

## **Prof Samantha Johnson, Prof Neil Marlow - Written evidence (PRT0018)**

### **About the authors:**

Samantha Johnson is a Professor of Child Development in the Department of Population Health Sciences, University of Leicester. She is a member of the Executive Committee of the British Association for Neonatal Neurodevelopmental Follow-up (BANNFU) and was a member of the NICE Guideline Committee who produced the current recommendations for the developmental follow-up of children and young people born preterm (NG72). Neil Marlow is Emeritus Professor of Neonatal Medicine in the Institute for Women's Health, University College London. Neil chaired and authored the NHS England Neonatal Intensive Care Transformation Review and Implementation Board, he also provided expert advice to the NICE Guideline Committee (NG72) and is the Director of the MRC EPICure studies of outcome following extremely preterm birth. Professors Johnson and Marlow were invited to provide oral evidence to the Preterm Birth Committee on 11<sup>th</sup> March 2024. This submission provides further evidence in support of that.

### **Summary of submission:**

- This submission supports the oral evidence previously given to the Committee by Professors Johnson and Marlow on 11<sup>th</sup> March 2024.
- We present evidence that preterm birth has adverse impacts on children's neurodevelopmental outcomes across the lifespan requiring enhanced developmental surveillance and support.
- We provide recommendations for improving developmental follow-up for children and young people born preterm.

### **Summary of recommendations:**

- Research should be conducted to better understand inequalities in the current provision of developmental assessments at four years of age.
- The National Neonatal Audit Programme should report on the content and the results of enhanced developmental assessments at two years of age, in addition to follow-up rates.
- The National Neonatal Audit Programme should report on the provision of enhanced developmental assessments at four years of age, including data on follow-up rates and the content and the results of those assessments.
- The results of standardised developmental and behavioural assessments carried out at two and four years of age should be recorded in the National Neonatal Research Database.
- Fields for entering the results of developmental assessments conducted at two and four years of age should be added to neonatal electronic patient record systems.
- Research should be conducted to evaluate enhanced developmental support and surveillance for children born preterm and their parents

### **This submission relates to three of the inquiry's topics of interest:**

- The implementation of existing NICE and NHS guidance on preterm birth.
- Longer-term impacts, care and support for preterm babies and their families.
- Data collection and monitoring in relation to preterm birth.

### **Problems to be addressed:**

- There are inequalities in the provision of developmental follow-up for children born preterm.
- There is a lack of developmental follow-up for babies born extremely preterm in the preschool years, prior to the transition to school.
- There is a lack of routine data collection relating to neonatal follow-up.

### **Evidence of increased risk of developmental problems and disorders following preterm birth:**

Babies born preterm (before 37 weeks of gestation) are at higher risk for developmental problems and disorders than babies born at term (at 37 weeks of gestation or more). Although a small proportion of preterm babies go on to have physical disabilities, the most common adverse outcomes are cognitive impairments (such as difficulties with memory, attention, and problem solving), motor impairments (difficulties with fine and gross motor skills), social and emotional problems (particularly anxiety, depression and withdrawn behaviour), and social and communication difficulties. Children born preterm are also more likely to have attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder, special educational needs and learning difficulties than term born children, leading to poor attainment at school.<sup>1,2</sup>

The risk of developmental problems and disorders increases with decreasing gestational age at birth; this means that the more preterm a baby is born, the greater the risk of difficulties later in life. Therefore, children born very preterm (before 32 weeks of gestation) and, in particular, those born extremely preterm (before 28 weeks of gestation), have the greatest risk of long term problems.<sup>1</sup> Developmental problems in early life can have lifelong impacts on health, wellbeing and economic

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<sup>1</sup> Wolke, Johnson & Mendonca, 2019: <https://doi.org/10.1146/annurev-devpsych-121318-084804>

<sup>2</sup> Alterman et al., 2022: <https://doi.org/10.1371/journal.pone.0271952>

potential, limiting life chances. Indeed, we have shown that developmental problems in infancy may persist into adulthood for individuals born extremely preterm.<sup>3,4</sup> Because of the high prevalence of developmental problems among children born preterm, it is crucial that developmental surveillance is instigated to identify difficulties early so that children can be referred for specialist healthcare services and intervention, and families can be supported from the earliest opportunity.

Surprisingly, the prevalence of neurodevelopmental impairment among children born extremely preterm has not declined over time. Our research has shown that children born before 26 weeks of gestation in 2006 continue to have similar rates of intellectual impairment, learning difficulties and attention, social and emotional problems compared with those before 26 weeks of gestation in 1995, despite improved neonatal care and increased survival rates over this period.<sup>5,6</sup> In fact, neonatal disorders remain the leading cause of life years burdened by disability worldwide.<sup>7</sup>

### **Evidence of the need for enhanced developmental surveillance and monitoring:**

All children are offered universal developmental screening conducted by a Health Visitor via the Healthy Child Programme, at 6-8 weeks, 6-12 months and 2-2½ years of age. However, the increased risk for developmental problems among preterm born children necessitates additional, enhanced developmental surveillance and monitoring to identify early those children requiring support.

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<sup>3</sup> Linsell et al., 2018: <http://dx.doi.org/10.1136/archdischild-2017-313414>

<sup>4</sup> Linsell et al., 2018: <https://doi.org/10.1007/s00787-018-1219-8>

<sup>5</sup> Marlow et al., 2021: <https://doi.org/10.1136/archdischild-2020-320650>

<sup>6</sup> Larsen et al., 2023: <https://doi.org/10.1007/s00787-023-02258-w>

<sup>7</sup> Global Burden of Disease Study 2019: [https://doi.org/10.1016/S0140-6736\(20\)30752-2](https://doi.org/10.1016/S0140-6736(20)30752-2)

Neonatal services have, for many years, offered routine follow-up for high risk births following guidelines produced by the British Association of Perinatal Medicine, but programmes vary widely in their structure and content. Recognising the need to standardise approaches to developmental monitoring, NICE produced evidence-based recommendations for the developmental follow-up of children and young people born preterm in 2017.<sup>8</sup> They stated that follow-up should “be provided as an integral part of a neonatal service working together with local health services” and that outcomes should be recorded “at specified time points for national audit” (NICE 2017, p.622). In particular, they recommend that neonatal services should offer children born <30 weeks of gestation, and those born at 30 to 36 weeks of gestation with additional risk factors for developmental problems, enhanced developmental surveillance which should include an assessment of the child’s development at 2 years of age using specified measures shown to have clinical utility in this population. The use of validated measures is important not only for the collection of standardised outcome data for audit purposes, but because clinical assessments alone have been shown to lack sensitivity for detecting cognitive and language impairments in this population.<sup>9</sup>

In addition, for the sub-group of children born extremely preterm, before 28 weeks of gestation, they recommend that a developmental assessment should be carried out at 4 years of age to identify problems, refer the child for specialist services if needed. In particular, NICE recommend that the results of developmental assessments should be recorded in the National Neonatal Research Database (NNRD) for children receiving enhanced developmental surveillance. As noted in our oral evidence to the Committee, the developmental assessment at four years of age is

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<sup>8</sup> NICE Guideline NG72: <https://www.nice.org.uk/guidance/ng72>

<sup>9</sup> Wong et al., 2018: <https://doi.org/10.1136/archdischild-2016-312535>

particularly important because subtle cognitive and social-emotional difficulties can be more readily detected at this age, and tests can be carried out that will provide results that are useful for educational planning. The latter will require significant improvements in information sharing between health and education services as, even where assessments are carried out at four years of age, information is not routinely shared with education settings for instructional planning. For recommendations relating to improving educational planning and support, including improving information sharing with education, please see the separate evidence submitted by Professor Samantha Johnson and Professor Camilla Gilmore.

There are wide inequalities in follow-up care nationally. In their annual 2023 report, the National Neonatal Audit Programme (NNAP) reported that 74% of very preterm born children had a two year assessment recorded in 2022, with only 24% (39 of 162) of units achieving the NNAP developmental standard of 90% of babies receiving a two year assessment.<sup>10</sup> Moreover, as noted in the oral evidence provided to the Committee by Hilary Cruickshank on 11<sup>th</sup> March 2024, only 6.7% of neonatal services surveyed in 2022 offered a four year assessment for babies born extremely preterm. It is unclear why assessments at four years of age are not routinely being offered to date. A lack of resource, a lack of clarity over who should be responsible for organising or carrying out the assessments, the lack of a routine system for recording the results, or the lack of routine reporting on the quality of these assessments may all contribute to the hitherto slow progress in establishing and evaluating these services.

NICE recommend that enhanced developmental surveillance should “be monitored by checking adherence to the recommendations in [the] guideline, including follow-up rates and outcomes, as part of the routine

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<sup>10</sup> <https://www.rcpch.ac.uk/resources/national-neonatal-audit-programme-summary-report-2022-data>

provision of neonatal care by neonatal operational delivery networks and commissioners". Although the NNAP reports data on whether a follow-up assessment took place at two years of age, it does not yet report on the content or results of these assessments (i.e., what tests were done and what the results were), nor does it provide any data relating to follow-up assessments at 4 years of age. Thus there is a lack of information on the quality of assessments at two years and on the provision and quality of assessments at four years of age. A move towards routine collection and reporting of audit data on the provision, content and results of the two and four year assessments would facilitate clinical audit and drive quality improvement in follow-up care.

### **Recommendations for improving developmental follow-up for children born preterm:**

We believe that the recommendations made by NICE in 2017 remain appropriate for the follow-up care of children born preterm. There has not been substantial change in the scientific evidence on which these were based and the recommendations are commensurate with neonatal follow-up programmes throughout Europe.<sup>11</sup> Although developmental assessments are performed slightly later in some European countries, this reflects the later school starting age in those countries. Although the recommended four-year assessment appears to occur a little earlier in the UK, this is appropriate given the earlier school starting age and provides a pre-school assessment which is in line with other countries.

Here we provide six recommendations for improving the quality of follow-up care for preterm born children. These centre around ensuring that developmental follow-up adheres to the guidance provided by NICE so that enhanced developmental surveillance is equitable and is standardised

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<sup>11</sup> Seppanen et al., 2023: <https://doi.org/10.1093/eurpub/ckad192>

nationally to facilitate quality improvement, clinical audit and research, as follows:

**1) Research should be conducted to better understand inequalities in the provision of developmental assessments at four years of age.**

A greater understanding of why many neonatal services are not yet implementing enhanced developmental assessments at four years of age is urgently needed to drive efforts to increase provision and reduce inequalities in care.

**2) The NNAP should report on the content and the results of enhanced developmental assessments at two years of age, in addition to follow-up rates.**

In addition to the current reporting on rates of follow-up, the NNAP should report on the developmental tests used and the results of those assessments at two years of age. This would allow monitoring of adherence to the guideline for developmental follow-up and provide data for audit purposes, as recommended by NICE. This would also facilitate evaluation of the consistency of follow-up care nationally and provide the data needed to drive improvements in quality of care. Indeed, the NNAP state that their long-term intention is to report on the outcomes of this assessment.

**3) The NNAP should report on the provision of enhanced developmental assessments at four years of age, including data on follow-up rates and the content and the results of those assessments.**

Given the limited provision of developmental assessments at four years of age, the NNAP should report on the number and proportion of neonatal services that offer these assessments, as well as on follow-up rates, the developmental tests used and the results of those assessments. This is urgently needed to drive improvements in the consistency and quality of care. This would also provide data for audit purposes, evaluating adherence to guidelines and for monitoring long term outcomes in this high risk population, as recommended by NICE.



**4) The results of developmental and behavioural assessments carried out at two and four years of age should be recorded in the National Neonatal Research Database (NNRD).** Routine collection of data by the NNRD on which developmental assessments are carried out as part of routine follow-up care and the results of those assessments would facilitate research to better understand and improve long term outcomes for children admitted for neonatal care.

**5) Fields for entering the results of developmental assessments conducted at two and four years of age should be added to neonatal electronic patient record systems to enable routine data collection.** In order for the NNAP and the NNRD to collect data on the administration and results of developmental tests assessments carried at two and four years of age, the fields required for entering these data should be made available in neonatal electronic patient record systems. This should include, as a minimum, fields to ascertain whether the child has received an assessment, reasons for lack of follow-up data, the name and results of any clinical assessments carried out, and the name and results of any developmental tests used. The latter should include tests specified for use by NICE plus additional commonly-used measures to assess development at two and four years of age.

**6) Research should be conducted to evaluate enhanced developmental support and surveillance for children born preterm and their parents.** Despite the recommendations made by NICE, there is a paucity of research evaluating enhanced developmental surveillance and support in improving outcomes for parents and carers and for preterm born children themselves. This is needed to inform future development of effective and acceptable follow-up services.

*25 March 2024*