

A guide for patients

Giving Consent to Fertility Treatment

Prior to starting fertility treatment you need to complete a number of consent forms. This is to allow us to be sure that you understand the treatment being planned and all its implications. We appreciate that it may sometimes seem like there is a lot of paperwork to go through, but the purpose of this is to help us deliver a good and safe service to you and to comply with the law governing fertility treatment.

This document describes the different consent forms and the issues to think about when completing them. In addition, our staff are always happy to answer any questions you may have about the consent forms and we will also discuss them at our face-to-face consultations with you. We also have a dedicated counselling service, which we encourage you to use, particularly if you are having treatment that involves using donated sperm, eggs or embryos.

Please remember that you have the right to withdraw or change your consent for this treatment at any time. You do not have to give us a reason for withdrawing or varying your consent. You must let us know in writing if you want to withdraw or change your consent and we will ask you to complete an updated set of forms. Please make an appointment to see one of our team to do so.

You must not consent to this treatment unless you have had all the information you need to understand the implications of this treatment. If you feel you need more information, please ask. We are here to help you understand your treatment choices and to remain in control of your own treatment.

1. Consent for treatment

This form is similar to ones you complete before any medical or surgical treatment. It asks you to consent to any procedures required, such as egg collection and embryo transfer. Prior to completing this, you should have an understanding of the procedure involved, whether it is to be carried out under sedation or anaesthetic and the potential risks.

2. Consent to disclosure of information (CD Forms)

Each partner undergoing treatment is required to complete a CD form.

Your absolute confidentiality is protected by law. We are not allowed to tell your general practitioner or anyone else about your treatment (other than in a medical emergency), unless you have specifically allowed us to do so. However, we very strongly recommend that you give consent for us to be able to inform your GP as well as other medical practitioners who may be required to look after you for your continuing care, for instance in pregnancy. This is for your safety and to improve the quality of care you receive. Your general practitioner and any other doctor receiving information about your fertility treatment is obliged to maintain confidentiality about it, just as they would with any other information concerning your medical care. We also recommend that you allow access to your information to administrative and audit staff that support our clinic. This is both to ensure the smooth working of the service and also to ensure that its processes and results can be monitored and improved for the benefit of patients.

We are legally obliged to collect certain information about you and your treatment and pass it to the Human Fertilisation and Embryology Authority (HFEA). This includes personal data such as your name and address, the type of treatment you had, the number of embryos transferred and whether your treatment led to pregnancy. Information is also collected about any children born as a result of treatment. If you give consent, the HFEA can release some of this identifying information to researchers, for the purposes of research projects that meet strict guidelines. You can choose not to allow this. However, we believe that this kind of research is potentially very valuable in assessing the efficacy and safety of fertility treatment, to develop new techniques and to study the effect of national policies. Being able to access identifying information may allow researchers to link records of fertility treatment with other healthcare records, which can be a powerful way of finding out whether there is a link between fertility treatment and important health outcomes.

You can choose to give consent to your identifying information being used for certain types of research only. If you choose to consent for the purposes of non-contact research only, you will never be contacted about research using your identifying information. This information will only be used to link the HFEA database with other databases.

If you consent to contact research, staff may contact you in the future if they think you may be suitable for a research study. Giving consent to be contacted does **not** mean that you are automatically consenting for any future research study.

3. Consent to the use and storage of sperm, eggs and/or any embryos produced from them

(MT form for men and WT form for women)

You can consent to the use of your gametes (eggs and sperm) and embryos for your own treatment, the treatment of others, research or training (or all of these). You can also give consent to the storage of these, which means freezing them for future use.

Before giving this consent you should be happy that you understand the nature, purpose and implications of the treatment being proposed. We will provide information about this to you at our face-to-face consultations and through written materials. We place a high priority on our patients being fully informed and staff will always be happy to provide clarifications and more information if you feel you require this. Please remember that you can specify extra conditions for storing or using your eggs, sperm and embryos.

When considering consent for storage of gametes and embryos, it is important to know that the statutory storage period is up to 10 years and can be specified on the consent form. In certain cases, storage can be extended beyond 10 years if you consent to this and a medical practitioner certifies that either you or the person to whom your gametes or embryos have been allocated has, or is likely to develop, premature infertility. In these cases, the opinion of the medical practitioner has to be renewed every 10 years, and the maximum period of time for which gametes and embryos can be stored is 55 years.

The law does not allow us to keep your gametes or embryos in storage beyond the date you have consented to. We will be in touch with you a few months before the end of the storage period to find out what you wish us to do. It is important that you keep in touch with us, in particular that you notify us of any change of address.

If the storage time limit is up, and you have not consented to extending this time limit, we are obliged by law to let any stored eggs, sperm or embryos perish, even if we have not been able to trace you first.

The consent forms MT and WT ask you whether you agree to be approached to participate in research studies involving your sperm, eggs or embryos. Agreeing to this does not commit you to participating in any particular research, rather it allows us to provide you more information which you can use to make a decision whether to participate or not. Research studies are all approved by Ethics Committees and are designed to help us understand infertility better and to improve the treatment of couples such as yourselves. However, we are aware that not everyone feels comfortable participating in research. Please be reassured that your treatment will not be affected whether you consent for research or not.

The consent form also asks you to think about what you would like to happen to your gametes and embryos if you were to die or become permanently incapacitated. We appreciate that considering some of these scenarios may be distressing, but it is important that you have given some thought to this. We find that this is actually quite a useful prompt for an important conversation between partners, as it asks you to think about uncommon but very distressing scenarios and helps you fully prepare for your treatment. Our staff and specialist counsellors are there to help you talk through any issues that may arise or to provide any clarification you may need.

4. Consent to parenthood

If you are having treatment with donor sperm, donor eggs or embryos created in vitro using donor sperm, you will be asked to complete the relevant consent forms before treatment takes place. This is to ensure that any child born has a legally recognised father or second parent. There is a difference in law between the legal status of a 'father' or 'second parent' and a person who has parental responsibility for the child. The law specifies who can be a parent in various circumstances. We will provide you information about who will be the legal parent(s) under the HFE Act 2008 and other relevant legislation in your individual circumstances.

Our patient information leaflet 'Legal Parenthood' lays out how the law applies in different scenarios and helps you understand who is allowed to be the legal parent and how this can be ensured.

The HFEA website www.hfea.gov.uk is an excellent source of information about this, and other issues discussed above.

Finally, in some cases, it may be useful to seek independent legal advice regarding legal parenthood and how the law would apply to your specific case.

5. Withdrawing, varying and restricting consent

You may **withdraw** your consent at any time up to the point that your eggs, sperm or embryos have been used in treatment, research or training, or been disposed of. To do so, please let us know straight away, in writing. We will ask you to complete the relevant HFEA consent forms designed for this purpose.

If one of the partners whose sperm or egg were used to create embryos withdraws their consent to the storage of those embryos, then we will take all reasonable steps to inform the intended recipient of the embryos. The embryos can be stored for up to 12 months after we receive written notification of the withdrawal of consent, provided the 12 months does not extend beyond the statutory storage period. However, if the intended recipient also consents to the destruction of the embryos then we will dispose of them straight away, as required by the HFEA.

You can also **vary** your consent if you change your mind at any time up to the point that your eggs, sperm or embryos have been used in treatment, research or training, or been disposed of. This may occur if, for instance, you were to change your mind about the use of your sperm, eggs or embryos in the event of your death. If this were to be the case, please let us know straight away in writing and we will go through the relevant consent forms with you.

You can also **restrict** your consent about the use or storage of your eggs, sperm or embryos. For instance, you can state that you wish their donation only to treat a known recipient. Restrictions can be stated on your main consent form or on a separate paper, signed, dated and attached to the form.