Worried they are getting worse?
Information for clinicians caring for neonates

A worried parent or carer is an important vital sign

Delayed recognition of clinical deterioration is a common theme in serious adverse events in NSW, across the country and internationally. Failing to listen and respond to concerns raised by parents and carers is a significant contributor to these events.

"I knew something was wrong, but nobody would listen."

Parents and carers know their baby best and are essential members of the care team, yet their observations are frequently underappreciated and underutilised in identifying early signs of deterioration.

In NSW, clinicians are now required to proactively ask and respond to a specific question to support recognition of deterioration:

"Are you worried they are getting worse?"

When does it apply?

Use your clinical judgement to guide when to ask the question. It is not intended for routine care of babies with no identified risk factors in the maternity setting.

It should be routinely asked for babies in the special care unit or in birthing and postnatal units where **identified risk factors** require regular observations.

Clinicians can ask this question at any time to support their assessments.

Inviting parents to share their concerns or changes they have noticed, early in any interaction, demonstrates that we are listening and committed to working in partnership with them.

It is also important that you regularly remind parents and carers to raise their concerns at any time they feel their baby is getting worse.

Won't we find that all parents and carers are worried?

Many clinicians already ask parents and carers to share their concerns. That's why it matters **how** you ask the question. It is important to focus on 'getting worse' rather than general worry.

Recent evidence from Monash Health in Victoria found that, in the paediatric setting, a caregiver expressing concern when asked "Are you worried they are getting worse?" was more often associated with critical illness in the patient than any single abnormal vital sign[1].

A parent or carer's 'Yes' response to the question only occurred 3 to 4% of the time and although rare, it is significant; it signals concern that can help you to identify early signs of clinical deterioration.

What does this mean for you?

Clearly explain to parents and carers that this question is routine care for babies at risk of deterioration. It acknowledges their vital role as part of their baby's care team, especially in recognising early signs of deterioration and in helping to support a timely clinical response.

To avoid unnecessary worry, you can introduce it as a standard safety question, for example: "We ask all parents of babies with risk factors a simple question:

"Are you worried your baby is getting worse?"

It's a way for you to tell us about any changes you have noticed. It doesn't mean something is wrong, and it helps us work together to keep your baby safe and to respond quickly if needed".

When do I ask the question?

Ask the question at the start of each set of vital sign observations. You can also ask it during clinical handover, medical rounds, or medical reviews. Document the response on the NSW

Health Standard Neonatal Observation Chart (SNOC).

The frequency should align with the minimum requirement for vital sign observations. When more frequent monitoring is needed, use your clinical judgement to determine how often it is asked.

If parents or carers are absent or asleep: Record the response as 'Not asked'.

A *'Yes'* response is a Yellow Zone trigger, and the following steps must occur:

Step 1: Listen and act on their concern

If you identify the concern does not relate to clinical deterioration, address it promptly or delegate to an appropriate team member.

Step 2: Recognise and respond

For medical staff: Following an assessment, review the management plan, including investigations, and consider escalation to a senior clinician.

For all other clinicians:

- Follow the Yellow Zone instructions for concerns about clinical deterioration, including a documented A-G assessment.
- Consult with the nurse or midwife in charge and decide whether a Clinical Review or other Clinical Emergency Response System (CERS) call is needed.
- If there is still a concern after an initial assessment, or a Clinical Review hasn't occurred within 30 minutes, escalate according to your local CERS protocol.

Any serious concern expressed by you, another staff member, parent, carer or family member must be escalated as a Rapid Response in line with the local CERS protocol.

Step 3: Communicate and document the plan

After the assessment, communicate the management plan to the parent or carer. If no further escalation is needed, document the concern, actions taken, and management plan in the baby's health care record.

How does this relate to REACH?

REACH remains a critical part of the NSW Health Deteriorating Patient Safety Net System. It provides parents, carers or family members a way to escalate their concerns if they are still worried their baby is getting worse.

The proactive approach of regularly asking *"Are you worried they are getting worse?"* is designed to complement REACH, not replace it. By asking **early and often,** you can identify and respond to deterioration before a REACH call is needed.

Cultural considerations

You should be aware of the cultural needs of Aboriginal people and people from culturally diverse backgrounds. Actively offer cultural support, such as an Aboriginal health worker or liaison officer, or other locally appropriate resources.

What about patients who do not speak English?

The question *"Are you worried your child is getting worse?"* has been translated into multiple languages. Ensure a copy of the translation sheet is readily available to staff so that all parents, carers and family members are asked the question. If the answer is 'Yes', engage an interpreter to further identify and understand their concerns.

Reference: Mills, E. et al. (2025). Association between caregiver concern for clinical deterioration and critical illness in children presenting to hospital: a prospective cohort study. *The Lancet Child & Adolescent Health*, https://doi.org/10.1016/S2352-4642(25)00098-7