

TITLE OF REPORT: Foetal Alcohol Spectrum Disorder Review – Update Report

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Summary

This report details the work undertaken to review the diagnoses of Foetal Alcohol Spectrum Disorder / Foetal Alcohol Syndrome.

Background

Concerns were raised by partner agencies, Local Authority and Public Health, in relation to a potential excess of Fetal Alcohol Spectrum Disorder/Fetal Alcohol Syndrome (FASD/FAS) diagnoses amongst the Gateshead paediatric population, particularly those children who are Looked After (LACYF). It was agreed by Gateshead NHS Foundation Trust (GHNT), in conjunction with Newcastle Gateshead Clinical Commissioning group (CCG), to review the diagnoses of this group to establish if those concerns are valid.

Actions so far:

1. Development of review tool to enable review of the children and young people on the FASD database which was set up by a retired Consultant Paediatrician. The review tool is based upon accepted diagnostic criteria for FASD.
2. Two meetings of health professionals (CCG and GHNT) to develop an outline plan of work with a further meeting planned for 06/10/17.
3. Review of diagnoses based upon clinical records using the review tool. So far this has been completed for over 60 cases (from a total of 223 on the FASD database which was compiled by the previous Designated Doctor LAC) with ongoing work to complete this. Each notes review takes 30 minutes and is being completed by 3 paediatricians in addition to their current workload. So far no organised face to face clinical review of patients has taken place although some individuals have been seen on an ad hoc basis for review either due to ongoing health issues or for planned reviews as part of their LAC status.

4. Dr Howey has attended two FASD Discussion meetings with representatives from Clinical Genetics, Newcastle Gateshead CCG and Consultant Paediatricians from Great North Childrens Hospital (GNCH) and Sunderland Royal Hospital (SRH). Several actions arose from this in relation to developing a regional way forwards for a consistent approach to FASD diagnosis. The difficulties within Gateshead were shared within the group who agreed with the approach being taken by GHNT/CCG. The aim of this group is to determine a jointly agreed approach to diagnosis which can be developed into a pathway of care for potential commissioning. Buy in is needed from stakeholders outside of health, most importantly education and educational psychology.

Review process so far:

The accepted diagnostic criteria for FASD that the review has been working to are:

- A. History of maternal alcohol intake in pregnancy (quantities needed to cause effects of FASD/FAS are uncertain with limited evidence available) **OR**
- B. Presence of typical facial features associated with FAS

AND

- C. Microcephaly (head circumference $<3^{\text{rd}}$ centile for age) in pre-school children **OR**
- D. Clear evidence of significantly impaired function across at least 3 domains of the FASD checklist

The review has also looked for the presence or absence of growth restriction (previously part of the diagnostic criteria and associated with FASD/FAS and if any genetic testing has been carried out to exclude the possibility of a genetic cause for a child's difficulties. The review has identified that information is not always available or recorded across the diagnostic categories. In order to stratify the security of diagnosis the information available has been coded as follows:

| Maternal alcohol intake | | Microcephaly | |
|--|---|--|---|
| Mum disclosed/agreed | 1 | Yes, clearly recorded | 1 |
| Documented in pregnancy/neonates | 1 | Not clear | 2 |
| Relative states drank | 2 | No microcephaly | 3 |
| Evidence of other substance use | 2 | | |
| Late booking/concealed preg | 2 | Genetic results | |
| No info available | 3 | Normal array/frag X | 1 |
| Mum denies | 3 | Not done | 2 |
| | | Abnormal | 3 |
| Facial features | | | |
| Yes clear facial features documented | 1 | Evidence of significant impairment across 3 domains | |
| Not clearly described or dysmorphic not typical of FAS | 2 | Yes, clearly described with evidenced assessments from other services | 1 |
| No facial features documented | 3 | No clear description of significant impairment or without supporting evidenced assessments from other services | 2 |
| | | No description of impairment | 3 |
| Growth restriction | | | |
| Yes, clearly recorded | 1 | | |
| Not clear | 2 | | |
| No growth restriction | 3 | | |
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Outcomes of cases reviewed so far:

60 cases have had review of their hospital (QEH) records against the above review tool. These were selected at random from the large number of 223 which is the total number of children and young people who were listed on the database compiled by the previous Designated Doctor LAC.

3/60 cases had no mention in any correspondence that any consideration was being given to them possibly having FASD/FAS. 2 of these were identified on the data base as “at risk” and one as “probable”.

6/60 cases were described in clinical correspondence as “possible/possible risk of FASD”. For all of these children the information available for the key diagnostic criteria of maternal alcohol intake and/or facial features of FAS was of category 2 based on the coding tables above.

16/60 cases were described in clinical correspondence as “probable FASD”. In one of these cases there was evidence of maternal alcohol use in pregnancy that could be coded as category 1 based on the tables above. For the remaining 15 children the information available for the key diagnostic criteria of maternal alcohol intake and/or facial features of FAS was of category 2 based on the coding tables above.

35/60 cases were described in clinical correspondence as FASD/FAS. For 10 of these there was category 1 information relating to maternal alcohol use in pregnancy or facial features however for only 2 was there level 1 information of significant impairment across 3 domains supported by evidenced assessments from other services.

Conclusion and next steps:

The data above would support the view that some children were receiving an FAS/FASD diagnosis without the relevant diagnostic criteria being clearly evidenced. This does not mean that these diagnoses are incorrect but in order to determine their validity further assessments will need to take place.

For many children and young people it may not be possible to determine if FASD/FAS is the correct diagnosis for them. This will be the case where children or young people do not have classic facial features of FAS and where information is unavailable regarding maternal alcohol intake during pregnancy and there is no realistic prospect of this being found. It is also important to consider that the diagnosis of FASD/FAS may be either a positive or a negative for any individual, eg positively helping them and their families to access support and services or negatively impacting upon their self-esteem. It is important therefore that if any diagnoses are removed that this is done sensitively and does not leave children and young people at a disadvantage or with unmet needs.

The next planned steps are to continue the notes review and then decide upon the need for clinical review. Further work is needed within Gateshead NHS Foundation Trust, in conjunction with partner agencies, to determine how this can be best achieved.

Recommendation

Families Overview and Scrutiny Committee is asked to receive the report and note the actions outlined.

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