

How many children have Fetal Alcohol Spectrum Disorder (FASD) in Greater Manchester?

What is FASD?

FASD is caused by alcohol consumption in pregnancy. It is a neurodevelopmental condition with lifelong cognitive, emotional and behavioural challenges. In addition to effects on the brain, FASD is a full-body diagnosis that is associated with more than 400 known conditions.

In Brief

- We carried out the first study in the UK to directly assess for FASD in a sample of children. This leaflet gives a summary of our findings.
- **We found that FASD is a significant problem that may affect 1.8% of children.**
- When including possible cases, this rises to **3.6%** of children.
- This means in Greater Manchester each year, between **619-1,238** babies may be born with FASD, and a similar number of affected children will be starting school each year.

We think the findings may be an underestimate, for two reasons:

Often the children who the teachers were most concerned about were **withdrawn** from the study by their parents or parents were **uncontactable**.

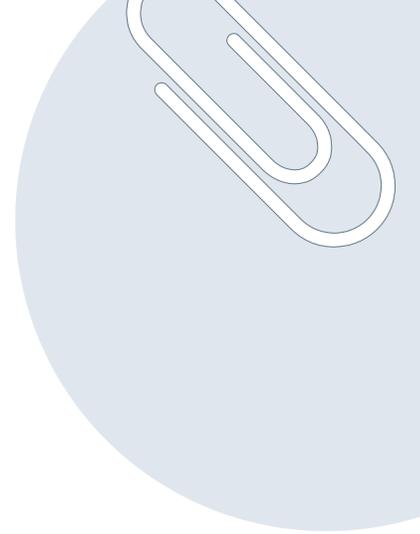
We only looked in **mainstream primary schools**. Children with FASD are likely to be over-represented in other settings, such as specialist **Social Emotional and Mental Health** schools.

Recommendations:

This preventable condition is relatively common, but rarely diagnosed. We need further, long-term investment into:

- Increased **access to diagnosis** for FASD.
- **Interventions to support** families and individuals affected by FASD (to reduce the burden of the condition on individuals, but also on other services)

The Study



We carried out a two-stage study to actively identify FASD in three mainstream primary schools in Greater Manchester, UK. We looked at an entire year group of children aged 8-9 years.

In the first phase, children were selected on the basis of factors known to be related to FASD risk: if they were small for their age; had any special educational needs; whether they were currently or previously in care; and whether they had significant social/emotional/mental health symptoms. Additionally, if parents had concerns, they were able to put their child forward for assessment. Children who screened positive at this stage were invited for further assessment. The further assessment included a range of questionnaires with the parent, and some tests, including an IQ test, on the child.

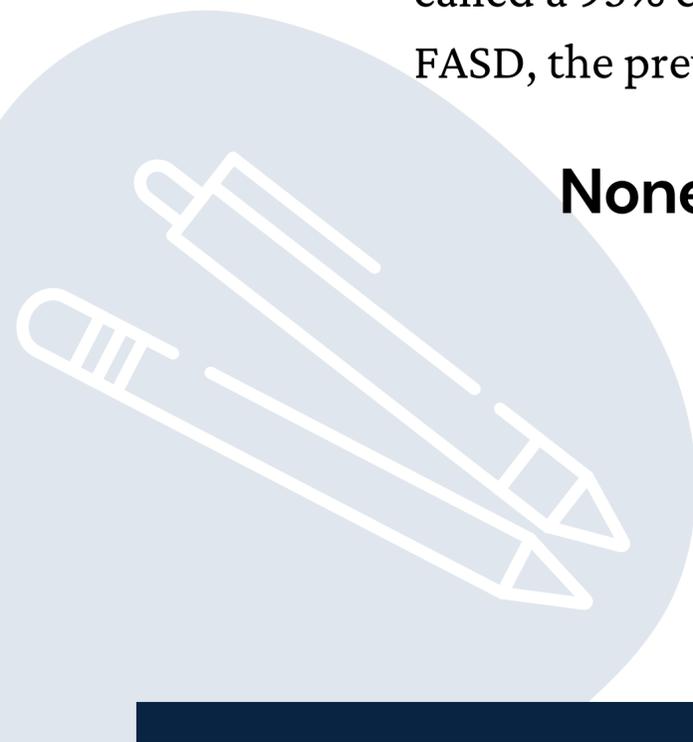
There were 220 children in the year group in the three schools. Of these, 50 (23%) screened positive at the first stage and were invited for a full assessment.

Twenty-six (12%) proceeded to stage-two assessment. Twenty-one had a developmental disorder. Of these, four had FASD and four were assessed as having possible FASD.

The crude prevalence rate of FASD was 1.8%. This is an estimate for these schools: the actual value is likely to fall between 1% and 3.5% (this range is called a 95% confidence interval). When we include all possible cases of FASD, the prevalence was 3.6% (95% confidence interval: 2.1-6.3%).

None of these children had previously identified with a developmental diagnosis.

The full scientific report of the study can be found on line at:
<https://doi.org/10.1111/acer.14705>



How did the parents and children feel about the study?

The area of prenatal alcohol exposure and FASD is highly sensitive. Concerns are often raised when doing this sort of study that the findings could be distressing for families.

For this reason, we asked parents from two of the schools to provide feedback. Parents told us that overall, they had a positive experience of taking part. Even though the result was sometimes a shock, the report on their child was accessible and helpful.

Parents told us that their child had either actively enjoyed taking part or had been indifferent. No parent reported that their child was distressed by taking part.

Some of the challenges

The study used a relatively small sample size, and used just three schools. This number was chosen in anticipation of it being challenging to gain access to schools. Before we started, we did a 'power calculation' to inform our study, which concluded that we would need to assess 170 children in order for it to be statistically highly likely to find cases of FASD.

Through our participating schools, we undertook assessments with 220 children.

Based on our findings we think it is highly likely that an average sized primary school (with 60-90 children in the target age group) would have at least one or two cases in that year group.

Screening for FASD is complex and expensive, the aim of the study was to screen enough children to provide useful information about the prevalence of FASD in Greater Manchester. In other words, we set out to see whether FASD was a significant problem, and we achieved that aim.

This work should be replicated in more parts of the country to get a better overview of the prevalence for the UK.

The study has been published in an international journal, and has undergone rigorous peer review.

The Researchers

The research was led by Professor Penny Cook from the **University of Salford**. The rest of the team at the University of Salford were the main researcher on the project, Robyn McCarthy, together with Dr Alan Price and Dr Clare Allely.

The project co-led by UK FASD expert Dr Raja Mukherjee, lead of the the **National FASD Clinic**. Professor Jill Clayton-Smith (**University of Manchester**), clinical geneticist and a dysmorphologist with expertise in diagnosing FASD, was also a member of the team. Prof Clayton-Smith and Dr Mukherjee led the case conferences and used their clinical expertise to identify FASD.

Dr Kate Fleming, FASD researcher from the **University of Liverpool**, provided epidemiological expertise to do the power calculations and provide the prevalence estimates.

Acknowledgments

Without the help of parents, guardians, children, head teachers and staff at participant schools this research would not have been possible. We also thank Róisín Reynolds and Rachael Nielsen from the Greater Manchester Health and Social Care Partnership for their support. Philip May provided advice and allowed us to use the Maternal Risk Questionnaire. The members of the independent steering group, including those with lived experience of caring for individuals with FASD, have provided invaluable support.



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