, Protection and Support (course code 45338916) at commencement of employment and every 5 years.

The module is highly recommended, based on location and role, for Registered Nurses (RN) (Community Health), RN Mental Health and other RNs, Enrolled Nurses and Aboriginal and Torres Strait Islander Health Workers in contact with breastfeeding mothers.

## **IMPLEMENTATION**

The Chief Executives or delegated officers of all NSW Health organisations must ensure the following actions are undertaken to implement the revised Policy Directive:

- All staff are made aware of the revised Policy Directive.
- Key personnel are made aware of their responsibilities in the revised Policy Directive.
- Designated lead is identified to develop local policies/guidelines/procedures to support the implementation of the revised Policy Directive.

## **Breastfeeding in NSW: Promotion Protection and Support Procedures**

## 1 BACKGROUND

## 1.1 Introduction

NSW Health recognises and supports the importance of creating and providing environments in its services and facilities, where breastfeeding is promoted, protected and supported by all staff.

This Policy Directive, Breastfeeding in NSW – Promotion, Protection and Support (policy) supports and encourages breastfeeding as the optimal way for a woman to feed her infant. The policy also recognises that all women and their families have the right to clear, impartial and evidence based information to enable them to make an informed choice as to how they feed and care for their infants.

The policy is designed to contribute to the following goals:

- increase the number of infants exclusively fed with breast milk on discharge from the birth admission
- increase the number of infants exclusively fed with breast milk to around six months of age
- increase the number of infants continued to be fed with breast milk, to 12 months and beyond, after the introduction of family foods at around six months of age.

## 1.2 Key definitions

Health workforce	Refers to medical officers, nurses, midwives, Aboriginal health workers, allied health workers caring for pregnant and breastfeeding women, their families and infants
Maternity continuum	Refers to the antenatal, intrapartum and postnatal periods
NSW Health organisations	Refers to districts, networks, services, pillars, facilities, hospitals, community based health services
Women and their families	Refers to pregnant women, mothers, fathers, partners, family and is inclusive of the LGBTIQ community

See glossary for further definitions.

## **2 THE EVIDENCE**

Breastfeeding is important for optimal infant nutrition, growth and healthy development, protection against infection and chronic disease, and benefits the mother's health. Breastfeeding provides short-term and long-term health, economic and environmental advantages to children, women, families and society.

The provision of evidence based quality care is integral to promoting, protecting and supporting breastfeeding in all NSW Health facilities and services. A literature review was conducted to inform the revision of the policy. For evidence from the recent literature review see Attachment 2.

## **3 THE POLICY CONTEXT**

This policy has been reviewed within the context of the following state, national and international policies, frameworks, and services. The most relevant are listed below with a more extensive list at Attachment 3.

#### **NSW State Health Plan Towards 2021**

This plan provides the strategic framework for NSW Health and sets priorities across the system for the delivery of 'the right care, in the right place, at the right time' for everyone. Direction One: Keeping People Healthy supports a healthy start to life through breastfeeding, good nutrition and a healthy weight gain in pregnancy. This direction is also in line with one of the 12 Premier's priorities, reduce overweight and obesity rates of children by 5% over 10 years.

## Healthy, Safe and Well a Strategic Health Plan for Children, Young People and Families 2014-2024 NSW Kids and Families

Healthy, Safe and Well is a 10-year strategic health plan focusing on preconception to 24 years of age. This plan's agenda is to renew efforts to promote health, prevent illness, embed early intervention and deliver integrated, connected care for all NSW children and families no matter where they live. The promotion of breastfeeding, in accordance with World Health Organisation (WHO) Standards and the Baby Friendly Health Initiative (BFHI), is a strategy under the plan.

## NSW Healthy Eating Active Living Strategy

This strategy provides a whole of government framework to promote and support healthy eating and active living in NSW and to reduce the impact of lifestyle-related chronic disease. This strategy aims to ensure that everyone has opportunities to be healthy through the delivery of evidence-based, interactive and relevant programs. One of the strategy's actions is to promote the initiation and duration of breastfeeding as a way to provide good infant nutrition and reduce the risk of overweight and obesity in childhood, adolescence and early adulthood.

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#### Australian National Breastfeeding Strategy

The Australian Government and jurisdictions are developing an enduring national breastfeeding strategy to replace the 2010-2015 strategy. This strategy encourages all public and private health

facilities/services to implement the BFHI steps to successful breastfeeding and to work towards or maintain BFHI accreditation. This policy will be reviewed, if required, once the national strategy has been released.

## Australian Dietary Guidelines

The early nutrition and growth of infants has an important effect on early morbidity and mortality. There is increasing evidence of the medium and long-term effects of nutrition on health. Infant growth is now recognised as one of the influences on health and longevity of life and breastfeeding is the foundation of early nutrition. NSW Health supports the use of the <u>National Health and Medical Research Council</u> <u>Australian Dietary Guidelines (2013)</u> and the <u>Infant Feeding Guidelines (2012)</u>.

## WHO 2006 growth charts

In 2012, all Australian states and territories agreed to adopt the WHO 2006 growth charts as the standard for Australian children aged 0–2 years. The WHO 2006 charts reflect growth patterns among children who are predominantly breastfed for at least 4 months and are still breastfeeding at 12 months.

## **Baby Friendly Health Initiative**

The role of the BFHI is to protect, promote and support breastfeeding by providing frameworks for:

- maternity services Ten Steps to Successful Breastfeeding (Attachment 4)
- community facilities 7 Point Plan (Attachment 5)
- neonatal services The Neo-BFHI: The Baby-friendly Hospital Initiative (Attachment 6).

These three frameworks promote the importance of all women and families receiving appropriate support and consistent up-to-date information about infant feeding. While breastfeeding is promoted, every woman and family is supported to care for their infant in the best and safest way possible regardless of feeding choices and circumstances.

## 4 THE PRACTICE GUIDE

There has been significant work by health professionals and service managers to promote, protect and support breastfeeding in NSW. While Australia has a high rate of breastfeeding initiation, in NSW there is considerable scope to increase the rates of initiation, full breastfeeding on discharge from birth admission and breastfeeding duration.

Breastfeeding initiation and duration are influenced by many factors. For this reason a multifaceted approach targeting change at an organisation, service delivery, community and individual level is recommended.

Implementing the following strategies will assist NSW Health organisations to increase the rates of initiation and duration of breastfeeding:

- i. Support infants being fed with breast milk
- ii. Provide additional support to Aboriginal women, their partners, families and communities
- iii. Provide additional support to women, their partners and families at risk of lower rates of breastfeeding initiation and duration
- iv. Strengthen continuity of care, referral pathways and support networks
- v. Support health professionals' education and professional development
- vi. Provide breastfeeding friendly environments
- vii. Ensure monitoring and surveillance
- viii. Support Australia's response to the Marketing in Australia of Infant Formulas: Manufacturers and Importers Agreement 1992.

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## i. Support infants being fed with breast milk

## **Best Practice**

NSW Health organisations providing maternity, neonatal and community child and family health services use the relevant BFHI frameworks to improve breastfeeding practices.

All women and their families receive consistent, evidence based information, education and support during the maternity continuum and early childhood periods regarding infant feeding.

NSW Health staff inform women and their families of accessible breastfeeding information, support and advice from evidence based sources such as the <u>Australian Breastfeeding Association</u>, <u>Pregnancy</u> <u>Birth and Baby Helpline</u>, or the <u>Raising Children Network</u>.

NSW Health organisations ensure all breastfed infants in their care receive breast milk from their birth mother except where there is access to a milk bank approved by the Chief Executive. Local arrangements should be made for special circumstances, including but not limited to, adoption, same sex couples, foster carers and surrogacy.

NSW Health organisations ensure that infants are not separated from their mothers for any length of time, unless clinically indicated, to support bonding and successful breastfeeding.

NSW Health organisations support women to continue breastfeeding when they or their infant are admitted, or present to, inpatient, emergency, outpatients or paediatric services.

Breastfeeding should be encouraged, welcomed and supported in all NSW Health organisations. It is important that there is a designated space with appropriate signage and facilities available for staff or visitors who need to breastfeed.

NSW Health organisations, caring for women and their families, implement/maintain or link with a breastfeeding reference group to facilitate policy implementation to protect, promote and support breastfeeding.

NSW Health organisations implement and evaluate evidence-based interventions that promote and support breastfeeding.

Health professionals should support women and their families to recognise the importance of breastfeeding for the health and wellbeing of their infants. NSW Health professionals are to fully support women and their families in their choice of infant feeding.

Evidence demonstrates that compliance with BFHI has a positive impact on short-term, medium-term and long-term breastfeeding outcomes. Education and support from professionals and/or peers, which is both timely and person-centred, is crucial to improving breastfeeding practices. Health professionals play a key role in providing education and support spanning the maternity continuum and early childhood periods.

Evidence also suggests that effective social support, peer support and influence from fathers/partners/families combined with reassurance and guidance from skilled practitioners can help women to overcome difficulties and find confidence in their own abilities to achieve their feeding goals.

Any breastfeeding promotion efforts and support should aim to enhance a mother's self-efficacy and confidence with respect to breastfeeding.

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#### ii. Provide additional support to Aboriginal women, their partners, families and communities

#### **Best Practice**

NSW Health organisations work in partnership with mothers of Aboriginal infants, their families and communities to promote, protect and support breastfeeding.

NSW Health organisations implement culturally appropriate evidence-based interventions that promote and support breastfeeding.

NSW Health organisations collaborate with other relevant government, non-government and community organisations to promote, protect and support breastfeeding.

Aboriginal infants are less likely to be breastfed than non-Aboriginal infants. It is suggested that promoting breastfeeding to the wider Aboriginal community would assist to create a stronger breastfeeding culture, and would support Aboriginal women to breastfeed.

## iii. Provide additional support to women and families at risk of lower rates of breastfeeding initiation and duration

## **Best Practice**

NSW Health organisations provide additional breastfeeding support to these women and their families in the maternity continuum and early childhood periods.

NSW Health staff offer referral for women, to evidence based services/programs such as <u>Australian</u> <u>Breastfeeding Association, Get Healthy in Pregnancy (GHiP)</u>, <u>Quitline and Quit for new life</u>.

Women at risk of lower initiation and duration of breastfeeding include:

- women who are less than 25 years of age
- obese women
- mothers of preterm and low birth weight infants
- women who smoke.

Mothers practicing early skin-to-skin contact with their newborns and kangaroo care, for infants in neonatal intensive care units, are more likely to breastfeed in the first one to four months of their child's life and continue for longer durations. Initiation of milk expression within one hour following birth increases milk volume in mothers of low birth weight infants.

Evidence highlights the effectiveness of parent groups, where peers are breastfeeding infants of a similar age, in improving breastfeeding rates/duration. Targeted peer counselling and social support, combined with professional support, is particularly important for younger mothers.

## iv. Strengthen continuity of care, referral pathways and support networks

#### **Best Practice**

NSW Health organisations maintain an effective and timely referral system from maternity, neonatal and paediatric units to community based child and family health services.

NSW Health organisations collaborate with relevant local government, non-government and community organisations to support women and their families to breastfeed.

Continuity of care enables women to develop a relationship with the same caregiver(s) throughout the maternity continuum and early childhood. There is strong evidence demonstrating that continuity of care models support initiation and duration of breastfeeding.

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Support in any form has been identified as a core component of programs to ensure good breastfeeding outcomes. Support provided for infant feeding may be from various sources including professionals, peer support and informal social networks. There is good evidence that a mixture of professional and peer support, for example as provided by the Australian Breastfeeding Association, is likely to be most effective in improving breastfeeding outcomes, particularly support around the perinatal period.

## v. Support health professionals' education and professional development

## **Best Practice**

NSW Health organisations ensure that the health workforce, caring for women and their families, complete the <u>HETI My Health Learning Course Code: 45338916 *Breastfeeding Promotion*. <u>Protection and Support</u></u>

NSW Health organisations provide and support access to education and continuing professional development, based on the BFHI frameworks, to the health workforce caring for women and their families.

NSW Health organisations provide access to evidence based breastfeeding guidelines/resources for the health workforce caring for women and their families.

All health professionals play a key role in promoting, protecting and supporting breastfeeding. Breastfeeding education which increases the knowledge and confidence of medical officers, nurses, midwives, Aboriginal health workers and other health professionals can lead to success in improving breastfeeding outcomes.

Access to consistent evidence based information and empathic communication skills are essential to professional development. The <u>WHO/UNICEF BFHI training package</u> is an effective health professional education package. Continuing professional development will enhance the knowledge, attitude and skills of the health workforce, enabling identification of predictors and barriers to breastfeeding.

Information to support health workers to protect, promote and support breastfeeding can be accessed via both the <u>NSW Health</u> and the <u>Australian Department of Health</u> websites.

## vi. Provide breastfeeding friendly workplaces

## **Best Practice**

NSW Health employees are encouraged and supported to combine breastfeeding and work.

NSW Health organisations work towards achieving the <u>Australian Breastfeeding Association</u> <u>Breastfeeding Friendly Workplace Accreditation</u>.

Providing support for breastfeeding is crucial to fostering a workplace that is free of discrimination, offers equal employment opportunity and is family friendly while improving the health outcomes of children. Support for breastfeeding in the workplace aids in the retention of the workforce, helps to maintain the workforce skill base, lowers staff turnover and assists in increasing morale.

NSW Health is committed to fostering a supportive work environment for breastfeeding employees. NSW Health staff should refer to their relevant Awards and Determinations regarding provisions around breastfeeding and working.

NSW Health supports action at a state level by encouraging early childhood education and care environments to support breastfeeding through the NSW Health Healthy Eating Active Living Strategy.

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## vii. Ensure monitoring and surveillance

## **Best Practice**

NSW Health seeks opportunities to develop a breastfeeding dashboard indicator linking it to relevant performance measurement tools at the national, state and local level.

NSW Health organisations monitor initiation and where able duration of breastfeeding rates.

Monitoring, research and evaluation are important to provide further insight into breastfeeding initiation and duration rates, as well as a better understanding of ways in which breastfeeding can be protected, promoted and supported. To date, all monitoring of breastfeeding in Australia has been completed by cross-sectional, retrospective or small regional cohort studies. While useful data are available, many studies use different definitions and sampling methods that make comparisons difficult.

In NSW, 'breastfeeding on discharge from hospital' is routinely collected via the Perinatal Data Collection.

viii. Support Australia's response to the Marketing in Australia of Infant Formulas: Manufacturers and Importers Agreement 1992 (MAIF)

**Best Practice** 

NSW Health organisations inform employees of their responsibilities under the MAIF Agreement and support them in meeting these responsibilities.

NSW Health staff comply with all relevant polices, such as <u>PD2005\_415</u> Sponsorships Policy - NSW Health, PD2009\_067 Fundraising Policy, PD2015\_045 Conflicts of Interest and Gifts and Benefits

NSW Health is required to comply with responsibilities under the <u>MAIF Agreement</u> in particular the following clauses:

- Clause 4: Information and education
- Clause 5: The general public and mothers
- Clause 6: Health care system
- Clause 7: Health care professionals.

This document sets out the obligations of manufacturers and importers of infant formula and gives effect to the principles of the WHO Code in an Australian context.

NSW Health recognises the need to support staff to notify the Australian Government Department of Health of potential breaches to the MAIF Agreement. Additional information on the MAIF Agreement including <u>Information for Lodging Complaints</u> regarding breaches can be found at the <u>Australian</u> <u>Government Department of Health MAIF Agreement</u> webpage.

## **5** LIST OF ATTACHMENTS

- 1. Implementation checklist
- 2. The evidence
- 3. International, national and state policy, services and frameworks
- 4. Baby Friendly Health Initiative Ten Steps to Successful Breastfeeding
- 5. The 7 Point Plan for the Protection, Promotion and Support of Breastfeeding in Community Health Services
- 6. Neo-BFHI The Baby-friendly Hospital Initiative for Neonatal Wards

## Attachments are available in the policy document at:

https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2018\_034

BREASTMILK: SAFE MANAGEMENT (GL2023 021)

321(21/09/18)

## GL2023 021 replaced PD2010 019

## **GUIDELINE SUMMARY**

NSW Health is committed to supporting the safe management of breastmilk in all NSW Health facilities to reduce the risk of misadministration of breastmilk and to manage any adverse incidents.

## **KEY PRINCIPLES**

NSW Health facilities are required to reduce the risk of the misadministration of breastmilk. This includes ensuring that all babies have secure identification in place and babies are not separated from their mothers without a compelling reason.

All expressed breastmilk is required to be safely managed and education is to be provided to parents and carers about this management.

If a baby is exposed to the wrong breastmilk, the relevant health professionals must conduct risk assessments, order and interpret screening, and initiate treatment as required.

All screening, management plans, results and counselling must be documented in the relevant health care record.

Local health districts and specialty health networks must ensure relevant staff:

- receive education and training to support the safe management of breastmilk, to identify risks and to manage adverse incidents
- implement strategies to reduce risk of the misadministration of breastmilk
- implement appropriate management if a baby receives the wrong breastmilk
- develop local policy and guidelines to support families who choose to intentionally feed their baby unpasteurised breastmilk from a nominated non-birth mother
- develop local policy, guidelines and procedures to:
  - o implement this Guideline
  - $\circ$  monitor practice
  - o document appropriately.

The Breastmilk: Safe Management guideline is available at: https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=gl2023 021

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#### APNOEA MONITORS (GL2012\_002) GL2012\_002 rescinds GL2005\_069.

This Guideline replaces GL2005\_069 Apnoea Monitors. It provides advice to clinicians that there is no objective scientific evidence that home apnoea monitoring devices are of any value in preventing Sudden Infant Death Syndrome (SIDS).

There is no objective scientific evidence that home apnoea monitoring devices are of any value in preventing Sudden Infant Death Syndrome. However, it is acknowledged that there is considerable community anxiety about Sudden Infant Death Syndrome and that home monitoring devices are available to the general public. It should be noted that there is no indication for apnoea monitoring for the general population.

It is recommended that only infants deemed to have had serious apnoea by a specialist paediatrician should be placed on apnoea monitoring and this should be accompanied by appropriate advice, training and support for parents. It is recommended that apnoea monitoring devices are only used in the following context:

- a) Adequate counselling before and during home monitoring by appropriately trained personnel;
- b) Adequate training in the use of monitor and resuscitation techniques;
- c) Continuous availability of medical, technical and emotional support services.

These aims may be most readily achieved if the management of an infant undergoing home monitoring is supervised by a hospital or other facility with appropriate specialised staff, including paediatricians and social workers.

# GROWTH ASSESSMENT IN CHILDREN AND WEIGHT STATUS ASSESSMENT IN ADULTS (GL2017 021 issued 17/11/2017)

#### PURPOSE

To support core patient care, this document describes the following:

- A standardised approach to measuring weight and height in children and adults, and to measuring length and head circumference in younger children.
- Interpreting and recording these measurements as part of determining weight status.
- Key equipment and patient considerations around taking these measurements.

#### **KEY PRINCIPLES**

Weight and height measurement of children and adults – or weight, length and head circumference measurement of younger children – should be performed on a regular basis as part of providing good clinical care. For example, it is necessary to measure weight, height and head circumference in order to monitor children's growth. It is also necessary to measure weight and height (or length) to determine weight status in children and adults.

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Standardised measurement and interpretation of weight, height, length and weight status, will improve the accuracy and usefulness of measurements over time and across facilities, and support clinical decision making.

#### **USE OF THE GUIDELINE**

This guideline helps clinicians perform weight, height, length, or head circumference measurements of their patients, and to use these measurements to assess their patients' weight status.

This guideline also helps managers design and establish workflow practices that enable routine measurements.

To download the guideline go to Growth Assessment in Children and Weight Status Assessment in Adults

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## CIRCUMCISION OF NORMAL MALE INFANTS (PD2020\_035)

#### PD2020 035 rescinds PD2012 009

## **POLICY STATEMENT**

Routine circumcision of normal infant males is **not** performed in public hospitals in NSWHealth. This **does not** apply to cases where there is a clear clinical need forintervention, nor directly to adult male circumcision.

Parents who request routine circumcision must be provided with accurate information the risks and benefits of circumcision.

## SUMMARY OF POLICY REQUIREMENTS

Parents who request circumcision for their infant son must be provided with accurate, unbiased and up to date information about the risks and benefits of the procedure.

Two resources that are recommended for staff:

- The Royal Australasian College of Physicians (RACP) guide for parents <u>RACP -circumcision a</u> guide for parents.
- The Sydney Children's Hospital's Network Fact Sheet: <u>SCHN factsheet maleinfant</u> <u>circumcision</u>.

Parents must also be referred to RACP statement on circumcision, RACP Statement -Circumcision.

#### THIS POLICY DIRECTIVE MUST BE READ IN CONJUNCTION WITH:

NSW Health Policy Directive *Waiting Time and Elective Surgery Policy* (<u>PD2012\_011</u>) (Section 2.3: Circumcision is listed as a discretionary procedure "*that should not routinely be performed in public hospitals in NSW unless there is a clear clinical need to improve a patient's physical health"*)

NSW Health Information Bulletin *Advice for referring and Treating Doctors – Waiting Time and Elective Surgery Policy* (<u>IB2012\_004</u>).

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## **TIERED NETWORKING ARRANGEMENTS FOR PERINATAL CARE IN NSW** (PD2023\_035)

## PD2023\_035 rescinded PD2020\_014 and IB2022\_026

## **POLICY STATEMENT**

The tiered perinatal networks provide a structure to support pregnancy and birth care through the appropriate use of maternity and neonatal services (capability); access to care appropriate to the level of assessed patient need (patient flow); and a 'whole of health' approach to the management of demand (capacity).

This Policy Directive provides guidance for NSW local health districts, and services in the ACT on the structure, functioning and governance of tiered perinatal networks.

## SUMMARY OF POLICY REQUIREMENTS

The Policy Directive refers to the care of women with high-risk pregnancy requiring referral and/or transfer of care to a higher-level facility. It describes maternal and neonatal services in NSW, their tiered perinatal network arrangements; the default protocol; the requirement for local health district operational plans and escalation pathways. Reference is made to unwell neonates who require higher level care at birth but does not include advice on the referral or movement of these patients.

Each tiered perinatal network is responsible for managing the service demands of its population. Higher level facilities are responsible for providing support, advice and management of the women who may require transfer within and across tiered perinatal networks.

Level 6 maternity facilities operate as a part of a statewide system of care and are required to support other tiered perinatal networks. Whenever a maternal transfer is needed the following principles apply:

- No woman is to be moved out of her tiered perinatal network without the advice of the tiered perinatal network Level 6 obstetric consultant.
- Women and their families are provided with timely and accessible information on the transfer process and offered support through Aboriginal Health Liaison Officers, Aboriginal Maternal and Infant Health Service staff, interpreters and/or other support services as required.
- The decision to transfer and determination of the urgency of transfer (medically agreed timeframe) must be made through discussion between the obstetric consultants at the referring and accepting facilities.
- Management of urgency and risk is aligned to the Maternal Transfers Decision Making Tool.
- Access to appropriate care must not be delayed due to maternal or neonatal bed finding. .
- The neonatal team is closely involved in the decision making/ care planning for planned high risk births or involved in the care of urgent transfers. However, where birth is not planned or anticipated within the next 12 hours, a neonatal bed is not required and obstetric decision making takes precedence.
- Obstetric consultant roster must be made available with contact numbers provided.
- No Level 6 to Level 6 maternal transfers should occur from 32 weeks. An exception could be where specific Level 6 neonatal services are required (such as surgical or cardiac).
- If during a transfer, there is deterioration in maternal condition the Aeromedical Control Centre must contact the obstetric consultant at the receiving facility for advice and transfer logistics.

- Higher level facilities are responsible for supporting the woman until transfer is complete, and for notifying the referring hospital if the destination changes.
- All facilities are responsible to accept return transfers from higher level facilities.

## The view the entire Tiered Networking Arrangements for Perinatal Care in NSW policy go to <a href="https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2023\_035">https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2023\_035</a>

347(19/10/22)

## NSW PAEDIATRIC SERVICE CAPABILITY FRAMEWORK (GL2017\_010 issued 1/6/2017)

#### PURPOSE

Service capability describes the planned activity and clinical complexity that a facility is capable of safely providing. The NSW Paediatric Service Capability Framework (the 'Framework') identifies the scope of planned activity for each paediatric service capability level and provides a mechanism for Local Health Districts to assess the planned service capability of their facilities.

Facilities must be capable of providing, at a minimum, all the planned clinical services described for their level. The Framework supports the provision of high quality, safe and timely care for infants, children and adolescents as close to home as possible.

#### **KEY PRINCIPLES**

Paediatric medicine service levels range from no planned service to Level 6 in the major children's hospitals.

Surgery for Children service levels range from no planned service to Level 6. Level 6 paediatric surgery is provided in specialist children's hospitals where paediatric surgery and complex genetic and metabolic services are located. There is no level 5 Surgery for Children Service.

This Framework does not cover Level 6 services.

#### **USE OF THE GUIDELINE**

Local Health Districts are responsible for determining the paediatric service capability level of their facilities, taking into account the clinical support services available (e.g. pathology, diagnostic imaging).

The Framework also includes the Paediatric Service Capability and Surgery for Children self-assessment checklists for assessing the planned service capability of a facility and a methodology to assist in service planning and risk management for paediatric medicine and surgery for children.

The Framework is supported by the NSW Paediatric Service Capability Framework Companion Toolkit.

To download the guideline go to NSW Paediatric Service Capability Framework

## MATERNITY AND NEONATAL SERVICE CAPABILITY (GL2022\_002)

GL2022\_002 replaced GL2016\_018

## **GUIDELINE SUMMARY**

This document guides NSW Health service executives, managers, clinicians, and health service planners in planning and delivering maternity and neonatal services. The guideline describes the planned activity and clinical complexity that a facility is capable of safely providing, and outlines the processes for assessment, notification and reporting.

## **KEY PRINCIPLES**

Local health districts (districts) and specialty health networks (networks) are responsible for assessing, maintaining and reassessing the service capability level of their maternity and neonatal services. District/networks are responsible for annual reporting of maternity and neonatal service capability levels.

The Secretary of NSW Health must be notified in advance of any planned commencement of a new maternity or neonatal service and/or closure or restriction of the range of maternity or neonatal services.

District/networks are responsible for conducting relevant risk assessments for any planned or unplanned change to services to support safety and quality practices, or at the request of the Ministry of Health. Local processes must be in place to manage any identified risks to operating at a designated service capability level.

Maternity and neonatal managers and clinicians must deliver services in line with the designated service capability level of their facilities and partner with other services within tiered perinatal network arrangements so women and newborns can receive the right care in the right place at the right time.

Accessible information must be provided to women and their families in the antenatal period about the capability of their local service. This will help them understand the care that can be provided locally and what to expect if transfer for higher-level care is required.

Care at all levels of service capability needs to be woman/person-centred (maternity), familycentred (neonatal), culturally safe and appropriate and respond to the diverse needs of women and families including health, mental health, disability, psychosocial and safety needs (including child protection and domestic and family violence).

Maternity and neonatal services implement value-based health care to improve outcomes and experiences for patients, the population, clinicians and service providers, and ensure value for the system.

#### To download the guideline go to:

https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2022\_002

341 (20/05/22)

## HUMIDIFIED HIGH FLOW NASAL CANNULA OXYGEN GUIDELINE FOR METROPOLITAN PAEDIATRIC WARDS AND EDs – 1<sup>ST</sup> EDITION (GL2016\_004)

#### PURPOSE

The Humidified High Flow Nasal Cannula Oxygen Guideline for Metropolitan Paediatric Wards and ED's, 1<sup>st</sup> edition has been developed to inform practice for clinicians caring for infants and children. This guideline was developed by a representative group of NSW Clinicians with expertise in acute paediatric care, paediatric intensive care, and paediatric respiratory care as part of a joint project between The Office of Kids and Families and MP4 (Metropolitan Paediatric Level 4 Units Sydney) and is aimed at achieving the best possible care in NSW.

## **KEY PRINCIPLES**

The guideline applies only to Metropolitan Paediatric Level 4 Units and Metropolitan Emergency Departments where paediatric patients are managed. It requires Chief Executives of Metropolitan Local Health Districts to determine where local adaptations are required or whether the guideline can be adopted in the current format.

The guideline reflects what is currently regarded as a safe and appropriate approach to commencement of Humidified High Flow Nasal Cannula Oxygen (HHFNC) and the care of infants while on HHFNC. The document should not be seen as a stringent set of rules to be applied without the clinical input and discretion of the managing professionals. Each patient should be individually evaluated and a decision made as to appropriate management in order to achieve the best clinical outcome.

#### **USE OF THE GUIDELINE**

Chief Executives of Metropolitan LHD's must ensure:

- Hospitals and facilities either adopt this protocol or adapt local protocols to comply with the *Humidified High Flow Nasal Cannula Oxygen Guideline for Metropolitan Paediatric Wards and EDs*
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this new guideline.

## ATTACHMENTS

1. <u>Humidified High Flow Nasal Cannula Oxygen Guideline for Metropolitan Paediatric Wards and EDs</u>, 1<sup>st</sup> Edition: Guideline</sup>

296(29/1/16)

## INFANTS AND CHILDREN INSERTION AND CONFIRMATION OF PLACEMENT OF NASOGASTRIC AND OROGASTRIC TUBES (GL2016\_006)

#### GL2016\_006 rescinds GL2016\_003

#### PURPOSE

The *Infants and Children Insertion and Confirmation of Placement of Nasogastric and Orogastric Tubes 1st edition* Guideline provides direction to clinicians and is aimed at achieving the best possible paediatric care in all parts of the state. The Procedural Guideline was prepared for the NSW Ministry of Health by an expert clinical reference group under the auspice of The Office of Kids and Families.

#### **KEY PRINCIPLES**

This Guideline applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts and specialty health networks to determine where local adaptations are required or whether it can be adopted in its current Clinical Practice Guideline format in all hospitals and facilities required to manage insertion and confirmation of nasogastric and orogastric tube placement in infants and children.

The Clinical Practice Guideline reflects what is currently regarded as a safe and appropriate approach to insertion and confirmation of nasogastric and orogastric tube placement in infants and children. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

#### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- This Guideline is adopted or local protocols are developed based on the *Infants and Children Insertion and Confirmation of Placement of Nasogastric and Orogastric Tubes 1st edition* Guideline
- Local protocols are in place in all hospitals and facilities likely to be required to insert a nasogastric or orogastric tube in a paediatric patient
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this revised guideline.

## ATTACHMENT

 Infants and Children Insertion and Confirmation of Placement of Nasogastric and Orogastric Tubes <u>1<sup>st</sup> Edition: Guideline</u>.

## MANAGEMENT OF SUDDEN UNEXPECTED DEATH IN INFANCY (SUDI) (PD2019\_035)

## PD2019\_035 rescinds PD2008\_070

#### PURPOSE

This Policy Directive outlines the mandatory requirements for management of Sudden Unexpected Death in Infancy (SUDI) in NSW Health facilities. It also outlines the role of NSW Health in the context of the NSW Government response to SUDI which includes the NSW Coroner and Police.

## **MANDATORY REQUIREMENTS**

SUDI is a reportable death under the Coroners Act 2009.<sup>1</sup> Most SUDI deaths occur in the community and are brought to their local emergency department, however SUDI can also occur in hospital. NSW Health's role in management of SUDI includes that local health districts and specialty health networks must:

- Ensure that local policies that guide management of SUDI are easily accessible for staff. This includes emergency departments as well as other areas that SUDI may occur such as maternity, paediatrics and intensive care. Information for staff on how to access locally networked paediatric services should be included.
- Ensure that adequate resources and education are provided so that staff can meet the needs of the infant and the parents/carers, and that parents/carers have access to expert medical advice, nursing care and social work. If necessary, these can be accessed via locally networked paediatric services. In some instances the situation may warrant transfer of the infant to a higher level facility.
- Nominate a hospital contact who will coordinate the SUDI response for example a social worker or nurse. This health professional will provide support to the parents/carers and coordinate completion of documentation required by NSW Health. A list of roles and responsibilities of agencies and staff involved in the SUDI response is at Section 6.1 Response to Sudden Unexpected Death in Infancy (SUDI) Roles and Responsibilities.
- Ensure that the infant's medical history is completed by a senior medical staff member and documented in the health care record. A checklist to support this is at Section 6.2 Medical History Guide Sudden Unexpected Death in Infancy. A copy of the infant's health care record must be forwarded to Forensic Medicine (NSW Health Pathology) within 24 hours of the infant's death.
- Ensure that support is available for staff who provide care to infants and parents/carers who have experienced SUDI. If necessary, this can be accessed via locally networked paediatric services.

Ensure there are processes to maintain the quality of care and patient experience of SUDI cases. This includes incident notification, documentation, case discussion that includes the perspective of parents/carers and staff and implementation of any identified improvement opportunities.

321(30/07/19)

## **IMPLEMENTATION**

Local health district chief executives are responsible for:

- Assigning responsibility, personnel and resources to implement this policy.
- Establishing mechanisms to ensure the mandatory requirements are applied, achieved and sustained as usual processes in the instance of a SUDI. This should include nomination of an executive sponsor.
- Ensuring that any local policy reflects the requirements of this policy and is written in consultation with the hospital executive, clinical governance unit and clinical staff.

## Management of Sudden Unexpected Death in Infancy (SUDI): Procedure.

## **1 INTRODUCTION**

## **1.2 About This Document**

Every year in NSW between 40 and 50 infants under the age of 12 months die suddenly and unexpectedly, with a cause unable to be determined immediately.<sup>1</sup> This procedure document explains and outlines NSW Health's role in the management of Sudden Unexpected Death in Infancy (SUDI) and should be used:

- When an infant is brought to a NSW Health facility, following a sudden, unexpected death
- When an infant is brought to a NSW Health facility after a 'near SUDI' and dies in hospital
- When there is a sudden, unexpected infant death during a hospital admission.

NSW Health's role in the management of SUDI includes:

- Care of the infant and the parents/carers
- Completion of the infant's medical history, with a copy of the infant's health care record forwarded to Forensic Medicine (NSW Health Pathology) within 24 hours of the infant's death
- Completion of the post mortem examination and liaison with other agencies involved in the Coronial process
- Participation in the NSW Government response to SUDI. A flowchart that outlines NSW Health's role in the SUDI response can be found at <u>Section 6.1 Response to Sudden Unexpected</u> <u>Death in Infancy (SUDI) Roles and Responsibilities.</u>

The SUDI response outlined in this document aims to:

- Establish where possible, the cause of death and assist parents/carers and their families to understand how and why the death may have occurred
- Provide parents/carers with information about any potential health risks for surviving family members
- Ensure timely completion of the infant's medical history. A checklist to support completion of the infant's medical history is attached at <u>Section 6.2 Medical History Guide Sudden</u> <u>Unexpected Death in Infancy</u>
- Support Forensic Medicine (NSW Health Pathology) to complete the post mortem examination, establish the cause of death and provide information for future SUDI prevention activities of NSW Health and other agencies
- Ensure that statutory obligations are met.2 This includes assisting the NSW Coroner and Police in their role of investigating the infant's death.

## **1.2 Changes From the Previous Policy**

- 1. This Policy Directive emphasises the need to provide parents/carers with any support they may need, including medical and nursing care, social work and referral to other services such as <u>Red</u> <u>Nose Grief and Loss</u>
- 2. All episodes of SUDI are to be accepted and managed in hospital, regardless of whether the infant's death occurred in hospital or prior to presentation. Facilities without an onsite paediatrician, paediatric nurse or social worker and can access support via their locally networked paediatric services. For more information about locally networked paediatric services see <u>GL2017</u> 010 NSW Paediatric Service Capability Framework
- 3. Local Health Districts/Specialty Health Networks (LHDs/SHNs) are not required to have facilities designated to respond to SUDI. It is expected that all facilities are able to initiate a SUDI response
- 4. The SUDI Medical History Protocol has been revised. For more information see <u>Section 6.2</u> <u>Medical History Guide – Sudden Unexpected Death in Infancy (SUDI)</u>
- 5. Information about requirements of a post mortem examination relates to Forensic Medicine and is therefore out of the scope for this policy.

## **1.3 Definitions**

## Sudden Unexpected Death in Infancy (SUDI):

The sudden, unexpected death of an infant:

- Less than 12 months of age
- And where the cause was not immediately apparent at the time of death.

This definition excludes infants who die unexpectedly in misadventures due to external injury (such as transport incidents) and accidental drowning.<sup>3</sup>

#### Sudden Infant Death Syndrome (SIDS):

The sudden, unexpected death of an infant:

- Less than 12 months of age
- With onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy, review of the circumstances of the death and the clinical history.<sup>4</sup>

## 2 CLINICAL GOVERNANCE

#### 2.1 Incident Notification

Where a sudden, unexpected death of an infant death occurs in the community and the infant is brought to a NSW Health facility, notification in the Incident Information Management System (IIMS) is not required and the presentation is to be managed as a SUDI, as outlined in this Policy.

As per NSW Health <u>PD2014\_004 Incident Management Policy</u> all deaths in hospital that are unrelated to the natural course of illness must be reported promptly in the IIMS. The Ministry of Health must be notified of the incident via a Reportable Incident Brief (RIB) within 24 hours.

321(30/07/19)

## 2.2 Health Care Record

Where a post mortem is to be conducted under the direction of the Coroner, the forensic pathologist (NSW Health Pathology) must have access to a copy of the infant's health care record. The health care record should be forwarded within 24 hours. For more information see <u>4.8 Management of the Infant's Health Care Record</u>.

## 2.3 Case Review

Following an episode of SUDI, by the next business day, the senior medical officer overseeing the case should review the infant's health care record and address any outstanding issues, including any referrals or follow-up for the parents/carers have been arranged.

LHDs/SHNs should also review all SUDI cases, this may be as part of a mortality and morbidity meeting. Where possible, other agencies involved in management of the case should be invited such as Forensic Medicine (NSW Health Pathology), Ambulance and Police.

Forensic Medicine (NSW Health Pathology) may also invite clinical staff to participate in a multidisciplinary review.

## 2.4 Staff Debrief

All staff involved in an episode of SUDI should be offered the opportunity to debrief, both with other staff and individually, if preferred, and be assisted in accessing other support services where required.

## **3** GENERAL PRINCIPLES

SUDI is a tragic event likely to create an intense response from the parents/carers and their families as well as health professionals. As there is no 'appropriate' response to an overwhelming experience such as SUDI, behaviour of the parents/carers and their families may seem unusual. The immediate care and support provided by health professionals can make a significant difference to parents/carers and their family's grief.

Regardless of the NSW Health facility that the SUDI case presents to, appropriate physical space that allows for privacy should be accessible so that discussions between the infant's parents/carers and staff can occur and that the SUDI response can be managed.

As with all episodes of patient care, where a SUDI case is managed in a NSW Health facility, accurate documentation in the health care record is required. For more information see NSW Health <u>PD2012\_069</u> Health Care Records – Documentation and Management.

## **4 PROCEDURE FOR MANAGEMENT OF SUDI**

SUDI cases will present in various ways, all of which require initiation of the SUDI response outlined in this document. This includes unresponsive or deceased infants brought by their parents/carers or by Ambulance, with or without Police involvement. Infants may be pronounced deceased prior to arrival, on arrival to the Emergency Department (ED), or after admission. Each of these presentations is considered a SUDI case and should be managed as outlined below.

The roles and responsibilities of each agency (Health, Police, Ambulance, Forensic Medicine and the Coroner) has been summarised at <u>Section 6.1 Response to Sudden Unexpected Death in Infancy (SUDI)</u> - <u>Roles and Responsibilities.</u>

## 4.1 Sudden Unexpected Infant Death in the Community

- Any infant that dies suddenly and unexpectedly in the community is to be taken to their nearest ED
- On arrival, any immediate care should be provided as per usual ED practice and the ED senior medical officer and nurse in charge notified

- The ED senior medical officer is to verify the infant's death (extinction of life) and let the parents/carers know. The infant should be registered as a patient and admitted
- A decision is to be made as to who will coordinate immediate care of the infant and the parents/carers, this may be a senior nurse or social worker
- The infant's medical history must be completed by a senior medical officer, using the <u>Medical</u> <u>History Guide – Sudden Unexpected Death in Infancy (SUDI) (Section 6.2)</u>. This should be the on-call paediatrician. If a paediatrician is not available, the locally networked paediatric service should be contacted to determine who will complete the infant's medical history
- Where the infant's death occurs outside of business hours, and social work is not available, clinical staff should provide a handover to social work by the next business day.

### 4.2 Sudden Unexpected Infant Death in Hospital

- Where a SUDI death occurs in a NSW Health facility, the Admitting Medical Officer (AMO) and nurse in charge of the shift are to nominate a staff member to coordinate care of the infant and the parents/carers, this may be a senior nurse or social worker
- The infant's death (extinction of life) is to be verified and the parents/carers informed
- The infant's medical history must be completed by a senior medical officer, using the <u>Medical</u> <u>History Guide – Sudden Unexpected Death in Infancy (SUDI) (Section 6.2)</u>. This should be the AMO or on-call paediatrician. If a paediatrician is not available, the locally networked paediatric service should be contacted to determine who will complete the infant's medical history
- Where the infant's death occurs outside of business hours, and social work is not available, a handover from clinical staff to social work should be provided by the next business day.

### 4.3 Reporting a Death to the Coroner

As per NSW Health <u>PD2010\_054 Coroner's Cases and the Coroner's Act 2009</u> and <u>IB2010\_058</u> <u>Coronial Checklist</u> sudden and unexpected deaths are reportable to the Coroner. Where any doubt exists as to whether a death should be reported, call the duty forensic pathologist or the clinical nurse consultant at the relevant Forensic Medicine (NSW Health Pathology) facility:

Business hours (8am - 4:30pm):

- Sydney (Lidcombe): 02 9563 9000
- Wollongong: 02 4222 5466
- Newcastle: 02 4935 9700

After hours calls should be directed to the Lidcombe Forensic Medicine facility. The relevant duty pathologist will be notified by the Lidcombe Forensic Medicine staff.

The State Coroner's Court may also be contacted for advice on 02 8584 7777.

Where a death is reportable to the Coroner, a death certificate must not be issued. Verification of death (extinction of life) is to be documented in the Report of a Death of a Patient to the Coroner (Form A) (State Form SMR010.510). For more information see NSW Health <u>PD2015\_040 Death – Verification of Death and Medical Certificate Cause of Death.</u>

### 4.3.1 Police

Where an infant is brought to a NSW Health facility without any contact with Police, Police should be notified of the death via the Police Area Command so that Police can notify the Coroner. Police will liaise with Family and Community Services where required.

If the infant is brought to a NSW Health facility by Police, the senior medical officer in charge of the shift or their delegate should take a handover, including whether the death has been reported to the Coroner and whether the parents/carers have any objections to a post mortem examination.

Once the infant's death has been confirmed, Police, in their role representing the Coroner, are responsible for the care of the infant's body, timely transfer of the infant to the appropriate Forensic Medicine (NSW Health Pathology) facility and investigation of the infant's death. Police will organise formal identification of the infant, this is to occur before the infant's body leaves the hospital.

Where there is uncertainty or concerns about the roles and expectations of Police in a NSW Health facility, the senior medical officer and nurse in charge should discuss their concerns with the most senior attending Police officer. Any ongoing concerns should be escalated via the Hospital Executive and the Police Area Command.

### 4.3.2 Notifying Forensic Medicine (NSW Health Pathology)

Once Police have been notified, the senior medical officer must inform the duty forensic pathologist or clinical nurse consultant at the relevant Forensic Medicine of the SUDI death as soon as possible. Ideally this should be the senior medical officer who completes the infant's medical history.

Forensic Medicine should also be informed of any existing pathology samples taken prior to death, such as blood and urine, as these samples may be required for further testing as part of the Coronial investigation process. Contact details for Forensic Medicine are in <u>Section 4.3</u>.

### 4.4 Care of the Infant's Body

As per NSW Health <u>PD2010\_054 Coroner's Cases and the Coroner's Act 2009</u> the hospital in whose care the infant's body is in, is responsible for the safe custody of the body until it is removed by Police. This implies that the infant's body will be in the same condition as when the death occurred and includes no interference with cannulas, incisions or dressings.

All contact with the infant's body must be supervised by Police or a health professional. From arrival to hospital and/or the time of death, no evidence relating to the possible cause of the infant's death is to be altered. However parents/carers may stay with their infant, under supervision, and with support of the hospital contact person. The parents/carers may hold their swaddled infant, however handling of the infant's body should be limited. The parents/carers will be able to see their infant again after the postmortem examination has taken place.

Hand/foot prints and locks of hair must not be taken until after the post mortem. Parents/carers can request that hand/foot prints and locks of hair are taken after the post mortem by the Forensic Medicine social worker.

### 4.5 Initial Care of the Parents/Carers

The hospital contact person is to coordinate care of the parents/carers, including organising a private space for discussions, access to toilets and refreshments, introductions to staff members, contacting of family/friends and access to any services they may need such as interpreter services, Aboriginal Liaison Services and religious/cultural organisations. Where parents/carers require medical review such as lactation advice or referral to mental health services, this should be discussed with the senior medical officer overseeing the SUDI response. See also Section 6.3 Factsheet - Breast care after the death of an infant.

On arrival to hospital parents/carers are to be informed of each step in the process, using terminology they can understand, and be given the opportunity to ask questions, including that:

- The circumstances of the infant's death means that the death is reportable under the Coroners Act.<sup>5</sup> Therefore any contact with the infant must be supervised by a health professional (or Police) at all times
- A comprehensive medical history of the infant and family members will be taken by a senior medical officer, while the infant's body is in hospital, to assist with establishing the cause of death
- The Police, in their role representing the Coroner, will likely ask questions about the circumstances of the infant's death and request that a next of kin formally identifies the infant's body
- The Police will explain the coronial process and provide them with a copy of the <u>Initial steps</u> <u>after a death is reported to the Coroner</u> brochure. Information provided should include:
  - That the purpose of the post mortem examination is to establish the cause of death
  - That the results of the post mortem may benefit surviving family members including siblings, for example by identifying any genetic diseases
  - o Details of where the post mortem will occur
- The Coroner must be notified of objections to the post mortem. If the parents/carers decide to object to the post mortem:
  - The Coroner must be made aware of objections to the post mortem. If health staff become aware of objections to the post mortem, Police should be informed. Objections to the post mortem should be recorded in the infant's health care record
  - Assistance in exploring the objection should be offered, further information can be sourced from the social worker at the appropriate Forensic Medicine facility
  - If the parents/carers object to a post mortem, they will be contacted by a representative from the <u>Coronial Information and Support Program</u> to discuss the objection and post mortem
- The Forensic Medicine social worker will contact the parents/carers by the next business day after the infant's body is admitted to the Forensic Medicine facility. Information and support about the coronial process and viewing of the infant's body can then be discussed
- A representative from the <u>Coronial Information and Support Program</u> may contact the parents/carers following the post mortem to discuss any organ retention
- A Forensic Medicine social worker will contact the parents/carers to provide interim results of the post mortem.

### 4.5.1 Initial Care of Siblings

SUDI presentations are particularly difficult when siblings of the infant have witnessed the death, discovery or resuscitation attempts of the infant. The assessment and care of surviving siblings, who may also present to hospital, is an important part of care. LHD/SHN social work should be able to provide resources and referrals to services that can provide support for siblings experiencing grief and loss, such as <u>Red Nose Grief and Loss</u>.

### 4.6 Completion of the Infant's Medical History

The <u>Medical History Guide - Sudden Unexpected Death in Infancy (SUDI) (Section 6.2)</u> is to be completed by a senior medical officer, as soon as possible after the infant's death. This should be the on-call paediatrician. If the paediatrician is not available, the senior medical officer should contact the locally networked paediatric service to determine who will complete the infant's medical history.

The <u>Medical History Guide - Sudden Unexpected Death in Infancy (Section 6.2)</u> includes details about the infant's health, parents/carers and events in the hours leading up to the infant's death, including the exact position the infant was found and the response of the parents/carers. Some questions may seem intrusive however they relate to known risks for infant mortality and may assist with establishing the cause of death. Where possible, information provided by the parents/carers should be recorded verbatim. Parents/carers should be given the opportunity to ask questions and discuss any concerns that they have.

It is recommended that a second staff member, ideally the hospital contact person, is present throughout the discussion with the parents/carers, about their infant's medical history. If you choose to include Police as observers during the medical history discussion, it is recommended that roles are agreed on before the discussion starts. Parents/carers should be reassured that Police presence does not indicate an assumption of implication of the death of the infant.

Details of those present during the discussion should be documented in the health care record.

### 4.6.1 Child Protection and Wellbeing

There are cases of SUDI that are the result of a non-accidental injury or neglect, therefore the safety and care of any children the parents/carers are responsible for must be considered. Care should be provided as per NSW Health's PD2012\_007 Child Wellbeing and Child Protection Policy.

Where there are concerns for the safety of any children the parents/carers are responsible for see:

- <u>NSW Mandatory Reporter Guide</u>
- Child Protection Helpline 132 111 (Family and Community Services).

NSW Health Child Wellbeing Units 1300 480 420 (Mon - Fri 8:30am - 5pm) can also be contacted for advice.

### 4.6.2 Screening for Metabolic and Genetic Diseases

In all SUDI cases, the senior medical officer should refer the infant's parents and siblings to their local GP for an ECG. More information can be found in NSW Health's <u>Management of the Death of a Child in</u> <u>Hospital Resource</u>.

The senior medical officer is to consider any conditions that may have implications for surviving family members for example metabolic disease or cardiac dysrhythmia. Features of possible genetic problems include a history of sudden, unexpected death in family members, recurrent syncope, epilepsy and drowning. If there are concerns, the medical officer should contact the relevant medical specialist about possible investigations of the infant and/or family members.

As the infant's death is reportable to the Coroner, no samples of any kind can be taken after death without the permission of the Coroner. If there is a request for peri-mortem specimen collection, call the forensic pathologist at the relevant Forensic Medicine facility. For contact details see <u>Section 4.3</u>.

### 4.7 Role of the GP

The paediatrician or senior medical officer is to contact the local GP to:

- Inform them of the infant's death
- Discuss any relevant information about the infant and the parents/carers
- Discuss investigations required, for example an ECG on the infant's parents and siblings
- Discuss advice provided about lactation
- Offer assistance with support and referral for the infant's parents/carers

### 4.8 Management of the Infant's Health Care Record

As per <u>PD2010 054 Coroner's Cases and the Coroner's Act</u> where a post mortem is to be conducted under the direction of the Coroner, the forensic pathologist must have access to a copy of the health care record as soon as possible.

The hospital is responsible for providing a copy of the health care record to the Coroner. Release of copies of health care records should be handled by the medical records department or their delegate. The health care record may be sent with the infant's body but should be collated, packaged and forwarded in a sealed envelope. Records should be sent to Forensic Medicine within 24 hours of the infant's death.

Admission documentation, the infant's medical history, the Ambulance clinical record, records of any medications given and the infant's growth charts should be sent to Forensic Medicine as part of the infant's health care record.

### 4.8.1 Following Transfer to Forensic Medicine (NSW Health Pathology)

Agencies that request a copy of the infant's health care record, including Forensic Medicine and Police, after the infant's body has been transferred to Forensic Medicine, should be referred to the hospital's medical records department.

If the infant's health care record is not received by Forensic Medicine within 24 hours of the infant's death, Forensic Medicine are to contact the hospital's medical record department.

Where a copy of the infant's medical history has not been received or further information is required, Forensic Medicine is to contact the senior medical officer who completed the infant's medical history. If the senior medical officer is not able to be contacted, the Director of Medical Services/Administration of the hospital or facility should be contacted.

### 4.9 Departure From the Hospital or Health Care Facility

Before parents/carers leave the hospital or health care facility, the hospital contact person should confirm any appointments made and discuss with the parents/carers notification of other health professionals previously involved in the infant's care.

Parents/carers may want to nominate a family member to act as a contact to assist with decision making on their behalf. Information, both written and verbal, about how to access further support and advice should also be provided such as:

- Child and Family Health Services
- Their local GP
- A medical specialist
- <u>Mental Health Services</u>
- Other health services such as the <u>Aboriginal Maternal and Infant Health Service</u> or <u>NSW</u> <u>Refugee Health Service</u>
- <u>Red Nose Grief and Loss</u>.

Practical assistance and advice should be offered to parents/carers including arranging transport home, care of siblings and funeral arrangements. Note parents/carers should not set a date for their infant's funeral until they have made contact with the Forensic Medicine social worker.

A representative from the hospital or health care facility overseeing care of the infant and the parents/carers should contact the parents/carers within a week of the infant's death, to offer support and confirm any referrals have been organised. This may be the social worker, the hospital contact person or the senior medical officer.

### 4.10 Forensic Medicine (NSW Health Pathology)

Once parents/carers have had the opportunity to spend time with their infant and the infant's medical history is complete, Police will arrange for the infant's body to be transferred to the appropriate Forensic Medicine facility. This should occur as soon as possible as extended delays can impact the post mortem examination and therefore timing of the report. Police arrange transfer of the infant's body via a government contractor, there is no cost for the transfer.

The hospital contact person should provide a handover to the Forensic Medicine social worker where the post mortem will occur. Contact details of the Forensic Medicine (NSW Health Pathology) social worker should be given to the parents/carers prior to transfer of the infant's body.

The Forensic Medicine social worker will:

- Accept a handover from the hospital contact person (usually by email)
- Contact the parents/carers to confirm that the infant's body has been admitted to the facility (by the next business day).

Forensic Medicine social work is available during office hours (8:00am to 4:30pm) at all sites. After hours social work service is available as follows:

- Sydney: 6pm 10pm on weekdays, 8am 8pm on Saturdays and Sundays
- Newcastle: 1pm 5pm on Saturdays and Sundays
- Wollongong: no after-hours social work support is available however the Wollongong Hospital social work team may accommodate requests for viewings after hours.

While the Coronial process is ongoing, up until after the final post mortem report has been discussed, parents/carers who have experienced the sudden unexpected death of an infant can access support, advice and referral to other services from Forensic Medicine social work.

### 4.11 The Post Mortem Examination

A post mortem (or autopsy) is a detailed examination of a body by a doctor who has training in this field. A post mortem is requested by the Coroner to inform a balanced, accurate finding regarding the cause of death. In NSW, all post mortem examinations after a SUDI death are undertaken at one of the three Forensic Medicine facilities, in Sydney, Wollongong or Newcastle.

As per <u>Section 4.5 Initial Care of the Parents/Carers</u> the Forensic Medicine social worker will contact the parents/carers to provide interim results of the post mortem. The Forensic Medicine social worker will also:

- If requested, arrange for hand/foot prints and locks of hair to be taken
- Facilitate viewings of the infant's body after the post mortem
- Ask if the parents/carers would like to be contacted by a Forensic Medicine social worker when the final post mortem report is available
- Confirm that the infant's body can be released to the funeral director.

If organ retention occurred as part of the post mortem, the parents/carers will be contacted by a representative from the <u>Coronial Information and Support Program (CISP)</u> to discuss approval by the Coroner, release, retention timeframes and options for disposal or return of organs.

### 4.12 Final Post Mortem Examination Report

Once the final post mortem report is complete, the Coroner will notify the parents/carers via a letter. Parents/carers can request a copy of the final post mortem report, requests by the parents/carers must be made to the Coroner in writing, this may be via email. There is no charge to parents/carers for a copy of the report. Some of the tests undertaken are complex so it may take months for the post mortem report to be available. It is not uncommon for the post mortem report to be inconclusive.

Note that requests for a copy of the post mortem report from NSW Health to the Coroner, must be made in writing from the hospital's Director of Medical Services (DMS) or Director of Clinical Governance (DCG) directly to the relevant Coroner. If the senior medical officer or paediatrician overseeing care of the infant and the parents/carers would like a copy of the post mortem report they should contact their DMS or DCG.

Once the final post mortem report is available, if parents/carers agreed to be contacted, the Forensic Medicine social worker will contact the parents/carers and offer to discuss the report. The Forensic Medicine social worker can also assist parents/carers with requesting a copy of the post mortem report from the Coroner.

Parents/carers can discuss the post mortem report with the Forensic Medicine social worker and the forensic pathologist. Parents/carers can also discuss the report with the hospital contact person, social worker, senior medical officer, paediatrician or general practitioner involved in their care.

Where there are unanswered questions about the post mortem report, parents/carers or clinical staff can contact Forensic Medicine social work at the relevant Forensic Medicine (NSW Health Pathology) facility for further discussion. Forensic Medicine social work will facilitate any discussion with the forensic pathologist that is required.

During discussions about the final post mortem report, any referrals or further support required by parents/carers are to be provided.

### **5 RELATED DOCUMENTS**

NSW Child Death Review Team. <u>NSW Child Death Review Team Annual Report 2017-18</u>. Sydney: NSW Ombudsman; 2018.

NSW Child Death Review Team. <u>Child Death Review Report 2015</u>. NSW Government Publication: NSW Ombudsman; 2016.

NSW Health PD2013\_007Child Wellbeing and Child Protection Policies and Procedures for NSW Health

NSW Health PD 2010\_054 Coroner's Cases and the Coroners Act 2009

NSW Health IB2010\_058 Coronial Checklist Summary

NSW Health PD2015\_040 Death - Verification of Death and Medical Certificate of Cause of Death

NSW Health PD2014\_004 Health Incident Management Policy

NSW Health <u>Management of the Death of a Child in Hospital Resource</u> (Office of Kids and Families, 2015)

NSW Health GL GL2005 063 Sudden Infant Death Syndrome (SIDS) and Safe Sleeping For Infants

NSW Health GL2017\_010 NSW Paediatric Service Capability Framework

The Royal College of Pathologists <u>Sudden unexpected death in infancy and childhood. Multiagency</u> <u>guidelines for care and investigation</u> 2016. The Royal College of Pathologists, London.

# 2. PAEDIATRI 6 ATTACHMENTS Response to Sudden Unexpected Death in Infancy (SUDI) -Roles and Responsibilities 'n

Response to Sudden Unexpected Death in Infancy (SUDI) - Roles and Responsibilities		
Role	Responsibilities	
Ambulance	Ambulance to attend, assess, attempt resuscitation (if indicated) and transport infant to hospital Complete an Ambulance Clinical Record and handover	
Police	Attend scene Explain Coronial process, provide Initial steps after a death is reported to the Coroner brochure Interview parents/carers and complete Police P79A form Ensure any objection to the post mortem is documented Liaise with Family and Community Services (FACS) Complete formal identification of the infant's body   Coordinate transfer of the infant's body to Forensic Medicine (NSW Health Pathology) Preserve and examine scene (Forensic Services, Police)	
Senior ED MO or AMO	Manage medical care, including verification of life extinction Coordinate completion of the infant's medical history (by the on-call paediatrician) Coordinate ongoing medical care of parents/carers, including documentation and referrals Coordinate staff debrief	
Paediatrician	Complete infant's medical history and documentation Consider medical cause or non-accidental injury Contact GP and relevant medical specialists Participate in Forensic Medicine (NSW Health Pathology) multi-disciplinary meeting if required	
Nurse in charge	Coordinate nursing care Liaise with hospital contact person about care of parents/carers Coordinate staff debrief	
Hospital contact person (social work/nurse)	Inform parents/carers of SUDI process Support parents/carers in spending time with infant (under clinician supervision with minimal handling) Organise practical support including private space, refreshments, support such as extended family, religious, cultural and Aboriginal Offer contact with Red Nose Grief and Loss Coordinate lactation support and/or referral, where required Provide handover to Forensic Medicine social work Provide handover to hospital social work (if not already aware)	
Forensic Medicine (NSW Health Pathology)	Pathologist completes post mortem examination Social work offers parents/carers support, advice and referral Social work and pathologist offer to discuss post mortem results with parents/carers Coordinates multi-disciplinary case review	
General practitioner	Provide information about the infant and parents/carers where required Organise ECG for parents and siblings Provide ongoing support and referral for parents/carers	
Medical records/clerical	Forward copy of infant's health care record to Forensic Medicine (NSW Health Pathology) within 24 hours of infant's death	
Coroner	Determine manner and cause of death and need for inquest based on post mortem report and police investigation Consider requests for release of post mortem report	
Clinical governance/ director medical services	Manage requests for post mortem report Distribute post mortem report to relevant clinician	
NSW Health PD2	019_035 Management of Sudden Unexpected Death in Infancy	

### 6.2 Medical History Guide – Sudden Unexpected Death in Infancy (SUDI)

### Medical History Guide - Sudden Unexpected Death in Infancy (SUDI)

The unexpected death of an infant is a tragedy for the parents/carers. Investigating infant deaths can be difficult as the situation is highly charged and emotional, and so it requires a unique and sensitive approach. This guide includes high level of detail about the infant's health, the infant's family and events in the hours before the infant's death, including the infant's exact position and the parent/carer behaviour and use of alcohol or drugs. While these questions may feel intrusive, they relate to known risks for infant mortality, help determine why the infant died and can be asked in a sensitive way.

A detailed medical history will help the forensic pathologist determine a cause of death, including whether the infant may have suffocated, or died from an undiagnosed medical problem. The history is also important in determining the presence of risk factors for Sudden Infant Death Syndrome (SIDS) and any potential child protection concerns.

The following points may assist you with the discussion:

- Where possible, have another clinician, such as a social worker or nurse, with you during the discussion with the family to provide support. If you choose to include the Police as observers while you take the history, agree on roles before starting.
- To build trust with the parents/carers start with less sensitive questions including contact information, general family history, the mother's pregnancy and health, psychosocial aspects and the infant's health, before moving onto the events leading up to the infant's death.
- Use the infant's name whenever possible. The Medical History Guide Sudden Unexpected Death in Infancy (Section 6.1) uses [infant's name] as a prompt.
- A suggested introduction is:

'I am so sorry about your loss. Some people describe feeling that it is not quite real, like a nightmare. I would like to help make sense of what has happened. I would like to find out why [infant's name] died and help you understand why. To do that I would like to find out as much as possible about your pregnancy, [infant's name] general health and sleeping and feeding patterns. I also need to ask some questions about you and your health as it will help us understand why some young babies die suddenly. Please let me know if you are uncomfortable with any of these questions.'

NSW Health PD2019 035 Management of Sudden Unexpected Death in Infancy Page 1

Medical History Guide - Sudden Unexpected Death in Infancy (SUDI)
1. Identification Infant's name Date of birth Date of death Sex M/F Ethnicity/Aboriginal/Torres Strait Islander Address Postcode
Personal information Name of mother (and address if different from infant) Date of birth Name of father (and address if different from infant) Date of birth Consanguinity (degree of relatives)
Healthcare providers Name of doctor completing the medical history Social worker Hospital contact person Other professionals Interpreter present GP name and address
Information retrieved from medical record As relevant, hospital, GP, midwife, infant's personal health record ('Blue Book') Ambulance staff Include growth chart in copy of medical record
NSW Health PD2019_035 Management of Sudden Unexpected Death in Infancy Page 2
<ul> <li>Medical History Guide - Sudden Unexpected Death in Infancy (SUDI)</li> <li>2. Details of transport of infant to hospital Place of death, home address as above/another location (specify) Time found Time arrived in emergency department (triage time) Resuscitation carried out At scene of death – police/ambulance/emergency department/hospital By who? Parents/carers/GP/ambulance paramedic/hospital staff/other (specify) Confirmation of death By who</li> <li>Time and date</li> </ul>
Location         3. Medical history         Taken to emergency department/hospital by         History given by         Relationship to infant         Family history         Details of family and household members, including names, dates of birth, health, any         previous or current illnesses including mental health, medications, occupation
Maternal parity and obstetric history         Parental relationships         Children, including children by previous partner         Household composition         Any previous childhood deaths in the family         Social history

2.44

2.	PAEDIATRICS	2.45
	Type and nature of housing	
	Major life events	
	Wider family support networks	
	History of family involvement with Family and Community Services	
	Domestic and family violence	
	Smoking, alcohol use	
	Infant's medical history	
	Pregnancy and delivery, perinatal history, feeding, growth, behaviour and development	
	Health and any previous or current illnesses, hospital admissions, medications	
	Routine checks and immunisations	
	Body systems review	
	Detailed narrative account of last 24 – 48 hours	
	(To include details of all activities and carers during the last 24-48 hours)	
	Any alcohol, medication consumed by parents/carers	
	Any medication given to infant	
	Details of infant's last sleep, including where and how placed to sleep	
	Details of feeding and care given	
	Further details of previous 2-4 weeks, including infant's health, any changes to routine, when	
	infant last seen by a health professional	
	NSW Health PD2019_035 Management of Sudden Unexpected Death in Infancy Page	3
Me	dical History Guide - Sudden Unexpected Death in Infancy (SUDI)	
	Events surrounding death	
	When infant was last seen alive and by who	
	Who found the infant, where and when, appearance when the infant found	
	Details of sleep environment, type of surface, mattress, bedding, objects, overwrapping or	
	over-heating. Face or head covered. Co-sleeping. Alcohol or drugs consumed by carers.	
	Who called emergency services	
	Details of any resuscitation at home, by ambulance and in hospital	
	For accidental/traumatic deaths, details of circumstances around the death, witnesses	
	Any other relevant history	
	May vary according to the age of the infant, nature of the infant's death	
	Genetic or metabolic disease	
	For concerns about genetic or metabolic disease, contact the paediatric metabolic	
	specialist for advice about investigations required	
	For concerns about a condition that may have implications for other family members, for	
	example cardiac dysrhythmia, contact the relevant specialist for advice about investigations	
	required Child protection and wellbeing	
	Child protection and wellbeing	
	If you have any concerns about non-accidental injury or neglect, follow usual child	
	protection procedures Conclusion	
4.0	Cause of death	
	From this history do you have an impression of the possible cause of death?	
<u> </u>	NSW Health PD2019 035 Management of Sudden Unexpected Death in Infancy Page 4	
	Now meaning D2017_055 Wanagement of Sudden Onexpected Death in mancy Page 4	

### SCHN Factsheet - Breast Care After the Death of an Infant

Copies of this brochure can be accessed via the Sydney Children's Hospitals Network website:

### Factsheet: Breast care for breastfeeding mothers after the death of a child



This fact sheet is for education purposes only. Hease consult with your doctor or other reach professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form.

# Breast care for breastfeeding mothers after the death of a child

Time after the death of your infant can be physically and emotionally exhausting. It is important that you have support during this time. When milk is not regularly removed from the breast, milk production eventually stops of its own accord. Some women experience breast engorgement, leakage of milk, discomfort and some pain during this time.

Often the only treatment needed to stop making milk, is limiting milk removal. To give your body the message to stop making milk, it is best to express only enough to keep your breasts comfortable, unless you need to clear a blockage to prevent mastitis. Caring for your breasts at this difficult time is important, as it will help make them more comfortable and reduce the risk of a blocked duct or mastitis. The following suggestions may provide some relief during this time.

### Suggestions as breasts become uncomfortable:

- Wear a well-fitting bra to provide firm breast support, rather than a tight breast binder.
- Breast pads will help absorb leaking milk. These can be the disposable or the reusable type. Change them as they become wet.
- Avoid excessive stimulation of the breast.
- Regularly applying cold compresses may provide pain relief e.g. chilled washers, cool gel packs or washed cabbage leaves can also help.
- Avoid excessive heat on your breasts.

- Consider taking analgesia as required to relieve pain and discomfort (for example paracetamol).
- Breasts should be handled gently during this time as they can bruise easily when engorged.
- Express a little milk to relieve fullness and make the breasts more comfortable. This won't interfere with the progress of suppression, as you are not emptying the breast. Hand expressing in a warm shower or bath
- can be effective as warmth and relaxation will encourage milk ejection without added nipple and breast stimulation.
- · Maintain a normal fluid intake.

### Things to watch out for:

- Engorgement- breasts become swollen, hard and painful. If this occurs it is recommended that you express your breasts completely once to relieve the pain. Then over the next few days express enough milk to keep your breasts comfortable. Applying cool packs, avoiding excessive heat and taking analgesia as needed to increase comfort may also help.
- Mastitis –lumps, red areas on the breast. Temperatures or flu like symptoms may indicate you have mastitis and medical assessment should be sought promptly.

### How long will I have milk for?

It may take weeks or months for your milk to disappear completely. Leakage may occur for some time after discomfort has settled.



This document was last reviewed on 30 August 2016

D The Children's Hospital at Westmand, Sydney Children's Rospital, Randwick and Rakidoscope Children, Young People and Ramilies.

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### The day of the funeral:

This will be a difficult and emotional day. The following hints may be helpful to consider:

- Express milk for comfort before the funeral and during the day as required.
- Wear a bra which is comfortable and well supported.
   Your bra should not be too tight.
- There may be some leakage of milk, so be prepared with some extra breast pads.
- Patterned and dark coloured tops are often less likely to show wet patches.
- Jackets or cardigans may help cover up wet spots.
- · Use analgesia as required, to help relieve breast pain.

### It is important you are well supported during this difficult time.

### Helpful organisations you may wish to contact for support include:

- SIDS and KIDS phone 1300308307 (24 hour bereavement support, counselling, support groups and workshops) www.sidsandkids.org
- Your local General Practitioner
- SANDS phone 1300 0 sands (1300 072 637) (Still born and Neonatal Death support 24/7 volunteer supporters are on call) www.sands.org.au
- Australian breastfeeding Association helpline phone 18006862686
   www.breastfeeding.asn.au
- Grief line phone 1300 845 745 (Confidential and anonymous telephone support, including counselling in diverse languages)

2.47

# 6.4 Implementation Checklist

LHD/Facility:			
Assessed by:			
IMPLEMENTATION REQUIREMENTS	Not commenced	Partial compliance	Full compliance
1. Local policies that guide management of			
SUDI are easily accesible for staff. This includes that all facilities are able to initiate a SUDI response.	<u>Notes:</u>		
<ol> <li>Information about how to access locally networked paediatrics services is easily accessible for staff.</li> </ol>	Notes:		1
3. Adequate resources and education are			
provided so that staff can meet the needs of the infant and parents/carers, including providing parents/carers with support and relevant referrals.	Notes:		
<ol> <li>Local guidance on allocation of the hospital contact person role is provided.</li> </ol>	<u>Notes:</u>		
5. Local processes support transfer of the			
infant's health care record to Forensic Medicine (NSW Health Pathology) within 24 hours of the infant's death, and include a copy of the infant's medical history.	Notes:	·	
<ol> <li>That support is available for staff who provide care to infant's and their parents/carers who have experienced SUDI.</li> </ol>	Notes:	·	·
7. Local processes maintain the quality of care and patient experience of SUDI cases.	Notes:	1	1

# **RECOMMENDED SAFE SLEEPING PRACTICES FOR BABIES** (GL2021\_013)

### GL2021\_013 resinds PD2019\_038

### **GUIDELINE SUMMARY**

The Guideline recommends safe sleeping practices to reduce the risk of Sudden Unexpected Death in Infancy (SUDI) and Sudden Infant Death Syndrome (SIDS).

### **KEY PRINCIPLES**

Health professionals use a partnership approach to engage and work with families in a culturally sensitive manner to build relationships and find ways to support families to keep their babies safe.

Carers receive consistent, clear information about the recommended safe sleeping practices routinely and opportunistically in antenatal, postnatal, newborn care and community settings until the baby is 12 months of age.

Risk assessments are conducted at specified points in care for factors that may indicate a higher risk of SUDI.

All care and care planning, including risk assessments, must be documented in the health record.

### **USE OF THIS GUIDELINE**

Local Health Districts and Specialty Health Networks must ensure relevant staff:

- receive education and training to provide safe sleeping information
- are aware of the evidence supporting the safe sleeping practices
- model safe sleeping practices
- are aware of the risk factors for SUDI and identify families who may require additional information, education and support
- develop local procedures and strategies to:
  - o to implement this Guideline
  - $\circ$  monitor practice.

The Recommended Safe Sleeping Practices for Babies guideline is available at: <a href="https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2021\_013">https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2021\_013</a>

339(27/02/21)

# MANAGEMENT OF CEREBRAL PALSY IN CHILDREN - A GUIDE FOR ALLIED HEALTH PROFESSIONALS

(GL2018\_006 issued 14/3/2018)

### PURPOSE

*Management of Cerebral Palsy in Children - A Guide for Allied Health Professionals* provides recommendations, information and guidance to support the clinical decision making of allied health professionals regarding the management of children with cerebral palsy. The guideline was prepared for the NSW Ministry of Health by an expert clinical reference group and is aimed at achieving the best possible paediatric care in all parts of the state.

### **KEY PRINCIPLES**

The guideline reflects what is currently regarded as a safe and appropriate approach to the management of children with cerebral palsy. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

As in any clinical situation and due to the heterogeneous nature of cerebral palsy, there are factors that cannot be covered by a single guide. Clinicians and clients need to develop individual treatment plans that are tailored to the specific needs and circumstances of the client. This guideline should be read in conjunction with other relevant guidelines, position papers, codes of conduct, and policies and procedures, at professional, organisational and Local Health District levels.

### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- This guideline is adopted or local protocols are developed based on *Management of Cerebral* Palsy in Children - A Guide for Allied Health Professionals
- Local protocols are in place in all hospitals and facilities likely to be required to care for children with cerebral palsy
- Ensure that all staff treating paediatric patients are educated and supported in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this revised guideline.

To download this guideline go to Management Of Cerebral Palsy In Children: A Guide For Allied Health Professionals

# FEEDING DIFFICULTIES IN CHILDREN - A GUIDE FOR ALLIED HEALTH PROFESSIONALS

### (GL2016\_007 issued 18/2/2016)

### PURPOSE

*Feeding Difficulties in Children - A Guide for Allied Health Professionals* provides recommendations, information and guidance to support the clinical decision making of allied health professionals regarding the management of children with feeding difficulties. The guideline was prepared for the NSW Ministry of Health by an expert clinical reference group under the auspice of The Office of Kids and Families and is aimed at achieving the best possible paediatric care in all parts of the state.

### **KEY PRINCIPLES**

The guideline reflects what is currently regarded as a safe and appropriate approach to the management of children with feeding difficulties. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

As in any clinical situation and due to the heterogeneous nature of feeding difficulties, there are factors that cannot be covered by a single guide. Clinicians and clients need to develop individual treatment plans that are tailored to the specific needs and circumstances of the client. This guideline should be read in conjunction with other relevant guidelines, position papers, codes of conduct, and policies and procedures, at professional, organisational and Local Health District levels.

### **USE OF THE GUIDE**

Chief Executives must ensure:

- This guideline is adopted or local protocols are developed based on *Feeding Difficulties in Children A Guide for Allied Health Professionals*
- Local protocols are in place in all hospitals and facilities likely to be required to care for children experiencing difficulties with feeding
- Ensure that all staff treating paediatric patients are educated and supported in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this revised guideline.

To download this guideline go to

Feeding Difficulties in Children - A Guide for Allied Health Professionals

296(18/2/16)

# SUSPECTED CHILD ABUSE AND NEGLECT (SCAN) MEDICAL PROTOCOL (GL2014\_012)

### PURPOSE

This protocol provides medical staff with a standard template and clinical guidance to record a forensically orientated medical assessment of a child or young person. A forensically oriented medical assessment is conducted to enable an opinion to be formed as to the probability that injuries have been caused intentionally or that neglect is present.

### **KEY PRINCIPLES**

Medical staff are required under the *Children and Young Persons (Care and Protection) Act 1998* to provide medical examinations of children and young people in need of care and protection when requested by Community Services or the NSW Police Force, s173; or upon order of the Children's Court, s53. The SCAN Medical Protocol should be used to document these examinations. As a minimum this protocol should be used to document findings in all s173 examinations. An examining doctor is required to provide a written report to the Director General Community Services following completion of a s173 medical examination. The NSW Police Force, the Joint Investigation Response Team (JIRT) and Community Services are required to serve the hospital with a notice requesting s173 medical assessment.

### **USE OF THE GUIDELINE**

The Protocol should be used in conjunction with NSW Health Policy Directive *PD2013\_007 Child Wellbeing and Child Protection Policies and Procedures for NSW Health* which provides information to assist health workers to recognise and respond to child wellbeing and child protection concerns by setting out the legislation; the interagency and NSW Health policies that empower health workers; child abuse and neglect risk indicators; the mandatory reporting requirements and the tools and response mechanisms to children and young people suspected at risk of significant harm.

The NSW Health State Forms Management Committee has endorsed the SCAN Medical Protocol as a form for State-wide use. The Protocol can be accessed as a downloadable self-print document from the NSW Health print portal <u>https://eprintondemand.salmat.com.au</u>

To download the Guideline please go to http://www.health.nsw.gov.au/policies/gl/2014/GL2014\_012.html

## 2. PAEDIATRICS NEONATAL ABSTINENCE SYNDROME GUIDELINES (GL2013\_008)

### GL2013\_008 rescinds PD2005\_494.

### PURPOSE

These Guidelines specifically address the management of newborns to mothers with a history of opioid use or opioid dependence, including women currently receiving opioid substitution treatment (methadone or buprenorphine) or using prescription pharmaceutical opioids (such as oxycodone, morphine, pethidine or tramadol).

While Neonatal Abstinence Syndrome (NAS) is more common in infants born to opioid dependent women than in infants born to women dependent on other drugs, the effect of polydrug use on NAS is not clearly established and is most likely dependent upon the specific combination and quantities of drugs used by the mother.

Provided that neonatal abstinence syndrome is appropriately managed, it is not currently known to be associated with long-term health problems.

### **KEY PRINCIPLES**

The Guidelines concentrate on two main aspects of care:

- 1. The care of the opioid-dependent pregnant woman from a drug and alcohol perspective based on "Harm Minimisation" principles, and;
- 2. The care of the newborn from a child protection perspective.

These guidelines should be used to guide clinical management; however clinicians must always consider the pregnant woman they are managing as an individual, and apply the guidelines appropriately.

Opioid dependent pregnant women have an increased risk of experiencing complications during pregnancy and of their infants experiencing adverse outcomes. The association is complex and may be affected by a range of factors including: poly substance use; inadequate antenatal care; poor nutrition; blood borne virus exposure; mental health problems; housing; and domestic violence. Births in mothers with opioid, stimulant or cannabis use diagnoses are associated with a number of negative neonatal outcomes. Babies are more likely to be born before the gestational age of 37 weeks, to be of low birth weight, and to be admitted to neonatal intensive care units or to special care nurseries than babies born to mothers without such a diagnosis.

Many women are more motivated during pregnancy to make important health and lifestyle changes. This is an ideal time to engage, or more fully engage, a woman in care for her drug use and other problems. A range of services are required to work collaboratively in order to ensure optimal outcomes for both the mother and newborn. The aim is to minimise the likelihood of complications and to provide comprehensive antenatal and postnatal care in a non judgemental, non-threatening environment.

### **USE OF THE GUIDELINE**

While the focus of these Guidelines is opioid dependent women it is recognised that other illicit drugs such as stimulants, sedatives, alcohol and some psychotropic medications may also be associated with NAS and these women and newborns may have similar care needs. Therefore, the care elements of the Guidelines (which exclude elements specifically relating to opioid pharmacology as found in parts of Sections 8.1, 8.2 and 9.5) also apply to this group of women and their infants.

185(05/09/13)

The Guidelines outline minimum standards for the management of NAS. Local Health Districts are responsible for ensuring that maternity services develop clear clinical protocols relevant to each maternity health care facility, based on these Guidelines.

Local policies and guidelines need to be formalised to ensure that the roles and responsibilities of the multidisciplinary team are clear. The guidelines provide advice on a continuum of care (Diagram 1), that includes care of the mother and infant from antenatal care through discharge and follow up.

A number of key priorities are identified in the NAS Guidelines and should be included in any local clinical guidelines or business rule: the early recognition and engagement of the opioid dependent pregnant woman and new mothers into multi-disciplinary team care (Section 6); the care of the newborn child Section 7); the postnatal care of both the mother and child (Sections 8, 9, 10); and the care and protection responsibilities of health workers clinically involved in the care of the newborn (Section 3).

Severe neonatal withdrawal is an indication for pharmacological management of NAS. The Neonatal Abstinence Score (or Finnegan Score – Refer Appendix 3) was developed to monitor the progress of infants experiencing neonatal abstinence due to opioid exposure in utero. It can be used as a trigger for pharmacological treatment of neonatal abstinence (Refer Section 8.2). Provided that neonatal abstinence is appropriately managed, it is not currently known to be associated with long-term health problems.

Section 5 deals with care of the mother's drug dependence during pregnancy and provides advice regarding withdrawal from heroin and assistance in determining a suitable Opioid Substitution Therapy, if required.

Section 6.6 provides advice regarding appropriate assessment and identification of risk for mother and foetus. This section outlines the process for prenatal reporting, including when reporting should be undertaken and the criteria used in assessing a need to report.

Section 8.2 outlines postnatal care of the infant. All infants born to drug dependent mothers should receive routine postnatal monitoring, along with specific assessment for the signs and symptoms of NAS using the Finnegan Neonatal Abstinence Severity Score (NASS) or modified Finnegan scale (See Appendix 3). Monitoring should commence within 2 hours after birth and be conducted 30 - 60 minutes after a feed. The score is an important guide for the appropriate pharmacologic treatment of NAS and health-care providers involved in the care of opioid-exposed infants must be educated in the appropriate application of these scores.

The issue of breastfeeding is complex because of the range of drugs used, their half-life and their interactions. Section 8.4 provides advice for breastfeeding based on the premise that breast milk is the most complete form of nutrition for infants, with a range of benefits for health, growth, immunity, and development. There are times however when the breast milk should be expressed and discarded, particularly following psychostimulant use.

To download the Guideline go to http://www.health.nsw.gov.au/policies/gl/2013/GL2013 008.html

2.54

185(05/09/13)

# **RURAL PAEDIATRIC EMERGENCY CLINICAL GUIDELINES, THIRD EDITION** (GL2021\_011)

### GL2021\_011 rescinded GL2020\_016

### **GUIDELINE SUMMARY**

The Guideline provides First Line Emergency Care Course (FLECC) trained nurses with best practice guidance for early management of acute and life-threatening conditions. It is relevant to rural and remote paediatric inpatient areas.

The Guideline aligns with the NSW "Between the Flags" program and facilitates management in the absence of immediate access to a medical officer. It improves overall care and outcomes for infants and children in rural and remote hospitals by allowing treatment to be commenced immediately.

### **KEY PRINCIPLES**

The Guideline is designed to:

- improve emergency care and outcomes for patients in the rural and remote health care settings of NSW
- assist rural and remote Emergency Departments (EDs) in NSW achieve benchmarking targets and best practice standards for patients presenting to emergency
- provide best practice guidance, and to support the role that many Registered Nurses currently perform in rural and remote settings.

In circumstances where a patient meets more than one guideline, the most lifethreatening condition should take priority and the most appropriate corresponding guideline commenced.

### **USE OF THE GUIDELINE**

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of the revised Guideline. Implementation should occur in conjunction with the local Clinical Emergency Response System (CERS) and continuing professional development.

Chief Executives must ensure that:

- the Guideline is adopted or that local protocols are in place in all hospitals and facilities likely to be required to provide emergency treatment to infants and children
- emergency nurses have the opportunity to access the First Line Emergency Care Course (FLECC).

FLECC-trained nurses must ensure that:

• a designated medical officer is notified as soon as practicable

FLECC-trained nurses and medical officers must ensure that:

- medication standing orders contained and used in the Guideline are reviewed and authorised by the designated medical officer as soon as possible (within 24 hours) and;
- the medical officer countersigns the record of administration on the patients' medication chart

Enrolled nurses and registered nurses who are not FLECC credentialed using the guideline to inform assessment and management, are not to undertake shaded interventions that require FLECC credentialing unless previous recognition of prior learning has been granted.

### The Guidelines can be downloaded at <u>Rural Paediatric Emergency Clinical Guidelines, Third</u> <u>Edition</u>

# 2.PAEDIATRICS2.56STANDARDS FOR PAEDIATRIC INTRAVENOUS FLUIDS: NSW HEALTH (SECOND<br/>EDITION) (GL2015\_008)

### GL2015 008 rescinds GL2014 009.

### PURPOSE

Intravenous fluids are important components of appropriate care for hospitalised children. Reports in the medical literature and warnings issued in other countries have highlighted the risks associated with use of low sodium content fluids. The importance of appropriate glucose content has also been identified.

The NSW Chief Paediatrician was tasked to engage clinical experts, Healthshare and a range of other partners in the development of state wide standards across all NSW facilities. The resulting *Standards for Paediatric IV Fluids: NSW Health* addresses fluid content, bag size, labelling, administration, procurement and storage.

Emerging new evidence and clinical experience motivated an early revision of the Standards, resulting in this second edition.

### **KEY PRINCIPLES**

The intended outcomes of the first edition of the standards regarding the content of IV fluids in children and neonates included:

- Reducing the risk of hyponatremia through increased sodium content and limiting the use of low sodium containing fluids.
- Addressing glucose requirements of children and neonates through increased glucose content.
- Consistent inclusion of potassium chloride as early as considered safe and appropriate.

The key changes in the second edition of the Standards regarding the content of IV fluids for children and neonates include:

- Incorporating further evidence supporting the use of isotonic saline solutions in IV maintenance therapy.
- Standardising the use of 1000mL bags in the care of children beyond the specialist children's hospitals.
- Incorporating Special Care Nursery practice and clarification around IV fluids for neonates.

The Statement of the *Standards for Paediatric Intravenous Fluids: NSW Health* (page 8) provides a summary of the recommended standards.

### **USE OF THE GUIDELINE**

The following priorities have been identified to facilitate the implementation of *Standards for Paediatric Intravenous Fluids: NSW Health* (second edition) into all relevant clinical areas; Communication, Education and Raising Awareness, Integration into Practice, Procurement and Monitoring.

To download the Guideline please go to Standards for Paediatric Intravenous Fluids: NSW Health (second edition)

250(03/09/15)

### 2. PAEDIATRICS STANDARDS FOR PAEDIATRIC INTRAVENOUS FLUIDS (IB2014\_066)

### PURPOSE

To advise clinicians and managers about the products recommended in the Standards for Paediatric IV fluids (GL2015\_005) published in August 2015. The Standards address the appropriate choice of IV fluids and measures related to their procurement, storage and safe administration.

Chief Executives are to ensure that the requirements of this information bulletin are communicated to all appropriate staff.

### **KEY INFORMATION**

All fluids recommended in the Standards are available for order from Baxter Healthcare. Some products are compounded and some products are manufactured in the Baxter Toongabbie facility.

### **Compounded IV Products**

Products that are compounded in the Baxter Pharmacy need to be ordered taking into consideration the appropriate lead time (please see the ordering document below).

As they are compounded these products are generally more expensive. If there is sufficient high demand for a compounded product then it may become a custom manufactured product (also known as Therapeutic Goods Administration or TGA Schedule 5A) with storage and cost benefits to healthcare facilities.

The only way to reduce the price of these products is to consistently order according to the Standards.

Schedule 5A Solutions (AHK codes) are made in the Baxter Toongabbie facility and are ordered through Baxter Customer Service. For your first order only a Pharmacist will have to sign a TGA Schedule 5A form. This does not mean these IV fluids will always have to be ordered by your pharmacy department. All subsequent orders will be covered by the initial TGA form. You are not able to receive your order until this form has been completed and returned to Baxter Healthcare. Each individual AHK code must have a signed TGA form. Therefore, your Pharmacist may need to complete several forms for your institution.

### **IV Bag Sizes**

500mL and 1000mL bags will be available to NSW facilities for an initial two years and usage monitored. As the Children's Hospitals only use the 1000ml bags, that price will be lower due to the higher demand. Fluids for neonates will continue to be supplied only in 500mL bags (or less).

### **Potassium Chloride Products**

All products containing potassium chloride (including compounded products) will now be supplied with a pink over-pouch.

### **Pre-Packaged Bags**

The practice of adding potassium chloride or glucose to paediatric IV fluids should be discouraged. If this practice is because of the cost of specific fluid bags, then the use of less expensive 1000mL bag versions should be considered in the interest of patient safety in paediatric areas (not for neonates).

It is strongly recommended that, wherever possible, pre-packaged bags of appropriate IV fluids are available and used with the correct concentrations of sodium, glucose and potassium, across all NSW facilities. The use of premade/pre-packaged IV Fluid bags in paediatrics is also encouraged by:

- Sydney Children's Hospitals Network Intravenous Fluid and Electrolyte Therapy Practice Guideline 2013 (page 5)
- Royal Children's Hospital, Melbourne Intravenous Fluids Clinical Practice Guideline.

### **Paediatric Infusion Sets**

As per NSW Health policy directive PD2010\_034, Section 3.3.10 – "Paediatric infusion sets with inline burette must be used for all children requiring intravenous therapy. An infusion pump should be used in all children".

### **Ordering enquiries**

For AHK and AHB Baxter IV fluid codes

Baxter Customer Service - Telephone - 1300 789646

For the compounded IVS.1000-5000 products Baxter Pharmacy Services: Telephone: 1800 227 487 or (02) 9848 1395

Fax: 1800 025 887 or (02) 9848 1155.

To avoid waste and reduce costs we encourage coordinated ordering across LHDs for the purchasing of less frequently used IV fluids.

Baxter – 2014 – Paediatric IV Fluids Order Form NSW

250(03/09/15)

### INFANTS AND CHILDREN: ACUTE MANAGEMENT OF ALTERED CONSCIOUSNESS IN EMERGENCY DEPARTMENTS (GL2014\_019)

### PURPOSE

The Infants and Children: Acute Management of Altered Consciousness in Emergency Departments: first edition Clinical Practice Guideline has been developed to provide direction to clinicians and is aimed at achieving the best possible paediatric care in all parts of the state. The Clinical Practice Guideline was prepared for the NSW Ministry of Health by an expert clinical reference group under the auspice of the state wide Paediatric Clinical Practice Guideline Steering Group.

### **KEY PRINCIPLES**

This guideline applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts to have local guidelines/protocols based on the attached Clinical Practice Guideline in place in all hospitals and facilities required to assess or manage children with altered consciousness.

The clinical practice guideline reflects what is currently regarded as a safe and appropriate approach to the acute management of altered consciousness in infants and children. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- Local protocols are developed based on the *Infants and Children: Acute Management of Altered Consciousness in Emergency Departments: first edition* Clinical Practice Guideline.
- Local protocols are in place in all hospitals and facilities likely to be required to assess or manage paediatric patients with altered consciousness.
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this new guideline.

To download the Guideline please go to Infants and Children: Acute Management of Altered Consciousness in Emergency Departments

231(18/12/14)

### 2. PAEDIATRICS 2.60 INFANTS AND CHILDREN: ACUTE MANAGEMENT OF COMMUNITY ACQUIRED PNEUMONIA (GL2018 007)

### GL2018 007 issued 16/03/2018 rescinds GL2015 005.

### PURPOSE

This Clinical Practice Guideline provides evidence based direction to clinicians in the acute management of community acquired pneumonia. It is aimed at achieving the best paediatric clinical care in the assessment and management of acute community acquired pneumonia and appropriate escalation responses across New South Wales.

### **KEY PRINCIPLES**

This Guideline applies to all facilities where paediatric patients are managed. It requires Chief Executives of all Local Health Districts and specialty health networks to determine where local adaptations are required or whether it can be adopted in its current format in all hospitals and facilities required to manage children with community acquired pneumonia.

The Clinical Practice Guideline reflects what is currently regarded as a safe and appropriate approach to the acute management of community acquired pneumonia in infants and children. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- This Guideline is adopted or local protocols are developed based on the Infants and Children: Acute Management of Community Acquired Pneumonia, March 2018 Clinical Practice Guideline.
- Local protocols are in place in all hospitals and facilities likely to be required to assess or manage paediatric patients with community acquired pneumonia.
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric guidelines.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this new guideline.

To download the Guideline please go to Infants and Children: Acute Management of Community Acquired Pneumonia

296(16/03/18)

# **STATEWIDE INFANT SCREENING – HEARING (SWISH) PROGRAM** (GL2010\_002)

## PURPOSE

This document sets out guidelines for the SWISH program including screening protocols and referral pathways. In doing so, the guidelines describe roles and responsibilities of staff; equipment and protocols for screening, coordination, audiological assessment and paediatric medical assessment.

Technology is available to diagnose hearing problems in the neonatal period. Early identification and intervention are important, with research suggesting that intervention commencing by 6 months of age may result in optimal speech and language development and minimise the need for ongoing special education.

## **KEY PRINCIPLES**

The Guidelines outline the responsibilities each stage has in the hearing screening pathway. Each Area Health Service (Area or AHS) has a SWISH Coordinator responsible for implementing and managing the screening program across all facilities in their Area. This model allows SWISH Coordinators flexibility to meet unique needs in their Area Health Service. SWISH Coordinators have adopted innovative approaches to ensure maximum screening capture such as service agreements with private hospitals and employing dedicated screeners to meet local needs (eg. Indigenous and Culturally and Linguistically Diverse (CALD) populations). (Chapter 2 & 3)

SWISH diagnostic audiology services are provided through the three tertiary paediatric hospitals which are the acute care hubs of the three paediatric services networks which cover the state (Greater Western, Northern and Greater Eastern and Southern). These hospitals are:

- The Children's Hospital at Westmead;
- John Hunter Children's Hospital, Newcastle; and
- Sydney Children's Hospital, Randwick.

Jim Patrick Audiology Centre is used as an overflow site for unilateral referrals in the Greater Western service network. Jim Patrick Audiology Centre is part of the Royal Institute of Deaf and Blind Children. (Chapter 4)

All referred newborns receive an audiological assessment. If a hearing loss is detected medical assessment and family support is available. A child who is diagnosed with hearing loss in the program could be referral to *Australian Hearing*, SWISH Hearing Support Services and other medical specialists. (Chapter 5)

If diagnosed as having hearing impairment, newborns are provided with options available for intervention services appropriate to the degree of hearing loss and specific diagnosis. Support is provided by the diagnosing Audiologist and SWISH Parent Support (Social Worker) in assisting parents to make the decisions. Parents are also consulted about early intervention, eg. hearing aids, cochlear implant and educational programs. (Chapter 6)

### **USE OF THE GUIDELINE**

The Guidelines of the Statewide Infant Screening - Hearing (SWISH) program are to be used by staff working specifically within the following roles of the NSW Statewide Infant Screening - Hearing program both in public and private sectors.

- Screening Staff (Chapters 2 and 3)
- Area Health Service SWISH Coordinators (Chapters 2 and 3)
- SWISH Diagnostic Audiologists (Chapter 4)
- SWISH Paediatricians (Chapter 5)
- SWISH Parent Support (Social Workers) (Chapter 6)

The Guidelines can be accessed at <u>http://www.health.nsw.gov.au/policies/gl/2010/GL2010\_002.html</u> 80(18/02/10)

# SAFETY AND WELLBEING OF CHILDREN AND ADOLESCENTS IN NSW ACUTE HEALTH FACILITIES (PD2022 053)

### PD2022\_053 rescinds PD2010\_032, PD2010\_033, PD2010\_034

### **POLICY STATEMENT**

NSW Health recognises that the physical, developmental, social and emotional needs of children and adolescents change over time, are unique and are different to the needs of adults. Children and adolescents are among the most vulnerable groups in healthcare settings.

NSW acute health facilities must provide care in line with children and adolescent's individual needs, capabilities, maturity and independence; consider the different risks of harm and have strategies in place to mitigate them.

### SUMMARY OF POLICY REQUIREMENTS

The promotion of safe, reliable, and effective patient centred care for children and adolescents is underpinned by the following principles as described in the <u>Charter on the Rights of Child and Young</u> <u>People in Healthcare Services in Australia</u>.

Children and adolescents being cared for in NSW Hospitals can expect:

- the highest attainable standard of healthcare
- equity of access and care for vulnerable population groups including Aboriginal peoples, people who live in rural and remote areas, culturally and linguistically diverse (CALD) communities, people with mental illness, children with intellectual or physical disability and those from socio-economically disadvantaged areas
- their best interests are the primary concern of all involved in their care care provided in line with their developmental stage and ability
- to be kept safe from all forms of harm
- care that supports their gender identity and expression trauma-informed care
- to be able to express their views, and to be heard and taken seriously
- respect for Aboriginal cultures, including recognition that health refers to social, emotional and cultural wellbeing
- respect for themselves as a whole person, as well as respect for their family and the family's individual characteristics, beliefs, culture and context
- to have their family relationships supported by the service providing care information to be provided in a form than is understandable to them
- to participate in decision-making and, as appropriate to their capabilities, to make decisions about their care
- to have their privacy respected
- to participate in education, play, creative activities and recreation
- continuity of healthcare, including well-planned care that takes them beyond the paediatric context.

Local Health Districts and Speciality Health Networks must communicate the information contained within this Policy to relevant facilities and staff; and ensure that consistent local policies are developed and distributed to relevant clinical areas.

Local Health District Chief Executives are responsible for assigning responsibility, personnel and resources to implement this Policy; establishing mechanisms to ensure the mandatory requirements are applied, achieved and sustained. Chief Executives are also responsible for ensuring that any local policy reflects the requirements of this policy and is written in consultation with the hospital executive, clinical governance unit and clinical staff.

# 1. BACKGROUND

This document was written in consultation with a reference group of clinical experts. Extensive statewide consultation informed further changes to the document.

This document includes:

- principles underpinning the care, safety and wellbeing of children and adolescents
- standards for the provision of clinical care
- standards for safety.

These principles and standards are essential components that enable NSW hospitals to provide care in the right place, at the right time, as close to home as possible.

# 1.1 About this document

The purpose of this Policy is to promote the safety and wellbeing of children and adolescents in NSW hospitals and acute health services.

This Policy applies to all acute health facilities where paediatric and adolescent patients are cared for. It mandates standards to ensure children and adolescents receive safe and appropriate care whilst in acute facilities.

This Policy must be followed by all organisations delivering acute health services. It is the responsibility of Local Health Districts / Speciality Health Networks to:

- communicate the information contained within this Policy to relevant facilities and staff; and
- adhere to and implement this Policy.

# **1.2 Key definitions**

Admitted patient	An admitted patient is a person:
	(i) whom a clinician with admitting rights to the facility has
	determined meets the admission criteria
	(ii) has undergone the admission process
	(iii) has not been separated by the facility.
	A patient treated solely within the ED is not an admitted patient.
Child and Adolescent under	A child or adolescent who has been removed from the care of their
Assumption of Care Order	parents/carers and their care has been assumed by Department of Communities and Justice.
Child and adolescent	For the purpose of this Policy, a child and adolescent is defined as
	aged up to their 16 <sup>th</sup> birthday. This Policy recognises that the needs of children and adolescents change with their age and developmental
	stage.
Paediatrics	The branch of medicine centred on the health and medical care of children and adolescents until transition to adult health services.
Parents/carers	Parents and carers is a broad term including those who are closest to
	the patient in knowledge, care and affection, for example parents,
	siblings, grandparents, aunts, uncles, cousins, friends, kin and carers.
	It also includes guardianship arrangements and extended familial
	relationships and kinship relationships for Aboriginal communities.

NSW Hospitals and Acute	This Policy covers health facilities and services where children and
Health Services	adolescents are treated and where the primary clinical purpose or
	<ul><li>treatment goal is to:</li><li>cure illness or provide definitive treatment of injury</li></ul>
	<ul> <li>cure timess of provide definitive treatment of injury</li> <li>perform surgery (other than when the exceptions documented in</li> </ul>
	• perform surgery (other than when the exceptions documented in the included guidelines apply)
	<ul> <li>relieve symptoms of illness or injury</li> </ul>
	<ul> <li>reduce severity of an illness or injury</li> </ul>
	<ul> <li>perform diagnostic or therapeutic procedures, and/or</li> </ul>
	<ul> <li>protect against exacerbation and/or complication of an illness</li> </ul>
	and/or injury which could threaten life or normal function.
	This policy includes Children's wards or units in NSW Hospitals and
	other areas in NSW Hospitals and outpatient services that treat
	children and adolescents. It does not include community health
	services.
Mature Minor	A minor who has a sufficient level of understanding and intelligence
	to enable them to understand fully what medical or healthcare
	treatment is proposed. Mature Minors may independently consent to or refuse medical or healthcare treatment (see the <u>NSW Health</u>
	Consent to Medical and Healthcare Treatment Manual). There is no
	set age at which a child or young person is capable of giving consent.
	It depends upon the treatment being proposed and the minor's ability
	to fully understand the implications of that treatment. The term
	Mature Minor is interchangeable with the term Gillick Competent. A
	court may still override a Mature Minor's consent to or refusal of
	treatment in the Mature Minor's best interests.
Paediatric admission	A paediatric admission refers to children and adolescents under 16
	years of age. Adolescents aged 16 years and older will usually be
	admitted to an adult ward or hospital. By exception, some 16 and 17
	year olds may be admitted to a children's ward/hospital following negotiation, including older adolescents who have not completed
	transition to adult health services for chronic or complex care.
Paediatric safe bed or	A safe bed or space is an environment which meets the physical,
environment	developmental, social and emotional needs of children and
	adolescents.
Safety	Avoidance of harm to patients from the care that is intended to help
	them, this includes consideration of harms in regard to:
	• cultural safety
	medication safety
	• mental health safety
	emotional safety
	• sexual safety
	• online safety
	• physical safety
	• infection prevention and control.
Transition	The purposeful planned movement of adolescents and young adults
	with chronic physical and medical conditions from child-centred to
<b>—</b> • • • •	adult oriented health care systems.
Trauma informed care	Trauma-informed care recognises the impact that traumatic events
	have on a child or adolescent's wellbeing. Trauma informed care
	involves:
	<ul> <li>understanding the impact of trauma on children and the family</li> </ul>
	<ul> <li>providing care in a place that is physically and emotionally</li> </ul>
	safe

2. PAEDIATRICS		2.65
	<ul> <li>ensuring the workforce is culturally competent and can implement practices that are respectful of cultural backgrounds</li> <li>helping children and adolescents who have been victims of trauma regain control of their day-to-day lives.</li> </ul>	
	<ul> <li>including communities in governance processes and decision making about the design of services.</li> </ul>	1-
Zero tolerance	A zero-tolerance approach means that as far as reasonably practicable action will be taken to prevent violence. Appropriate action will be taken to protect staff, patients and visitors from the effects of violence, while ensuring clinical services continue to be provided in a way that maximises the safety of patients, staff and others. Action may include both clinical and / or non-clinical interventions as appropriate.	

# **1.3 Legal and legislative framework**

NSW Hospitals and Acute Health Services have statutory obligations regarding the care and protection of children and young people under the Children and Young Persons (Care and Protection) Act 1998.

For more information about other legal obligations with regards to the safety and wellbeing of children, please refer to relevant Policy Directives, or contact the <u>Legal Branch</u> at NSW Health for assistance.

# 2. CLINICAL CARE

Services must align with the eight standards outlined in the <u>National Safety and Quality Health Service</u> <u>Standards</u>.

# 2.1 Alignment with role delineation and service capability

NSW Hospitals must provide a defined scope of services as described in the <u>NSW Health</u> <u>Guide to the</u> <u>Role Delineation of Clinical Services</u>.

All NSW Hospitals must provide clinical services in line with the facility's scope of services for paediatric medicine and surgery for children and adolescents.

The <u>NSW Health Guide to the Role Delineation of Clinical Services</u> describes the minimum support services, workforce and other requirements for clinical services to be delivered safely. Service capability describes the planned activity and clinical complexity that a facility is capable of safely providing.

The NSW Health Guideline *NSW Paediatric Services Capability Framework* (<u>GL2017\_010</u>) identifies the scope of planned activity for each paediatric service capability level and supports the provision of high quality, safe and timely care for infants, children and adolescents as close to home as possible.

Suggested links and reading Charter on the Rights of Children and Young People in Healthcare Services Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service (NSQHS) Standards User guide for acute and community health services organisations that provide care for children Integrated Prevention and Response to Violence, Abuse and Neglect Framework The first 2000 Days Framework NSW Youth Health Framework 2017-24

# 2.2 A Networked Approach

NSW Health services must use appropriate networks to support the provision of high-quality healthcare across NSW as close to home as possible. There are a range of networks including the NSW Children's Healthcare Network, the Agency for Clinical Innovation Paediatric Network and other relevant peer networks.

Suggested links and reading The Children's Healthcare Network The ACI Paediatric Network The ACI Network Pages

# 2.3 Triage and Assessment in Emergency Departments

Triage is an essential function in Emergency Departments (EDs) and ensures that patients are treated in the order of their clinical urgency with reference to their need for time-critical intervention.

EDs must comply with the NSW Health Policy Directive *Triage of Patients in NSW Emergency Departments* (PD2013\_047) which outlines the role, key responsibilities and the processes that support efficient and safe triage.

Following triage, the NSW Health Policy Directive *Emergency Department Patients Awaiting Care* (<u>PD2018\_010</u>) outlines the requirements for communication, the environment, recognition of deterioration and commencement of clinical care.

Suggested links and reading

Guidelines on the implementation of the Australasian Triage Scale in Emergency Departments The ACI: Paediatric Network Resources

# 2.4 Recognising and Responding to Deteriorating Patients

NSW Health Policy Directive *Recognition and management of patients who are deteriorating* (<u>PD2020\_018</u>) mandates that local systems, structures and processes must be in place to support the recognition, response to and management of the physiological and mental state deterioration of patients.

Clinicians who provide care for children and adolescents must understand the clinical differences between deteriorating children, adolescents, and adults. This includes training in the recognition of the sick and deteriorating child or adolescent.

All NSW Hospitals must ensure all staff are made aware of the local Deteriorating Patient Safety Net System, including how to activate their local Clinical Emergency Response System (CERS), and their roles and responsibilities under the system. This includes

R.E.A.C.H. (Recognise, Engage, Act, Call, Help is on its way) for patients and parents/carers to escalate concerns about changes to a patient's condition.

All clinicians who provide direct patient care must complete the mandatory Between the Flags - Deteriorating Patient Learning Pathway training, including the Paediatric patient module.

# 2.5 Plan of Care

Paediatric patients in a hospital must have a clearly defined and documented treatment plan of care that includes:

- the name and contact details of the Attending Medical Officer (AMO) a diagnosis (provisional or definitive)
- a treatment plan consistent with clinical practice guidelines a plan for hydration, nutrition and fluid balance
- observation type and frequency, outline in the deteriorating patient policy expected frequency of clinical review and estimated date of discharge, and
- changes in patient condition aligned with the deteriorating patient policy.

### PAEDIATRICS 2.

A comprehensive and contemporaneous record of care must be documented in the patient's health record with changes in condition noted at the time they occurred including actions taken.

The process of care planning must reflect the preferences of the child, the adolescent, and their parents/carers and:

- be tailored to children and adolescents' individual needs
- consider the need for attachment, which allows a patient to connect with and gain reassurance from their parent/carer during times of need or distress
- involve the planning for continuity of care after admission. •

All children and adolescents admitted to NSW Hospitals must have a risk screen completed to identify, escalate, and manage risks or concerns.

Clinicians must consistently use the risk screening and assessment approaches and processes as directed by state, district or network, and facility policies.

Districts, networks and facilities must facilitate access to validated screening tools and provide clinicians with clear pathways to follow when screening to identify need for further assessment and planning of risk mitigation strategies.

### Suggested links and reading

Paediatric Clinical Practice Guidelines

NSW Health Information Bulletin Paediatric Clinical Guidelines (IB2020 041) Australian Commission on Safety and Quality in Health Care, The National Safety and Quality Health Service (NSOHS) Standards Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service (NSOHS) Standards User guide for acute and community health services organisations that provide care for children

CEC: Fall and entrapment prevention

# 2.6 Escalation of Care

NSW Hospitals must have escalation plans in place to ensure the appropriate accommodation of a sick or injured child and/or adolescent, in accordance with NSW Health Policy Directive Critical Care Tertiary Referral Networks (Paediatrics) (PD2010 030) and NSW Health Policy Directive Emergency Paediatric Referrals (PD2005 157).

# 2.7 Consultation with on-call Specialists

General Practitioners who admit children or adolescents under their care must contact the local or regional paediatrician within 12 hours of admission to develop a collaborative plan for ongoing management. Consultation is required daily thereafter, or when there is handover to a new admitting doctor.

Consultation is required at any time when there is deterioration, inadequate response to treatment, diagnostic uncertainty or activation of the Clinical Emergency Response System (CERS) by staff, the patient or family/carer. Clinicians must refer to the local facility's CERS which outlines the requirement for response to a deteriorating patient within its care. The local CERS must include the escalation process for transferring patients that require higher- level care to a facility that can provide it.

Decisions regarding inpatient care for children and adolescents with mental health problems must be determined in line with the NSW Health Policy Directive Children and Adolescents with Mental Health Problems Requiring Inpatient Care (PD2011 016).

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# 2.8 Workforce

Children and adolescents must be cared for by staff with appropriate skills, experience and qualifications to meet their physical, psychological, developmental, communication and cultural needs.

Staff caring for children and adolescents must have completed statewide and Chief Executive directed mandatory training requirements for clinical staff who provide care for children and adolescents. The mandatory training <u>Matrix and Targeting Guide</u> provides an overview of mandatory training requirements.

Completion of Health Education and Training Institute (HETI) core training modules in paediatric resuscitation, recognition of the deteriorating patient, child protection training, and, for staff administering medication, paediatric medication safety training, are recommended. Staff caring for children and adolescents must keep up to date with any changes to the mandatory training requirements.

All wards/units/departments must have access to clinical education.

There must be a nurse/midwife with appropriate experience in the In Charge of Shift role where a Nurse Unit Manager is absent. To ensure safe systems of work and patient safety, staffing should be determined by consideration of:

- requirements for paediatric drug checking and various other patient-related procedures
- the number and acuity of the patients within each ward, unit and department within a clinical service
- the skill level of nurses required to provide care.

### Suggested link Public Health System (Nurses' and Midwives') State Award

# 2.9 Improving Access to Care

To ensure children and adolescents receive the right care, at the right time, closer to home, NSW Hospitals must:

- provide a range of modalities of care to support the provision of child and adolescent care (this may include but is not limited to Hospital in the Home (HITH), outpatient and ambulatory care clinics, and virtual care, also known as telehealth)
- provide access to appropriate specialist staff and facilities in line with and networking arrangements and service capability.

### Suggested reading

NSW Health Guideline Adult and Paediatric Hospital in the Home Guideline (GL2018\_020)

# 2.10 Outpatient Care

Outpatient services for children and adolescents must be provided in line with the NSW Health Guideline *Outpatient Services Framework* (GL2019\_011) and ensure the provision of youth friendly services for adolescents as outlined in the NSW Health Policy Directive *NSW Youth Health Framework* 2017-24 (PD2017\_019).

# 2.11 Continuity of Care

Systems must be in place to ensure continuity of healthcare, including:

- coordination between and within the various services working with children, adolescents and their parents/carers
- continuity across different geographically locations post discharge care
- appropriate planning for transition to adult services for those with chronic/long term health issues.

### Suggested links and reading

NSW Health Policy Directive Departure of Emergency Department Patients (<u>PD2014\_025</u>) <u>CEC:</u> <u>Safety Huddles</u>

# **3. SAFETY PROCEDURES**

# 3.1 Safety of children and adolescents whilst in care

NSW Hospitals must ensure the safety of children and adolescents in terms of the following:

- cultural safety
- medication safety
- mental health
- safety emotional safety
- sexual safety
- online safety
- physical safety
- infection prevention and control.

All children and adolescents must be located in a paediatric safe bed regardless of the availability of a paediatric ward or unit.

A paediatric safe bed is a bed, located anywhere within a facility (including ED, imaging or a general ward or unit), that meets the criteria for ensuring the safety of the child and adolescent in line with the following principles.

Children and adolescents must be:

- cared for in a safe and appropriate environment that meets their physical, developmental, cultural and psychosocial needs
- easily observed and supervised at all times
- protected as much as possible from the sights and sounds associated with adult care in areas outside of designated paediatric wards, including EDs, Radiology, Operating Theatres and Recovery
- safe from harm from other patients, parents/carers and staff
- cared for by appropriately trained and skilled staff with access to ongoing professional development, current clinical guidelines and timely clinical guidance and advice
- communicated with and listened to in a manner that enables understanding and respect

NSW Hospitals that provide care to children and adolescents must:

- allocate the necessary workforce capacity to meet the needs of patients
- facilitate access to an Aboriginal Health Worker for cultural consideration for Aboriginal children and adolescents
- implement screening, supervision and training to staff to ensure children and adolescents are free from harm
- ensure the individual characteristics, beliefs and cultural contexts of the child, adolescent and their parents/carers are respected
- ensure that Healthcare interpreter services are available and offered to all children, adolescents and their families who do not speak English, or speak English as a second language
- facilitate support for children and adolescents from parents/carers, including the ability for a parent/carer to be accommodated with the child or adolescent
- enable patients to be partners in their own care, to the extent that they choose
- ensure that children, adolescents and their parents/carers are provided with information about their health care that takes into account their level of health literacy
- provide appropriately sized medical equipment, furniture and amenities
- ensure that painful procedures do not occur within a child or adolescent's bed space unless it is an emergency, there are infection concerns or moving the patient will cause more distress
- provide care and support to children, young people, parents/carers to minimise pain, anxiety and distress associated with treatment and procedures

- ensure compliance with NSW law on obtaining consent to medical treatment from patients or their substitute consent providers in line with the NSW Health Consent to Medical and Healthcare Treatment Manual. This includes enabling consent to treatment by mature minors (see definitions) who have the capacity to understand fully what medical or healthcare treatment is proposed.
- Where there are separate paediatric areas within EDs, they must remain available for children or adolescents.

### Suggested links and reading

NSW Health Policy Directive Responding to Sexual Assault (adult and child) Policy and Procedures (PD2020\_006)

NSW Health Policy Directive Sexual Safety – Responsibilities and Minimum Requirements for Mental Health Services (PD2013\_038)

NSW Health Policy Directive Infection Prevention and Control Policy (PD2017\_013) CEC: Medication Safety Standard 4: Medication Safety, Safety and Quality Improvement Guide Office of the Children's Guardian: Child Safe Standards CEC: Paediatric Cot and Bed Allocation Guide (CaBAG) ACI: Transition Care Network Sydney Children's Hospitals Network: TRAPEZE

# **3.2 Cultural safety**

NSW Hospitals must have strategies in place to ensure access to safe and holistic healthcare that supports Aboriginal peoples and people of culturally and linguistically diverse (CALD) backgrounds as partners in their own care.

NSW Health staff must have an understanding of health equity. Staff must provide healthcare that is responsive to the needs of Aboriginal and CALD children, adolescents and their families. All children, adolescents and their families who do not speak English, or speak English as a second language must be offered a NSW Healthcare Interpreter.

Section 2, Part F of the NSW Health guide to the role delineation of clinical services, outlines the levels of complexity for Aboriginal health services provided within any service level.

Suggested links and reading

NSW Health Guideline Communicating positively: A guide to appropriate Aboriginal terminology (GL2019\_008) The Aboriginal Cultural Engagement Self-Assessment Tool National Standards user Guide for Aboriginal and Torres Strait Islander Health NSW Health Plan for Healthy Culturally and Linguistically Diverse Communities 2019-2023 Refugee health policy NSW Health guide to the role delineation of clinical services

# **3.3** Co-location of Adults with Children or Adolescents

The safety of the child or adolescent must be the primary consideration in decisions about co-location of adults and children/adolescents.

In a paediatric ward there must be only child and adolescent admissions.

Where there is an exceptional need for the child/adolescent to be cared for outside a paediatric ward for example in an intensive care unit, maternity unit (for the purposes of delivering), or a mental health unit, they must be in a paediatric safe bed (see Section 3.2).

In all exceptional circumstances a decision about where to admit the patient must be made by the paediatrician or senior clinician, be documented in the clinical notes, and reviewed for safety factors within 24 hours.

To protect children and adolescents from unwanted exposure, including casual overlooking and overhearing:

- children/adolescents must have separate bathrooms (no shared bathroom facilities with adults)
- adult patients must not pass through areas caring for children to reach their own facilities
- children/adolescents must not be required to pass through an adult ward or unit to access facilities
- appropriate security measures must be installed where appropriate, for example secure doors with swipe card access.

## **3.4 Child Protection**

NSW Hospitals must undertake mandatory child related screening of employees and ensure all staff who care for children and adolescents receive education and training about the protection of children and adolescents.

NSW Hospitals must ensure that all staff are aware of and comply with their responsibility to protect the health, safety and wellbeing of children and adolescents as outlined in the Child Wellbeing and Child Protection Policies and Procedures for NSW Health.

NSW Health staff must follow the Child Wellbeing and Child Protection Policies and Procedures for NSW Health. This includes:

- use of the decision tree in the Mandatory Reporters Guide (MRG) to decide when to report and what to report in relation to child protection concerns
- consultation with the NSW Health Child Wellbeing Unit mandatory reporting
- documentation and information exchange as per the Child Wellbeing and Child Protection Policies and Procedures for NSW Health.

#### Suggested links and reading

NSW Health Policy Directive *Child Wellbeing and Child Protection Policies and Procedures for NSW Health* (PD2013\_007)

NSW Health Policy Directive Domestic Violence: Identifying and responding (PD2006\_084) Mandatory Reporter Guide Mandatory Reporters: what to report and when About Child Protection and Wellbeing Children's Guardian Act 2019: Part 4 - Reportable Conduct Scheme

Chapter 16A of the Children and Young Persons (Care and Protection) Act

## 3.5 Children or Adolescents under Assumption of Care Orders

Where the Department of Communities and Justice (DCJ) have assumed care responsibility of a child or adolescent in accordance with the Children and Young Persons (Care and Protection) Act 1988 and they are in a NSW Hospital, the Hospital must comply with the child wellbeing and child protection procedures for NSW Health. Section 9.9 *Assumption of Care Responsibility of a Child or Young Person by Community Services on Health Premises*.

#### Suggested reading

NSW Health Policy Directive Child Wellbeing and Child Protection Policies and Procedures for NSW Health (PD2013\_007)

# **3.6 Children and Adolescents leaving the ward or being discharged from hospital**

NSW Hospitals must have systems in place to ensure that when children and adolescents leave a ward or unit that they are accompanied by an appropriate parent/carer, and that their whereabouts (including time of departure and return) is known and documented.

Systems must also be in place to ensure that when children and adolescents are discharged from hospital that they are accompanied by an appropriate parent/carer.

## 3.7 Management of Violence and Aggression

NSW Health facilities must maintain a zero-tolerance approach to violence and establish work systems and environments that enable, facilitate and support the zero-tolerance approach.

This includes a zero-tolerance approach to violence perpetrated by patients and others against staff, patients or visitors. Hospital managers must exercise their responsibilities in relation to preventing and managing violence, in line with NSW Health Policy Directive *Preventing and Managing Violence in the NSW Health Workplace – A Zero Tolerance Approach* (PD2015 001).

As part of the ongoing management of work health and safety risks, all NSW Hospitals must have in place a violence prevention program that focuses on the elimination of violence related risks.

# **3.8** Children and adolescents with acute behavioural or mental health problems

NSW Hospitals admitting children and adolescents for acute mental health care must comply with the NSW Health Policy Directive *Children and Adolescents with Mental Health Problems Requiring Inpatient Care* (PD2011\_016) and the Mental Health Act 2007.

NSW Hospitals must:

- apply the principle of least restrictive care
- maximise the child or adolescent's choices, rights and freedom as much as possible whilst balancing safety (people accessing services, staff and others) and health care needs
- ensure consultation with an appropriate clinician if assessment and management is required
- ensure staff providing care have the appropriate knowledge, skills and capabilities to work with children and adolescents with acute behavioural or mental health issues. This includes completion of all mandatory training required to work with people experiencing mental health problems.

NSW EDs must have a Safe Assessment Room – a clinical area designed to accommodate the needs of patients with, or at risk of developing Acute Severe Behavioural Disturbance (ASBD), who require assessment in a therapeutically supportive environment.

Seclusion and restraint must only be considered as a last resort after less restrictive alternatives have been trialled or considered and the safety of staff must be maintained at all times in accordance with NSW Health Policy Directive Seclusion and Restraint in NSW Health Settings (PD2020\_004). Suggested links and reading

NSW Health Guideline *Management of patients with Acute Severe Behavioural Disturbance in Emergency Department* (GL2015\_007)

Provision of Trauma Informed Care

## **3.9** Facilities for parents and carers

Facilities for parents/carers to stay nearby to their child or adolescent must be provided, for example a lounge chair or folding bed in the ward or unit or a chair in ED. Allowing parents/carers to stay with their child or adolescent in hospital has a positive impact on the child and parent/carer stress and increases the child or adolescent's coping ability.

NSW Hospitals must:

- make it possible for a parent/carer to always remain with their child or adolescent. The only circumstance in which this does not apply is for exceptional cases where the adolescent states they do not want their parent/carer to remain with them. In such cases a decision must be documented in the clinical notes and regularly reviewed with the adolescent.
- Provide amenities to facilitate the comfortable stay of parents/carers at the child or adolescent's bedside.
- Facilitate culturally appropriate arrangements to support Aboriginal children and adolescents.
- Orientate parents/carers to the relevant areas within the facility and relevant practices to enable them to safely assist with the basic care needs of their child/adolescent.
- Notify parents/carers of any pending transfer arrangements for their child/adolescent.
- Ensure that parents/carers of children and adolescents requiring surgery are able to accompany their child/adolescent to the operating theatre and have access to the recovery room.
- Ensure parents/carers are able to be present at the induction of anaesthesia for children and adolescents, and allowed into recovery as soon as possible.

Additional facilities for the parents/carers that must be provided are:

- facilities for nutrition, such as a kitchenette with fridge and microwave
- facilities for breastfeeding and for breast milk storage
- access to amenities such as a shower, toilet and washing facilities.

#### Suggested links and reading

NSW Health Guideline Safe Assessment Rooms (GL2020 001)

Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service (NSQHS) Standards User guide for acute and community health services organisations that provide care for children

## **3.10 Gender Specific Accommodation**

The needs and preferences of adolescent patients must be sought, recorded and respected, regardless of their sexuality, gender identity or intersex variations.

Bathroom facilities do not need to be designated as gender specific as long as they accommodate only one patient at a time and can be locked by the patient (with an external override for emergency use only).

Parents/carers accompanying children must use adult visitor bathroom facilities, except where their child or adolescent is in a single room with an en-suite bathroom.

Suggested reading

NSW LGBTIQ+ Health Strategy 2022-2027, Implementation Plan 2022-2027 and Summary of Evidence

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## 3.11 Safe and Appropriate Transfers

NSW Hospitals must ensure the safe and timely transfer of children and adolescents whose medical condition requires care at a different level from that of the presenting hospital in line with NSW Health Policy Directive *Children and Adolescents – Inter-Facility Transfers* (PD2010\_031).

When transporting children and adolescents around the hospital they must not be left unattended at any time. If the child or adolescent is acutely unwell or post-operative an appropriate clinical escort must be provided.

## 3.12 Transition of care

Health services must have a formal transition process in place to transition adolescents to adult services, in line with the principles outlined within <u>Key Principles for Transition of Young People from Paediatric to Adult Health Care</u>.

Facilities that manage children and adolescents with chronic conditions must identify a person within the patient's clinical team to act as a transition coordinator/facilitator. This person may be any member of the multidisciplinary team.

Their role is to identify children and adolescents, ensure that they receive education packages and are referred to appropriate services such as Trapeze and ACI Transitional Care Coordinators.

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#### 2. PAEDIATRICS GUIDELINES FOR HOSPITALS AND MATERNITY STAFF IN THEIR RESPONSE TO PARENTS CONSIDERING THE ADOPTION OF THEIR CHILD (PD2005 545)

#### PD2005\_545 supersedes circulars 82/296 and 82/297, Health Commission Policy on Adoption.

This is a circular for the NSW Health system that outlines principles and guidelines for hospitals and maternity staff in their response to parents considering the adoption of their child. These guidelines are being issued to ensure that current legislation is complied with and contemporary good practice principles are followed.

Local policies and protocols of public health organisations should be updated to reflect these guidelines. These guidelines are also recommended to private health care facilities for general use as a standard of good practice.

These guidelines are particularly relevant to and should be specifically noted by the following NSW Health staff:

Maternity services - nursing, medical and allied health staff; Paediatricians and Paediatric Registrars; Hospital Social Workers; Medical Records Staff to note section 3.7 of the Guidelines.

The NSW Department of Community Services is currently preparing new adoption legislation which will repeal, replace and consolidate the *Adoption of Children Act 1965* and the *Adoption Information Act 1990*. In addition, it is anticipated that the new *Children and Young Persons (Care and Protection) Act 1998* will be proclaimed in the second half of 2000, and will replace the *Children (Care and Protection) Act 1987*. This circular has been written to reflect the directions of this new legislation. Following the proclamation of these new Acts this circular will be reviewed and updated.

#### **GUIDELINES FOR HOSPITALS AND MATERNITY STAFF IN THEIR RESPONSE TO PARENTS CONSIDERING THE ADOPTION OF THEIR CHILD**

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#### 2. PAEDIATRICS GUIDELINES FOR HOSPITALS AND MATERNITY STAFF IN THEIR RESPONSE TO PARENTS CONSIDERING THE ADOPTION OF THEIR CHILD

#### 1. PRINCIPLES

- 1.1 Parents considering offering their expected or newly born child for adoption, should be accorded and advised of the same rights, privileges, responsibilities, treatment/s, information and support services as any other parent in the hospital. Parents should be cared for with sensitivity and in a non-judgemental manner.
- 1.2 As adoption severs a child's legal relationship with his/her family of birth, it is important that parents are informed of all alternative care options for their child and are assisted to consider these options. Adoption is one of the placement options for parents who do not wish or are unable to care for their child. It is the most radical form of substitute care for a child.
- 1.3 Parental choice throughout the process is to be respected. Parents should at all times be the ones to make the decisions about contact with, feeding and care of the baby. The decisions of the parent/s may change over time. For example, the decision to adopt is not always made antenatally, or if considered antenatally may change following birth of the baby. It is also useful to recognise that at any one point in time a parent may be ambivalent about adoption, that is have diverse feelings simultaneously.
- 1.4 The rights of both the child's parents to participate in decisions concerning the child should be taken into account.
- 1.5 Parental wishes for confidentiality regarding a decision about adoption of their child are to be respected by health professionals.
- 1.6 Parents are the legal guardians of their child, unless a Court has removed their parental responsibilities or made them joint guardians with a third party. Consent to medical treatment for the child is to be given by the child's legal guardian. NSW Health <u>PD2005\_406</u> department's policies in relation to consent to medical treatment and the provision of information to patients.
- 1.7 The parents of the child have the right to name the child. The name given to the child by the parents is the child's legal name and should be used to identify the child. However, that name may be changed by legal processes.
- 1.8 Unless specified in the medical report form required by the *Adoption of Children Act 1965*, a baby for adoption does not require any specific tests as a result of the adoptive process. The baby should receive the routine screening tests and any other that are medically indicated.
- 1.9 The loss experienced by parents through the adoption of a child may be profound and lifelong. Feelings of grief and loss may be accompanied by significant distress. Affected parents should be offered appropriate support and comfort. Follow-up counselling should be offered for persistent or severe distress or those at highest risk (eg poor social support, a history of significant losses or mental health problems) with identified pathways to specialist mental health care if required.

## 2. DEPARTMENTAL ROLES AND RESPONSIBILITIES

#### 2.1 NSW Health System

- 2.1.1 The role of NSW Health staff is to ensure that the health needs of mother and baby are met. The aim is to ensure the best physical and emotional health outcome for the family. NSW Health staff also provide health care and assessment of the child. Information about the child is provided to the Department of Community Services or licensed private adoption agency.
- 2.1.2 While the mother and baby are the primary focus of the maternity service, the role of the father and extended family is also to be acknowledged and accommodated in the provision of care and support.
- 2.1.3 The NSW Health system has no role in arranging adoption or witnessing adoption consent.

#### 2.2 Department of Community Services and licensed private adoption agencies

2.2.1 The Department of Community Services and the licensed private adoption agencies are the only bodies authorised to make adoption arrangements.

Making adoption arrangements involves:

- counselling which will include assisting the parents to explore their reasons for considering adoption, explaining alternatives to adoption and ensuring their understanding of the effects of an adoption order;
- witnessing consent;
- preparing the adoption plan;
- placement of the child;

and, facilitating the appropriate provision of:

- ongoing counselling and support for parent/s following consent;
- follow up for grief and loss issues of the parent/s and family.
- 2.2.2 Once all required consents to the child's adoption have been given by the parent/s, or dispensed with by the Court, the Director-General of the Department of Community Services becomes the legal guardian of the child. This includes cases where the adoption arrangements are being made by a private licensed adoption agency.
- 2.2.3 The Department of Community Services and the licensed private adoption agencies can make arrangements for the temporary care of the child. Temporary care is usually arranged with the consent of the parents, who are encouraged to maintain regular contact with the child. For most infants the period of temporary care is likely to be of only several weeks duration to enable the parents to resolve their situation.
- 2.2.4 The maximum period usually available for temporary care is 6 months. The temporary care arrangement may be terminated at any time by the parents or the agency that made the arrangement (the Department of Community Services or the licensed private adoption agency, as the case may be).

## 3. LEGISLATIVE FRAMEWORK

#### 3.1 General

- 3.1.1 Adoption practice is principally governed by the *Adoption of Children Act 1965* (ACA), the *Adoption Information Act 1990* (AIA), some sections of the *Children (Care and Protection) Act 1987* (CC&PA), and their respective Regulations.
- 3.1.2 The NSW Department of Community Services is currently preparing new adoption legislation which will repeal, replace and consolidate the *Adoption of Children Act 1965* and the *Adoption Information Act 1990*. In addition, it is anticipated that the new *Children and Young Persons (Care and Protection) Act 1998* will be proclaimed in the second half of 2000, and will replace the *Children (Care and Protection) Act 1987*.
- 3.1.3 Parents are the legal guardians of their child, unless a Court has removed their parental responsibilities or made them joint guardians with a third party. The Director-General of the Department of Community Services becomes the child's exclusive guardian under the adoption process when all consents to the child's adoption by a parent or guardian have been given or dispensed with by the Supreme Court.

#### 3.2 Adoption

- 3.2.1 Adoption is a legal process which ends the legal relationship and responsibilities between the child and his/her parents and establishes a new legal relationship and responsibilities with the adoptive parents. (Section 35 ACA)
- 3.2.2 Adoptive placements of non-related children can only be arranged by the Department of Community Services or a licensed private adoption agency. Any other adoptive placement of a child with a non-related person is an unauthorised adoption placement and in breach of the Act. (Section 51 ACA)
- 3.2.3 Relative is defined in the adoption law as the grandparent, uncle or aunt of the child, whether by blood, adoption or marriage. (Section 6 ACA)
- 3.2.4 Once all required consents to the adoption have been given by the parents or guardians of the child, or dispensed with by the Supreme Court, the Director-General of the Department of Community Services becomes the exclusive guardian of the child and remains exclusive guardian until:
  - the making of the adoption order or an order in lieu of adoption;
  - the adoption consent(s) are revoked; or
  - the Director-General terminates the arrangement, including the return of the child to the parents (Section 34 ACA);
  - the Supreme Court makes an interim order that the child become a ward of the Minister (Section 34(4) ACA).
- 3.2.5 Adoption orders are made through the NSW Supreme Court.

#### 3.3 Adoption Consent

3.3.1 The Department of Community Services or the licensed private adoption agency is responsible for making the arrangements for a qualified person, under the legislation, to witness the adoption consent.

- 3.3.2 For the mother of a child, consent to adoption may legally be given at any time on or after the fifth day of the child's birth. (Section 31 (2) ACA)
  - for many women the consent to adoption is given at a time well beyond this minimum period;
  - a mother may be discharged from hospital without her child when she is ready/medically fit, without signing an adoption consent.
- 3.3.3 The father of a child can give his consent at any time after the child's birth.
  - a) The legislative provisions relating to the involvement of a child's father in the adoption decision are complicated. Men who acknowledge their paternity should be accorded the right to be involved in decisions concerning their child, including the adoption decision. (*The Status of Children Act 1996*, Sections 26 and 31A ACA)
  - b) Clarification of the adoption consent requirements in respect of fathers should be sought from the Department of Community Services or the licensed private adoption agency. A father's consent to his child's adoption is definitely required if:
    - the child was born of his marriage; or
    - the child was born of his defacto relationship and the child is part of the household; or
    - the father has been appointed a guardian by a court and has custody of the child.
- 3.3.4 For adoption consent to be valid and legal (Sections 29 & 31 ACA, Regulations 21-24):
  - a) It must not have been obtained by fraud, duress or other improper means.
  - b) The parent must understand the nature of the consent and be in a fit condition to give consent. For example: the parent should not be ill, receiving medication or treatment that could affect decision processes, or suffering an acute psychiatric condition.
  - c) When medical certification of the mother's fitness to consent is provided, consent to adoption can legally be given by a mother before the fifth day of the child's life. However this situation is highly unusual. Adoption consent cannot be signed before the birth of the child.
  - d) Consent must be given on the prescribed form and attested to by a qualified witness. Only certain categories of people are qualified in the *Adoption of Children Regulation* to witness a consent.
  - e) The qualified witness has certain obligations to fulfil under the Regulations before the parent can sign the consent. These are:
    - to be satisfied of the identity of the person giving consent;
    - to ensure the parent received, at least 72 hours before signing consent, written information about the effect of giving consent and the rights of the parties concerned in an adoption;
    - to afford the parent ample opportunity to read the consent documents;
    - to be satisfied the parent understands the effect of signing the consent; and
    - if the parent is under the age of 16, before consent is given, a report of a registered psychologist, or other appropriate expert, is required of the capacity of the parent to understand the effect of signing an adoption consent.

- 3.3.5 Following consent, the period for a parent to revoke or withdraw their consent is 30 days. (Section 28 ACA)
  - a) Consent is revoked by the parent notifying in writing the Deputy Registrar of the NSW Supreme Court of their intention to revoke their consent.
  - b) A form for revocation is included in the parent's consent documents.
  - c) The Department of Community Services or the licensed private adoption agency will notify the parent of the impending expiry of the revocation period at least 7 days before its expiry. (ACA Regulation 26)
  - d) On revocation, the parent resumes their guardianship of the child.
  - e) If a parent has revoked their consent, but is unable to resume the care of their child, a temporary care agreement will need to be signed while the parent considers the child's future.

#### 3.4 Leaving Hospital

- 3.4.1 Under Section 27 (2) of the *Children (Care and Protection) Act 1987* it is an offence for a person to permit a child, unless s/he is in the care of his/her mother, to be taken from hospital without the consent of the Director-General.
- 3.4.2 When the child is ready to leave hospital, if a parent is unable to care for the child and has not signed the adoption consent, temporary care arrangements should be made for the child by the Department of Community Services/licensed private adoption agency. The parent/s will be asked to sign a Temporary Care Agreement with the Department of Community Services or enter into a private fostering arrangement with a licensed foster care or private adoption agency.
- 3.4.3 If the parent/s have not signed adoption consent, do not agree to sign a temporary care arrangement and are unwilling to resume the care of the child, the child should be notified to the local office of the Department of Community Services.
- 3.4.4 Where the child is to be discharged to the care of a Department of Community Services temporary foster carer, the carer must provide the hospital with a letter containing the consent of the Director-General of the Department of Community Services to their care of the child and show identification. The letter and copy of the identification are to be placed on the child's hospital record.
- 3.4.5 Where a child is to be discharged to the care of a licensed private adoption agency carer, the carer must provide the hospital with a letter signed by the Principal Officer of the agency and show identification. The letter and copy of the identification are to be placed on the child's hospital record.

#### 3.5 Contact

- 3.5.1 The adoption legislation does not place any statutory restrictions on the degree of contact a parent may have with their child in hospital.
- 3.5.2 As a general rule, prior to adoption consent the child's parent/s decide on the level of contact they wish with the child, whether the child is to room in with the mother, or be cared for in the nursery etc. However, if an assessment of risk for the child has led to the Department of Community Services assuming the care of the child under the *Children (Care and Protection) Act* (Section 62A), the level of contact should be determined by the Department of Community Services.

3.5.3 Once all required adoption consents have been given, because the guardianship of the child has changed, the level of contact should be negotiated between the parent/s, Department of Community Services/licensed private adoption agency and the hospital.

#### **3.6** Registering the birth and naming the child

- 3.6.1 The *Births, Deaths and Marriages Registration Act* requires a parent to notify the Registry of the birth of a child within a month of the birth. Where the parents are not married to each other, the father's details can only be included on the registration if both parents sign the information form. Both parents should be encouraged to record their names.
- 3.6.2 If the child is subsequently adopted, this acknowledgment of a man's paternity will affect the rights of the adopted person and the father under the *Adoption Information Act 1990*. Acknowledgment of a man's paternity will allow the adoptee to receive identifying information about his/her father and the father will be able to access identifying information about the child.
- 3.6.3 The name given to the child by the parents is the child's legal name (unless changed as a result of an adoption order) and should be used to identify the child.

#### 3.7 Records

- 3.7.1 The *Adoption Information Act 1990* (AIA) gives adopted persons, their birth parents and adoptive parents the right to certain information about themselves and each other. This includes their access to medical and social work records. The information that can be accessed is prescribed by the AIA.
- 3.7.2 Access by an adopted person to records related to his/her birth parent require the person to present a 'Supply Authority' from the Department of Community Services or a copy of their original birth certificate released under the AIA prior to June 1998.
- 3.7.3 Similarly a birth parent cannot access information from an adopted child's records without the appropriate authority.
- 3.7.4 Since the NSW *Archives Act 1960*, adoption records have been retained in the State Archives in perpetuity.
- 3.7.5 NSW Health <u>PD2010\_050</u>, *Adoption Act 2000* Release of Information, outlines guidelines to be followed in respect of adoption related enquiries to public hospitals.

#### 4. HOSPITAL PRACTICE

#### 4.1 Antenatal care

- 4.1.1 If adoption is being considered, the maternity/hospital social worker would normally be involved in the management and care of the woman. A referral to a social worker should be made following discussion and agreement by the woman/couple.
- 4.1.2 Information, education, support and counselling should occur regarding the birth plan and birthing process. A birth plan should be agreed so that the hospital is able to offer appropriate care. The birth plan is to include:

- the wishes of the parent/s regarding their involvement with the baby after delivery;
- who else is to be involved, eg the grandparents of the baby and other support people;
- how much contact they will have with the baby;
- memorabilia of the baby that may be wanted by the parents, eg photographs, hand/foot prints, cot cards, identification bands, the Blue Book.

#### 4.2 Birth

- 4.2.1 Antenatal staff are to ensure the appropriate transfer of information to the delivery suite and postnatal ward to ensure that appropriate care in line with the wishes of the parent/s is provided. Confirmation of the birth plan is to occur, along with reassurance to the woman/ couple that they are able to alter the birth plan at any time so that their needs are met.
- 4.2.2 At delivery there should be no obstacle to the parent/s being shown or handling their child should they wish to do so, providing this is medically feasible.
- 4.2.3 Following the birth, the midwife usually informs the maternity/hospital social worker (if involved) that the baby has been delivered. The decision and timing of notification of the birth to the adoption agency is made by the parent/s who may wish to consult with and seek the assistance of the hospital social worker.
- 4.2.4 If no prior discussion has occurred between hospital staff and the woman/couple and adoption is discussed at this point in care (ie birth/postnatal) a referral to the maternity/hospital social worker should be made as soon as possible.

#### 4.3 Consent to medical treatment of the child

- 4.3.1 Generally, the parent/s are the legal guardian/s of the child, parental consent to medical treatment or a Court order is required. However, in an emergency, medical practitioners may act without the consent of a parent or guardian (Section 20A, *Children (Care and Protection) Act 1987*).
- 4.3.2 If there is an arrangement in place for temporary care, consent to medical treatment may be provided by the Department of Community Services or the licensed private adoption agency as the case may be, if the consent of the parent/s is unable to be obtained (the Department of Community Services or licensed private adoption agency will obtain parental consent where possible).
- 4.3.3 If the Director-General of the Department of Community Services has become the child's legal guardian, consent to medical treatment is required from the Department of Community Services.

#### 4.4 Postnatal care

- 4.4.1 The parent/s choose where the baby is to be cared for following the birth, that is rooming in with the mother or cared for in the nursery. The parent/s choose the degree of contact they have with the baby and whether the baby is breastfed.
- 4.4.2 If an assessment of risk for the child has led to the Department of Community Services assuming the care of the child under section 62A of the *Children (Care and Protection) Act 1987*, postnatal care of the child and the degree of contact between the child and the parent/s should be determined by the Department of Community Services.

4.4.3 The parent/s have the right to name the child and are responsible for completing the birth registration form. The baby is to be identified at all times by the name given by the parent/s.

#### 4.5 Mementos

- 4.5.1 Having first obtained the permission of the parent/s, two sets of mementos of the baby such as photographs, hand/foot prints of the baby, cot cards, identification bands should be gathered and two Blue Books (Personal Health Records) issued.
- 4.5.2 Mementos of the baby and the Blue Book should be offered to the parent/s. If the parent/s do not want to take these mementos at this time, permission from the parent/s should be requested for the mementos to be forwarded the Department of Community Services/licensed private adoption agency to be held on file for the parent/s if requested in the future.
- 4.5.3 It is usual practice for the Department of Community Services/licensed private adoption agency to request mementos on behalf of the child. A set of these items is to be gathered for the child and forwarded to the Department of Community Services/licensed private adoption agency on request. Hospital staff should explain to the parents that these items are given to the adoptive parents to provide the child with mementos of his/her birth.
- 4.5.4 No identifying details other than the baby's first name should appear on the set of mementos and Blue Book provided to the adoptive parent of the child.

#### 4.6 Discharge

#### 4.6.1 Temporary Foster Care

- 4.6.1.1 The baby should leave the hospital for temporary foster care as early as practicable. The Department of Community Services or licensed private adoption agency arranges the temporary foster care and ongoing access of the parent/s to the child in consultation with the parent/s.
- 4.6.1.2 The Nurse Unit Manager or delegate is to be advised by the Department of Community Services/licensed private adoption agency when the foster parents will be coming to collect the baby. The Department of Community Services or licensed private adoption agency provide the foster parents with a letter giving consent for the child to be discharged into their care. Identification should also be provided by the foster parents. This letter and a copy of the identification is to be placed in the child's hospital record.

#### 4.6.2 Medical Report Forms

- 4.6.2.1 There are two statutory medical reports to be completed on a child to be placed for adoption (Clause 19 Adoption of Children Act Regulation). These are Medical Report following Birth of a Child and Medical Report on Child. These forms are to be completed by the relevant medical officer prior to discharge and forwarded to the Department of Community Services or licensed private adoption agency. Copies of the medical report forms are attached.
- 4.6.2.2 Before a child's discharge from hospital, it is helpful for the relevant medical officer to provide a referral to an appropriate medical practitioner for ongoing medical examination and care of the child. This will assist the Department of Community Services or licensed private adoption agency to comply with the relevant Regulation in regard to ongoing medical care.

### 4.6.3 Discharge Planning

- 4.6.3.1 Prior to the child's discharge from the hospital, the foster parent/s are to be advised by hospital staff of their local Early Childhood Health Service and encouraged to access this service while the child is in their care.
- 4.6.3.2 Discharge planning should also address the health needs of the parent/s, including the physical and mental health needs. The maternity/hospital social worker may remain available to the parent/s and their family following discharge for follow up consultation. Other options for ongoing support should be identified in consultation with the adoption agency. Parent/s who are severely affected by loss may be vulnerable to (postnatal) depression and may require specific follow-up to monitor their mental health with access to appropriate treatment, if necessary.
- 4.6.3.3 Hospital staff should ensure that the mother is given appropriate advice and information on all aspects of the postnatal period physiological and emotional. As well as social work support this should include:
  - information and explanation about normal and abnormal physiological processes after child birth;
  - an offer of domiciliary midwifery visits after discharge;
  - information on who to contact if problems arise;
  - information on the importance of arranging a 6 week postnatal visit.

#### 5. ADOPTION SERVICES

A parent considering the adoption of their child may be referred for information about adoption and counselling to the NSW Department of Community Services or one of the private adoption agencies licensed to make arrangements for an infant's adoption.

The contact details for these agencies are:

Adoption and Permanent Care Section Adoption Services Branch NSW Department of Community Services Level 13, 130 George Street Parramatta NSW 2150 Telephone: 9865 5900, 9865 5911, 9865 5966, 9865 5974, 9865 5992. Website: http://www.community.nsw.gov.au Email: adoption@community.nsw.gov.au

Anglicare Adoption Services 19A Gibbons Street Telopea NSW 2117 Telephone: 9890 6855 Facsimile: 9890 6899 Email: <u>adoptions@anglicare.org.au</u>

Centacare Adoption Services 9 Alexandra Avenue Croydon NSW 2132 Telephone: 9745 3133 Facsimile: 9744 7123 Email: adoption@centacare.aust.com

Barnardos Find-a-Family Program is also a licensed private adoption agency, however provides services to children over the age of 2 requiring adoptive placement.

These organisations also have information, pamphlets and resources on adoption.

#### 6. MEDICAL FORMS

Copies of the two statutory medical reports to be completed on a child to be placed for adoption (Clause 19 *Adoption of Children Act Regulation*) are attached:

- Medical Report following Birth of a Child
- Medical Report on a Child

## ADOPTION OF CHILDREN ACT 1965 REGULATION 29 (1)

## Medical Report Following Birth of Child

NAME OF CHILD:		
Date of child's birth: Time of birth:		
Place of child's birth:		
Birth Weight: Length at birth:		
Head circumference at birth:		
Evidence of developmental defect, injury	v, infection or other disability:	
APGAR RATING: (see overleaf) Score Heart rate Respiratory effort Muscle tone Colour of infant Reflex irritability Total MOTHER'S NAME:	Code A - 9 to 10 B - 7 to 8 C - 5 to 6 This baby is D - 3 to 4 E - 0 to 2	(A (B (C (D (E
Age:		
Parity:		
Height:		
Ethnic group:		
Serological tests for syphilis done on the	mother in puerperium:	

Result:

Details of labour and delivery:

GENERAL COMMENT: (The examiner's assessment of the child's physical status)

Name and address of doctor	
Date of examination:	
Signature:	

## APGAR RATING -- at one minute

Estimated exactly 1 minute after birth -- preferably by 2 observers:

HEART RA	= 1 = 2	A heart rate of 100-140 is considered good and given a score of two, a rate of under 100 receives a score of one, and if no heartbeat is seen, felt or heard, the score is zero.
	beat seen, felt or heard	
	te of under 100	
	te 100-140	
RESPIRAT	ORY EFFORT	An infant who is apnoeic at 60 seconds after
	= 0	birth receives a score of zero, while one who
	= 1	breathes and cries lustily receives a two
	= 2	rating. All other types of respiratory effort, such as irregular, shallow ventilation are
0 = Ap	noeic at 60 secs.	scored one. An infant who has gasped once at
(in	cluding one or more gasps,	thirty or forty-five seconds after birth and who
the	n apnoea)	then becomes apnoeic, receives a zero score,
1 = Irre	egular shallow ventilation	since he is appoeic at the time decided upon
2 = Bre	eathed and cried lustily	for evaluation.
MUSCLE 7	ΓΟΝΕ	A completely flaccid infant receives a zero
	= 0	score and one with good tone and
	= 1	spontaneously flexed arms and legs, which
	= 2	resist extension, is rated two points.
	mpletely flaccid	
	or tone	
2 = Good tone, spontaneously flexed		
	ns and legs	
COLOUR	= 0	A score to two is given only when the entire
	= 1	child is pink.
	= 2	
0 = Cv	anosed deeply	
1 = Slightly cyanosed		
	tire child pink	
	RRITABILITY	Response to external stimuli-lactile or
= 0		thermal.
	= 1	
	= 2	
0 = No	response	
	eble cry	
	gorous cry	

#### ADOPTION OF CHILDREN ACT 1965 REGULATION 29 (1)

#### **Medical Report on Child**

(To be made wherever possible by a Paediatrician but where necessary by other examining medical practitioner.)

Note for the Guidance of Examining Doctor:

The examination is intended to provide a record, available to the adoptive parents, of the child's apparent mental and physical condition so that information which would have been available to them as natural parents and which may be of importance for the future welfare of the child, so far as practicable will be available. The doctor is not asked to give his opinion as to the suitability of the child for adoption.

NAME OF CHILD:
Sex:
Date of Birth:
Estimated Gestation:
Present Veight:
Present Length:
Present head circumference:
BEHAVIOUR: Startle reflex:
General activity and vigour:
Capacity to take feedings:
Abnormal behaviour or posture:
EVIDENCE OF DEVELOPMENTAL DEFECT, INJURY, INFECTION OR OTHER DISABILITY:*
LABORATORY DATA

	(	H.B. Film
Blood	(	
	(	Serological Tests for Syphilis

2.	PAE	EDIATRICS	2.91
	(	Reducing substances	
Urine	(	Albumin	
	(	Phenyl Pyruvic Acid (or Guthrie Blood Test)	

GENERAL COMMENT: (The examiner's assessment of the child's physical status and behaviour)

Name and address of doctor:				_
Date of examination:				
Signature:				-
				_
* The examination should inc	lude, if applicable, in	ter alia:		
<u>At any age</u>				
Capacity of infant to focus eyes on obje	ect held about 30 cms. fr	om face and moved fi	rom side to side.	
Squint. Visual activity.	Nystaginus.	Cataract.	Retinopathy.	
Mouth and Palate.				
Hearing Bell. Watch. Human voice/wl				
Evidence of developing head control.				
Co-ordination. Laterality (Dominance)			ip. Talipes.	
Descent of testes. Hernia. Naevi. Abd			A (1	
Pyspnoea. Stridor.	Productiv	e cough.	Asthma.	
Evidence of Mongolian defect. Pubescence, Menstruation.				
Central or peripheral Cyanosis. Heart r	nurmur or obnormal rhi	thm Equated nulse		
Central of peripheral Cyanosis. Heart I	numur or abnormal my	unn. remotat pulse.		
Additional matters in respect of child or	ver three months of age			
Capacity to respond to invitation to smi			and hold rattle etc. Excess	ix

Capacity to respond to invitation to smile; to follow movement of examiner; to grasp and hold rattle etc. Excessive rhythmical activity (e.g. head rolling, banging). Developing power to maintain sitting posture, with support. Let\_135A

## MATERNITY - MATERNAL GROUP B STREPTOCOCCUS (GBS) AND THE MINIMISATION OF NEONATAL EARLY - ONSET GBS SEPSIS (GL2017 002)

#### GL2017\_002 rescinds GL2016\_021, PD2005\_240

#### PURPOSE

This Guideline provides guidance for two standard approaches used to identify women for whom intrapartum antibiotic prophylaxis (IAP) should be offered to reduce the risk of intrapartum transmission of Group B Streptococcus (GBS) to the neonate and minimise the risk of early-onset Group B Streptococcus (EOGBS) sepsis.

#### **KEY PRINCIPLES**

This Guideline provides Local Health Districts (LHD) with current, evidenced-based information to facilitate LHDs to ensure:

- Women are identified for whom intrapartum antibiotic prophylaxis (IAP) should be offered to reduce the risk of intrapartum transmission of GBS to the neonate and minimise the risk of EOGBS
- Appropriate assessment, detection, and escalation of neonates at risk of, or exhibiting signs and symptoms of EOGBS which occurs in the first 0 7 days following birth
- The importance of information and support for maternal choice is acknowledged.

#### **USE OF THE GUIDELINE**

The Chief Executives of NSW LHDs are responsible to:

- Select either a routine antenatal culture-based approach or a risk factor-based approach
- Ensure the development and implementation of local protocols or operating procedures in line with the approach chosen across all maternity facilities offering maternity services
- Ensure the chosen approach is consistently applied and neonatal morbidity and mortality associated with EOGBS sepsis is monitored and reviewed as per NSW Health <u>PD2011\_076 Deaths Review</u> <u>and Reporting of Perinatal Deaths</u> and NSW Health Policy Directive <u>PD2009\_003 Maternity Clinical Risk Management Program.</u>

The guideline can be downloaded here:-<u>Maternity - Maternal Group B Streptococcus (GBS) and minimisation of neonatal early-onset GBS sepsis</u>

2.92

271(19/1/17)

#### NSW PAEDIATRIC CLINICAL CARE AND INTER-HOSPITAL TRANSFER ARRANGEMENTS (PD2023\_019)

#### PD2023\_019 replaced PD2010\_030 and PD2010\_031

#### **POLICY STATEMENT**

NSW Health is committed to providing the right care, in the right place, at the right time and as close to home as possible. Many infants, children and adolescents will be able to receive the clinical care they need at a local service. If their needs are outside a service's capability and capacity to deliver the required care, an inter-hospital transfer must be arranged.

#### SUMMARY OF POLICY REQUIREMENTS

To provide appropriate clinical care and inter-hospital transfers for paediatric patients, NSW Health services must operate at their designated service capability level within agreed local health service arrangements and in partnership with transport and retrieval services. NSW Health services may also have local arrangements in place for paediatric inter-hospital transfers with specialist health services and retrieval services in bordering jurisdictions.

NSW Health organisations are to develop local guidance in line with this Policy Directive. This guidance must outline local arrangements for services (including Multipurpose Services) to follow when accessing clinical consultation to support care delivered locally as well as care involving inter-hospital transfer. Inter-hospital transfer processes are to include escalation of care to higher-level services and return transfer close to home when medically appropriate.

All services must work together to provide a network of care for NSW paediatric patients. Within local arrangements, higher-level services are responsible for providing lower-level services with support, advice and management of paediatric patients, including patients requiring inter-hospital transfer.

As supra-Local Health District services, Level 5 and 6 neonatal and Level 6 paediatric services must provide services for paediatric patients located within NSW and the ACT.

When an inter-hospital transfer is being considered, clinical decision-making must primarily match the paediatric patient's condition to the most appropriate service and consider:

- service capability and capacity of referring and receiving services
- capability and capacity of transport and retrieval services
- providing care as close to home as possible
- child and adolescent and family needs and preferences
- logistics such as weather and modes of transport.

Transfer decisions are to be made through discussion between responsible clinicians at the referring and receiving services. The Newborn and paediatric Emergency Transport Service (NETS) must be involved when an immediate response for transfer is needed and when clinical escort decisions require additional specialist clinical advice. NETS will facilitate care plan decision-making for these transfers through hosting conference calls with all clinical decision-makers.

Retrieval teams are responsible for the clinical care of a patient from the time of handover from the referring treating team until the patient is handed over to the destination service.

If an infant, child or adolescent in a hospital close to the border with an adjoining state requires a crossborder inter-hospital transfer, NETS will arrange transport or retrieval via NETS or NSW Ambulance or request the relevant jurisdiction's retrieval service to respond.

If a bordering jurisdiction's retrieval team is conducting the transfer, NETS will maintain contact with the referring treating team and provide clinical leadership until NETS confirms that the bordering retrieval team has taken over direct patient care. On handover, governance of the transport process moves to the bordering jurisdiction's transport/ retrieval service.

Management of urgency and risk are shared responsibilities of all parties involved in the transfer.

When transfer to higher-level care is required, the patient is to be appropriately transported within the medically agreed time frame to the nearest service that can provide the needed care. Treating teams at higher-level services are responsible for accepting referrals or finding an appropriate alternative if they do not have capacity to provide the needed care.

For return transfers, destination planning (identification of most appropriate service and bed-finding) is led by referring services and must be assisted by higher-level services if required.

Local health districts and the Sydney Children's Hospitals Network will optimise access to appropriate care close to home through services operating at their designated service capability level and actively managing patient flow.

Infants, children, adolescents and their families/carers are to be provided with timely, culturally appropriate and accessible information about clinical care, decisions and the transfer process.

A family member/ carer must be supported to travel with their child during an inter-hospital transfer wherever possible and appropriate, in consultation with the transport/ retrieval service.

Infants, children, adolescents and their families/ carers are to be offered relevant services and supports including through Aboriginal health workers, Aboriginal Maternal and Infant Health Service (AMIHS) staff, interpreters, cultural and diversity supports, social workers and other services as required.

The NSW Paediatric Clinical Care and Inter-Hospital Transfer Arrangements policy is available at: <u>https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2023\_019</u>

347(07/08/23)

## **NEONATAL CONSULTATION, REFERRAL AND TRANSFER ARRANGEMENTS IN COLLABORATION WITH NETS** (IB2020\_015)

#### PURPOSE

This Information Bulletin clarifies the process for those seeking neonatal consultation, referral and transfer arrangements for an unwell neonate.

#### **KEY INFORMATION**

Newborn and paediatric Emergency Transport Service (NETS) is a statewide emergency service for clinical advice and/or retrieval of critically ill neonates, infants and children. NETS is a single point of access for public and private hospitals in NSW and the ACT.

All neonatal critical care transfer requests must be made through NETS.

NETS will coordinate a conference call between the referring clinician and receiving consultant in a tertiary and/or regional hospital to discuss neonatal patient care. This will include immediate care, escalation of local and regional support and transfer or neonatal retrieval.

NETS will provide advice to the referring facility on the final destination of the neonatal transfer and coordinate beds if required.

Where there is a difference of opinion regarding a neonatal transfer, the final decision to transfer will be made by the NETS medical retrieval consultant, in line with the NSW

Health Policy PD2010 030 Critical Care Tertiary Referral Networks (Paediatrics).

The Tiered Perinatal Network (TPN) Level 6 facility has a responsibility to accept the neonate if no other facility can accept the transfer.

The referring facility will update details on the Patient Flow Portal (PFP)/Inter-Hospital Transfer (IHT) with the patient details. For non PFP users, the receiving facility will enter the PFP/IHT.

#### Contact NETS on 1300 362 500

Early notification will enable early assistance.

In a time-critical emergency, NETS notification can occur

prior to full patient assessment and investigation.

NETS can be contacted on www.nets.org.au

327(30/04/20)

#### PAEDIATRIC CLINICAL PRACTICE GUIDELINE (IB2020 041)

# IB2020\_041 rescinds PD2011\_038, PD2013\_053, GL2014\_013, PD2012\_056, PD2010\_063, PD2011\_024 and PD2010\_053

#### PURPOSE

This Information Bulletin is to notify NSW Health that Paediatric Improvement Collaborative (PIC) Interstate Clinical Practice Guidelines have now been published and are hosted by the Royal Children's Hospital Melbourne.

The PIC is a collaboration between Royal Children's Hospital Melbourne, Safer Care Victoria (SCV, Victorian Department of Health), the NSW Agency for Clinical Innovation (ACI) and Clinical Excellence Queensland.

Provision of Interstate Clinical Practice Guidelines through PIC aims to reduce variation in care.

#### **KEY INFORMATION**

The PIC adapts Victorian State-wide and Royal Children's Hospital Melbourne Clinical Practice Guidelines (CPG) so that they can be used by Queensland, New South Wales & Victorian clinicians.

Interstate Clinical Practice Guidelines are reviewed on a rolling 2-year cycle. When a new guideline is required it is written using the tri-state collaboration process.

CPGs that have been reviewed and developed under the PIC process are hosted by the Royal Children's Hospital Melbourne webpage www.rch.org.au

Interstate clinical practice guidelines are now available at: https://www.rch.org.au/clinicalguide/

The Interstate Clinical Practice Guidelines are endorsed for use in NSW, therefore NSW Health policy documents for Clinical Practice Guidelines on the same topics as PIC Interstate Clinical Practice Guidelines are no longer current.

333(19/11/20)

#### MANAGEMENT OF INFANTS AND CHILDREN WITH CONGENITAL TALIPES EQUINOVARUS (GL2014\_014)

#### PURPOSE

The *Management of Infants and Children with Congenital Talipes Equinovarus (CTEV) Practice Guideline* has been developed to ensure a consistent, evidence based approach to the multidisciplinary management of infants and children born with structural CTEV in NSW. It is to be used in conjunction with the 'learnpaediatrics Congenital Talipes Equinovarus e-learning module' and practical training such as the Ponseti Education Day conducted by the Sydney Children's Hospitals Network (Randwick and Westmead).

The Practice Guideline was prepared for the NSW Ministry of Health by an expert clinical reference group.

#### **KEY PRINCIPLES**

This Guideline reflects what is currently regarded as a safe and appropriate approach to care and should be used as a guide to be followed in respect of each individual presentation. Each patient should be individually assessed and a decision made as to appropriate management in order to achieve the best clinical outcome. Local protocols may be developed based on this State-Wide guideline and all clinicians involved in the treatment of patients born with structural CTEV should be educated in the use of the guideline and locally developed protocols.

This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation.

## It does not replace the need for the application of clinical judgement to each individual presentation.

#### **USE OF THE GUIDELINE**

Chief Executives should ensure:

- Local protocols are developed based on the *Management of Infants and Children with Congenital Talipes Equinovarus (CTEV)* Practice Guideline.
- Local protocols are in place in all hospitals and facilities likely to be required to assess or manage infants or children with CTEV.
- Ensure that all staff treating infants and children are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of the new guideline.

To download the Guideline go to http://www.health.nsw.gov.au/policies/gl/2014/GL2014 014.html

#### INFANTS AND CHILDREN: ACUTE MANAGEMENT OF BRONCHIOLITIS (GL2018\_001)

#### GL2018\_001 issued 10/01/2018 rescinds PD2012\_004.

#### PURPOSE

This Clinical Practice Guideline provides evidence based clinical direction for clinicians in the acute management of bronchiolitis in infants. It is aimed at achieving the best clinical care in the assessment, escalation and management of acute bronchiolitis in infants.

#### **KEY PRINCIPLES**

This Guideline applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts and Specialty Health Networks to determine where local adaptations are required or whether it can be adopted in its current format in all hospitals and facilities required to manage acute bronchiolitis in infants.

The Clinical Practice Guideline reflects what is currently regarded as a safe and appropriate approach to the management of acute bronchiolitis in infants. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

#### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- This Guideline is adopted or local protocols are developed based on the Infants and Children: Acute Management of Bronchiolitis, Clinical Practice Guideline
- Local protocols are in place in all hospitals and facilities likely to be required to manage paediatric patients with bronchiolitis
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this revised guideline

The Guideline can be downloaded from Infants and Children - Acute Management of Bronchiolitis

296(10/01/18)

#### **INFANTS AND CHILDREN: ACUTE MANAGEMENT OF SORE THROAT** (GL2014\_021)

#### GL2014\_021 rescinds PD2006\_019.

#### PURPOSE

The *Infants and Children: Acute Management of Sore Throat, third edition* Clinical Practice Guideline has been revised to provide direction to clinicians and is aimed at achieving the best possible paediatric care in all parts of the state. The Clinical Practice Guideline was prepared for the NSW Ministry of Health by an expert clinical reference group under the auspice of the state-wide Paediatric Clinical Practice Guideline Steering Group.

#### **KEY PRINCIPLES**

This guideline applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts and specialty health networks to have local guidelines/ protocols based on the attached Clinical Practice Guideline in place in all hospitals and facilities required to assess or manage children with sore throat.

The Clinical Practice Guideline reflects what is currently regarded as a safe and appropriate approach to the acute management of sore throat in infants and children. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

#### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- Local protocols are developed based on the *Infants and Children: Acute Management of Sore Throat: third edition* Clinical Practice Guideline.
- Local protocols are in place in all hospitals and facilities likely to be required to assess or manage paediatric patients with sore throat.
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this new guideline.

To download the Guidelines please go to <u>http://www.health.nsw.gov.au/policies/gl/2014/GL2014\_021.html</u>

# YOUTH HEALTH AND WELLBEING ASSESSMENT GUIDELINE (GL2018\_003 issued 1/2/2018)

#### PURPOSE

This guideline presents the current best evidence for conducting a youth health and wellbeing Assessment. Its purpose is to inform practice for healthcare providers to achieve the best possible care in NSW.

This guideline is primarily for clinicians caring for young people (12-24 years old) in a paediatric, adolescent or adult healthcare setting.

This guideline supports NSW Health's commitment to implement appropriate psychosocial assessment tools, such as HEEADSSS, to assess and respond to the holistic health and wellbeing needs of young people outlined in the <u>NSW Youth Health Framework 2017-2024 (PD2017\_019)</u>.

#### **KEY PRINCIPLES**

Youth health and wellbeing assessments are important to assist clinicians to identify and respond early to areas of concern in a young person's life that might affect their health and wellbeing.

The youth health and wellbeing assessment is not a diagnostic tool. It is a holistic, flexible approach designed to build rapport and engage with a young person in a clinical setting. The information gathered can then be used to directly address any concerns and/or refer a young person for a specialist response.

The most widely used youth health and wellbeing assessment tool in Australia and internationally is known as a HEEADSSS assessment. Each letter of HEEADSSS reflects a major domain of a young person's life. Capturing information in each domain helps reveal risks, behaviours and protective factors. It helps to identify areas of intervention where the clinician can work with the young person to achieve better health outcomes.

- **H** Home
- E Education and Employment
- E Eating and Exercise
- A Activities, Hobbies and Peer Relationships
- **D** Drug Use (cigarettes, alcohol)
- S Sexual Activity and Sexuality
- S Suicide, Self-Harm, Depression, Mood, Sleeping Patterns
- **S** Safety and Spirituality

In general, a youth health and wellbeing assessment (12-24 years old) should be conducted with every young person who attends a health service or hospital. Where appropriate young people in an adult or paediatric inpatient area within a hospital should have a youth health and wellbeing Assessment completed in conjunction with other screening assessment/admission processes.

Clinical judgement should be used to determine the appropriateness of the assessment for 12-24 year olds. This includes considering the young person's health condition, maturity, the environment and health service context (for example, sufficient time or privacy may not be available in an Emergency Department context).

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In general an assessment is done through conversation with a young person. On some occasions, where it is more appropriate a young person can be asked to complete the Youth Health and Wellbeing Assessment Chart (Appendix 1).

It is essential that clinicians/healthcare workers read and understand this guideline in particular Sections 6 to 11 of the Guideline.

- Section 6 Issues covered by a youth health and wellbeing assessment
- Section 7 When to conduct a youth health and wellbeing assessment
- Section 8 Youth health and wellbeing assessment flow diagram
- Section 9 Self-completed assessment using Youth Health and Wellbeing Assessment Chart
- Section 10 Setting up and concluding the assessment
- Section 11 Contraindications and cautions

#### **USE OF THE GUIDELINE**

This guideline should be considered when conducting Youth Health and Wellbeing Assessment with young people (12-24 years old) who attend a health service or hospital.

This document outlines the -

- approach that should be taken by NSW Health staff when conducting a youth health and wellbeing assessment (Sections 7 10)
- ssues to consider when implementing the youth health and wellbeing assessment within different health settings and with different age groups (Sections 11 12)

A range of resources for workers are available to support Youth Health and Wellbeing Assessment when needed (Appendices 1-4).

The document should not be seen as a prescriptive set of rules to be applied without the clinical input and discretion of the managing health professionals. Each patient should be individually evaluated and a decision made as to appropriate management in order to achieve the best clinical outcome.

To download the guideline go to Youth Health and Wellbeing Assessment

296(1/2/18)

#### INFANTS AND CHILDREN: INITIAL MANAGEMENT OF FEVER OR SUSPECTED INFECTION IN ONCOLOGY AND STEM CELL TRANSPLANTATION PATIENTS (GL2015 013)

#### PURPOSE

The Infants and Children: Initial Management of Fever or Suspected Infection in Oncology and Stem Cell Transplantation Patients, first edition Clinical Practice Guideline has been developed to provide direction to clinicians and is aimed at achieving the best possible paediatric care in all parts of the state. The Clinical Practice Guideline was prepared for the NSW Ministry of Health by an expert clinical reference group under the auspice of NSW Kids and Families.

#### **KEY PRINCIPLES**

This guideline applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts and specialty health networks to determine where local adaptations are required or whether it can be adopted in its current Clinical Practice Guideline format in all hospitals and facilities required to manage infants and children undergoing therapy for cancer or stem cell transplantation presenting with fever or suspected infection.

The clinical practice guideline reflects what is currently regarded as a safe and appropriate approach to the management of fever or suspected infection in infants and children undergoing therapy for cancer or stem cell transplantation. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. **It does not replace the need for the application of clinical judgement to each individual presentation**.

#### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- Hospitals and facilities either adopt this protocol or adapt local protocols to comply with the Infants and Children: Initial Management of Fever or Suspected Infection in Oncology and Stem Cell Transpantation Patients, first edition Clinical Practice Guideline
- Local protocols are in place in all hospitals and facilities likely to be required to manage paediatric oncology and stem cell transplantation patients with fever or suspected infection
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this new guideline.

The guideline Infants And Children: Initial Management Of Fever Or Suspected Infection In Oncology And Stem Cell Transplantation Patients can be downloaded at the following link – Infants and Children: Initial Management of Fever/Suspected Sepsis in Oncology /Transplant Patients

#### PAEDIATRICS 2. PAEDIATRIC PROCEDURAL SEDATION - GUIDE FOR EMERGENCY DEPARTMENTS, WARDS, CLINICS AND IMAGING

#### (GL2018 011 issued 4/5/2018)

#### **PURPOSE**

Paediatric Procedural Sedation - Guide for Emergency Departments, Wards, Clinics and Imaging provides direction to clinicians and is aimed at achieving the best possible paediatric care in all parts of the state. The guide was prepared for the NSW Ministry of Health by an expert clinical reference group.

#### **KEY PRINCIPLES**

This guide applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts and Speciality Health Networks to determine where local adaptions are required or whether it can be adopted in its current format in hospitals and facilities required to manage procedural sedation of paediatric patients.

This guide applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts and Speciality Health Networks to determine where local adaptions are required or whether it can be adopted in its current format in hospitals and facilities required to manage procedural sedation of paediatric patients.

This guide reflects what is currently regarded as a safe and appropriate approach to the management of procedural sedation for paediatric patients. However, as in any clinical situation there may be factors which cannot be covered by a single guide. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

#### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- This guide is adopted or local procedures are developed based on the PaediatricProcedural • Sedation Guide for Emergency Departments, Wards, Clinics and Imaging.
- Local protocols are in place in all hospitals and facilities likely to be required to manage • paediatric patients requiring procedural sedation
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this revised guideline.

To download this guidelines go to Paediatric Procedural Sedation - Guide for Emergency Departments, Wards, Clinics and Imaging

#### NEONATAL - JAUNDICE IDENTIFICATION AND MANAGEMENT IN NEONATES ≥ 32 WEEKS GESTATION (GL2016 027)

*GL2016\_027* incorporates content from obsolete Guideline *GL2007\_001* Neonatal Exchange Transfusions in NSW as notified in IB2016\_062.

#### PURPOSE

This Guideline provides a framework for the early identification and management of jaundice in neonates  $\geq$  32 weeks gestation. Approximately 60% of neonates born at term and 85% of preterm neonates will develop jaundice. Many of these neonates will develop 'physiological jaundice', which is usually benign. However, when unconjugated serum bilirubin levels are too high, bilirubin can cross the blood brain barrier. Bilirubin is neurotoxic, particularly to the auditory nerve and basal ganglia, which can result in brain injury and lifelong disability. It is important therefore, to identify those neonates at risk of acute bilirubin encephalopathy and kernicterus.

#### **KEY PRINCIPLES**

This Guideline applies to all NSW Public Health Organisations providing care for neonates  $\geq$  32 weeks gestation which should include:

- The identification at birth of neonates with risk factors for neonatal jaundice
- Regular visual assessment from birth of all neonates
- Management of neonatal jaundice identified in the first 24 hours of age
- Management of neonatal jaundice identified  $\geq$  24 hours of age
- Follow-up care for neonates discharged at less than 3 days of age with risk factors for jaundice or jaundice at discharge
- Assessment and escalation of care for neonates with prolonged jaundice > 14 days of age in a term neonate, and beyond 21 days in a preterm neonate.

#### **USE OF THE GUIDELINE**

The Chief Executives of all NSW Local Health Districts are responsible for the implementation of this guideline within their services / facilities to ensure:

- Local processes and operating procedures are developed in line with this document to manage neonates ≥ 32 weeks gestation to ensure:
  - o Prompt appropriate identification, management and escalation of neonatal jaundice
  - o Equipment is used, maintained and its effectiveness is monitored
  - o Discharge is planned and follow up processes are in place
  - Assessment and appropriate escalation of care for neonatal jaundice > 14 days of age in a term neonate and beyond 21 days in a preterm neonate.
- The Directors of Clinical Governance inform relevant staff in maternity, neonatal services and biomedical departments of this new Guideline
- Morbidity and mortality associated with neonatal jaundice is monitored and reviewed.

To download the Guidelines please go to

Neonatal - Jaundice Identification and Management in Neonates 

2 32 Weeks Gestation

#### HYPOXIC ISCHAEMIC ENCEPHALOPATHY IN NEWBORNS - RECOGNITION, MONITORING AND EARLY MANAGEMENT (IB2023 028)

#### IB2023\_028 replaced PD2010\_006

#### PURPOSE

This Information Bulletin notifies the NSW Health system of the publication of the Clinical Practice Guide <u>Hypoxic ischaemic encephalopathy in newborns - recognition, monitoring and early management</u>.

#### **KEY INFORMATION**

The Hypoxic ischaemic encephalopathy in newborns - recognition, monitoring and early management provides guidance on the management of newborns with hypoxic ischaemic encephalopathy who may benefit from therapeutic hypothermia.

The Clinical Practice Guide is accompanied by a parent information sheet Therapeutic hypothermia (cooling) to protect babies with hypoxic ischaemic encephalopathy (HIE) and the evidence check document Therapeutic hypothermia in neonatal hypoxic ischemic encephalopathy.

The management of newborns with HIE includes:

- identification and management of newborns with encephalopathy through the use of the Newborn Encephalopathy Pathway
- assessment of the severity of encephalopathy in newborns using the Encephalopathy Severity Tool every hour in the first six hours of birth
- criteria for initiating therapeutic hypothermia for newborns and initial management in neonatal units.

#### **General principles**

Resuscitation and stabilisation of the newborn should be prioritised before commencing therapeutic hypothermia.

Therapeutic hypothermia must not be commenced without discussion with the Newborn and Paediatric Emergency Transport Service (NETS) and a tertiary centre neonatologist.

All newborns for whom therapeutic hypothermia has been commenced should be transferred to a neonatal intensive care unit (NICU) for ongoing management.

#### Reporting

Reporting processes via the incident management system (ims+) should be in place to monitor the incidence of newborns with moderate or severe encephalopathy. Serious incidents, including term newborns diagnosed with severe HIE or who receive therapeutic hypothermia, should be notified to the NSW Ministry of Health via a Reportable Incident Brief in accordance with the NSW Health Policy Directive Incident Management (PD2020\_047).

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## CHILD WELLBEING AND CHILD PROTECTION POLICIES AND PROCEDURES FOR NSW HEALTH (PD2013 007)

## PD2013\_007 rescinds PD2005\_299, PD2006\_104, PD2007\_023, PD2011\_057, PD2011\_065, GL2011\_008, IB2010\_005, IB2012\_002.

#### PURPOSE

This policy articulates the professional and legal responsibilities of all health workers to promote the health, safety, welfare and well-being of children and young people, working collaboratively with interagency partners in the shared system of child protection in NSW. These responsibilities apply whether workers are providing health care directly to children and young people or to adult clients who are parents/carers or are pregnant.

This policy informs Local Health Districts, Specialty Health Networks, other health services and health workers about the tools and resources available and the interagency arrangements in place to assist them to meet their responsibilities and provide a consistent NSW Health response to child protection and wellbeing.

#### MANDATORY REQUIREMENTS

Every health worker has a responsibility to protect the health, safety, welfare and wellbeing of children or young people with whom they have contact.

The legal responsibilities of health services and health workers are identified in the following legislation:

Children and Young Persons (Care and Protection) Act 1998

- Collaborate with interagency partners and comply with information exchange provisions to promote the safety, welfare and wellbeing of children and young people, including taking reasonable steps to coordinate the provision of services with other agencies;
- Meet requirements for mandatory reporting of children and reporting of young people (or classes/groups of children or young people) at suspected risk of significant harm (ROSH);
- Report unborn children where it is suspected they may be at ROSH after their birth;
- Respond to the needs of children and young people after making a report to Community Services or to the NSW Health Child Wellbeing Unit;
- Respond to Community Services' and Children's Court requests to provide health services and or Community Services and Police Force requests to provide medical examinations and treatment;
- Assist with Children's Court proceedings when required.

# Commission for Children and Young People Act 1998/Child Protection (Working with Children) Act 2012

• Meet requirements to ensure that only people with valid Working with Children Checks are engaged in child related work (where a child is under the age of 18 years).

#### Ombudsman Act 1974

• Maintain systems to prevent 'reportable conduct' by health workers and for reporting and responding to alleged reportable conduct involving NSW Health employees.

The policy responsibilities of health workers are to:

 Recognise and respond appropriately to the vulnerabilities, risks and needs of families, children and young people when providing any health service;

- Collaborate across NSW Health services and with interagency partners to support and strengthen families and promote child health, safety, welfare and wellbeing;
- Use the <u>Mandatory Reporter Guide</u> and seek assistance from the NSW <u>Health Child Wellbeing</u> <u>Unit</u> to help identify children or young people at suspected risk of significant harm (ROSH);
- Seek assistance from the <u>NSW Health Child Wellbeing Unit</u> and the <u>Family Referral Services</u> to help respond to vulnerable families, children and young people below the ROSH threshold;
- Actively seek feedback from Community Services after making a child protection report and continue to support the child, young person or family consistent with the health worker's roles and responsibilities;
- Follow the <u>Child Wellbeing and Child Protection NSW Interagency Guidelines</u> and other agreed interagency procedures when working with children, young people and families, including in relation to information exchange, High Risk Birth Alerts, Prenatal Reporting, escalation of child protection concerns, assumption of care by Community Services and out of home care health assessments;
- Collaborate in joint investigation and response to matters involving alleged child sexual assault or serious child abuse or neglect leading to criminal proceedings; and
- Participate in mandatory and/or other child protection training for NSW Health workers.

# IMPLEMENTATION

Chief Executives across the NSW public health system are responsible and accountable for:

- 1. Ensuring that this policy and the associated *Child Wellbeing and Child Protection Fact Sheet for NSW Health Workers* are understood and implemented by all health workers; and
- 2. Enabling frontline staff to operationalise this Policy Statement in accordance with the attached *Child Wellbeing and Child Protection Policies and Procedures for NSW Health.*

To access the **Child Wellbeing and Child Protection Policies and Procedures for NSW Health** please go to <u>http://www.health.nsw.gov.au/policies/pd/2013/PD2013\_007.html</u>

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### STATEWIDE EYESIGHT PRESCHOOLER SCREENING (StEPS) PROGRAM (PD2018\_015)

#### PD2018\_015 rescinds PD2012\_001

#### PURPOSE

The purpose of this policy directive is to guide StEPS coordinators in the consistent implementation and management of the Statewide Eyesight Preschooler Screening (StEPS) program at the Local Health District (LHD) level.

This policy directive describes the roles and responsibilities of StEPS personnel and training requirements, identifying four year old children for vision screening, vision screening protocols, referral processes and reporting requirements so that childhood vision problems can be detected early and treatment outcomes maximised.

#### MANDATORY REQUIREMENTS

LHDs must ensure compliance with the requirements set out in this policy directive as the basis for administering the StEPS program in LHDs. Mandatory requirements for the StEPS program are:

- Vision screening protocols relating to consent, vision screening, assessment, referrals, referral follow up, and reporting and data management (Section 2).
- All four year old children in LHDs, including disadvantaged groups and children with special needs, should be offered the StEPS program, to meet StEPS performance benchmarks (Section 3).
- StEPS vision screening staff must be suitably trained and provided with the necessary equipment and resources to conduct vision screening (Sections 4 and 5).
- All standardised templates attached to this policy are used by LHDs when administering the StEPS program (Section 7).
- LHDs must develop operating processes consistent with this policy directive, to maximise screening and meet local needs in each LHD.

#### **IMPLEMENTATION**

The Ministry of Health provides funding to assist LHDs in the implementation of the StEPS program in NSW. This policy directive applies to all staff and relevant managers involved in delivering the StEPS program in LHDs across NSW.

#### **Roles and Responsibilities**

Ministry:

- Provide mandatory requirements and guidelines for the implementation and management of the StEPS program.
- Evaluate the overall efficiency and performance management of the StEPS program in LHDs across NSW.
- Meet regularly with all LHDs through the StEPS Coordinators Meetings to review overall progress and implementation of the StEPS program in LHDs.
- Ensure the content of this StEPS policy directive is effectively communicated to all staff involved in coordinating the StEPS program in NSW.

#### LHDs:

- Actively identify all four year old children in their LHDs to offer them a free StEPS vision screen.
- Assign responsibility and personnel to implement the StEPS program in line with this policy directive.
- Ensure appropriate vision screening staff are employed, that vision screening staff are trained to undertake the StEPS vision screen, and staff are provided with appropriate equipment and resources to carry out the functions of the StEPS program.
- Ensure compliance and full implementation of this policy directive in their LHD.
- Ensure that the budget provided for the StEPS program is expended on implementing the StEPS program.
- Provide all required reports to the Ministry of Health relating to screening activity, referrals, assessments, follow ups, monitoring and reporting.
- ensure that StEPS performance benchmarks are achieved and maintained (Section 3.3)
- Ensure the content of this StEPS policy directive is effectively communicated to all staff involved in implementing the StEPS program in the LHD.

# 1. BACKGROUND

The Statewide Eyesight Preschooler Screening (StEPS) program is a universal, evidence based, free vision screening program for all four year old children in NSW.

The program actively identifies all four year old children in NSW to offer them a free StEPS vision screen and is designed to identify childhood vision problems early, prior to school entry, so that treatment outcomes can be maximised.

The StEPS program is an important component of the NSW Child Health Screening and Surveillance Program, as documented in the NSW Personal Health Record (PHR), the 'Blue Book'. The NSW PHR recommends a vision examination at the newborn health check, vision surveillance at the 1-4 week, 6-8 week, 6 month, 12 month, 18 month, 2 year and 3 year child health checks, and a monocular visual acuity screen at the 4 year child health check.

Vision develops from birth to approximately eight years of age, and is fully mature by the mid-teenage years. Early identification and treatment of eye and vision problems aims to optimise vision prior to starting school and reduces the likelihood of permanent vision loss. The StEPS program targets children at four years of age, the first opportunity for a child's visual acuity to be reliably screened at a population level.

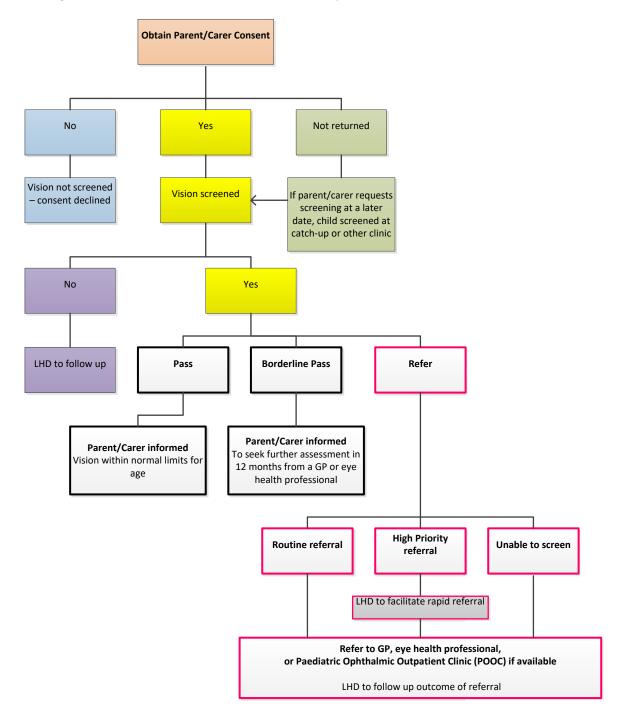
While eye health surveillance can monitor a child for outward signs of eye or vision problems, the two most common childhood vision problems, amblyopia and refractive error, cannot be detected by family history, vision surveillance or observing a child's behaviour or appearance. These vision disorders can only be detected if a monocular visual acuity screen is conducted by a trained vision screener.

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# **2 VISION SCREENING PROTOCOLS**

#### 2.1 StEPS Referral Pathway Flowchart

The figure below outlines the StEPS Referral Pathway:



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### 2.2 Pathway for screening, referral, assessment and follow up

LHDs must have clearly documented protocols, consistent with this StEPS Policy Directive for approaching services to offer the StEPS vision screening program, offering parents/carers the StEPS vision screen for their child, the provision of the vision screening service, documenting the outcome of the vision screen, informing parent/carers of the outcome of the vision screen, and for referral and follow up of referrals.

Standardised templates attached to this policy (Section 7) must be used to implement and administer the StEPS program in NSW.

#### 2.3 Consent

Consent from parent/carer for child to participate in the StEPS program at a preschool, child care centre or other service must be obtained prior to undertaking the StEPS vision screen. The following standardised information letter and consent forms are to be used to obtain signed consent:

- *StEPS Important Notice for all Parents/Carers* (Attachment 2).
- *StEPS Consent and Results Form* (Attachment 3).

Consent forms, information letters and flyers about the StEPS program and LHD privacy information should be provided to the preschool/child care centre where the screening will occur at least two weeks prior to the screening date. Completed and signed consent forms must be collected prior to the screening date or on the day of screening. Consent may be accepted by the StEPS vision screener up to and including the day of screening. If verbal consent is provided, this must be documented on the consent form by the vision screener.

If a consent form is returned and the parent/carer has consented to screening, but the child is absent on the day of screening, a follow-up screening offer should be made. At least two vision screening follow up offers should be made (and documented) where consent is obtained but screening is not conducted.

<u>If the consent form is not returned</u>, LHDs should have screening options available for parents/carers who request screening for their child at a later date, such as catch-up and other clinics.

If consent is not provided, that is, the consent form is returned but consent is declined, this must be recorded appropriately.

To monitor and assist in accurately recording the number of StEPS vision screenings offered, it is recommended that LHDs enquire about the number of children who:

- Are four years of age, or who will be turning four years of age.
- Are eligible to attend school in the following calendar year.
- Are attending the centre where the StEPS vision screening will take place
- Are able to provide the correct corresponding number of consent forms.

The target group of children for StEPS screening are those aged four years who are starting school the following year. Children who are five years of age and have not previously received a StEPS vision screen are also eligible to be offered the StEPS program. Three year old children who are eligible to start school the following year may be screened at the StEPS coordinator's discretion.

# 2.4 Vision Screening

LHDs must coordinate and organise the StEPS vision screening with relevant parties at a suitable screening location. Consideration should be given to preschools/childcare centres with specific attendance patterns such as split week attendance to ensure a high uptake of screening and the number of screening days required to screen all children appropriately. StEPS vision screening staff should arrange an appropriate area to conduct the StEPS vision screening in consultation with the preschool/child care centre.

Wherever possible, StEPS vision screening staff must conduct a monocular visual acuity screening test using the approved 6 metre HOTV logMAR chart or Sheridan Gardiner Linear Chart. If the screening location does not have the required space available for the 6 metre chart, the approved 3 metre HOTV logMAR or Sheridan Gardiner Linear Chart can be used. The matching board corresponding to the chart used is to be provided to all children to enable children to match the letter indicated to by the vision screener with the letter on the matching board.

Vision screeners should also review the consent form carefully noting any parental/carer concerns, perform a visual inspection of the eyes and observe the child carefully (for example, does the child constantly close one eye in sunlight, do both eyes move together equally in all direction of gaze, does the child consistently tilt their head or turn their face to one side) to determine if any abnormalities may be present which could affect either the vision or the child's general eye comfort. If there are concerns following visual inspection of the eyes, for example, red eyes, red lid margins, or excessive watering, the child should be referred to their General Practitioner. Vision screeners should carefully observe and refer any possible eye or vision abnormalities even if the visual acuity result is within normal range.

To conduct a monocular visual acuity test, the screener must occlude the left eye first using the recommended occlusion glasses. A folded tissue is placed between the occluded eye and the glasses. If the child already wears glasses, use a single-use eye patch with a tissue between their glasses and the eye patch. LHD infection control procedures must be followed.

The test results for each eye must be accurately recorded by the vision screener on the *StEPS Consent* and *Results Form* (Attachment 3) and *Notification of StEPS Vision Screening Results Letter* (Attachment 4) as appropriate.

# 2.5 Documenting Results of the Vision Screening

# 2.5.1 Consent and Results Form

The vision screener must complete the results section of the *StEPS Consent and Results Form* (Attachment 3) to document the vision screening results.

All sections of the *StEPS Consent and Results Form* must be completed, signed and dated. Relevant actions relating to completing a *StEPS Results Notification Letter* and *StEPS Referral Letter* must be identified on the form. All *StEPS Consent and Results Forms* must be promptly forwarded to the StEPS Coordinator as per LHD procedures.

# 2.5.2 Notification of StEPS Vision Screening Results Letter

The *Notification of StEPS Vision Screening Results Letter* (Attachment 4) is used to inform parents of the outcome of vision screening and must be completed and forwarded to all parents/carers of children who participated in the StEPS program.

Notification of the vision screening result should be provided as soon as practical, preferably on the day of the screening.

If the parent/carer has indicated on the *StEPS Consent and Results Form* (Attachment 3) that the child is under the care of an eye health professional, the vision screener must advise on the *Notification of StEPS Vision Screening Results Letter* (Attachment 4) for parent/carer to continue care. If there are any concerns about the child's current treatment, vision screeners must discuss this with their StEPS Coordinator. LHDs should encourage parents/carers to add the *Notification of StEPS Vision Screening Results Letter* to their child's Personal Health Record.

All parents are encouraged to ensure their child attends a Before School Health Assessment at 4 years of age, as per the NSW Personal Health Record (Blue Book).

# 2.5.3 Inclusion of forms and letters in the electronic medical record

If the child's electronic medical record is available, the *StEPS Consent and Results Form* (Attachment 3) is scanned and forms part of the child's electronic medical record. The *StEPS Referral Letter* (Attachment 5) may be scanned and included as correspondence accompanying the child's medical record.

# 2.5.4 Confidentiality

All information collected and results are confidential and must not be provided to or discussed with others, including staff at the preschool or child care centre, without parent/carer consent. To ensure privacy, all *Notification of StEPS Vision* 

*Screening Results* letters (Attachment 4) are to be placed in a sealed envelope with the child's name on the outside of the envelope. Vision screeners must liaise with relevant parties (e.g. preschool/child care director) at the screening location to determine the most appropriate mechanism for providing the results of the StEPS vision screen to parents/carers.

# 2.5.5 StEPS Referral Letter

All parents/carers of children who require a referral must be provided with a *StEPS Referral Letter* (Attachment 5). The referral letter may be completed by the vision screener, StEPS Coordinator or Administration Officer as per LHD procedures.

# 2.6 Referral Criteria

The StEPS program uses pass/refer criteria that correlate to specific, evidence-based visual acuity results. Following the StEPS vision screen, the criteria for making a referral based on the vision screening result are as follows:

- a) Pass visual acuity of 6/9 (3/4.5) or above
  - A child with visual acuity of 6/9 (3/4.5) or above in both eyes is considered to have passed the StEPS visual acuity screen.
  - Referral is not required.
- b) Borderline Pass visual acuity of 6/9-1 (3/4.5-1) or 6/9-2 (3/4.5-2)
  - A child with visual acuity of 6/9-1 (3/4.5-1) or 6/9-2 (3/4.5-2) in one or both eyes is considered a borderline pass.
  - Parents/carers are advised to re-test in 12 months by an Eye Health Professional.
- c) Refer visual acuity of less than 6/9-2 (3/4.5-2) in one or both eyes
  - A child with visual acuity of less than 6/9-2 (3/4.5-2) in one or both eyes is considered to have not passed the StEPS visual acuity screen.
  - Parents/carers are advised to have their child's eyes tested by a General Practitioner or Eye Health Professional.

### d) Refer - obvious pathology

- A child with obvious pathology on observation of external eye and adnexa that is currently untreated should be referred for review.
- Parents/carers are advised to have their child's eyes reviewed by a General Practitioner.

#### e) High Priority Referral - visual acuity of 6/18 (3/9) or less in one or both eyes

- A child with visual acuity of 6/18 (3/9) or less in one or both eyes is considered a high priority referral.
- Parents/carers are advised to have their child's eyes tested by a General Practitioner or Eye Health Professional as a matter of urgency.
- Referral may be made to Paediatric Ophthalmic Outpatient Clinics (POOCs) according to *StEPS Referral Protocols for POOCs* (Attachment 6).

#### f) Refer - unable to be screened

- A child who has a valid consent but is unable to be screened, for example if they are uncooperative or unable to perform the test, should be referred.
- Parents/carers are advised to follow up with an Eye Health Professional.

#### 2.7 Follow-up of referrals

All referrals from the StEPS Program must be actively followed up by the StEPS Coordinator as per this Policy Directive and LHD procedures. Wherever possible, StEPS Coordinators should ensure that High Priority Referrals receive a diagnostic vision assessment within one month, and other referrals receive an assessment within six months.

StEPS Coordinators are to offer assistance to families to ensure the child receives a diagnostic eye assessment within the appropriate timeframe. This may include, but is not limited to, offering secondary screening Orthoptic services and/or referral to the StEPS Paediatric Ophthalmic Outpatient Clinics (POOCs). StEPS Coordinators should consider any barriers to receiving a diagnostic assessment and subsequent treatment and assist families wherever possible to access appropriate services.

StEPS Coordinators must monitor all follow up referrals and report on the outcomes. If no eye health professional report is received and the outcome is unknown, the parent/carer must be contacted to determine the outcome and the result recorded. If possible, the name of the eye health professional who provided the assessment/treatment should be sought from the parents and the eye health professional then contacted to confirm the outcome.

The *StEPS Referral Outcomes Report* (Attachment 10) must be completed to record the outcome of the referral as a result of the StEPS vision screening. These reports can be used to demonstrate the accuracy of vision screening undertaken and the effectiveness of the StEPS program.

# 2.8 Mandatory Reporting for the StEPS program

StEPS Coordinators must complete and submit StEPS Screening Activity and StEPS Referral Outcomes reports for the StEPS program to the Ministry. Where an electronic medical record system is available in the LHD, electronic reporting and data extraction files should be submitted as reports to the Ministry. If electronic medical records are not available, these may be submitted as manual reports using the following templates:

- Quarterly *StEPS Screening Activity Report* (Attachment 9)
- Quarterly *StEPS Referral Outcomes Report* (Attachment 10)

# 2.9 Data Management

LHDs are responsible for developing and maintaining a database to record all children who have participated in the StEPS program. This will enable ease of scheduling, screening, tracking referrals, follow up referrals, reporting on referral outcomes and responding to enquires from parents/carers on vision screening.

All children who have participated in the StEPS program must be recorded on a database developed and maintained by LHDs. This database must include client/patient identifying details and parents contact details in accordance with PD2007\_094 Client Registration Policy', as well as screening location, date of screening, result of screening, follow up of referrals, and the outcome and diagnosis following referral where applicable. It is recommended that terminology used to record the outcomes of referrals is consistent with language used in the referral outcomes report.

Where an electronic medical record system is available in the LHD, the appropriate electronic documentation for StEPS should be completed and data extraction files submitted as reports to the Ministry of Health.

# 2.9.1 Retention and Disposal of StEPS patient/client records

For <u>all</u> children who receive a StEPS vision screen, the *StEPS Consent and Results Form* (Attachment 3) must be incorporated into the main Community Health client record system and retained until the child attains or would have attained the age of 25 years. This applies to children who are found to have no abnormality on screening, as well as those children who receive a borderline pass or are referred for any reason.

Where the StEPS Consent and Result Form is in paper format and is not imaged or scanned, the original paper form must be retained for 25 years. It can then be disposed of according to LHD procedures.

Where the StEPS Consent and Result Form is imaged or scanned, the original Form should be retained until it has been verified that the scanned copy clearly displays all elements of the original record, as per NSW State Records 'General Retention and Disposal Authority – Public Health Services: Patient/Client Records' (GDA 17). Once verified, the paper Form can then be disposed of according to LHD procedures. The imaged Form must be retained for 25 years.

# **3 IDENTIFYING FOUR YEAR OLD CHILDREN**

# 3.1 Identifying Four Year Old Children

All four year old children in NSW are to be actively identified to be offered a free StEPS monocular visual acuity screen by StEPS Coordinators within their designated LHDs. Strategies to identify four year old children may include, but are not limited to, contacting the following services to offer the StEPS program:

- preschools
- child care centres
- family day care services
- early intervention services
- refugee services
- Child and Family Health Services
- Playgroups
- immunisation clinics
- Department of Education and Communities, Schools for Specific Purposes

- Community vision screening days
- School Orientation programs (this strategy should only be used where the eligible child was not able to be identified through alternative strategies).

# 3.2 Disadvantaged groups of children and children with special needs

Disadvantaged groups of children and children with special needs are to be actively identified to ensure they are offered StEPS screening. For the purposes of the StEPS program, the following groups of children are classified as 'disadvantaged groups':

- Aboriginal and Torres Strait Islander children.
- Children attending 'Early Intervention Services'.
- Children attending 'Schools as Community Centres (SACCs) Playgroups'.
- Children whose parents attend Mental Health Services.
- Children in 'Out of Home Care'.
- Refugee children.
- Socioeconomically disadvantaged children.

Children with special needs are children who have been identified with developmental delay and/or neurological deficits.

StEPS Coordinators are to develop local strategies that meet the needs of their LHD in order to ensure maximum vision screening and equity of access to the StEPS program for all four year old children.

# **3.3 Service Level Agreement**

The Service Level Agreement of the StEPS program is:

• A minimum of 80% of eligible four year old children have screening conducted

Wherever a parent/carer completes a StEPS consent form and agrees to their child participating in the StEPS program the LHD must make every effort to ensure that the child's vision is screened according to StEPS protocols.

LHDs are to ensure that the StEPS Service Level Agreement is maintained according to the estimated target population numbers of four year olds in their LHD provided by the Ministry of Health.

# 4 StEPS PERSONNEL

# 4.1 Vision Screening Staff

StEPS vision screening staff are employed by LHDs, under the supervision of LHD StEPS Coordinators to conduct monocular visual acuity screening assessments for four year old children.

StEPS vision screening must be conducted by suitably trained staff competent in using the StEPS vision screening equipment to undertake vision screening for four year old children. Screening assessments are undertaken in locations deemed appropriate by LHDs and can include settings such as preschools, child care centres, community settings and Child and Family Health Services.

StEPS vision screening staff are responsible for:

• liaising effectively with preschool and child care centre staff, parents, team members and other health care professionals in a professional and caring manner

- conducting vision screening according to vision screening protocols consistent with this StEPS policy directive relating to obtaining consent, referral processes, appropriate testing set up, vision screening equipment gathering and utilising information as required for effective vision screening
- ensuring the vision screening process creates minimal disruption to the location where screening is undertaken
- ensuring the confidentiality and privacy of the child is maintained at all times and all relevant information about the screening process and vision screening results is provided to parents/carers
- ensuring all mandatory requirements and reporting mechanisms relating to vision screening, consent, referrals processes, notification of results and LHD protocols are undertaken
- adhering to all LHD Work Health and Safety and Infection Control protocols
- maintaining vision screening equipment and reporting malfunctioning equipment to the StEPS Coordinator
- advising the StEPS Coordinator of any issues, incidents, problems or concerns that arise during a vision screening session.

#### 4.2 StEPS Coordinator

StEPS Coordinators are employed by LHDs to implement, coordinate and manage the day to day operations of the StEPS program.

StEPS Coordinators develop and maintain strong links with all relevant stakeholders in their LHD, such as child health services, parents and carers, early childhood education and care providers, eye health professionals, general practitioners, medical specialists, Aboriginal Community Controlled Health Services, early intervention and coordination programs and other government and non-government agencies, to promote the StEPS program and to ensure the StEPS program is delivered effectively in their respective LHDs.

StEPS Coordinators are responsible for:

- ensuring all four year old children in their LHD are actively identified and offered a StEPS vision screen, including providing screening services as required
- recruiting vision screening staff as required, training and/or arranging the training to be provided to StEPS vision screeners by a suitably qualified health professional
- supervision and professional development of StEPS vision screeners to ensure that competency in vision screening is achieved and maintained, and that all applicable LHD protocols are followed
- ensuring transportation is available for StEPS vision screeners to travel to screening locations, according to resources available in the LHD. This may include access to a motor vehicle or approval to use private vehicles with the provision of a mileage allowance according to LHD protocols
- ensuring all appropriate supplies and maintenance of equipment, relevant forms and promotional material is available to conduct StEPS vision screening
- maintaining the confidentiality and privacy of the children screened and providing support to parents as appropriate in the period between vision screening and diagnostic assessment

- developing vision screening protocols for screening, referral, assessment and follow up consistent with the StEPS Policy Directive
- developing local processes to ensure disadvantaged groups of children and children with special needs are actively identified for the StEPS program
- data management and monitoring of key performance indicators, vision screening referral rates, referral outcomes, follow up referrals and submitting relevant reports to the NSW Ministry of Health as required.
- setting up and maintaining a database to record information on all four year old children who participated in the StEPS program for quality management
- effectively managing the LHD StEPS budget to ensure the program is implemented efficiently in the LHD including all printing costs relating to information flyers, brochures, letters and forms on the StEPS program
- attending NSW Ministry of Health StEPS Coordinators meetings as required and being the main point of contact for the StEPS program in their LHDs

# 4.3 StEPS Administration Officer

StEPS Administration Officers are employed by LHDs to provide administrative duties as deemed appropriate by the StEPS Co-ordinator. Duties may include, but are not limited to, arranging and confirming vision screening bookings, organising consent form packages, StEPS data entry and general office tasks.

### 4.4 Orthoptist

Orthoptists may be employed to provide comprehensive secondary vision screening for children referred via the StEPS program. Orthoptists may also provide vision screening services for children identified with 'special needs' and undertake additional vision screening tests considered appropriate to a child's individual developmental level. Orthoptists may also investigate and diagnose ocular motility disorders and assist in transitioning the family to timely diagnostic assessment services where appropriate.

Orthoptists may also assist in the training of vision screening staff.

#### 4.5 StEPS Outpatient Clinics

Dedicated StEPS tertiary Paediatric Ophthalmic Outpatient Clinics (POOCs) have been established for children identified with potentially significant vision loss and referred as a 'High Priority Referral'. POOCs will ensure that such children receive a diagnostic vision assessment in a timely manner so that treatment outcomes can be maximised. Ongoing management and treatment of a child diagnosed with a vision problem via POOCs should be at the discretion of the eye health professional in consultation with the parent/carer.

Referrals to POOCs are available from anywhere in NSW. Children can be referred according to *StEPS Referral Protocols for Paediatric Ophthalmology Outpatient Clinics (POOCs)* (Attachment 6). The *StEPS Referral Form for POOCs* is at Attachment 7.

# **5 TRAINING**

# 5.1 StEPS Training Package

To be certified as competent, vision screening staff must:

• satisfactorily complete modules one and two of the *StEPS Training Package* through the NSW Health Education and Training Institute (HETI).

- complete a minimum of four hours practical experience at a screening location (with the StEPS Coordinator or an Orthoptist if possible).
- be assessed as competent after three months of screening using the *StEPS* Competency Checklist for Vision Screeners (Attachment 8) and annually thereafter.

#### 5.2 Supervision and Professional Development

Following completion of modules one and two, in addition to supervised practical experience, ongoing professional development and mentoring opportunities for vision screeners should be locally arranged by LHDs as appropriate. This may involve opportunities to work with an experienced vision screener for the first three months of vision screening wherever possible; participation in Orthoptic clinics; and/or other professional development opportunities identified by the LHD.

It is the responsibility of the StEPS Coordinator to ensure that all dedicated StEPS vision screening staff, and all LHD staff who undertake StEPS vision screening, are proficient in undertaking a StEPS vision screen prior to being deemed qualified to undertake a StEPS vision screen unsupervised.

Ongoing supervision and performance management of vision screening staff, and other health staff who provide StEPS vision screening, is to be undertaken by LHDs according to LHD protocols. This should include performance reviews of vision screening staff referral rates and where appropriate, actions undertaken to address performance factors and skill development.

# **6 GLOSSARY OF TERMS**

#### Adnexa

For the purposes of this document, adnexa refers to the appendages of the eye. These include but are not limited to the eyelids, conjunctiva, lacrimal apparatus and orbit.

#### Amblyopia

Amblyopia is reduced or 'dim' vision in an eye which appears to be normal. It is sometimes called 'Lazy Eye'. This is a serious eye defect which often goes undetected in childhood. If amblyopia is not diagnosed and treated early, the vision in the affected eye may be permanent and cannot be corrected with glasses or surgery.

#### **Eye Health Professional**

For the purposes of this document, an *Eye Health Professional* refers to registered ophthalmologists, orthoptists and optometrists.

#### **Refractive Error**

A refractive error occurs when the shape of an eye is abnormal or does not bend (or refract) light properly, which results in blurred vision. The three most common refractive errors are myopia (short sightedness), hyperopia (long-sightedness) and astigmatism.

#### HOTV logMAR chart

A visual acuity screening chart used in the StEPS program. LogMAR charts feature the same number of letters on each line, which progressively reduce in size according to a geometrical progression.

#### Sheridan Gardiner Linear Chart

A visual acuity screening chart used in the StEPS program. Linear charts feature an increasing number of letters on each line, which linearly reduce in size.

#### **Visual Acuity**

Visual acuity refers to the measurement of the eye's capacity to see an object, for example a letter on a vision chart, at a certain distance. This measurement is taken one eye at a time with the child wearing their correcting glasses or contact lenses (when needed). It is usually recorded in a format that compares the child's vision results to a certain standard.

#### **Visual Acuity Screening**

Also referred to as vision screening, this is the testing of visual acuity using pass/fail criteria to a specific standard correlated to an age appropriate level of acceptable vision.

#### **Vision Surveillance**

Vision surveillance is defined as the monitoring of vision development for signs of eye or vision problems and includes observation, family history, reported visual behaviours and some vision tests, e.g. corneal reflections, ocular movements and response to occlusion.

#### 7 LIST OF ATTACHMENTS

#### To view attachments listed below please go to: https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2018\_015\_

- 1. Implementation Checklist
- 2. StEPS Important Notice for all Parents/Carers
- 3. StEPS Consent and Results Form
- 4. Notification of StEPS Vision Screening Results letter
- 5. StEPS Referral Letter
- 6. StEPS Referral Protocols for Paediatric Ophthalmology Outpatient Clinics
- 7. StEPS Referral Form for Paediatric Ophthalmology Outpatient Clinics
- 8. Competency Checklist for Vision Screeners
- 9. StEPS Screening Activity report
- 10. StEPS Referral Outcomes report

321(22/05/18)

# **PAEDIATRIC PROCEDURAL SEDATION - GUIDE FOR EMERGENCY DEPARTMENTS, WARDS, CLINICS AND IMAGING** (GL2018\_011)

#### PURPOSE

Paediatric Procedural Sedation - Guide for Emergency Departments, Wards, Clinics and Imaging provides direction to clinicians and is aimed at achieving the best possible paediatric care in all parts of the state. The guide was prepared for the NSW Ministry of Health by an expert clinical reference group.

#### **KEY PRINCIPLES**

This guide applies to all facilities where paediatric patients are managed. It requires the Chief Executives of all Local Health Districts and Speciality Health Networks to determine where local adaptions are required or whether it can be adopted in its current format in hospitals and facilities required to manage procedural sedation of paediatric patients.

This guide reflects what is currently regarded as a safe and appropriate approach to the management of procedural sedation for paediatric patients. However, as in any clinical situation there may be factors which cannot be covered by a single guide. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. It does not replace the need for the application of clinical judgement to each individual presentation.

#### **USE OF THE GUIDELINE**

Chief Executives must ensure:

- This guide is adopted or local procedures are developed based on the Paediatric Procedural Sedation Guide for Emergency Departments, Wards, Clinics and Imaging.
- Local protocols are in place in all hospitals and facilities likely to be required to manage paediatric patients requiring procedural sedation
- Ensure that all staff treating paediatric patients are educated in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this revised guideline.

This Guideline and the attachements are available at: https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=gl2018 011

# **NEW STREET SERVICE POLICY AND PROCEDURES** (PD2018\_035)

#### PURPOSE

This Policy specifies the procedures and minimum standards for delivering New Street Services, and sets out the NSW Health framework for effective clinical practice in responding to children and young people with harmful sexual behaviours and their carers.

#### MANDATORY REQUIREMENTS

This Policy requires that New Street Services:

- prioritise the safety and wellbeing of young people who have been sexually harmed and those who are potentially at risk
- facilitate access to treatment for eligible families and caregivers of children and young people aged between 10 and 17 years who have engaged in harmful sexual behaviour, with priority given to those aged between 10 and 14 years, Aboriginal children and children with complex needs
- deliver services in ways which minimise harm
- integrate with NSW Health Violence Abuse and Neglect services, particularly Sexual Assault Services
- collaborate with interagency partners at local and district levels
- operate under a Service Agreement between the Local Health District in which the New Street service is located and the Sydney Children's Hospital Network, to receive clinical direction, advice and support
- comply with New Street staffing profiles as set out in the New Street Service Policy and Procedures
- deliver services in a culturally safe way
- participate in the New Street Advisory Committee
- apply the clinical processes and practices set out in the New Street Service Policy and Procedures
- comply with NSW Health Violence Abuse and Neglect Service Standards.

#### **IMPLEMENTATION**

Chief Executives are responsible and accountable for:

- establishing mechanisms to ensure the directives and requirements of the New Street Service Policy and Procedures are applied, achieved and sustained
- ensuring that NSW Health staff understand and are aware of their obligations in relation to the New Street Service Policy and Procedures and related policies and procedures
- ensuring resources are available to deliver and meet the directives and requirements of the New Street Service Policy and Procedures
- ensuring that NSW Health staff are trained to operationalise and implement the New Street Service Policy and Procedures
- communicating with the Ministry of Health through the Prevention and Response to Violence, Abuse and Neglect (PARVAN) Unit on reporting, communications and performance in relation to the New Street Service Policy and Procedures
- ensuring NSW Health staff are advised that compliance with the New Street Service Policy and Procedures is part of their patient / client care responsibilities.

New Street managers are responsible for:

- ensuring the requirements of the New Street Service Policy and Procedures are disseminated and implemented in their service
- monitoring implementation and compliance with the New Street Service Policy and Procedures.

NSW Health workers are responsible for:

• implementing and complying with the directives and requirements of the New Street Service Policy and Procedures.

#### This policy and the procedures are available at:

https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=pd2018\_035

321(21/09/18)

# PASTEURISED DONOR HUMAN MILK FOR VULNERABLE INFANTS (PD2018\_043)

#### PURPOSE

NSW Health is committed to the safe, equitable and ethical provision of pasteurised donor human milk (PDHM) to vulnerable infants in Neonatal Intensive Care Units (NICU).

Vulnerable infants refer to those infants at an increased risk of necrotising enterocolitis. This includes preterm infants, very low birth weight infants and other infants assessed as clinically high risk.

A partnership between NSW Health and the Australian Red Cross Blood Service (ARCBS) has been established in order to provide PDHM to these infants through the 'NSW Health Agreement for Pasteurised Donor Human Milk'. PDHM is supplied to NICUs on a cost-recovery basis.

This Policy supports mothers of vulnerable infants to optimise lactation; to supplement breast milk feeding of vulnerable infants with PDHM when mothers own milk is insufficient and ensure access to PDHM is equitable across NSW and in accordance with clinical need.

Only facilities with NICUs are eligible to receive PDHM. This Policy outlines the responsibilities of local health districts (districts) and Sydney Children's Hospital Network (SCHN) NICUs who choose to participate in the provision of PDHM to vulnerable infants under the NSW Health Agreement.

# MANDATORY REQUIREMENTS

To receive PDHM districts and SCHN must:

- Implement the attached, Pasteurised Donor Human Milk for Vulnerable Infants Protocol (the Protocol)
- Ensure they have sufficient resources to meet the requirements of this service.
- Ensure each ARCBS Milk Bank Coordinator complies with:
  - NSW Health Occupational Assessment, Screening and Vaccination Against Specified Infectious Diseases policy.
  - NSW Health Code of Conduct.
  - National Criminal Record completed by ARCBS and sighted by facility.
  - Local orientation procedures.

- Support donor recruitment within their facilities.
- Provide appropriately trained staff to ensure that adequate ongoing lactation support is offered, and that NICU breastfeeding rates on discharge are optimal.
- Provide facility-specific data for the purpose of quarterly performance monitoring in accordance with Section 1.6 in the Protocol.
- Coordinate the management of reactive serology screening results for hospital-based donors as per Appendix 1 in the Protocol.

# **IMPLEMENTATION**

The districts/SCHN Chief Executives or delegated officers must ensure the NICUs undertake the

following actions:

- All NICU staff are made aware of the Policy and Protocol.
- Appoint an authorised person to act as the 'Agency Contract Manager', as outlined in Section 14 in the Protocol, who will also be the point of contact for supply management in case of PDHM shortage.
- Key personnel are made aware of their responsibilities in the Protocol.
- Designated lead to develop local guidelines to support the implementation of the Policy and Protocol.

Supply of PDHM to NICUs during a shortage is determined by the principles of state-wide equity, with state-wide eligibility being determined as per the attached Protocol and not by the individual NICU. The monitoring reports will be compiled quarterly by the Health and Social Policy Branch, Strategy and Resources Division, Ministry of Health. These reports will be provided to the PDHM Governance Committee and Clinical Advisory Group for review.

Documentation of ARCBS Milk Bank Coordinator compliance with NSW Health policy and Code of Conduct can be performed at one site and these documents shared with other relevant sites to streamline credentialing processes in NSW.

Other relevant NSW Health Policies are:

- Breastfeeding in NSW: Promotion, Protection and Support
- Breast Milk: Safe Management

# This policy and the Pasteurised Donor Human Milk for Vulnerable Infants – NSW Health and Australian Red Cross Blood Service Partnership Service Protocol is available at:

https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=pd2018\_043

321(27/11/18)

# FIRST 2000 DAYS FRAMEWORK (PD2019\_008)

### PURPOSE

The First 2000 Days Framework (the Framework) is a strategic policy document which outlines the importance of the first 2000 days in a child's life (from conception to age 5) and what action people within the NSW health system need to take to ensure that all children have the best possible start in life.

#### MANDATORY REQUIREMENTS

Local Health Districts and Speciality Health Networks will ensure that strategies to implement the First 2000 Days Framework appear within their local plans, commencing by 1 July 2019.

Local Health Districts and Specialty Health Networks will provide an annual report, on request, to the NSW Ministry of Health on progress against their implementation plan.

#### **IMPLEMENTATION**

Local Health Districts and Specialty Health Networks have lead responsibility for implementing the Framework within their district or network. They are to use the information provided in the Framework about the first 2000 days and opportunities for action to inform local priority setting and planning against the Framework's strategic objectives. The three objectives of the Framework are:

- 1. All staff in the NSW health system understand and promote the importance of the first 2000 days and the best opportunities for action
- 2. The NSW health system provides care to all and works in partnership to promote health, wellbeing, capacity and resilience during the first 2000 days
- 3. The NSW health system provides additional services for those who need specialised help, when they need it.

NSW Ministry of Health, will support implementation of the Framework. The Branch will monitor implementation through annual reports that will be requested from Local Health Districts and Speciality Health Networks about progress towards priorities in their local plans.

#### This policy and the First 2000 Days Framework are available at: https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=pd2019 008

321(08/02/19)

# FIRST 2000 DAYS IMPLEMENTATION STRATEGY (IB2021\_011)

#### **SUMMARY**

The NSW Health First 2000 Days Implementation Strategy was developed to assist Local Health Districts and Specialty Health Networks in implementing the First 2000 Days Framework, including providing information to assist them in developing their local plans.

# This information bulletin and the Frist 2000 Days Implementation Strategy are available at: <a href="https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=IB2021\_011">https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=IB2021\_011</a>

#### PAEDIATRICS 2.

# **MATERNITY - MANAGEMENT OF MONOCHORIONIC TWIN PREGNANCY** (GL2020 011)

# **PURPOSE**

This Guideline provides best practice guidance to clinicians caring for women with monochorionic (MC) twin pregnancies. It promotes consistent recognition, monitoring, reporting, management and appropriate referral within the tiered NSW Maternity and Neonatal (Perinatal) Networks to optimise fetal and maternal wellbeing.

# **KEY PRINCIPLES**

This Guideline applies to all NSW Public Health Organisations (PHOs) providing maternity services. The Guideline:

□ endorses the Royal Australian and New Zealand College of Obstetrics and Gynaecology (RANZCOG) recommendations for MC twin pregnancies (see Section 2)

□ recommends that women with MC twin pregnancies require as a minimum, antenatal care from a Level 4 maternity service in consultation with a Level 5 or 6 maternity service, and planned birth at a Level 5 or 6 maternity service in line with NSW Maternity and Neonatal Service Capability Framework GL2016 018 (see Section 1.6)

□ defines minimum standards for the frequency of ultrasound scanning and ultrasound reporting for women with a MC twin pregnancy (see Section 2.2 and Appendix 1)

□ recommends all Tiered Perinatal Networks have an agreed pathway to communicate ultrasound scan results between ultrasound departments and maternity care providers in line with Tiered Networking Arrangements for Perinatal Care in NSW PD2020 014 (see Section 1.6).

# **USE OF THE GUIDELINE**

Chief Executives of Local Health Districts are responsible for:

- ensuring appropriate referral, escalation and transfer of care for women with MC twin • pregnancies in line with this Guideline and NSW Maternity and Neonatal Service Capability Framework GL2016 018 (see Section 1.6)
- developing local referral to and reporting pathways for appropriate obstetric ultrasound providers with capability to assess a twin pregnancy (see Section 1.5)
- monitoring and review of outcomes for women diagnosed with MC twin pregnancy (see • Section 6).

The Maternity - Management of Monochorionic Twin Pregnancy Guideline can be downloaded at https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2020 011

329(11/05/20)

# MANAGEMENT OF POSITIONAL PLAGIOCEPHALY BY ALLIED HEALTH PROFFESIONALS (GL2020\_013)

# **GUIDELINE SUMMARY**

The Guideline was developed to provide best practice guidance for management of infants with positional plagiocephaly.

The objectives of the Guideline are to:

- assist clinicians working in primary and secondary health service areas with early detection and assessment and of infants with positional plagiocephaly
- provide clinicians with best practice guidance for management of infants diagnosed with positional plagiocephaly
- provide clinicians with best practice guidance for referral of infants with positional plagiocephaly to tertiary services (e.g. Craniofacial–Helmet clinic).

# **KEY PRINCIPLES**

The Guideline should be used in conjunction with the *Physiotherapy management of plagiocephaly* eLearning module available through the NSW Health Education and Training Institute (HETI) online learning portal, My Health Learning.

Key principles for the Guideline are outlined further in Section 1.3. The Guideline is one component of clinical decision making and provides a guide for best practice for clinicians working with infants with suspected or diagnosed positional plagiocephaly.

# **USE OF THE GUIDELINE**

Chief Executives must:

• ensure that the Guideline is adopted and that local policies based on the Guideline are in place in all hospitals and facilities likely to be required to care for children with positional plagiocephaly.

Directors of Clinical Governance are required to:

- inform relevant clinical staff treating paediatric patients of this guideline
- ensure that all staff treating infants are educated and supported in the use of the locally developed protocols for referral and management of positional plagiocephaly.

The Management of Positional Plagiocephaly by Allied Health Professionals Guideline can be downloaded at <u>https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2020\_013</u>

329(12/06/20)

# **CLINICAL DETERMINATION FOR BOARDER BABY REGISTRATION** (GL2020 020)

# **GUIDELINE SUMMARY**

This Guideline clarifies when a neonate (a baby up to 28 days of age) is required to be registered in the **Patient Administration System (PAS)** as a boarder. It sets out the responsibilities for the assessment and care of neonates who are accommodated in a NSW Public Health Organisation (PHO) to ensure patient safety and quality care.

# **KEY PRINCIPLES**

- A neonate less than 10 days of age who is in hospital cannot be registered as a 'boarder'. Neonates under 10 days of age who remain in hospital or return to hospital because the caregiver (usually the mother) is unwell must be an admitted patient.
- A neonate 10 or more days of age **not requiring clinical care**, may be a boarder when accompanying the caregiver who is an admitted patient. In this case the neonate is not an admitted patient and should be registered as a boarder.
- A neonate in a PHO must have a clinical assessment by an appropriate medical officer prior to admission or registration as a boarder.
- Regardless of the admission status all neonates should have two identification bands in place preferably on each ankle.
- Care planning for the neonate should be individualised and take into consideration the caregiver's clinical condition, physical and mental health, the impact of treatment on the caregiver's capacity to care for the neonate, and any additional supports required for the family,
- Any neonate, irrespective of age, whose caregiver (or sibling of the same multiple birth) is admitted for treatment of sepsis, must be physically assessed, investigated where appropriate and monitored for sepsis. A neonate in these circumstances would usually be admitted and should not be registered as a boarder.
- Wherever possible caregivers and neonates should not be separated. Support, protection and promotion of breastfeeding is essential.

# LOCAL HEALTH DISTRICT RESPONSIBILITIES

Local health districts are responsible for developing local Guidelines, pathways and resources to ensure:

- neonates receive appropriate care in an appropriate place
- assessment, care and care planning is documented
- correct registration of all neonates in the PAS

The Clinical Determination for Boarder Baby Registration Guideline can be downloaded at <a href="https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2020\_020">https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2020\_020</a>

331(25/08/20)

# SYPHILIS IN PREGNANCY AND NEWBORNS (PD2023\_029)

# **POLICY STATEMENT**

NSW Health is committed to addressing concerning increases in the number of women diagnosed with syphilis in pregnancy (maternal syphilis) and mother-to-child transmission of syphilis (congenital syphilis) resulting in adverse outcomes including preterm birth, low birth weight, congenital anomalies, fetal loss or stillbirth, and neonatal death. Congenital syphilis is an entirely preventable disease and its occurrence reflects a failure of delivery systems for antenatal care and syphilis control programs.

# SUMMARY OF POLICY REQUIREMENTS

This Policy Directive introduces new antenatal syphilis screening intervals for all pregnant women, and outlines Local Health Districts (Districts), Specialty Health Networks (Networks) and service level responsibilities to ensure appropriate referrals, assessment and management of syphilis in pregnancy and neonates.

This Policy Directive must be read as a supplement to existing gold-standard clinical guidance outlined in the current edition of the Australasian Society for Infectious Diseases (ASID) guidelines <u>Management of</u> <u>Perinatal Infections</u>.

Assessment, diagnosis, and treatment of maternal and congenital syphilis is multifaceted and requires a multidisciplinary response. Leadership at Districts and Networks must ensure that local processes are in place to enable effective implementation of this Policy Directive including identified referral pathways and responsibilities for follow-up of women at risk of syphilis in pregnancy, and pregnant women diagnosed with syphilis in pregnancy.

All pregnant women in NSW must be offered syphilis screening as part of their first antenatal visit blood screen and again at 26-28 weeks gestation. Pregnant women who have received minimal or no antenatal care, or are at risk of missing an appointment, should be opportunistically screened for syphilis and blood-borne viruses Hepatitis B and HIV at the service they present at, regardless of gestation. Documentation of all antenatal syphilis screening must be entered into the relevant District maternity database and medical records.

All positive syphilis results in pregnancy should be discussed with a clinician who has expertise in managing and treating syphilis. Local pathways must be developed to ensure pregnant women are referred to maternity services, and all relevant services are informed including sexual health services, the local public health unit and primary care services to facilitate appropriate contact tracing and treatment where relevant.

Timely assessment and initiation of treatment is essential for all cases of maternal syphilis per the Australasian Society for Infectious Diseases (ASID) guidelines <u>Management of Perinatal Infections</u>. All pregnant women diagnosed and treated for syphilis in pregnancy need the details of their investigations and management, and recommendations for future testing requirements clearly documented in their medical records. Local pathways must be developed to ensure maternal and neonatal assessment is clearly documented in the patient's medical record in a manner that ensures this is flagged at the time the pregnant women presents for birth.

Responsibility for neonatal follow-up must be clearly defined on discharge identifying the most appropriate service as relevant to the local context and woman's needs (such as paediatric outpatient clinic or outreach service). Auditing processes must be developed to monitor and review follow-up care and clinical outcomes.

All cases of congenital syphilis are to be investigated as a clinical incident and entered into the Incident Management System (ims+) with a harm score relevant to the case. NSW Health employees must be aware of the importance of reporting incidents and near misses to ensure timely investigation and ensure lessons are learnt to facilitate the elimination of congenital syphilis in NSW

The complete Syphilis in Pregnancy and Newborns policy is available at <a href="https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2023\_029">https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2023\_029</a>