

Lauren Ingledow – Written evidence (PRT0065)

1 I am writing to provide evidence as an adult born preterm. I was born in 1988, at 26 weeks gestation and weighing 430g, with a 20% chance of survival. The cause of my early arrival was due to my mother developing early on-set pre-eclampsia.

2 I am acutely aware of how lucky I am regarding, not only my survival, but also requiring no serious / invasive interventions during my time in NICU (Neonatal Intensive Care Unit), apart from common necessities such as ventilation, oxygen therapy and feeding.

3 Within this I recognise that that other elements such as genetics, epigenetics and lifestyle will be contributing factors to outcomes.

4 The most apparent impact is vocal chord damage, recognised in specialised areas as being a result of prolonged ventilation. Outside of these areas, lack of awareness and understanding about my birth history it is often assumed that I am unwell and elicits comments that over time have become immensely frustrating and reduced my confidence in speaking. I experience daily difficulties in using my voice for extended periods of time and it is difficult to project my voice make myself heard in busy / noisy environments.

5 I was discharged at 2 years old from developmental follow up assessments and at 3 years old following hospital assessment. The belief was that, whilst I still demonstrated some developmental delays, I was generally fit, healthy and would catch up with my full term peers given time. Due to poor survival rate and lack of long-term follow up data available at the time, this was based on lack of "evidence" to the contrary. However, humans have a 9 month gestational period as this is the optimum time needed to develop to ensure the best possible outcomes, and that missing crucial developmental periods may have consequences later in life.

- Assessments at age 2 for all born preterm.
- Assessments at age 4 < 28 weeks gestation must be a priority. I would suggest that this provision may need to be extended as more evidence comes to light.
- Continued monitoring of progress by informed professionals.

6 It is heartening to see that psychological provision is improving and there is growing recognition and support available that encompasses the traumatic experience of preterm birth and impact that the NICU environment has on families and the individual. However, it is vital to acknowledge that this has been a relatively recent development. There are many that have not had access to these sorts of provisions and it is crucial that this is extended to include clinicians dealing with adolescents and adults.

7 Compared to my full term peers, I have heightened stress responses that could be related to my time in NICU. These include hyperhidrosis, attuned awareness of artificial lighting, noise sensitivity and sensitivity to unexpected touch. This extends to sensitivity around my wrist area when wearing long sleeved clothing.

- The extension of provision of psychological support beyond NICU and discharge, to provide on-going support for families.
- Informed psychological support across the life course for individuals born preterm which acknowledges, and understands, the potential impacts of developmental differences, NICU environment and potential for increased risk of mental health impacts.

8 As babies and children, we are wholly reliant on our parents and the professionals they encounter, such as health visitors and primary care, to provide realistic and informed information, advice and support

surrounding potential outcomes. These outcomes are related to a potential for increased risk, rather than a guarantee. Being given access to this information raises awareness, allows for informed choices to be made and early intervention where required.

9 With hindsight, I found nursery distressing at times. I am now aware that this may be attributed to being overwhelmed by the environment and an awareness of differences in comparison with my full term peers. This included my awareness of a sense of frustration from adults at my reduced ability to start, and finish tasks and difficulties switching from one activity to another. In retrospect the size of play equipment hindered my ability to develop fine motor skills.

10 Regarding education, my experiences are very relatable to the oral evidence provided, in that my difficulties were often subtle and spread across multiple areas and this was put down to an assumption that these were "character" traits of laziness and in-attention rather than an understanding that brain connectivity and processing speed may be different, and that I was struggling with the school environment itself.

The Prem Aware Award is an excellent demonstration of how awareness could be implemented and extended and would have been extremely beneficial to myself and others born preterm.

Recommendations

- Awareness of prematurity across education – to encompass those currently within the system.
- Prematurity incorporated into teaching modules and Continuous Professional Development – in my view this should be compulsory not voluntary.
- Accommodations and adaptations to the school environment, based on individual needs. Such as extra time provision for examinations.

11 In my experience, primary care practitioners are not aware of birth history and details of premature birth do not appear to be flagged on birth records. Evidence concerning the increased risk of longer term health outcomes (Crump,2020; Prior and Modi 2020) does not appear to be cascading down to those on the frontline.

12 This lack of understanding is creating barriers to discussing concerns, further investigation, and ongoing management of conditions. Frequently, emphasis is being placed on the “here and now”, such as lifestyle factors, when these may be a contributing factor, rather than root cause.

13 There are also incidences where the impacts of symptoms do not correlate with the test results and outcomes seen, suggesting that there may be differences in mechanisms that are currently not fully understood. As examples, not fitting the expected profile for diagnosis of Type 2 diabetes or awareness of reduced nephron numbers in relation to gestational age which may impact kidney function.

14 This is of particular importance once those born preterm have reached adulthood, as it is unfair to be requiring assistance from our parents in order to be “believed” about our pre-term birth status. In addition, it is not appropriate to be expected to research and provide this evidence for ourselves. We need the experience and guidance of professionals.

15 In light of the increased risk, it is plausible to assume that a routine follow up or screening programme – like the NHS Health Check programme for those aged 40 – 74, could be implemented at an earlier age for those born preterm, to mitigate some of this risk. Recommendations for addressing preterm birth history and recommendations for clinical practice have been suggested by Kelly *et al.* 2021.

Recommendations

- Awareness of prematurity and understanding of the associated risks regarding health across the life course to be shared across the healthcare sector, including allied professionals.
- Prematurity and birth weight included as flags within the NHS system – these will need to be applied retrospectively to capture all those born preterm but could be achieved by routinely asking the question “Were you born preterm?”.
- Routine monitoring across the life course to mitigate risk and reduce impacts.
- Prematurity included as a referral category to consultant level.
- Prematurity across the life course considered as a specialism, with the creation of multi-disciplinary clinics.

16 Without acknowledgement, formal assessment and support, many of the issues highlighted above have obstructed my potential for job satisfaction and earning capacity. I am highly dependent on a favourable environment to execute the skills with which I have difficulty. I appreciate that within current assessment criteria I may not reach threshold for a formal diagnosis, for example, Attention Deficit Disorder. However, these “traits” are having an impact within the work place – when they are viewed as wilful and deliberate, rather than a difference in processing and that this is emphasised in fast-paced, pressured environments. I also must highlight again the influence of difficulty sleeping, managing stress and other aspects of physical health which are contributing to these difficulties.

Recommendations

- Tailored careers advice.
- Awareness of potential impacts of prematurity within the workplace.

- Support and adaptations to the environment where needed.

17 It is positive to see the on-going research into the impacts of prematurity. There are two key areas I would like to promote, continued investigation into stress in those born preterm and also accelerated ageing.

18 Prematurity has an impact across all stages of life and all aspects of life. To understand these impacts they must not be looked at in isolation.

In summary

- The transference of current knowledge and evidence into practice will go some way to mitigating the struggles being experienced currently and open the door for mitigation and intervention.
- An increased awareness across society of the impacts of preterm birth would be useful.
- Acknowledgement of the impacts of preterm birth in adulthood will help current generations, and also pave the way for future generations to access support they may need.

References

Crump C. (2020) An overview of adult health outcomes after preterm birth. *Early Hum Dev.* ;150:105187.

Kelly, M.M, Tobias, J. (2021) Recommendations to optimize life-long health and wellbeing for people born preterm, *Early Human Development*, Volume 162, 105458.

Prior, E, Modi, N. (2020) Adult outcomes after preterm birth, *Postgraduate Medical Journal*, Volume 96, Issue 1140, 619–622.

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