Your consent to the disclosure of identifying information

HFEA CD form

About this form

Who should fill in this form?

Fill in this form if:

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

There are a number of ways in which your clinic or the HFEA may want to use and share your information, either to:

- support your care and treatment eg, contacting your GP for your medical history,
- to help them provide better services, **or**
- for medical or other research.

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, your storage or donation to be shared with other non-HFEA licensed people.

For example, if your clinic needs to contact your GP to get information about your past medical history, you need to give your consent so that they can explain to your GP why they need this information. Your clinic cannot disclose any identifying information without this consent (other than in a medical emergency). You can change or withdraw your consent at any time by asking your clinic for new forms.

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 needs to 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)** *Place clinic sticker here*

1.2 **Your surname**

1.3 **Your date of birth** D D M M Y Y

1.4 **Your NHS/CHI/passport number** *(please circle)*

For clinic use only

HFEA centre reference

Patient number *Assigned by clinic*

Other relevant forms

HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY

2 About your partner

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

Place clinic sticker here

2.1 **Your partner's first name(s)**

2.2 **Your partner's surname**

2.3 **Your partner's date of birth**

D D M M Y Y

2.4 **Your partner's NHS/CHI/passport number** *(please circle)*

3 About your identifying information - clinic purposes

3.1 **Your clinic will hold identifying information about you in relation to your or your partner's treatment, your storage or donation. Do you consent to this identifying information being disclosed (to the extent permitted by the Act) to the following groups of people:**

- Your GP
- Other healthcare professionals outside your clinic in order to provide the best possible medical care to yourself or your partner named in section 2
- Auditors or administrative staff outside of the clinic to enable them to perform functions designated to them in connection with the clinic's licensable activities?

☐ Yes, all of the above

☐ No, only some of the above ▶ *Specify below who your information may be disclosed to:*

- ☐ My GP
- ☐ Other healthcare professionals outside your clinic in order to provide the best possible medical care to yourself or your partner named in section 2
- ☐ Auditors or administrative staff who give essential support to your clinic

☐ No, not to anyone (other than in a medical emergency)

Page declaration

Your signature ✗

Date D D M M Y Y

4 About your identifying information - medical or other research purposes

Your information

During the course of your or your partner's treatment, your storage or donation, information about yourself (including your health and other issues relevant to your donation or 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 made safer or more effective.

Your consent

The law allows for information that identifies you (for example your name and date of birth) to be used in research, although this may only happen if you give your consent.

If you are donating eggs, sperm or embryos for the treatment of others, any consent given in this section will not affect your legal rights and responsibilities as a donor.

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 used by researchers, then the HFEA may also release identifying information about any children you might have as a result of treatment.

Equally, if you do not consent in this section to your identifying information being used by researchers, then the HFEA will not release identifying information about any children you might have as a result of treatment.

Notifying your centre

You should notify your centre if you want the identifying information of any children you might have as a result of treatment to be handled differently to the consent you give in this section. Notification, if necessary, should be given after any child's birth.

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

Continues on the next page

Page declaration

Your signature

✗

Date

D D M M Y Y

For clinic use only Patient number

4 Medical or other research purposes *continued*

4.1. Do you consent to your identifying information that relates to your or your partner's treatment, your storage or donation being disclosed for the purpose of research?

This could involve contact or non-contact research (for information about these two types of research please read the descriptions in section 4.2).

☐ No, neither contact nor non-contact research ▶▶ *Go straight to section 5*

☐ Yes, contact and non-contact research ▶▶ *Go straight to section 5*

☐ Yes, but just contact or non-contact research, not both ▶ *Go to section 4.2 to choose which type of research*

4.2. 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.

Do you consent to your identifying information that relates to your or your partner's treatment, your storage or donation being disclosed for the purpose of research that does not involve your direct participation ('non-contact')?

☐ No

☐ Yes

Continues on the next page

Page declaration

Your signature

✗

Date

D D M M Y Y

4 Medical or other research purposes *continued*

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.

Do you consent to your identifying information that relates to your or your partner's treatment, your storage or donation being disclosed for the purpose of research that would involve your direct participation ('contact')?

☐ No

☐ Yes

Page declaration

Your signature

✗

Date

D D M M Y Y

5 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 sections 3 and 4 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 4, 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 D D M M Y Y

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 D D M M Y Y

Witness's name

Witness's signature ✗

Date D D M M Y Y