

TITLE OF REPORT: FAS/FASD REVIEW UPDATE

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SUMMARY

The purpose of this report is to give a final update on the work to review the diagnoses of Foetal Alcohol Syndrome (FAS) and Foetal Alcohol Spectrum Disorder (FASD) since this was last presented in April 2019.

The report will cover the following areas:

- Outcomes of the review
 - Current FASD assessment pathway
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BACKGROUND

1. Further to the previous report (dated April 2019) which provided the background and introduction to the review of Looked After Children and Young People in Gateshead, in whom a diagnosis of Foetal Alcohol Spectrum Disorder (FASD) had been made or considered, this report provides a final update and conclusion to the review.

REVIEW PROCESS

2. The reviews were undertaken in the same way as previously detailed in earlier reports.
3. In total, 98 patients (including those mentioned in previous reports) were identified from a pre-existing database.
4. There were 9 exclusions for the following reasons:
 - Sadly, 1 young person died prior to their review.
 - 1 young person moved abroad.
 - 2 had been mistakenly included but there was no evidence of FASD ever being considered.
 - 2 young people declined to be seen.
 - 2 young people did not attend for their appointment.

- 1 young person had already been reviewed by a consultant paediatrician prior to the start of this review.

RESULTS

5. 89 patients had their review completed.

6. The table below shows the review outcomes:

Classification in original database	Number reviewed	Number where FAS/FASD confirmed	Number where FAS/FASD diagnosis rescinded or not confirmed	Number where alternative diagnosis confirmed	Number where information is outstanding
Definite FAS/FASD	30	12 (one with concurrent genetic diagnosis) 40%	12 40%	6 20%	0
Probable FAS/FASD	35	3 8.5%	29 83%	3 8.5%	0
Possible FAS/FASD	24	1 4.2%	21 87.5%	2 8.3%	0
Total	89	16	62	11	0

DISCUSSION

7. Included within the “possible FAS/FASD” were patients who were listed as “at risk” of FASD. Many of these individuals were indeed at risk of FASD due to documentation of antenatal exposure to alcohol, but were not displaying features of FASD, therefore they were included in the “FAS/FASD diagnosis rescinded or not confirmed” category.

8. It is important to note that in the group where the diagnosis was rescinded or not confirmed, for some patients this was solely due to there being insufficient (or completely absent) confirmation of antenatal exposure to alcohol. It is also important to note that this does not entirely exclude the possibility of the child or young person being exposed to and/or affected by antenatal alcohol.

9. As mentioned in earlier reports, there have been a range of scenarios encountered in the review appointments and after the review outcomes have been communicated. These are listed again below:
- a. For some young people the removal of the diagnosis was a relief as they themselves felt that it was not a reflection of them and it was a potentially damaging label for them to carry forwards into adult life.
 - b. For some young people the review appointment was particularly difficult eg where the young person was not aware that this was a potential diagnosis that had been given to them or when talking about possible maternal alcohol intake in pregnancy eg when the birth mother had died.
 - c. For some young people the removal of an FAS/FASD diagnosis due to the absence of evidence of maternal alcohol intake in pregnancy left the child/young person potentially vulnerable with significant presenting problems but with no clear diagnosis. In these circumstances the clinical team have made appropriate referrals on to other services for further assessments and support.
 - d. For some children and young people a clear alternative explanation for their developmental and behavioural difficulties was found eg a previously undetected chromosomal abnormality. This would have implications for them as adults potentially passing this on to their own children and ensures that those future offspring would be accurately diagnosed.
 - e. For some children and young people confirmation of their diagnosis gave them and their carers reassurance. This was important for several at a time when they were aware that the review process was ongoing.
 - f. Birth mothers who were able to give a clear and convincing account that they had not consumed alcohol in pregnancy.

CURRENT FASD ASSESSMENT PATHWAY

10. There is not currently a commissioned FASD assessment service in Gateshead.
11. Referrals are accepted for patients with difficulties which may or may not be related to FASD although it is made clear that this is not a formal assessment service. Investigations and/or onward referrals will be carried out as deemed necessary.
12. If it is felt that there is enough evidence to consider a diagnosis of FASD, the Canadian FASD guidelines ⁽¹⁾, in conjunction with a pathway proposed regionally, are used. The evidence used to confirm a diagnosis should be documented and if there is any uncertainty, then discussion with a consultant colleague is undertaken.

13. Guidance on the diagnosis of FASD is being developed by NICE (National Institute of Clinical Excellence) ⁽²⁾ and our assessment process will be reviewed in light of that guidance once available.

RECOMMENDATIONS

14. The Overview and Scrutiny Committee is asked to note the contents of the report.

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April 2021

REFERENCES

1. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. Cook JL et al. CMAJ, February 16, 2016, 188(3)
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