

**Freedom of Information Request**

**Ref: UHB 18-437**

Date 16 August 2018

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trusts response is as follows:

**1) Who provides expert evaluation of gender assignment in newborns with Disorders of Sex Development?**

We do not use the term 'gender assignment' . If the question is about determining apparent sex or sex of rearing then this is undertaken by the DSD MDT with the parents.

**2) Does the trust use a multidisciplinary team that deals with the evaluation and long-term management and needs of patients with Disorders of Sex Development?**

Yes

**3) If yes to question 2, can you provide contact details for the team?**

Contact can be made through the DSD Team Bristol Royal Hospital for Children or through the Paediatric Endocrinology team.

**4) What specialties are represented on the multidisciplinary team (e.g. paediatric subspecialists in endocrinology, surgery, and/or urology, psychology/psychiatry, gynaecology, genetics, neonatology, and, if available, social work, nursing, and medical ethics)? Please list them.**

Paediatric subspecialists in Endocrinology, Urology, Psychology, Radiology, plus Adolescent & Adult Gynaecology, Adult Endocrinology, Clinical Genetics, Neonatology, Clinical nurse specialists, and links with medical ethics

**5) When dealing with Disorders of Sex Development, what guidelines, if any, do decision makers follow?**

- Clinical Standards for Management of an Infant or Adolescent presenting with a suspected disorder of sex development (DSD).  
[https://www.bsped.org.uk/media/1371/dsd-standards-november\\_2017.pdf](https://www.bsped.org.uk/media/1371/dsd-standards-november_2017.pdf)
- Ahmed SF, Achermann JC, Arlt W, et al. Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015). Clinical Endocrinology. 2016;84(5):771-788.

- Martine Cools et al on behalf of the COST Action BM1303 working group 1. Caring for individuals with a difference of sex development (DSD): a Consensus Statement. Nature Reviews Endocrinology 2018. <https://doi.org/10.1038/s41574-018-0010-8>
- SW regional referral guidelines

**6) How many people are referred to this team per year (please give numbers for the last five years)?**

We are unable to provide the relevant information for this request as it depends on the definitions— whether referred to the whole DSD MDT or components, whether for review and assessment or specifically those with an ongoing DSD issues. Those referred may not all turn out to have a DSD issue. Neither have we have the admin resource to record consistently. But approximately 2 /month are referred for review although may not all ultimately have DSD issues.

If you still require this information, please could you specify exactly what information you require.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Trust Secretary  
University Hospitals Bristol NHS Foundation Trust  
Trust Headquarters  
Marlborough Street  
Bristol  
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information

(such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

**FOI Team**  
**UH Bristol NHS Foundation Trust**