As a parent of a child born at 24 weeks, I recognise a lot of the trends you've described. One of the biggest issues is working memory and executive function, but school don't seem to be able to find ways of helping him with these. Where should we signpost them to try to get the help he needs in this area?

Response from chat - Please signpost them to the free PRISM training at www.pretermbirth.info This has strategies that can be used to support children with attention and working memory difficulties

Is PRISM and Prem Aware only cover early years and primary or span whole educational journey?

Response from chat - Yes! the PRISM training is relevant for all education practitioners and educational psychologists, including early years, primary and secondary schools. Prem Aware Award is also available to secondary schools too.

I wonder if Sam you have done any work that looked at the birth month/nicu discharge and readmission and school outcomes impact? Is there any opportunity to link your work with Tim's? (sorry if I missed discussion of this!)

Response from chat - There is evidence particularly from the Institute for Fiscal Studies in the general population that children born in the summer months have poorer attainment that those born earlier in the academic year. This is the same for preterm children and might impact them more especially those born extremely preterm in the summer and end up in school an academic year earlier than if they had been born at term (in Sept onwards). Hope that helps!

How do we find out which schools are already involved in Prem Aware Award and how would you advise schools can get on aboard?

Response from chat - there is an up-to-date list of all Prem Aware settings on The Smallest Things website - <u>Prem Aware - New Year Report 2025 — The Smallest Things</u>

Given the high chance of educational challenges for children born prematurely should all children born prematurely be given an IDP/EHCP once they start their education? It can then be removed if not needed rather than fought for with the delay that entails.

Response from chat - There would not be sufficient resource for this and most children will not need one, especially those born late or moderately preterm. It is probably better for educators to be aware of likely areas of need so any difficulties can be picked up early and the EHCP process started as soon as possible if needed. This is the aim of the Prem Aware Award

Have you heard much negative feedback in relation (to RSV) vaccination?

Response from chat - In our unit at Leicester we have a fair number of families of preterm babies who decline all vaccines including Nirsevimab, we can offer the information including these figures on how common hospitalisations are, many of which are RSV, and document our discussions.

If a baby is born prematurely outside of the RSV seasons, should Nirsevimab still be considered?

Response from chat - We are currently following Green Book recommendations:

Selective immunisation of very and extremely preterm infants To reduce the risk of severe disease, infants born very or extremely prematurely (less than 32 weeks) are recommended to receive a dose of nirsevimab (Beyfortus®) during or preceding their first RSV season. Typically infants being discharged from hospital for the first time between mid-September and the end of February should be immunised with nirsevimab while an inpatient.

Green Book Chapter 27a RSV

We will see if this changes in the coming years

Further information provided by Tim van Hasselt in the chat

For further information about family experiences of PICU admission following neonatal care, my colleague Dr Sarah Seaton published this paper, which is free to access:

Creating a home with a critically ill child: A qualitative study exploring the experiences of parent...

Her excellent study uses interviews with families to look more closely at their experiences.

If you would like to contribute to our research survey:

For healthcare professionals who look after children with multiple long-term conditions: Professional and academic survey: children with multiple long-term conditions study – Fill in form

For parents, families, and adults with long-term conditions from childhood: <u>Patient and public involvement survey</u>: children with multiple long-term conditions study – Fill in ...

And finally, see link for preterm birth infographics for PICU and hospital admissions, codesigned with families and healthcare professions: https://timms.le.ac.uk/preterm-birth-and-paediatric-intensive-care/