

Freedom of Information request 395-19

Request and Response

I am writing to request as much information as it is possible for you to share, on how your health board treats patients experiencing recurrent miscarriage. In order to research the equity of service across Scotland for patients experiencing repeated pregnancy loss, I am seeking as much information as possible regarding the processes, timescales and medical tests involved in recurrent miscarriage investigations. I am also interested in further exploring the incidence rate of repeated pregnancy loss by gaining an estimate of the number of patients across Scottish health boards referred for recurrent miscarriage investigations. Furthermore, of these patients, I am particularly interested in the percentage for whom a problem or medical issue is identified versus those for whom all tests come back 'normal'. I will attempt to break down my queries into as detailed a list of questions as possible. I have provided both my postal address and my email address and have no preference for whether I receive my response by mail or email; whatever is most convenient for yourself. It appears to be a long list of questions, but many of them should be easily answered by someone familiar with the fertility/miscarriage processes.

Under current guidelines in your health board, what is the process by which a patient would be referred for investigations following recurrent miscarriage:

1. Does a 'chemical pregnancy' count as a miscarriage in this process?
Yes
2. How many miscarriages warrant further investigations, and do they have to be concurrent?
3 consecutive miscarriages
3. Is the patient referred on to your fertility clinic, a Recurrent Miscarriage Clinic/Specialist or somewhere else?
They are referred to the combined Miscarriage/Infertility Clinic.
4. How long does this referral take?
Referral times can vary depending on outpatient activity but are within current waiting time standards.
5. Please detail all tests or investigations that are carried out as standard following recurrent miscarriage? (Including any blood tests, physical examinations, tissue testing (on both partners, and/or foetal tissue).
Tests - as per RCOG guidelines. Antiphospholipid antibodies, USS uterus if not done already, genetic analysis of tissue from miscarriage. Thrombophilia screen if miscarriage 2nd trimester.
6. How long do the results take on average?
Antiphospholipid antibody screen can take 2-3 weeks, genetic results can take up to 4 weeks
7. Are there further additional tests one can be referred on for and what circumstances would lead to this occurring?
No other routine testing - unless initial genetic testing is abnormal
8. What are all the available treatment options available to patients following tests?
9. What support or treatment options are available for patients whose tests all come back normal, but they continue to experience miscarriages?
If test are all normal, there is no evidence of benefit for any treatment. If antiphospholipid antibody screen is abnormal, the patient would be offered aspirin and heparin in future pregnancy.

With regard to the volume of patients experiencing recurrent miscarriage, do you have any data on how many referrals are made in your health board per year? If it is not too arduous to provide any data you have, that would be great, otherwise could you provide data from the last decade?

1. How many new referrals are made every year for patients who have experienced recurrent miscarriage?
This information is not held electronically, this data may be held in a patient's notes but to extract this data would require a manual trawl of all records and the cost of carrying out this work would exceed the limit set in the Fees Regulations of the FOI(S)A 2002 and therefore we are not required to provide.
2. Of these patients: a) How many (or what percentage) had an identified medical issue identified as a result of their investigations and b) how many (or what percentage) patients had all their investigative tests come back normal?
This information is not held electronically, this data may be held in a patient's notes but to extract this data would require a manual trawl of all records and the cost of carrying out this work would exceed the limit set in the Fees Regulations of the FOI(S)A 2002 and therefore we are not required to provide.

Further questions:

1. Are recurrent miscarriage patients entitled to or offered any counselling or similar support in your health board? If so, is this offered as standard or on a case by case basis?
Counselling is offered where appropriate via Primary Care
2. What is your health boards stance on the field of reproductive immunology?
There is no policy - as per RCOG guidelines there is no current evidence of benefit.
3. Specifically, what is your health boards stance on Natural Killers Cells and their possible link with recurrent miscarriage?
As per RCOG guidelines – no evidence – therefore no policy or agreement.
4. Under what circumstances would a patient be referred on to a Tommy's clinic? And how many patients are referred to a Tommy's clinic in your health board per year?
NHS Borders have not referred a patient to a Tommy's clinic.
5. Under what circumstances would a patient be referred on to a private specialist? And how many patients a year are referred on to private specialists by your health board per year?
Patients would not be referred to a private specialist.
6. What are the options for surrogacy for recurrent miscarriage patients and what is your standard process around this? And how many patients progress with this option?
Surrogacy may be considered if there was a structural uterine abnormality which was thought to be the cause of the miscarriage. Fertility treatment for this would be covered if the patient fitted current fertility funding criteria, but surrogacy costs, in line with current practice in Scotland, would not be covered. Data is not held on patient volume.
7. What are the options for egg donation for recurrent miscarriage patients and what is your standard process around this? And how many patients progress with this option?
Egg donation would be considered and funded if there was evidence of premature ovarian insufficiency and the patient fulfilled current referral criteria. Data is not held on patient volume.
8. How many recurrent miscarriage patients (excluding any with identified genetic issues from karyotype testing that require IVF with pre-implantation genetic screening) go on in the future to require IVF? Of these, how many have live births? And how many have further miscarriages?
This information is not held, therefore under Section 12 of the FOI(S)A 2002 this data cannot be provided.

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **395-19** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.