

Information for Patients

Pre-implantation Genetic Testing (PGT)

What is PGT?

Pre-implantation genetic Testing (PGT) is a specialised technique which combines in vitro fertilisation (IVF) technology with genetic testing. There are several types of PGT. This leaflet covers the two specific types that the genetics department can refer for. PGT for a genetic condition caused by a single gene disorder (PGT-M) and PGT for a structural rearrangement (PGT-SR).

The testing is performed at an early stage when the embryos are not yet inside the woman's womb. It is an approach which can help couples avoid passing on certain inherited conditions to their future children. It may also help couples who have had recurrent miscarriages because of a genetic condition.

This leaflet will provide you with some general information about PGT-M/SR to help you reach a decision about whether you would like to pursue this option.

PGT is carried out by specialist services. There are several around the country but not one in Manchester, so some travel will be needed.

What conditions can be tested for using PGT-M/SR?

PGT-M/SR can be used to test for specific conditions, and you should ask your geneticist or genetic counsellor whether a test is available for the condition in your family.

All conditions tested will need a license from the human embryology and fertilisation authority (HFEA). Where no license is in place a specialist centre can make an application if the condition meets the criteria needed. In some cases, a license may already be in place.

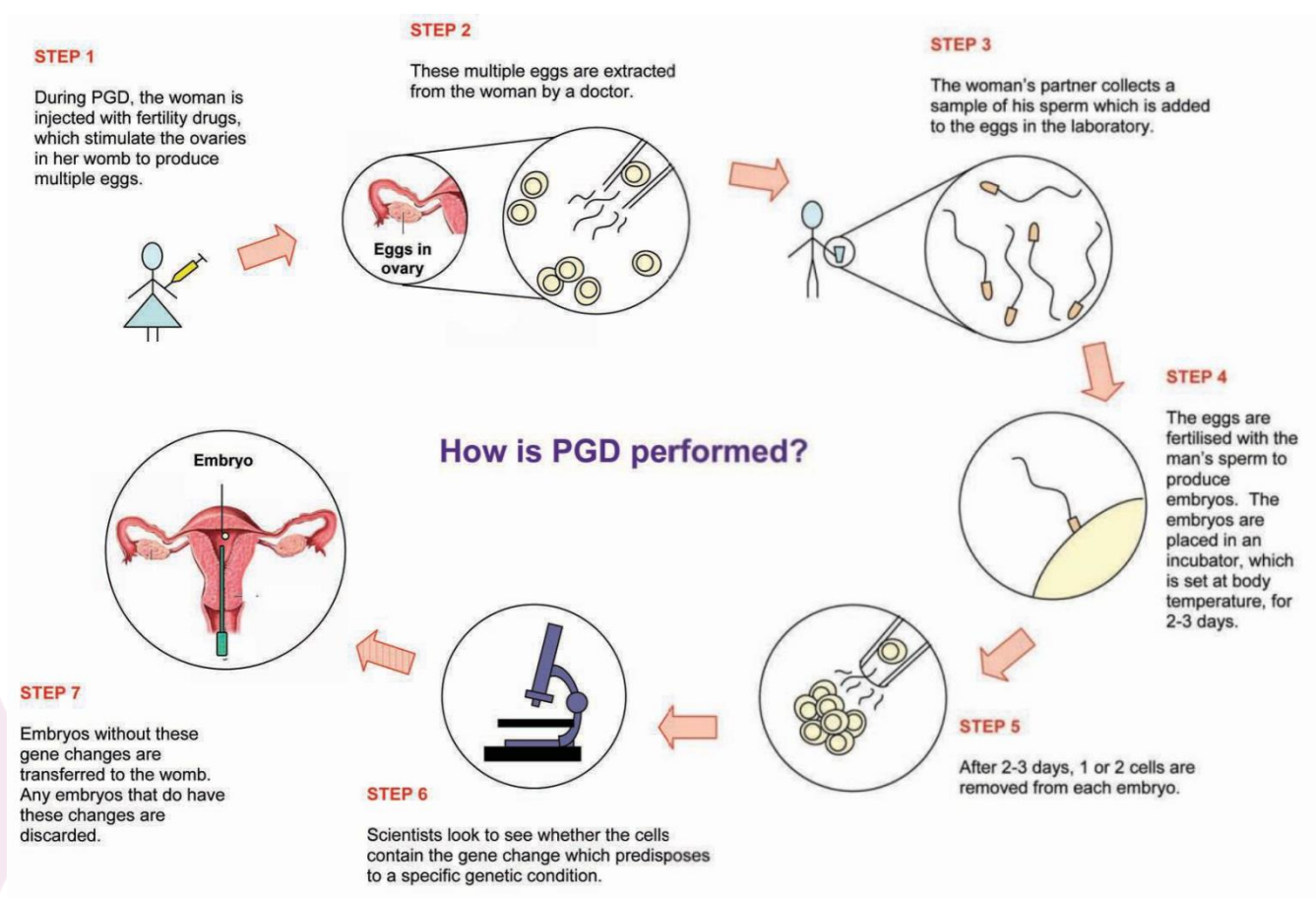
In some cases it may not be possible to offer PGT in your specific circumstance and this would be advised by the specialist service.

How is PGT-M/SR performed?

Please see the diagram below. Each embryo is tested for the specific genetic condition at an early stage after the eggs have been fertilised by sperm in a laboratory. Unaffected embryos can be transferred into the woman's womb. Usually, one unaffected embryo is transferred per cycle of PGT. Any additional unaffected embryos can be frozen for possible future use and transferred at a later stage.

Sometimes all the developing embryos are affected by the condition, and at other times, no embryos develop at all. In these cases, no embryos would be transferred.

The laboratory testing on the embryos is not 100% accurate. In less than 1 in 100 cases, an affected embryo has been transferred to the woman's womb. The accuracy of the test and options for additional testing in pregnancy will be discussed by the PGT service.



How long does PGT-M/SR take?

It is likely to be approximately 8-18 months between the first PGT appointment and the start of treatment. Needing a licence application will add to this estimate. During this time there may be several consultations, for some you will need to travel. PGT is not currently offered in Manchester. There are a number of centres in the UK where PGT-M/SR is offered, and we can discuss this with you. We refer most of our patients to the main London centre which has satellite centres in the North West.

How is PGT Funded?

PGT-M/SR is available on the NHS if a couple fulfil a number of specific criteria:

- The risk of conceiving an affected pregnancy must be 10% or more.
- The female partner should be under the age of 40 years when treatment is commenced.
- The female partner should have a BMI of more than 19 and less than 30.
- Both partners should be non-smokers.
- There should be no living unaffected child from the current relationship.
- The HFEA must have licensed the indication for PGT.
- The couple should not be seeking PGT primarily because they are infertile.

Couples meeting these criteria are eligible to receive up to 3 complete cycles of IVF/ICSI in conjunction with PGT.

You are unlikely to receive funding if:

- You already have a child unaffected by the familial condition with your current partner.
- The female partner is aged 39 or over.
- The female partner has a BMI (Body Mass Index) of 30 or more.

You can self-fund PGT cycles, which are likely to cost a minimum of £10,000 per cycle, but the exact cost may vary and will be confirmed by the specialist centre.

How successful is PGT-M/SR?

Approximately 1 in 3 women (33%) have a successful pregnancy after each cycle of IVF using PGT. This means that for each PGT cycle, 2 out of 3 women (66%) either do not get pregnant at all or have a miscarriage. If a couple get as far as having the embryos transferred, then approximately 1 in 2 of these couples will be successful. Success rates are published by the HFEA.

What are the risks associated with PGT-M/SR?

IVF treatment can cause a complication known as ovarian hyperstimulation syndrome (OHSS). Occasionally, when the woman is injected with the fertility drugs, her ovaries become overstimulated. This can cause fluid retention, abdominal discomfort, enlarged ovaries, nausea and vomiting. More severe cases can cause circulatory and breathing problems which may be life threatening.

What are the alternatives to PGT?

Couples may opt to have children without having any testing at all. Other couples may choose alternative methods of prenatal diagnosis, such as amniocentesis or chorionic villus sampling.

These involve testing samples from an unborn baby when a pregnancy is already established. If the unborn baby is diagnosed as being affected by the condition, the couple will need to decide whether or not to continue with the pregnancy. Some couples may choose to adopt children or use donor eggs or sperm to avoid passing on certain conditions to their children.

What happens if I want to be referred to a PGT clinic?

PGT can be a very emotionally and financially-demanding process so it is important that couples are well informed about their decision to go ahead with it. Couples will need to use all the resources and support available to them, which can include ongoing contact with the Clinical Genetics service here in Manchester.

Your clinical geneticist (doctor) or genetic counsellor can refer you for an initial discussion appointment. This appointment will give you the opportunity to ask questions and find out more about PGT before reaching your decision.

For more information

Contact our department at the address or telephone number given below. We would be happy to discuss the options for referral to a PGT centre offering NHS treatment, or alternatively there are other private centres whose details we can discuss with you if appropriate to the genetic condition or your family situation.

You can find more information about PGT and the centres offering it on the Human Fertilisation and Embryology Authority website, www.hfea.gov.uk
This is the organisation that regulates fertility treatment in the UK.

Guys and St Thomas is the main London centre offering PGT. Their website is:

<https://www.guysandstthomas.nhs.uk/our-services/pre-implantation-genetic-testing-pgt-msr>

Manchester Centre for Genomic Medicine

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The department is staffed Monday-Friday, 9.00 am to 5.00 pm.

Website: www.mangen.co.uk

Seen in clinic by (doctor): _____

And (Genetic Counsellor): _____

Telephone number: _____

Family reference number: _____