Consultation on national clinical guidance for the assessment of signs of life for spontaneous births before 24^{+0} weeks of gestational age where active survival-focused care is not appropriate

MBRRACE-UK Signs of Life Guidance Development Group

The members of the MBRRACE-UK Signs of Life Guidance Development Group would like to thank everyone who responded to the consultation on the draft National Clinical Guidance for the assessment of signs of life for spontaneous births before 24^{+0} weeks of gestational age where active survival focused care is not appropriate. The consultation ran from 15/12/2019 to 09/03/2020. The number of individuals and organisations responding to the consultation was extremely high for this type of consultation with over 250 respondents and we welcome everyone's thoughts and insight. The vast majority of respondents strongly welcomed the guidance. Here we present our response to the key themes that arose in the feedback directly relating to this clinical guidance and describe how the guidance has been modified. All comments were agreed by consensus by the Guidance Development Group.

The release of this response has been delayed due to the challenges of bringing the clinical guidance group together during the Covid-19 pandemic. We are now in the process of revising the guidance with an anticipated release date of autumn 2020.

If you require any further detail please email lucy.smith@le.ac.uk

Summary response

Births included in the guidance

Are births less than 22 weeks to be included in the guidance?

The guidance applies to all births before 22 weeks of gestation and we have amended the wording to clarify their inclusion. There is national consensus at present that active, survival-focused care is inappropriate for babies born before 22 completed weeks of gestation. Active, survival-focused care gradually becomes more appropriate as the pregnancy advances, depending on many obstetric and neonatal factors as well as the location of care (See: British Association of Perinatal Medicine Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation: A Framework for Practice https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019). Following feedback we have removed the text saying "signs of life are relatively unlikely at this gestation" and have amended the description of births at this gestation to be "small and immature" rather than "small and fragile".

Why are births <24 weeks where active survival focused care is planned not included?

This guidance was developed to address variation in practice regarding whether deaths of babies born before 24^{+0} weeks of gestational age are reported as a miscarriage or registered as a live birth and subsequent neonatal death. It was the consensus of the group that the majority of this variation in practice applies to the most extreme preterm births (often before 22 weeks of gestation), where active, survival-focused care is not considered appropriate. In the event of active, survival-focused care being agreed at gestations below 24 weeks, it is anticipated that this will be undertaken in the presence of senior neonatal staff with expertise in the assessment of signs of life. This guidance complements the British Association of Perinatal Medicine Perinatal Management of Extreme

Preterm Birth before 27 weeks of gestation: A Framework for Practice (https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019) and we refer readers to this guidance to help inform decisions around initiation of active survival-focused care

Are births at 24 weeks of gestational age and over included in the guidance?

This guidance was developed to address variation in practice regarding whether deaths of babies born before 24^{+0} weeks of gestational age are reported as a miscarriage or registered as a live birth and subsequent neonatal death. Feedback from the consultation regarding whether the guidance could be applied to spontaneous births at or after 24^{+0} weeks of gestational age (where palliative care is planned because of the presence of severe life-limiting conditions) suggested due to the different registration practices from 24 weeks gestation onwards, the guidance should not apply to these births and we have amended the guidance accordingly.

Can this guidance be used in pre-hospital settings or where gestation is unknown?

The same principles may be applicable to spontaneous births before 24^{+0} weeks of gestation in pre-hospital settings and an appendix for these pre-hospital births will be included in the published guidance providing additional detail for these scenarios.

Why are medical terminations of pregnancy for fetal anomaly excluded from the guidance?

The focus of this guidance is the assessment of signs of life in spontaneous births. Based on feedback, existing law regarding birth and death registration in the context of termination of pregnancy appears to create significant challenges for health professionals, women and bereaved parents but this is outside the remit of this guidance. The needs and expectations of women and families undergoing medical termination of pregnancy may be different and we recommend that this be addressed in separate guidance.

Defining signs of life

How many signs of life need to be observed to determine live birth?

We have aligned this guidance with the views of the World Health organisation, where live birth is defined as any evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached. Therefore a birth where one or more signs of life are displayed should be recorded as live born. For clarification we have reworded “at least one of the following" to “one or more of the following”.

Can delineation between reflexes and signs of life be more precisely defined?

The feedback on the assessment of signs of life predominantly affirmed the pragmatic approach taken in the draft guidance, although there was some variation in opinion ranging from requests for more prescriptive criteria and others requesting less prescriptive criteria. The Guidance Development Group considered these responses and decided that the current wording aligned with the majority view. The group felt that being more prescriptive could only be achieved through the introduction of arbitrary definitions that may have unintended consequences regarding birth registration.

Will the suggestion that fleeting activity is not a sign of life but a reflex lead to additional distress for parents?

There are many reported instances of disagreements between parents and healthcare professionals, where parents observe signs that they believe to constitute signs of life in their baby but their baby's death is recorded as a miscarriage. This guidance aims to help reduce the occurrence of this scenario by offering healthcare professionals support in determining signs of life in these births in a more consistent way. Following feedback we have further highlighted the importance of good communication with parents, and that even when there is little time for in depth discussion prior to birth, a compassionate warning that baby may make reflex movements but that these are not necessarily 'signs of life' is vitally important and may save much heartache and misunderstanding for parents and professionals later.

Who should assess and attend to confirm live birth

We recommend a doctor, usually the attending obstetrician, should be called to confirm the presence of signs of life as when the baby dies it will enable completion of a neonatal death certificate. We do not recommend any specific level of seniority of staff, and note that consultant staff may not always be immediately available. Units should ensure appropriate training and support for any trainees undertaking the confirmation of live birth.

More information is needed on palliative care provision

We recognise the difficulty of balancing the physical needs of the baby to minimise any distress they may be experiencing with the physical, emotional and psychological needs of the parents to whom the baby has just been born and have emphasised this in the guidance. We have included additional reference to the NICE guidance NG51 on End of life care for infants, children and young people with life-limiting conditions to support staff in this situation.

Ease of use of the guidance

Can you provide a tool for quick and easy access to the main messages?

We appreciate the need to convey the messages of the guidance in a short easily accessible format and will include a visual summary of the guidance. We have also ensured the document is more succinct and accessible for clinical use.