



J Margaret Woodhouse, Cardiff University

Nicola Enoch, Positive About Down Syndrome

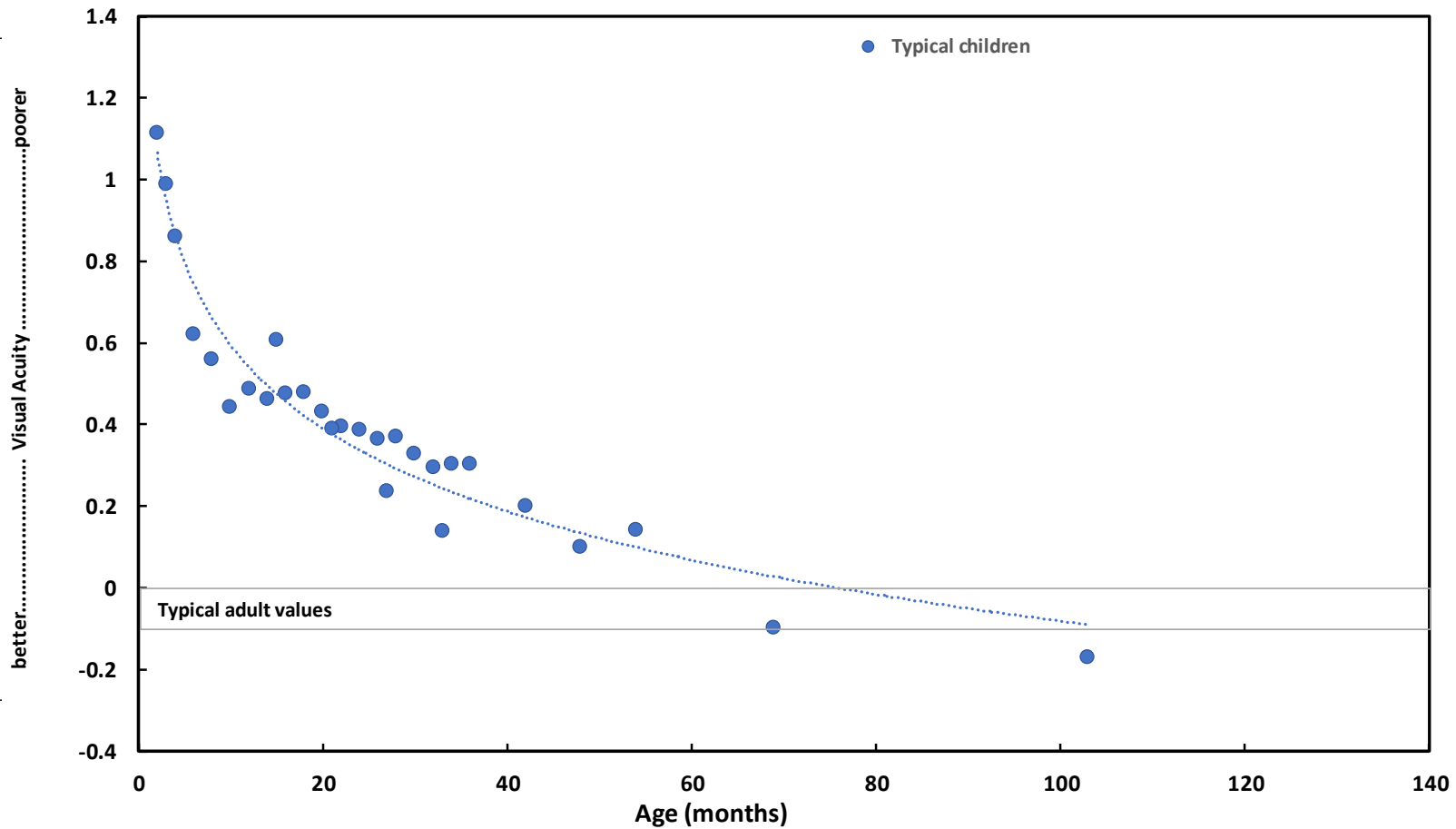
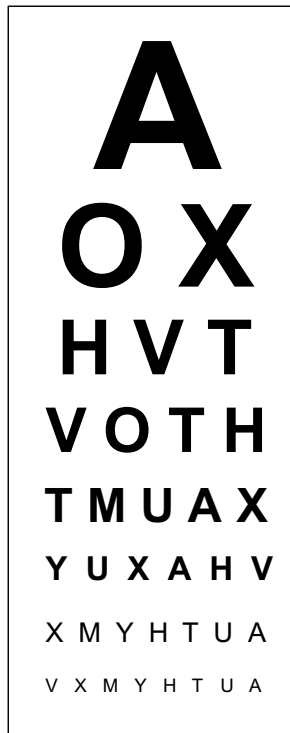
Nystagmus

Involuntary rhythmic movement (wobble) of the eyes

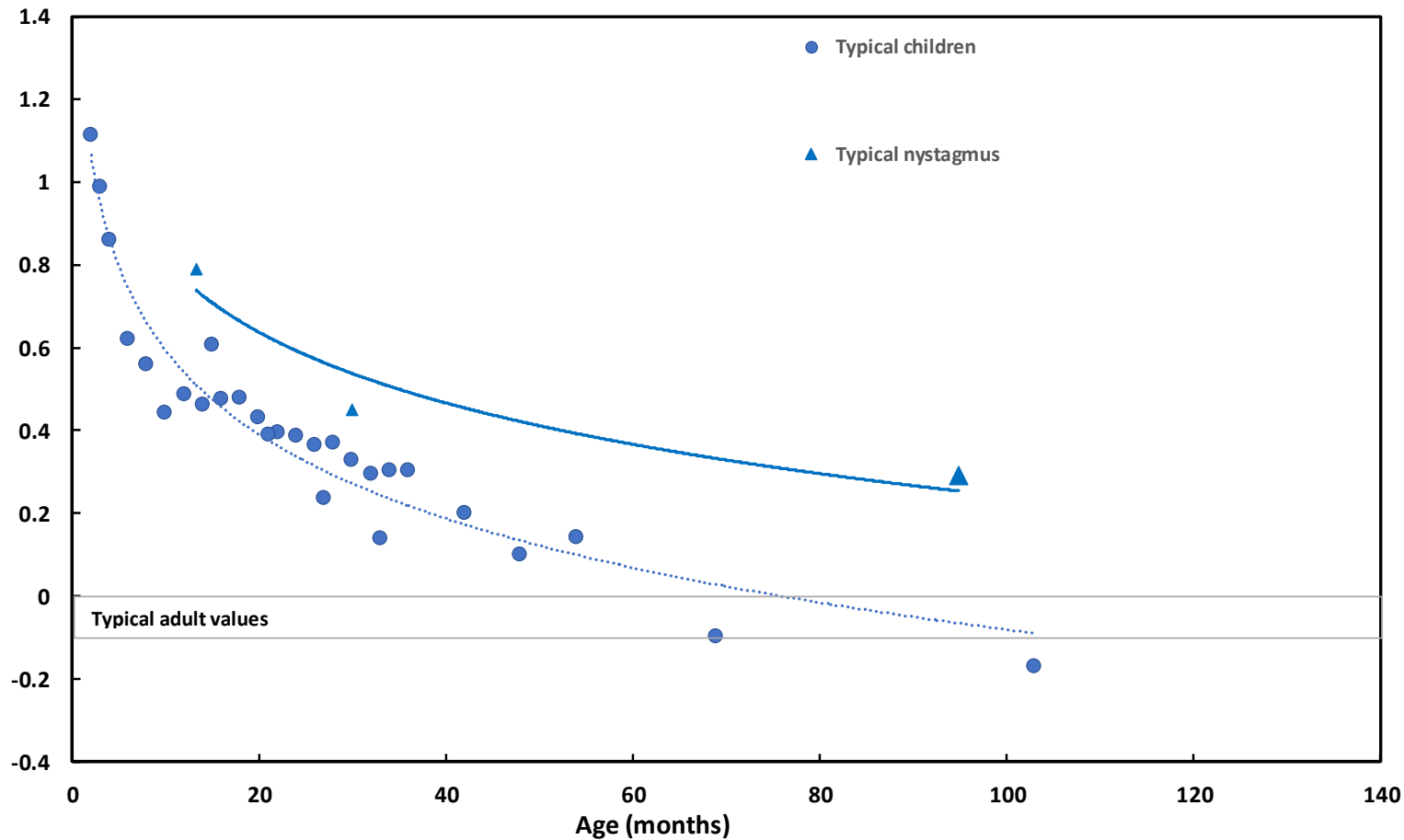
Appears in the early weeks of life



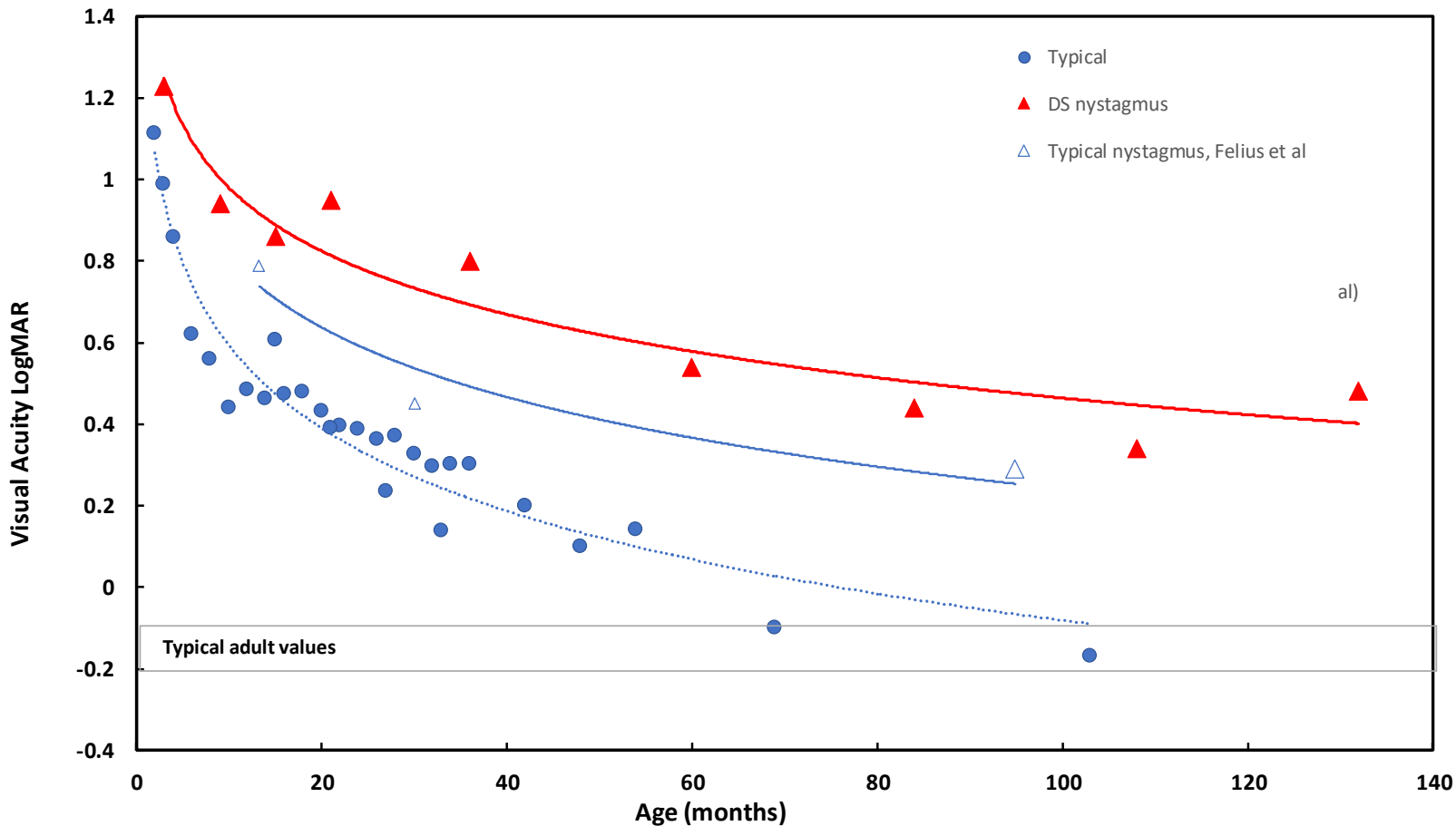
Visual Acuity – typical children



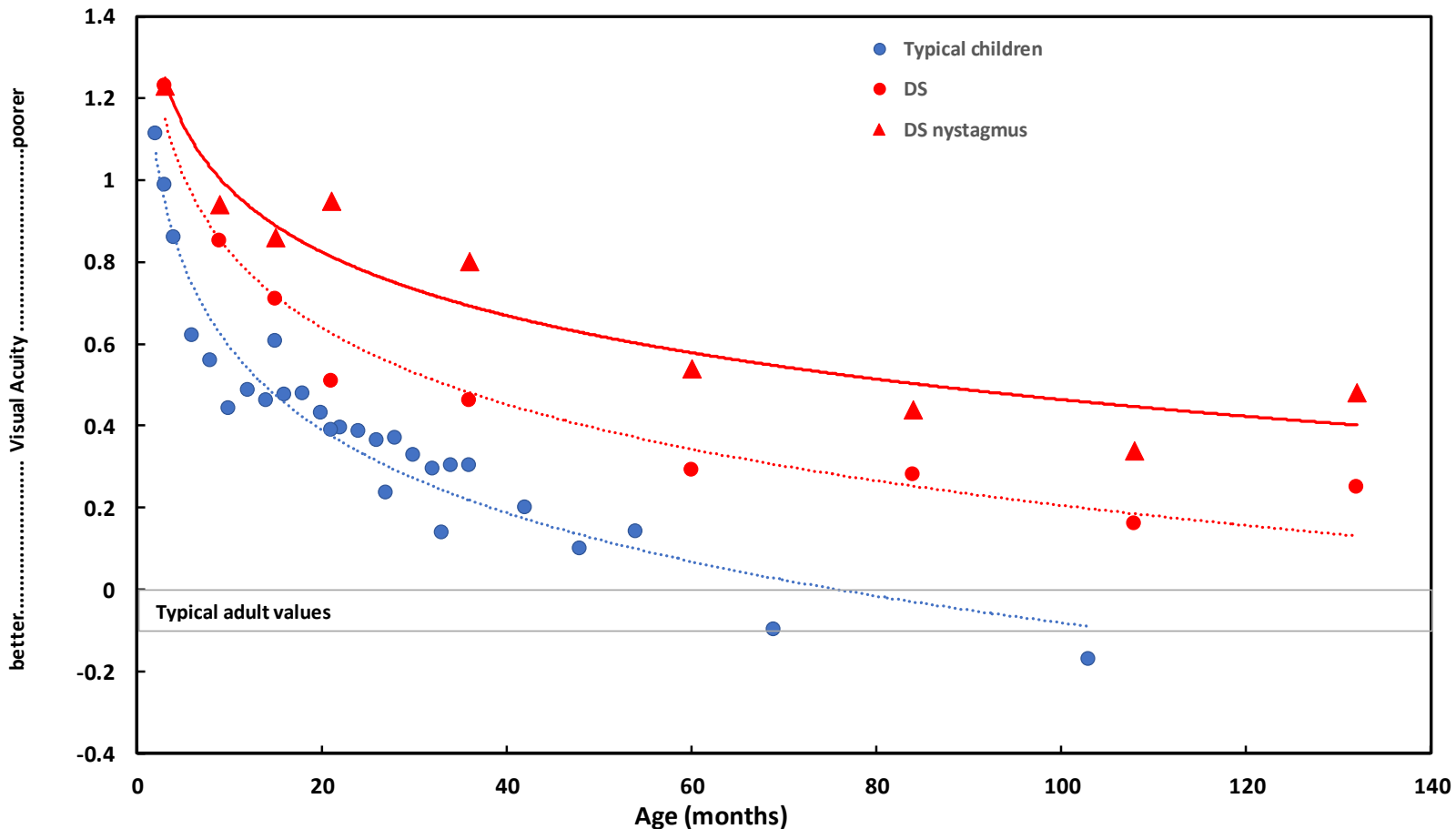
Visual Acuity – typical children with nystagmus



Visual Acuity – children with Down syndrome

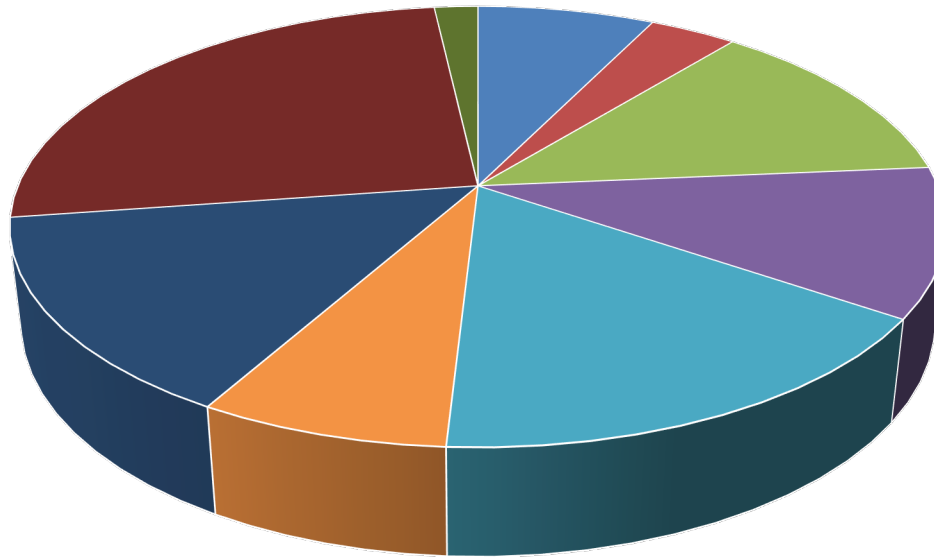


Visual Acuity – children with Down syndrome and nystagmus



- Who we sent it to
- How long survey was open for
- 59 responses
- 4 cases were ‘suspected, awaiting diagnosis’
- 55 cases

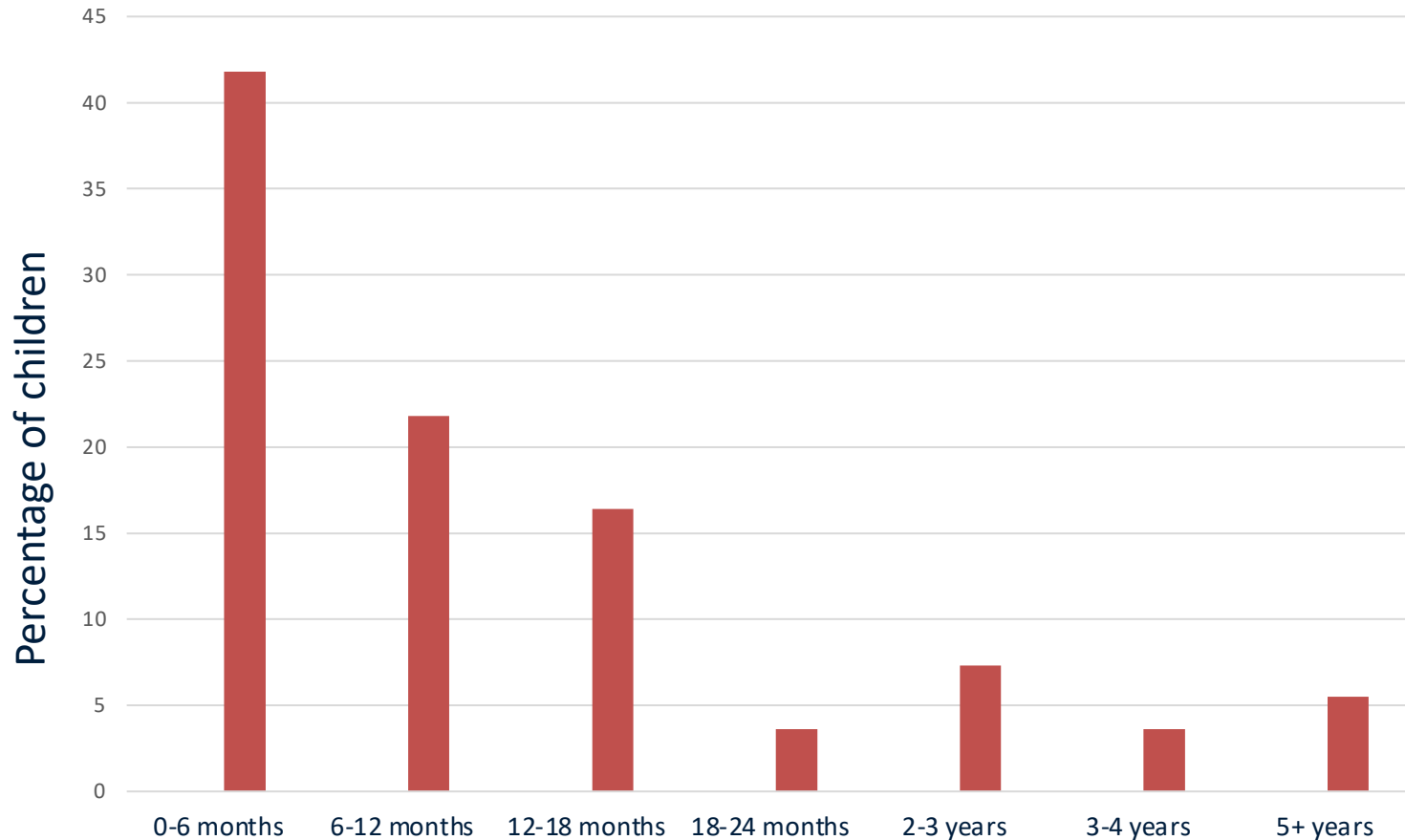
Which region of the UK are you based in?



- | | | |
|--------------|-----------------|-----------------|
| ■ Scotland | ■ Northern | ■ North West |
| ■ North East | ■ East Midlands | ■ West Midlands |
| ■ South West | ■ South East | ■ Wales |

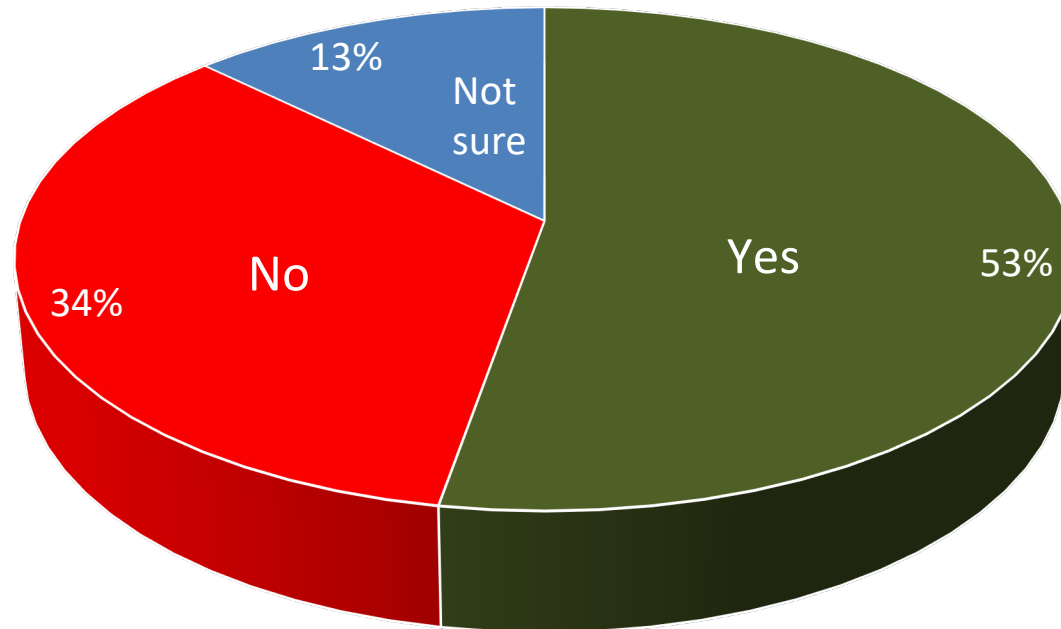
All regions represented

At what age was your child diagnosed?



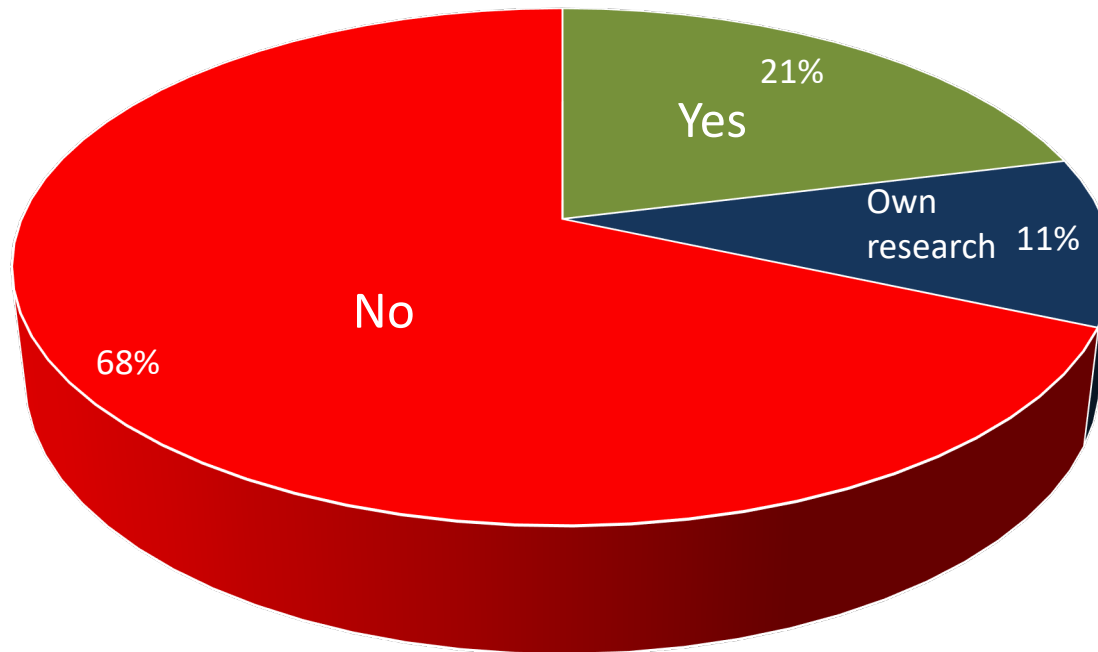
- All three cases of diagnosis after 5 years were diagnosed by an optometrist, not hospital
- One case of diagnosis at 2-3 years was diagnosed by an optometrist, not hospital

Have you ever had an explanation from the hospital of how nystagmus affects the way your child sees?



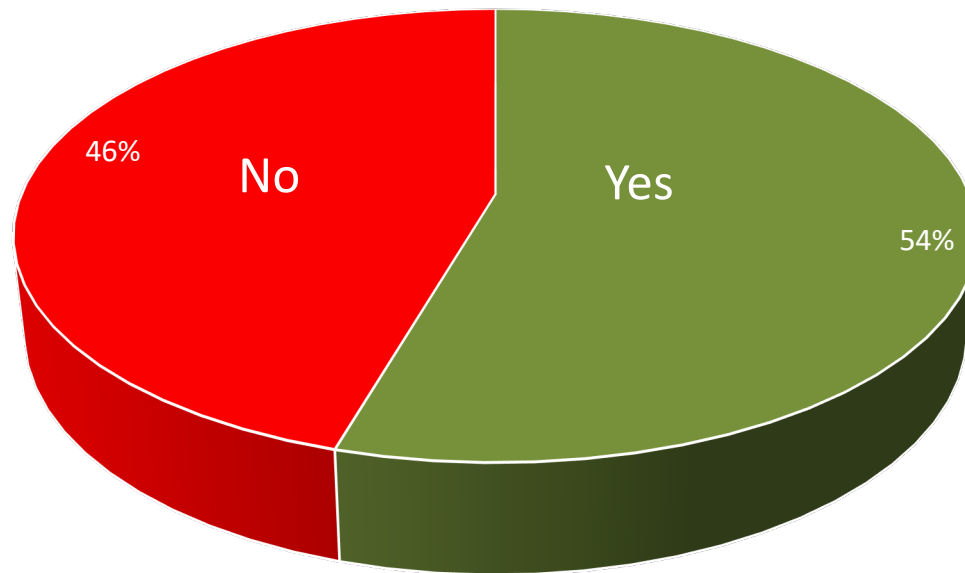
- Over **ONE THIRD** of families have never been told about their child's vision by hospital staff

If the hospital has not provided an explanation, have you received information from anywhere else?



- Excluding the 'Not Sures', 24% of families of children with nystagmus have had NO explanation of how the condition affects their child's vision

Is your child supported by the VI service?



- Almost half of children with nystagmus are not supported by the VI service

- Our collaborators:
 - Asma Zahidi
 - Jon Erichsen
 - Lee McIlreavy
 - All children and families who contribute to our studies
- Zahidi AAA, McIlreavy L, Erichsen JT, Woodhouse JM. Visual and refractive status of children with Down's syndrome and nystagmus. Invest Ophthalmol Vis Sci. 2022;63(2):28. doi.org/10.1167/iovs.63.2.28