Lothian NHS Board

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Date: 20/07/2026
Our Ref: 11525
Enquiries to loth.freedomofinfomation@nhs.scot

Dear

FREEDOM OF INFORMATION – MRKH SYNDROME CARE PATHWAY

I write in response to your request for information in relation to the MRKH Syndrome care pathway in NHS Lothian.

Question:

I am requesting information held by your Trust relating to the diagnosis, management and support of patients with Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome.

Question:

1. Clinical pathways and diagnosis. Please provide copies of any clinical guidelines, protocols, or care pathways relating to: a) Diagnosis of MRKH syndrome; b) Investigation of suspected Müllerian anomalies or congenital absence of uterus and/or vagina; c) Referral pathways into specialist gynaecology or tertiary services for MRKH.

Answer:

Patients are diagnosed in Paediatric endocrinology services, usually when referred for primary amenorrhea. SDSS resources. The relevant Ref Help guidance for referrals can be found here: https://apps.nhslothian.scot/refhelp/guidelines/paediatrics/paediatric-endocrinology-diabetes/puberty/delayed-puberty-in-girls/

There ae no specific guidelines used for MRKH. Patients would be referred to paediatric endocrinology services and from there they may be referred to the lead gynaecologist for the DSD service.

Question:

2. If recorded and readily accessible, please also provide: a) Average time from referral to confirmed diagnosis of MRKH; b) Typical number of appointments prior to diagnosis.

Answer:

This information is not collected centrally. Information may be held in individual patient records, but in order to provide the information you request it would be necessary to review each patient record over the period you have specified, requiring significant resources. Under section 12 of the Freedom of Information (Scotland) Act 2002, NHS Lothian is not

required to respond to your request if the resources required to do so equate to more than £600 in cost.

Question:

3. Multidisciplinary care. Please provide details of MRKH management within your Trust, including: a) Whether care is delivered via a multidisciplinary team (MDT); b) Professional groups involved (e.g. gynaecology, nursing, psychology, psychosexual therapy, endocrinology); c) Whether psychological support is routinely offered at or shortly after diagnosis; d) Any written guidance regarding timing or referral to psychological support; e) Whether formal MDT review processes exist for MRKH patients

Answer:

Care is provided by a multidisciplinary team including paediatric endocrinology consultants, paediatric endocrinology nurses, genetics, paediatric surgeons, biochemists, gynaecology and radiology. The DSD Multidisciplinary Team meets every four weeks and all cases are discussed.

There is no specialist psychology input for patients with DSD, and no written guidance regarding this.

Question:

4. Psychological and supportive care. Please provide information on: a) Availability of psychological support services for MRKH patients; b) Availability or referral pathways for psychosexual therapy or sexual wellbeing support; c) Waiting times for psychological or psychosexual support (if recorded)

Answer:

There is no psychological support as part of the DSD service. Referral to psychological services or psychosexual support is available if needed, these would be added to all referrals to these services.

Question:

5. Trauma-informed care and communication. Please provide any policies, guidance, or training materials relating to: a) Trauma-informed care in gynaecology or reproductive health services; b) Communication of sensitive diagnoses (including MRKH); c) Breaking bad news in gynaecology or reproductive health contexts; d) Consent and safeguarding procedures for intimate examinations in these services. Additionally, please confirm: a) Whether trauma-informed care training is provided to relevant staff; b) Whether such training is mandatory, recommended, or audited.

Answer:

There is no specific guidance for trauma informed care in gynaecology or reproductive health services. Communication skills are assessed as part of non-technical skills in CiPs in

the training eportfolio. Online training modules are available and communication skills are reviewed as part of appraisal each year, in particular through the MSF. Trauma informed care training is not specifically provided to staff, and is not mandatory or audited.

There is mandatory training for staff in capacity and consent, which covers safeguarding procedures for intimate examination.

Question:

6. Patient information materials. Please provide copies of any patient information materials provided to MRKH patients, including: a) Diagnostic information leaflets; b) Information on management options, including non-surgical vaginal dilator therapy (where applicable); c) Fertility counselling information; d) Sexual health, intimacy, or relationship support materials (if available)

Answer:

Patients are directed to the Scottish DSD Network website which includes an MRKH leaflet and a vaginal dilatation leaflet. There is also a DSD families website with Top Ten Tips for dilatation.

No specific materials on sexual health, intimacy or relationship support are available.

Question:

7. Service activity data (last 3 years available). If recorded and held in a retrievable format, please provide: a) Number of patients diagnosed with MRKH; b) Number of MRKH patients referred for psychological support; c) Number of MRKH patients referred for psychosexual therapy (if applicable)

Answer:

The paediatric endocrinology team and gynaecologist for DSD have not diagnosed MRKH in the past three years. No patients have been referred for psychological support or for psychosexual therapy.

Question:

8. Vaginal dilator support services. Please confirm: a) Which service provides information and support regarding non-surgical vaginal dilator therapy (e.g. gynaecology, pelvic health physiotherapy, or other service); b) Whether written patient guidance or materials are used to support this process.

Answer:

The gynaecology service provides this support through the DSD clinic. The Top Ten Tips for vaginal dilatation available on the DSD families website.

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 https://www.foi.scot/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: https://org.nhslothian.scot/FOI

Yours sincerely

ALISON MACDONALD
Executive Director of Nursing Midwifery and AHPs
Cc: Chief Executive