

Your consent to disclosing identifying information (part two- research purposes)



About this form

This form is produced by the Human Fertilisation and Embryology Authority (HFEA), the UK's independent regulator of fertility treatment and human embryo research. For more information about us, visit www.hfea.gov.uk.

Who should fill in this form?

Fill in this form if:

- you or your partner are receiving fertility 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 a donor, any consent given in this form will not affect your legal rights and responsibilities. Your information will only be disclosed to the parties you agree to on this form.

What do I need to know 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
- what identifying information may be disclosed and how it would be shared, and
- how you can make changes to, or withdraw, your consent.

If you are unsure of anything in relation to this, please ask your clinic.

If you are being treated together with a partner, both you and your partner must fill in a copy of this form. Before completing it, please discuss with your partner what information you agree to be disclosed as there may be implications if you do not consent to the same level of disclosure.

If you are unable to complete this form because of physical illness, injury or disability, you may direct someone else to complete and sign it for you.

Why do I have to fill in this form?

Your clinic holds identifying information about you such as your name, address and date of birth as well as information about your treatment or care. By law, your clinic must submit some of this information to the HFEA to be stored on a secure fertility treatment database called the HFEA Register.

Sometimes your clinic, or the HFEA, may want to share some of this identifying information for medical or other research purposes, for example, to investigate how fertility treatment can be made safer or more effective.

Your clinic and the HFEA are not allowed to share identifying information for research purposes unless you provide your written consent for this. This form allows you to provide your consent to sharing your information for this reason.

When filling in this form, make sure you sign the declaration on every page to confirm that you have read the page and fully agree with the consent and information given. When you have completed this form you may request a copy of it from your clinic.

For clinic use only (optional)

HFEA centre reference

Patient number assigned by clinic

Other relevant forms

1 About you

1.1 **Your first name(s)** *Place clinic sticker here*

1.2 **Your surname**

1.3 **Your date of birth**

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

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/HCN/passport number (please circle)**

3 Disclosing your identifying information to support advances in medical research

Large health databases held by organisations such as the HFEA can be a valuable resource for researchers to support advances in medical research. Using a limited amount of your identifying information (for example your name and date of birth), they are able to link databases together and perform research which would be otherwise impossible to do. All research is carefully reviewed by your clinic or the HFEA before being approved.

Recent examples of research projects include:

- Health outcomes for IVF babies: exploring whether the general health of children born as a result of fertility treatment differs from that of naturally conceived children.
- Ethnicity and treatment success: exploring whether there is a link between patient ethnicity and treatment success.

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Page declaration

Your signature

Date

For clinic use only (optional)

Patient number

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Disclosing your identifying information to support advances in medical research *continued*

- Cancer risk in children born after IVF/ICSI: this project showed no increase in the overall risk of cancer among British children born after assisted conception during the 17-year study period.

For more examples of recently approved projects go to the HFEA's website:

www.hfea.gov.uk/about-us/our-data.

Children born as a result of treatment

By consenting to your identifying information being disclosed for research purposes, you are also consenting to identifying information about any child(ren) born as a result of your treatment being disclosed. Legally, you are responsible for deciding whether identifying information about your child(ren) is disclosed until they reach the age of 16 or an age when they are deemed legally competent to give consent themselves. If you want identifying information about any children born as a result of treatment to be handled differently, you should contact your clinic to notify them after your child(ren) is/are born.

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

Types of research

There are two types of valuable research you can consent to on this form – non-contact and contact.

Non-contact research

If you choose to give consent for non-contact research only, you will never be contacted about research. Data which is routinely collected during the course of your treatment could be used by researchers. It will only be seen by the research team, or those who link the datasets, and is subject to strict security and confidentiality controls. You will never be identified in any publications about the research.

3.1 Do you consent to non-contact research?

☐ Yes ☐ No

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 this consent does not mean that you have already agreed to take part in any study – it means you agree to be contacted in the future to discuss the possibility of this. 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.

3.2 Do you consent to contact research?

☐ Yes ☐ No

Page declaration

Your signature

X

Date

Declaration

Please sign and date the declaration

Your declaration

- I declare that I am the person named in section one of this form.
- I declare that:
 - before I completed this form, I was given information about the different options set out in section three 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 three, 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 or 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

X

Date

DD MM YY

If signing to witness consent

If you have completed this form at the direction of the person consenting (because they are unable to sign for themselves due to physical illness, injury or disability), you must sign and date the declaration below. There must also be a witness confirming that the person consenting is present when you sign the form.

Representative's signature

I declare that the person named in section one of this form is present at the time of signing this form and I am signing in accordance with their direction.

Representative's name

Representative's signature

X

Relationship to the person consenting

Date

DD MM YY

Witness's name

Witness's signature

Date

DD MM YY