

TITLE OF REPORT: FAS/FASD REVIEW UPDATE

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SUMMARY

The purpose of this report is to give Overview and Scrutiny Committee an update on the work to review the diagnoses of Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorder since this was last presented in October 2017.

The report will cover the following areas:

- Background
 - Progress to date (end of April 2019)
 - Outline plan of future work
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BACKGROUND

1. Concerns were raised by partner agencies, Local Authority and Public Health, in relation to a potential excess of Foetal Alcohol Spectrum Disorder/Foetal 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.
2. An initial notes review was completed looking at the sets of notes of 60 of 223 cases that had been held on a database. The notes review confirmed that some children had received an FAS/FASD diagnosis without the relevant diagnostic criteria being clearly evidenced. It was agreed that in order to determine the validity of the diagnosis those labelled as FAS/FASD further assessment of this population was needed.

REVIEW PROCESS

3. A staged approach to the review process was agreed starting with those children and young people who are LACYF. It was agreed that for those LACYF who were identified on the database as definite/probable/possible FAS/FASD their annual statutory Review Health Assessment would be completed by one of a small group of consultant paediatricians who would also use that as an opportunity to consider the evidence in relation to FAS/FASD. LACYF were prioritised in relation to how they were classified on the database with greater priority given to those who were identified as

“definite” but also prioritising to ensure that no one left care at 18 without being offered an appointment to be seen.

4. At the Review Health Assessment the consultant Paediatrician considered the information available in relation to the diagnostic criteria for FAS/FASD:

This involved looking for evidence of:

A Maternal alcohol intake in pregnancy and/or the child or young person having facial features consistent with pre-natal alcohol exposure.

AND

B Evidence of the child or young person having significant impairment across three out of 7 neurodevelopmental domains:

- Motor skills
- Neuroanatomy/neurophysiology
- Cognition
- Language
- Academic achievement
- Memory
- Attention
- Executive function including impulse control and hyperactivity
- Affect regulation
- Adaptive behaviour, social skills or social communication

Where there was uncertainty regarding the child/young person’s presentation or the history of maternal alcohol use in pregnancy further information was sought from other sources and for some children and young people further investigations were arranged. This has involved (where appropriate) analysis of genetics bloods (SNP array and Fragile X), seeking out information from Educational Psychology and other developmental assessments, writing to or meeting with birth mothers to ask about their alcohol intake in pregnancy, reviewing historical health records for the children and young people, reviewing historical Childrens Services records for the birth family.

Where there was any uncertainty if the diagnosis of FAS/FASD was appropriate there was a group discussion between the consultants to determine a consensus view.

PROGRESS TO DATE

5. 56 appointments have been offered. The availability of appointments has been limited by the capacity of the clinic team who are carrying out the review as in all cases this is being done over and above their usual clinical role. Each clinic appointment takes 1 hour with the same amount of time allocated for the associated administrative time.

6. 41 children and young people have been reviewed as of 30th April 2019. The discrepancy is due to some young people choosing not to attend their appointment and some appointments being cancelled/postponed due to other commitments of the child and family.
7. The table below shows the outcomes of the review appointments:

Classification in original database	Number reviewed	Number where FAS/FASD confirmed	Number where FAS/FASD diagnosis rescinded	Number where alternative diagnosis confirmed	Number where information is outstanding
Definite FAS/FASD	28	9	12	3 (genetic diagnosis)	7
Probable FAS/FASD	7	0	2	0	5
Possible FAS/FASD	6	1 child also affected by chromosomal abnormality	5	0	0

8. The clinical team noted that the impact of the FAS/FASD diagnosis, attending the appointment and having the diagnosis reviewed and in a number of cases rescinded was variable upon the child and young person. The following scenarios were encountered:
- 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 e.g. 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 e.g. 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.

OUTLINE PLAN OF FUTURE WORK

- 9.** The clinical team plan to continue the reviews in the manner set out above. This gives an approximate end date of January 2020 for reviewing the LACYP with an FAS/FASD diagnosis but this does not take into account cancelled appointments or any potential changes to the capacity of the team to cover this work. Once this work is complete then consideration will be given as to the need to review any non-LACYP with a historic FAS/FASD diagnosis.

RECOMMENDATIONS

- 10.** The committee is asked to note the contents of this report and the progress to date.

Dr Carmen Howey, Clinical Lead Paediatrics on behalf of Gateshead NHS Foundation Trust