

Ref no: 115110718  
From: Research  
Date: 11/07/18  
Subject: Disorders of Sex Development

## REQUEST

I am writing to request information under the Freedom of Information Act 2000. The information is for a research project examining Disorders of Sex Development in the UK. The project is being conducted by Dr Fae Garland (University of Manchester), Prof Michael Thomson (University of Leeds, University of Technology Sydney), Dr Mitch Travis (University of Leeds) and Dr Joshua Warburton (University of Leeds)

We seek information about the evaluation and care given to those with Disorders of Sex Development. We are interested in the procedures carried out by the Trust, and how far international standards of best practice are being engaged with.

We have put together a list of questions, which we would be grateful if you could answer in this order:

1. Who provides expert evaluation of gender assignment in newborns with Disorders of Sex Development? If Trust paediatricians have any concerns that might be suggestive of any new born baby having an ambiguous gender, then the baby is immediately referred/transferred to the local tertiary centre, Alder Hey Children's Hospital, to their urology, genetics and endocrine teams for expert evaluation and ongoing management of the disorder.

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? Please see response to Q1.

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

N/A

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. N/A at this Trust.

5. When dealing with Disorders of Sex Development, what guidelines, if any, do decision makers follow? Please see response to Q1 above.

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 information you require as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trust's obligations under the Data Protection Act 1998. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the Act.