

Information for Patients

Pre-implantation Genetic Diagnosis (PGD)

What is PGD?

Pre-implantation genetic diagnosis (PGD) is a specialised technique which combines in vitro fertilisation (IVF) technology with genetic testing. 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 PGD in order to help you reach a decision about whether you would like to pursue this option.

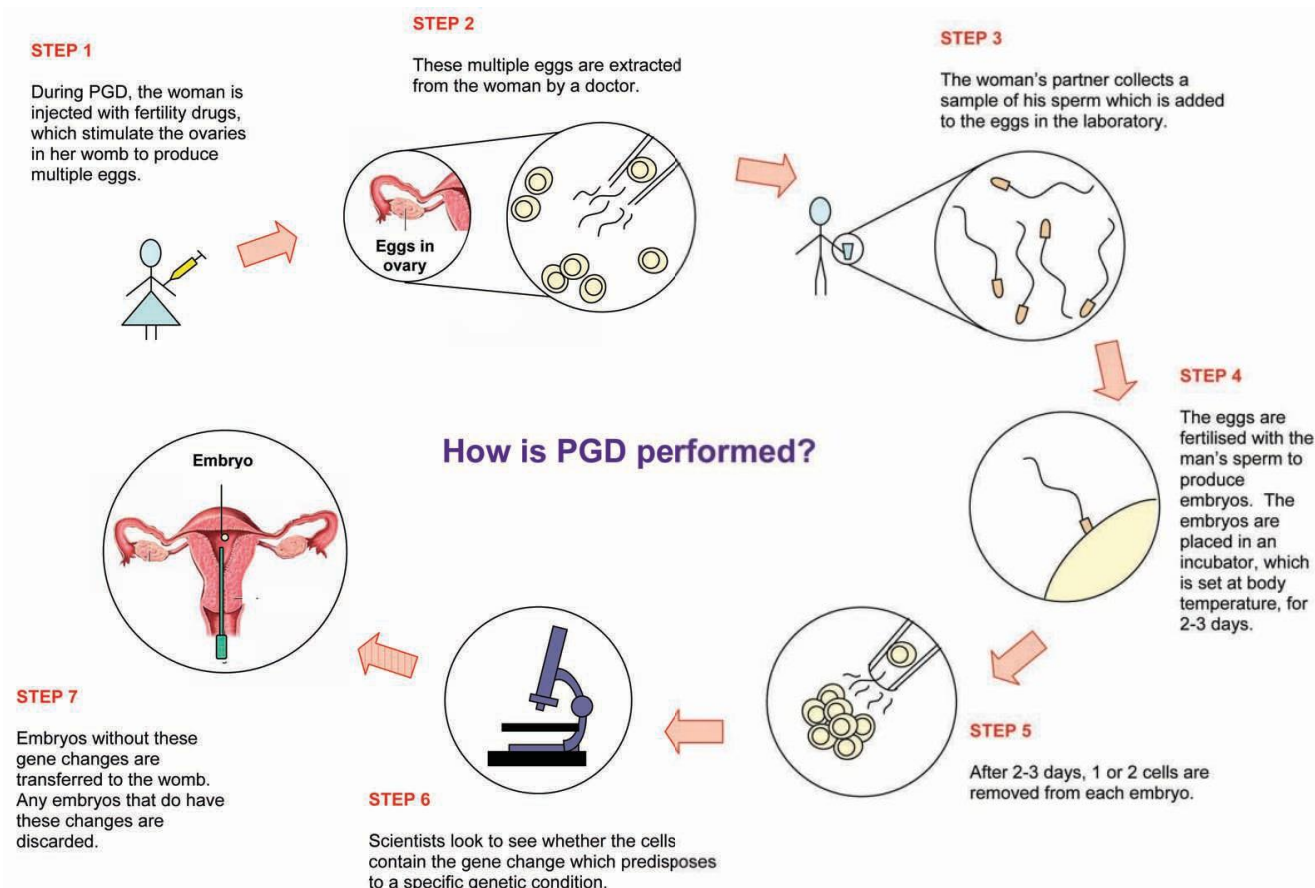
What conditions can be tested for using PGD?

PGD 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.

How is PGD performed?

Please see the diagram on page 2 of this leaflet. Each embryo is tested for the particular genetic condition at around 2-3 days after the eggs have been fertilised by sperm in a laboratory. Unaffected embryos can be transferred into the woman's womb. Usually no more than two unaffected embryos are transferred per cycle of PGD. Any additional unaffected embryos can be frozen 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.



How long does PGD take?

It is likely to be approximately 8-12 months between the first PGD appointment and the start of treatment. During this time there may be a number of consultations for which you will need to travel. PGD is not currently offered in Manchester. We commonly refer patients to two centres in London, although you may be able to have some appointments more locally at satellite clinics in Leeds. There are also some other centres in the UK where PGD is offered.

How much does PGD cost?

Currently, many couples receive funding for one cycle of PGD through their Clinical Commissioning Group (CCG). The information here will be reviewed as the Government's planned changes for the NHS are implemented.

You are unlikely to receive funding if:

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

Couples may decide to pay for further PGD cycles. Each cycle currently costs between £8,000 and £11,000 which is inclusive of the cost of the fertility drugs.

How successful is PGD?

Approximately 1 in 5 women (20%) have a successful pregnancy after each cycle of IVF using PGD. This means that for each PGD cycle, 4 out of 5 women (80%) 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 3 of these couples will be successful. Women who do conceive are offered prenatal testing to double-check that the embryo is unaffected by the genetic condition because PGD is still quite a new technique.

What are the risks associated with PGD?

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.

Whilst PGD is relatively safe, it is still a new technique, so all babies born as a result of PGD are carefully followed up. There is also the possibility that twins or triplets will be conceived if more than one embryo is replaced. This can carry a higher risk of complications for the babies and mother.

What are the alternatives to PGD?

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 then have 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 PGD clinic?

PGD 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 PGD before reaching your decision. This appointment is free of charge.

For more information

Contact our department at the address or telephone number given below. The details for the two NHS PGD departments we work with are given below. There are other private centres whose details we can discuss with you if appropriate to the genetic condition or your family situation.

Manchester Centre for Genomic Medicine

Sixth Floor
Saint Mary's Hospital
Oxford Road Manchester M13 9WL

Telephone: (0161) 276 6506 (Reception)
Facsimile: (0161) 276 6145

Department staffed Monday - Friday, 9.00 am to 5.00 pm.

Website: www.mangen.co.uk

The Centre for Pre-implantation Diagnosis Assisted Conception Unit

11th Floor, Tower Wing
Guy's Hospital,
Great Maze Pond
London SE1 9RT

Website: www.pgd.org.uk (where there is more patient information)

Pre-implantation Genetic Diagnosis Team Institute for Women's Health

University College London
86-96 Chenies Mews
London WC1E 6HX
Website: www.ucl.ac.uk/PGD

Seen in clinic by (doctor): _____

And (Genetic Counsellor): _____

Telephone number: _____

Family reference number: _____