SCOPE DEFINITION

Guideline Title: *Newborn bloodspot screening (NBS)*

Scope framework	
Population	*Which group of people will the guideline be applicable to?* Newborn babies
Purpose	*How will the guideline support evidence-based decision-making on the topic?* • Support newborn screening within relevant national and state frameworks, and legislation • Identify relevant evidence related to newborn bloodspot screening and management
Outcome	*What will be achieved if the guideline is followed?* *(This is not a statement about measurable changes / not SMART goals)* • Provide evidence informed information about newborn bloodspot screening • Support: o Best practice management of newborn screening practices o Early identification/diagnosis of conditions and diseases
Exclusions	*What is not included/addressed within the guideline* • Routine baby care • Management (diagnosis, investigation, ongoing treatment) of diseases/conditions screened • Protocols for local collection of NBS after discharge • Protocols for local dispatch of cards • Laboratory testing and interpretation of NBS cards • Elements specific to Queensland Clinical Guideline *Standard care*

Clinical questions

Question		**Likely Content/Headings/Document Flow**
Introduction		Communication Clinical standards Service levels responsibilities
1.	What is newborn bloodspot screening (NBS)?	• Overview • Description and overview of diseases/conditions screened o Genetic o Metabolic o Hormonal o Other
2.	What preparation is required for NBS screening?	• Parental engagement o Antenatal discussion o Written and verbal information (including future use of sample cards) o Informed consent process (including benefits of test and risks of declining) • Review of clinical history o Family history of genetic, metabolic, hormonal or other diseases/conditions o Maternal (e.g. antenatal steroid use, previous fetal death)
3.	What information is required about the baby?	• Baby clinical status (e.g. well and preterm) • Date and time of birth o Feeding status

		○ Intravenous fluids (e.g. glucose, TPN) ○ Received a blood transfusion ○ Ambiguous genitalia • Feeding history : timing, milk type, if NBM, LBW/unwell
4.	What care is indicated for baby before, during and after procedure?	• Comfort measures: ○ Non-pharmacological breastfeeding, expressed breast milk, skin to skin, swaddling ○ Pharmacological (e.g. sucrose) • Positioning (foot hanging down) • Warmth • Site monitoring/care
5.	What are the best practice recommendations for NBS sample collection and storage prior to dispatch?	• Equipment required (appendix) • Completion of card information (example card in appendix) • Procedure ○ ID checks ○ Skin preparation ○ Correct collection sites ○ Sampling technique ○ Management of sampling site (e.g. haemostasis, observation) • Documentation of collection, e.g. ○ NBS card ○ Baby's personal health record ('red book') ○ Clinical pathway • Process to maintain integrity of sample before, during and after dispatch (e.g. drying, storing)

Potential areas for audit focus (to be refined during development)

Audit items will relate to the desired outcomes and the clinical questions

- What is the proportion of repeat screens due to poor sample collection?
- What is the proportion of positive screens followed up within 24 hours of notification?
- What is the proportion of repeat screens followed up within 24 hours of notification?