

## FETAL ALCOHOL SYNDROME

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**Abstract** Fetal Alcohol Syndrome (sometimes known as FAS) is a rare condition which occurs when the developing baby is exposed to alcohol in the womb. Alcohol can cross the placenta into an unborn baby's blood stream. The exposure of an unborn baby to alcohol can then affect the development of the brain, leading to challenges in learning and development. Alcohol can also affect the development of other parts of the unborn baby's body, particularly the face.

The exact amount of alcohol that cause Fetal Alcohol Syndrome is unknown but FAS can be completely prevented by avoiding the use of alcohol in pregnancy.

In the UK and Ireland we currently know little about the exact numbers of babies and children affected by Fetal Alcohol Syndrome and the services they require to support them throughout their childhood. The aim of the study is to answer both these questions and ultimately improve the treatment and support we can provide to babies, children and families affected by Fetal Alcohol Syndrome.

This study is not investigating Fetal Alcohol Spectrum Disorder.

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**Website** [www.rcpch.ac.uk/bpsu/fas](http://www.rcpch.ac.uk/bpsu/fas)

**Coverage** United Kingdom and Republic of Ireland

**Duration** October 2018 to October 2019 (13 months of surveillance)

**Research objectives**

- Describe the incidence (new cases) of FAS in children 0-16 years of age.
- Examine in what proportion of these cases does the available information allow confirmation of FAS using the CDC criteria and the incidence of these confirmed cases.
- Report the gender distribution, age at diagnosis, clinical features, number of cases with and without affected siblings or maternal half-siblings, comorbidity and ethnicity.
- Describe services being accessed by babies and children with FAS.
- Undertake international comparison with FAS studies undertaken in Australia and New Zealand.

<b>Case definition</b>	<p>Any child &lt; 16 years old newly diagnosed with FAS in the last month based on the presence of all three of the following clinical features:</p> <ol style="list-style-type: none"> <li>1. Facial features: <ul style="list-style-type: none"> <li>- Smooth philtrum</li> <li>- Thin upper lip</li> <li>- Short palpebral fissures</li> </ul> </li> <li>2. Poor growth: <ul style="list-style-type: none"> <li>- In utero &lt; 10th centile for gestational age</li> <li>- Postnatal – FTT</li> </ul> </li> <li>3. Structural or functional brain abnormality: <ul style="list-style-type: none"> <li>- Head circumference &lt; 10th centile or microcephaly with increasing age</li> <li>- Abnormal brain scan</li> <li>- Developmental delay / learning difficulties</li> <li>- Abnormal neurological signs</li> </ul> </li> </ol> <p>A history of maternal alcohol use during pregnancy is not required for reporting and cases may be reported if this is uncertain or unknown.</p>
<b>Reporting instructions</b>	Please report any cases of babies or children under 16 years of age meeting the surveillance case definition of FAS whom you have seen in the last month in the UK or the Republic of Ireland.
<b>Methods</b>	Active surveillance will be undertaken through the BPSU for a 13-month period. Data will be collected from reporting clinicians at initial notification using standardised questionnaires.
<b>Ethics approval</b>	This study has been approved by London - Camden & Kings Cross Research Ethics Committee (REC reference: 17/LO/1020; IRAS project ID: 212510); HRA Confidentiality Advisory Group (reference: 17/CAG/0161); and the Scottish Public Benefit and Privacy Panel (1718-0262).
<b>Support group</b>	FAS Aware UK ( <a href="https://www.fasaware.co.uk/">https://www.fasaware.co.uk/</a> )
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