

Your consent to the disclosure of identifying information (Part 2- Research purposes)

HFEA
CD form



About this form

Who should fill in this form?

Fill in this form if:

- you or your partner are receiving treatment, or
- you are storing eggs, sperm or embryos for your or your partner's future treatment.

Do not fill in this form if you are donating your eggs, sperm or embryos for the treatment of others, or you are a patient using donor eggs, sperm or embryos in your treatment.

If you are being treated together with a partner, both you and your partner must fill in a copy of this form.

Why do I have to fill in this form?

Your clinic or the HFEA may want to use and share your information for medical or other research purposes.

Under the Human Fertilisation and Embryology Act 1990 (as amended), you need to give your consent if you want identifying information about you, in relation to your or your partner's treatment or your storage to be shared with other non-HFEA licensed people.

Neither your clinic nor the HFEA can disclose any identifying information for research purposes without this consent.

You can change or withdraw your consent at any time by asking your clinic for new forms, but it will not be possible to withdraw your information from research where your information has already been included in any analysis.

Before filling in this form

Before you fill in this form, your clinic should make sure that you receive all the relevant information you need to make fully informed decisions.

They should make sure you understand:

- the implications of giving and placing restrictions on your consent,
- the reasons why identifying information may be disclosed, and
- what identifying information may be disclosed and how it would be shared.

Why is there a declaration on every page of this form?

There is a declaration on every page where you sign to confirm that you have completed the section or page and fully agree with the consent and information given.

After filling in this form

After you have filled in this form, make sure that you have a photocopy of it.

1 About you

1.1	Your first name(s)	<i>Place clinic sticker here</i>
	<input type="text"/>	
1.2	Your surname	
	<input type="text"/>	
1.3	Your date of birth	1.4 Your NHS/CHI/passport number (please circle)
	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

For clinic use only

HFEA centre reference

Patient number *Assigned by clinic*

Other relevant forms



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2 About your partner

Only complete this section if you are receiving treatment with your partner.

2.1 **Your partner's first name(s)** *Place clinic sticker here*

2.2 **Your partner's surname**

2.3 **Your partner's date of birth** 2.4 **Your partner's NHS/CHI/passport number (please circle)**

3 About your identifying information - medical or other research purposes

Your information

During the course of your or your partner's treatment, information about yourself (including your health and other issues relevant to your treatment) is collected.

If you are receiving treatment, then information about any child born as a result of this will also be collected. Some of this information is sent to the HFEA and recorded on the HFEA Register.

This information can be of great use to researchers investigating, for example, how treatment can be improved.

Your consent

The law allows for information that identifies you (e.g. your name and date of birth) to be disclosed to researchers, although this may only happen if you give your consent.

Children born as a result of treatment

The HFEA will use any consent you give in this section to inform how, in future, information on the HFEA Register is processed about any child born as a result of your treatment, until they reach the age of 16.

For example, if you consent in this section to your identifying information held on the HFEA Register being disclosed for medical and non-medical research purposes, then the HFEA may also release that of any child born as a result of your treatment.

Equally, if you do not consent in this section to your identifying information being disclosed for research purposes, then the HFEA will not release that of any child born as a result of your treatment.

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Page declaration

Your signature

Date

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3 Medical or other research purposes *continued*

Notifying your centre

You should notify your centre if you do not wish the consent you give in this section about the use of your own data to inform how data about children is processed. Notification, if necessary, should be given after the child's birth.

It is your right to change the consent you give here at any time.

3.1. Do you consent to identifying information from the HFEA Register being disclosed to medical and non-medical researchers?

This information can be about your or your partner's treatment, including any storage of your eggs, sperm or embryos and donation of your eggs, sperm or embryos for research (if applicable).

This could involve a member of staff from the centre where you received treatment contacting you to inform you of a particular research study for which you may be a suitable participant.

- No ►► *Go straight to section 4*
- Yes ►► *Go straight to section 4*
- Yes, but only for some types of research ► *Go to section 3.2.*

3.2. Please specify the types of research that you wish to provide consent for.

Non-contact research

If you choose to give consent for non-contact research only, you will never be contacted about research. However, data which is routinely collected during the course of your treatment could be used by researchers to help answer questions about risks or outcomes of fertility treatments.

All research is carefully reviewed before being approved. We expect to approve around 5 studies a year. Patient identifying information (like date and place of birth) will only be used to link data from the HFEA Register to another health database. It will only be seen by the research team and is subject to strict security and confidentiality controls. You will never be identified in any subsequent publication.

Examples of studies which have been approved are two studies which investigate whether women's or children's long term health are affected by IVF. No patients or children will be contacted as part of either of these studies.

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3

Medical or other research purposes *continued*

I consent to information about my treatment being disclosed for the purpose of research that does not involve my direct participation. This might include studies that involve linking HFEA register information to other health databases, in order to carry out statistical analyses.

No

Yes

Contact research

If you consent to contact research, staff at your centre may in future contact you, if they think you might be suitable to take part in a research study. Giving consent for this particular contact to happen does not mean that you have already given consent to take part in any study. If your centre does contact you about a study you will be under no obligation to take part in research. You can grant or refuse consent to any study at any time without it affecting the care you receive and without giving a reason.

I consent to information about my treatment being disclosed for the purpose of research that would involve my direct participation.

I understand that this could involve a member of staff from the centre where I received treatment contacting me to inform me of a particular research study for which I may be a suitable participant. I also understand that any possible participation in a study is entirely optional and that the consent I give on this form is only to being contacted with an invitation to participate.

No

Yes

Page declaration

Your signature

X

Date

DDMMYY

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4 Declaration

Please sign and date the declaration

Your declaration

- I declare that I am the person named in section 1 of this form.
- I declare that:
 - before I completed this form, I was given information about the different options set out in section 3 of this form, and
 - the implications of giving my consent, and the consequences of withdrawing this consent, have been fully explained to me.
- I understand that I can make changes to or withdraw my consent at any time but that it will not be possible to withdraw my information from research where my information has already been included within analysis.
- I declare that, in relation to section 3, I have read and understood the information provided and have had the opportunity to ask questions and seek further clarification. I understand that the choices I have made about participating in research will not affect the care and treatment I receive. I have given / withheld my permission freely.
- I understand that information on this form may be processed and shared for the purposes of and in connection with the conduct of licensable activities under the Human Fertilisation and Embryology Act 1990 (as amended) in accordance with the provisions of that Act.

Your signature

Date

If signing to witness consent

If the person consenting is unable to sign for him or herself because of physical illness, injury or disability, someone else representing the person can sign the form at his or her direction as a record of his or her consent. There must also be a witness confirming that the person consenting is present when the representative signs the form.

Representative's signature

I declare that the person named in section 1 of this form is present at the time of signing this form and I am signing in accordance with his or her direction as a record of his or her consent.

Representative's name

Representative's signature

Relationship to the person consenting

Date

Witness's name

Witness's signature

Date