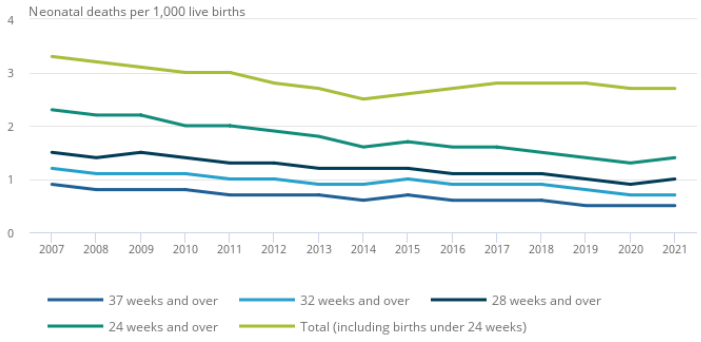
Dr Lucinda Perkins – Written evidence (PRT0073)

The adverse consequences of preterm birth are a universal issue across the United Kingdom and as such, the Preterm Birth Committee should consider including all 4 nations of the UK as part of this much needed Inquiry. Wales, where I live and work, has the highest childhood poverty of any other UK nation, amplifying the challenges we face in optimising and improving equity of outcomes for babies born preterm. If inclusive work is not possible within the current Inquiry then a requirement for equivalent appropriately resourced workstreams for each devolved nation should be mandated and in such a way that this work can be collated to represent the landscape for the whole of the United Kingdom.

Babies born preterm are disproportionately represented in national childhood mortality data across the four nations of the United Kingdom. In 10 year childhood mortality data from Wales over half of all deaths occurred in infants under 1 year of age with the majority of these occurring in babies under 28 days of age. Causation was attributed to prematurity related issues in 46% of neonatal deaths. This heavy burden of mortality is borne out across all 4 nations of the UK with longitudinal data from England and Wales showing that the more premature a baby is born the higher the mortality.

Figure 3: Shorter gestational ages are associated with higher neonatal mortality

Neonatal mortality rates by gestational age, England and Wales, 2007 to 2021



Source: Office for National Statistics – Child and infant mortality in England and Wales: 2021

Investing in Perinatal Palliative Care

The high burden of mortality means that a proportion of babies will not survive however optimal their care and so we must be able to define what good looks like for these families. Providing high quality neonatal care to infants born prematurely requires skills not only in neonatal intensive care medicine but also in perinatal palliative care. This area of our practice has not received the resources required and this is something we need to push hard to change. It is imperative that the Preterm Birth Committee considers how we train and support perinatal teams to support families facing uncertainty by empowering them with high quality perinatal palliative care skills. Alongside this we must invest in the specialist paediatric palliative care workforce across the UK. As we move to an era of more individualised family centred care, including offering intensive care to babies born profoundly preterm (70% of infants born at 22 weeks gestation die despite intensive care) we must acknowledge that families and teams face huge uncertainty when caring for these babies. High quality perinatal palliative care is not limited to providing compassionate end-of-life care, where appropriate, but rather providing holistic physical, emotional, social and spiritual support to families whose baby faces a potentially life-limiting condition. We must move away from the idea that perinatal palliative care is only considered for babies who are dying, as survivorship is increasingly recognised as a potential outcome for babies facing uncertainty. To provide the highest standard of care we must resource building collaborative working relationships between perinatal teams and specialist palliative care teams to fit the needs of local populations. We must create standards that define what good looks like for these families and this must have the patient and parents voice at its heart. Current availability of specialist paediatric palliative care services across the UK varies very significantly by region, this needs to change. The Association of Paediatric Palliative Medicine (APPM) would be very

happy to contribute to the Committee's work to inform this conversation (https://www.appm.org.uk/).

Equitable Care: Empowering perinatal Teams

Many of the determinants of adverse outcomes of preterm birth lie outside the control of health alone, but as a perinatal community we can make differences to patient care and reduce inequity by investing in local leadership. In Wales we are proud to have seen significant progress in reducing variation in perinatal optimisation (interventions delivered around the time of birth which evidence shows improve outcomes for babies born preterm) through a dedicated programme called PERIPrem Cymru (Perinatal Excellence to Reduce Injury in Preterm birth, Cymru), launched in March 2023. Thanks to support from Welsh Government, through the NHS Executive, this national programme of work, adapted from the award-winning model developed in the South West of England, has already reduced variation in delivery of a 10 intervention evidence-based bundle shown to improve survival and reduce severe brain injury in babies born preterm at less than 34 weeks gestation. Our vision is to deliver effective perinatal optimisation to 'Pob Babi, Bob Tro' (Every Baby, Every Time) through co-production with families and the wider perinatal community. In 2023 we have delivered 434 more life and brain saving interventions to vulnerable preterm babies across Wales with the latest National Neonatal Audit Programme (unverified) data showing Wales now outperforming any other network in the UK for the composite perinatal optimisation performance metric. To achieve this it has been essential to invest in perinatal teams at a local level but with a shared national vision. Preterm birth is difficult to predict, to effect change more broadly we need to tackle education and awareness at a societal level through a public health programme so the public know what preterm birth looks like and its implications. Preventing the adverse effects of preterm birth cannot be addressed by acute health services alone. Mortality data shows the stark

inequity of outcome based on socioeconomic factors with the death rate in children in the most deprived socioeconomic quintile 70% higher than in the least deprived quintile from 10 year data for Wales. This is before we even consider what impact socioeconomic factors have on risk of experiencing adverse childhood events and individuals ability to access high quality education. If we seek to prevent preterm birth and reduce its adverse consequences for families, we need to address the huge challenge of addressing social determinants of health and consider carefully how we best support the most vulnerable babies and families in our society.

A Less Narrow Lens: Better Defining Outcomes

Whilst preventing preterm birth is incredibly important, babies will still be born prematurely. We must better define and measure outcomes for these babies to allow individualised intervention throughout childhood and support each child to achieve their highest possible function and quality of life. Within health we currently view neurodevelopmental outcomes following preterm birth through far too narrow a lens at a national level. We focus heavily on short term outcome measures. Even the excellent National Neonatal Audit Programme (NNAP) which benchmarks services across the UK speaks largely to short-term outcomes with only an arbitrary neurodevelopmental at 2 year capture speaking to 'longer term' outcomes. Attempts for a modest step forward in standardising 4 year developmental assessment for preterm babies born less than 30 weeks gestations in the UK, recommended in national (NICE) 'Developmental follow-up of children and young people born preterm' guidance back in 2017, has still not be realised some 7 years later. This reductionist approach in defining outcomes for families not only allow prevents us fully understanding each child's needs, so that they can be met fully, over the course of childhood but is a huge disservice to the wonderful lives many

babies go on to live. We need those born preterm and their parents to tell us what good looks like and what matters most to them as families.

Evidence shows that providing timely early therapy intervention improve outcomes for babies born preterm at high risk of cerebral palsy. The vulnerable babies most likely to benefit from this intervention need to be identified early to support intervention at a time of high brain neuroplasticity in the first months and years of life. And yet there remains wide variation in the availability of early assessment and therapy intervention services to families nationwide. We desperately need to address this. Lack of assessment and understanding of how preterm birth affects the whole life course in turn perpetuates a lack of investment in meeting the health, developmental, educational and emotional needs of children and adults born preterm in the future.

Finally, it is crucial we work more closely with education services and adult health colleagues to address the adverse effects of prematurity across the life course and not just those issues arising in infancy. The broader effects of prematurity are becoming better recognised in terms of long term health needs, educational attainment and quality of life. We need much better tools to assess quality of life informed by those with lived experience of preterm birth to agree Patient Reported Observation Measures and Patient Reported Experience Measures in this space. This needs to be defined not only by 'deficits' in function, which is important so we can support children, but also by broader measures of what 'high quality of life' looks like in childhood and adulthood for babies born preterm, in terms of health and happiness.

Many thanks for inviting evidence to the Preterm Birth Committee House of Lord Inquiry and the opportunity to request that families in devolved nations are recognised as part of the national Inquiry, that the specialist paediatric palliative care workforce are considered and to highlight the urgent need to redefine how we measure outcomes for these families by asking them what good looks like.

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