

Ref: FOI/GS/ID 5595

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Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Down Syndrome.

You asked:

- 1. Do you have a care pathway for expectant women who receive a screen positive result for Down syndrome? If so, please provide a copy/link.*
- 2. When a pregnant woman receives a screen positive result for Down syndrome is she referred for counselling? If so, to whom and when?*
- 3. What training do the staff providing counselling have appertaining to a) providing counselling & b) knowledge of Down syndrome?*

Trust response:

1. Please see the attached the guideline which is currently being reviewed and the template letter we individualise and send to women with a screen positive result.



Reviewed Guideline-
Down's, Edward's anc



Screen positive
summary letter Feb 2

2. All screen positive results for Down's syndrome are given by a screening coordinator. As per the guideline, women are offered a face to face appointment and phone/email communication, according to the woman's preference.

In addition to counselling by the screening coordinator, women are signposted to the NHS choices website, the Down's syndrome Association website and to

Antenatal Results and Choices (ARC) who are an organisation offering support to parents who are given positive screening results

3. ARC provide training for professionals and the screening coordinators have attended their 3 study days as listed below. The newly appointed deputy screening coordinator will be applying at the next opportunity

Day 1: Communication skills and delivering difficult news - the implications of antenatal screening and diagnosis

Day 2: Supporting parents decisions

Day 3: When a prenatal diagnosis is made: Providing best care

The screening coordinators knowledge of Down's syndrome has been developed over the last 10-15 years working in antenatal and newborn screening. They have experience of giving all screen positive Down's screening results during this time and supporting parents who choose to continue an affected pregnancy. The screening coordinators are involved in generating support from other appropriate health care professions involved in the care of affected pregnancies, including fetal medicine specialists, fetal cardiology, specialist midwives for infant feeding and the lead Consultant Paediatrician.