Perinatal Mortality in Ireland

Message from our public representative Siobhan Whelan

As the patient advocacy representatives with lived experience on the perinatal mortality working group within the NPEC, I acknowledge all the work and collaboration undertaken between the individual's assigned to this task from each maternity unit and the staff at the NPEC. The learning from this and previous annual audits and all other investigative processes is paramount to the quality care improvements necessary and patient safety of all future service users.

Per the National Office of Clinical Audit (NOCA) criteria and after the corrected adjusted Perinatal Mortality Rate (PMR) for major congenital anomalies and in utero transfers per unit, no outliers have been identified.

There were 357 precious little lives lost per the criteria used for this mandated National Perinatal Mortality Audit report and behind each little life is a family impacted forever. Therefore, I fully endorse the repeated NPEC recommendation for 'Protected Time & Resources for Implementation of Findings' from this annual report.

I also endorse the recommendation for a 'Public Awareness Pre- Conception Health Programme', with specific aim at secondary and college level students. This has the potential to reach all of childbearing ages.

Modifiable factors and behavioural changes such as maternal age, healthy weights and BMI, socioeconomic factors and substance misuse can play a significant factor in how a pregnancy will progress and its outcomes. Identifying, educating and reducing a risk factor before it becomes a problem is a key factor going forward. The Making Every Contact Count (MECC) initiative must be promoted and employed more gainfully.

It makes perfect sense that a 'Communication Policy' is implemented now to ensure accurate and timely sharing of information between maternity units and paediatric centres regarding a baby's wellbeing and outcome. This should result in ensuring appropriate risk assessments and follow up care for the mother and baby concerned or in a subsequent pregnancy. It is surprising that this is not the case already!

While there has been a small improvement in antenatal detection of fetal growth restriction noted in this 2021 report compared to previous years, it has not been significant enough. I fully endorse the recommendation on 'Fetal Growth Restriction'. Figures 1.12 & 1.13 in the report give a clear visualisation of the number of babies who were severely small for gestational age and sadly died. While also being mindful of the babies who thankfully survive pregnancy and delivery and get to go home safely with the help of great care from the maternity and special care baby units, but who are also unexpectedly below their expected weights for gestation. Historically, NPEC reports have highlighted that antenatal screening for fetal growth, diagnosis of inter uterine growth restriction (IUGR) and timely delivery are key to addressing perinatal loss. The time is now for action! Simple, cost-effective screening measures go a long way to helping reduce preventable harm rates, giving every baby an equal chance to life and survival.

Surveillance of fetal growth is also incorporated in the 'Care Bundles' recommendation. The recommended 'Care Bundle' approach is evidence based and proven successful from other countries such as the UK, New Zealand, Netherlands, Canada etc. The Netherlands had the highest reduction in their mortality rates by prioritising the learning points from all audit and review processes. We now have the evidence to endorse this recommendation within the Irish maternity services.

Dr Tamara Sanchez covers this, in greater detail in her comprehensive 'invited commentary'. She also flags an important point: that women need to find and understand relevant information concerning perinatal loss.

I feel that a certain amount of 'broad terminology' is now used in some areas such as 'Placental Issues' and this may have the potential for ambiguity. Such broad terminology now leaves some conditions invisible in this audit report and no doubt in others. This may affect the transparency and accuracy of the prevalence of such conditions. One such example is vasa previa. I am assured by the NPEC that there have not been any perinatal deaths due to vasa praevia reported to this clinical audit since 2016. There may have been cases that were safely delivered by LSCS. The NPEC have published findings on perinatal deaths due to vasa previa on their website under the icon 'research projects'. A detailed description on placental pathology terminology is also available online. Thankfully having achieved antenatal screening in pregnancy earlier this year for this condition via the newly developed Anatomy Ultrasound Clinical Guidelines, we should see eradication almost of vasa praevia as a cause of perinatal death. But I felt it important to use it as a good example for clear auditing purposes and that re-examination of such broadness now be explored.

In light of the Patient Safety (Notifiable Incidents and Open Disclosure) Act 2023 and related policies, I would now question the need for 'confidential enquiries'. Under development and agreement for piloting in ten maternity units to date in Ireland now is the 'Perinatal Mortality/Morbidity Event Review Tool' (PMMERT). The aim of the PMMERT is to standardise chart reviews for the assessment of perinatal deaths and poor outcomes. This review tool will allow recommendations to be developed and actioned.

While the work and consensus behind it is valued and appreciated, I now respectfully have reservations to the recommendation for confidential enquries on a few aspects. Firstly, when you compare the confidential enquiries used in the UK to their numerous high profile Hospital Trust's Reviews recently on preventable harms in their maternity settings, I am not seeing the much-wanted benefits of said enquiries in the UK. Recommendations from these enquiries have not been implemented.

Secondly, with the HSE Service Plan Budget allocation impacted by budget cuts and while trying to reduce duplication processes referenced in this report, one could ask would it not be more appropriate to expand the perinatal notification form and use the existing review pathways available under the Incident Management Framework (IMF) and Open Disclosure to gather all the data necessary for the full clinical picture and learning in such cohorts ?

Important consideration and more transparency would have to be given to how the 'confidential enquiry' works alongside the IMF process and how this benefits the families affected and the learning processes already in place.

Thirdly, given that this audit is now endorsed by the National Clinical Effectiveness Committee and submission to the audit is mandatory now and with the above named 2023 Policy Act, compliance to all learning data disclosures should be openly and timely forthcoming now?

Lastly, I wish to highlight the limits to when postmortems are offered and carried out, which appears to be deviating from national standards. Every family should be fully informed of their rights and the benefits to a perinatal postmortem.

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They must also be informed of the free, independent Patient Advocacy Service available to them at the first instance of unexpected outcomes. This service supports and helps empower parents to make fully informed decisions in such circumstances. The upcoming consultation on the coroner service will be an important opportunity to share the perspective of families/patient advocates.

I would once again like to acknowledge all the work and collaboration by NPEC and the Maternity units. I hope the group continues to grow, working towards quality care improvements and the safety of all future service users. It is important that their work and learnings are supported fully by the gatekeeper's of the safety of our children waiting to be born now in Ireland.

Yours sincerely,
Siobhan Whelan
Patient representative,
NPEC Perinatal Mortality Group

For more information about the audit and access to the full report, please access our website.

Listen to Siobhan Whelan speak about the perinatal mortality audit endorsement