

Ms Sandra Butcher
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Date: 29/08/2018
Our Ref: 2808

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Dear Ms Butcher

FREEDOM OF INFORMATION – FOETAL ALCOHOL SPECTRUM DISORDERS

I write in response to your request for information in relation to foetal alcohol spectrum disorders in NHS Lothian.

Question:

The following conditions fall under the Foetal Alcohol Spectrum Disorder (FASD) umbrella: Foetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Alcohol-Related Birth Defects (ARBD), Foetal Alcohol Effects (FAE) and partial Foetal Alcohol Syndrome (pFAS)) or neurodevelopmental disorders linked to prenatal alcohol exposure (NDPAE).

1. [Please provide] copies of any policies that the Trust has on the prevention of FASD, and on the diagnosis and post-diagnostic care pathway for patients with an FASD. Also your policy on the training of Trust personnel to manage patients with FASD.

Answer:

Please note that there are no NHS Trusts within NHS Scotland.

NHS Lothian does not have any formal policies on the diagnosis and post diagnosis care pathway for patients with FASD at present.

NHS Lothian staff are active members of the SIGN (Scottish Intercollegiate Guidelines Network) group which is considering the evidence for FASD diagnosis in Scotland. It is hoped that this will be finalised later this year, following a consultation. The publication of the guideline will inform the future configuration of FASD services in NHS Lothian.

NHS Lothian Paediatricians and Allied Health Professionals joined training on assessment for FASD in 2013 provided by the Scottish Government and NHS Lothian staff have regularly attended FASD clinical forum sessions to help inform and train them in FASD recognition. As part of this case studies have been presented and work has been done with

colleagues in NHS Ayrshire and Arran who are undertaking a pilot on multi disciplinary assessment for FASD.

Question:

2. Any information you hold on services your Trust provided for FASD for a) prevention education following the 2016 Chief Medical Officers' guidelines that the safest course is not to drink while pregnant or attempting to become pregnant;

Answer:

Each woman is asked about their alcohol intake at the ante natal booking with the midwife which is within 12 weeks of becoming pregnant and is given information about alcohol use during pregnancy and problem alcohol use and dependence.

Question:

b) diagnosis for both children and adults; c) post-diagnostic care in the financial years beginning 2013, 2014, 2015, 2016, 2017 and 2018.

Answer:

NHS Lothian Community Paediatricians, who are specialists in child development, have been assessing children with possible FASD at community and multi disciplinary clinics over the last few years. A variety of tools are used for assessment, including the Washington 4 digit code. Follow up support has provided through the Getting it Right for Every Child (GIRFEC) framework with regular review by community paediatricians, appropriate therapy input and psychological support, if required, and child planning meetings to review the child's progress and ensure all necessary supports are in place to allow the child to reach their full potential.

In 2018, NHS Lothian and the City of Edinburgh Council have been piloting a service development for FASD. This involves a multi disciplinary clinic delivered in the Royal Hospital for Sick Children outpatient department by community paediatricians, occupational therapists and speech and language therapists. Following the clinic, a triage and formulation meeting takes place, which includes educational psychologists. The pilot is still running at present and the results are being collated.

Question:

3. Information on the number of Doctors in your Trust who currently provide diagnostic and/or post-diagnostic services for FASD? Please provide their names and posts. Whether your Trust employs specifically trained professionals, including but not limited to nurses, psychologists, occupational therapists and speech and language therapists, to provide specialised services for patients on the FASD spectrum? If so, in what specialties, and how many? Please provide their names and posts.

Answer:

All community paediatricians, allied health professionals and psychologists have a role in assessing the needs of children who present with development delay and educational difficulties and in providing appropriate levels of intervention and support in line with the GIRFEC framework.

NHS Lothian does not have any staff employed in a specific role to deliver services to children with FASD.

Question:

4. Information on training provided to personnel in your Trust on FASD, or provided by others and accessed by your personnel.

Answer:

Please refer to the answer to question 1 above.

Question:

5. Information you hold on whether your Trust sends patients for FASD diagnosis to the National FASD Clinic in Surrey (<https://www.fasdclinic.com/>)? Did your refer any patients to the National FASD Clinic in 2013, 2014, 2015, 2016 and 2017, and in 2018, and if so, how many in each year?

Answer:

NHS Lothian has not made any referrals of cases to the National FASD Clinic in any of the years requested.

Question:

6. What was your budget for services for FASD in each financial year since that starting in 2013 and including the current financial year?

Answer:

There is no specific budget allocated for FASD services.

Question:

7. Please provide copies of any agreed plans you have to expand the budget or services in coming years.

Answer:

There are plans to prepare a Business Case for a FASD Service in NHS Lothian. This will follow the publication of SIGN guidelines and evaluation of Edinburgh pilot service both described above and will inform resources required to provide a Lothian wide service.

I hope the information provided helps with your request.

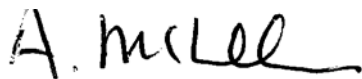
If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the reviewer at the address at the top of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at:

<http://www.nhslothian.scot.nhs.uk/YourRights/FOI/Pages/default.aspx>

Yours sincerely

A handwritten signature in black ink that reads 'A. McMahon'.

PROFESSOR ALEX MCMAHON
Executive Director of Nursing Midwifery and AHPs
Cc: Chief Executive