

	MHRA, with the addition of studies referred to at 4.3.			
05/02/2014 3.2	SCAAC agreed on the areas of expertise that are required on the panel. New recruits will be added to the membership.	Anna Rajakumar	October 2014	The areas of expertise missing has been identified. Recruits will be approached in the coming months.

## DRAFT TEXT FOR GETTING STARTED GUIDE

### What to think about before starting treatment (p23)

#### How much will it cost?

We do not regulate the cost of treatment. Private clinics set their own prices for treatment, which vary. However, since clinics are in competition with each other, prices tend to be similar.

When discussing prices with clinics, it's important to find out exactly what the price includes. Some include consultation fees and any recommended tests in their overall price, others may not. Some clinics may offer some free counselling, and others may charge for this. Fertility drugs are usually an extra cost and can be very expensive.

#### Costed treatment plans

Your clinic should give you a costed treatment plan, detailing the specific procedures you need. This can help you understand how these costs are calculated.

Your clinic should also give you regular cost updates as your treatment progresses or changes. If you don't understand what a particular charge is for or how it is calculated, ask your clinic to explain.

#### Reduced fees for egg and sperm donors

Some clinics offer IVF cycles at a reduced cost if you donate some of your eggs for others to use (egg sharing).

Some clinics also offer IVF cycles at a reduced cost if a man donates his sperm for others to use (sperm sharing).

#### Additional costs

Some clinics may offer additional services which will carry an extra cost. This could include endometrial scratching (a process of "scratching" the lining of the uterus in order to improve the chances of implantation), time-lapse imaging (a series of pictures that show the development of an embryo without removing them from the incubator) or embryo glue (sometimes suggested to help implantation). Some of these treatments are being researched and their efficacy explored. If a clinic is including such services in your treatment plan, we would recommend that you discuss this in detail with your clinician so you can be fully informed about whether you require these optional services.

#### HFEA fees

We do not charge individual patients for fertility treatment. Clinics, both NHS and private, pay us a fee towards the costs of being regulated and inspected.

The fee is based on the number of treatments clinics carry out.

Some private clinics pass on this fee to their patients. Others cover the cost in their overall treatment fees. If you are paying for treatment, ask your clinic about their practice.

**Benefits of the HFEA fee**

Our fee enables us to make sure your clinic is complying with the law and is providing safe and appropriate treatment.

## Using donated sperm, eggs and embryos in your treatment (p44 & 45)

### Using donated sperm

Donor insemination (DI) can be used with intrauterine insemination (IUI) or in vitro fertilisation (IVF) to help you become pregnant using sperm from a donor.

Sperm donors are screened at a licensed clinic for sexually transmitted diseases and some genetic disorders. If you are using sperm from a donor you know, it will need to be quarantined for six months before your treatment.

### How does using donated sperm work?

Donated sperm is used for donor insemination with IUI or for IVF. The procedure for using donated sperm varies depending on your clinic and the fertility treatment you are having. A typical procedure will be similar to the following:

1. The clinic may do checks before starting treatment, such as:

- taking details of you and your family's medical history
- a physical examination
- screening for HIV, hepatitis B and C, cytomegalovirus (CMV), syphilis and gonorrhoea
- blood sugar and blood pressure
- hormone tests to make sure you are producing eggs
- taking a full blood count and identifying your blood group,
- a tubal patency test to make sure your fallopian tubes are open and healthy, and
- any relevant genetic testing.

2. Treatment takes place at the time you ovulate (when an egg is released from an ovary). Some clinics recommend fertility drugs to help increase your egg production.

3. In donor insemination (DI), the sperm are put into a thin tube which is then used to place the sperm at the entrance to your cervix (the neck of your womb) or into the womb itself, using IUI. The procedure is normally painless, although a few women may experience temporary, menstrual-like cramping. It is often possible for your partner to be with you.

4. After treatment, you may be advised to rest for a while before going home.

### Using donated embryos

Embryos can be donated by people who have completed their fertility treatment or by those who cannot use them in their own treatment.

## How does using donated embryos work?

Broadly, the procedure for using donated embryos is as follows:

- Your clinic will try to select donors whose physical characteristics match those of yourself and your partner (if you have one) as closely as possible.
- The donors will have been screened for infectious diseases such as HIV, hepatitis B and C and cytomegalovirus (CMV) and **any relevant genetic tests**.
- The donated embryos will have previously been frozen. The procedure for thawing and transfer is as for frozen embryo transfer.

## **Genetic testing (p49-51)**

Embryos created through in vitro fertilisation (IVF) or intra-cytoplasmic sperm injection (ICSI) can be tested for certain inherited conditions or abnormalities before they are transferred to your womb. This helps to ensure that only unaffected embryos are chosen.

### **Pre-implantation genetic diagnosis (PGD)**

Pre-implantation genetic diagnosis (PGD) enables people with a heritable condition in their family to avoid passing it on to their children. It involves checking the genes of embryos created through IVF.

#### **Is PGD for me?**

Most people use this treatment not because they have fertility problems but because they want to avoid passing on a genetic disease. You may wish to consider having your embryos genetically tested if:

- you have had to terminate previous pregnancies because of genetic conditions
- you already have a child with a serious genetic condition, or
- you have a family history of a serious genetic condition.

#### **Which genetic conditions can be tested for during PGD?**

PGD can be used to test for over 250 genetic conditions. The full list of conditions that can currently be screened for is available on our website.

We must, by law, agree that a particular genetic condition meets certain criteria (including that it is serious enough) before clinics are permitted to test for that condition. Even if we have approved a condition for testing, clinics must make their own judgment about whether PGD is appropriate for a particular patient.

#### **Sex selection**

Some genetic diseases, such as Duchenne muscular dystrophy, affect boys but not girls (girls may still 'carry' the gene for the disease but they will not suffer from it). In this case the embryos are examined to find out the sex and only female embryos are transferred to the womb.

In the UK, it is illegal to use embryo testing for social sex selection. You can use sex selection only to avoid having a child with a serious medical condition, not for non-medical reasons.

Find out how PGD works on our website: [www.hfea.gov.uk/fertility](http://www.hfea.gov.uk/fertility)

#### **Pre-implantation genetic screening (PGS)**

PGS (also known as aneuploidy screening) involves checking the chromosomes of embryos conceived by in vitro fertilisation (IVF) or intra-cytoplasmic sperm injection (ICSI) for common

abnormalities. Chromosomal abnormalities are a major cause of the failure of embryos to implant, and of miscarriages. They can also cause conditions such as Down's syndrome. Chromosomes are the structures inside cells that contain genes and control how the cell works and what it does.

### **Is PGS for me?**

Many specialists no longer recommend PGS, believing that it does not increase the chance of having a baby. However, it could be offered if:

- you are over 35 and have a higher risk of having a baby with a chromosome problem (such as Down's syndrome)
- you have a family history of chromosome problems
- you have a history of recurrent miscarriages
- you have had several unsuccessful cycles of IVF where embryos have been transferred, or
- your partner's sperm is known to be at high risk of having chromosome problems.

Find out how PGS works on our website: [www.hfea.gov.uk/fertility](http://www.hfea.gov.uk/fertility)

### **New technologies**

Technology in this area is progressing quickly and clinicians are now offering a broad range of testing options including methods such as karyomapping (a method of embryo testing that uses genetic information from relatives to provide an analysis of single gene defects). New methods provide patients with the opportunity to access genetic information that may relate to their potential offspring and themselves, and it is important that you discuss your options in detail with your clinician. You may also want to discuss your particular situation with a clinical geneticist/counsellor who can outline what tests may be appropriate and what the information will mean.