Important information for people who have donated eggs, sperm or an embryo in the past. What you need to know



If your donation was after 01 April 2005 (in a licensed UK fertility clinic*) your donation was not anonymous.

From 2023 onwards: the first cohort of donor conceived people (conceived via identity release donation) are turning 18.

It is possible that someone conceived from your donation may identify you either by making an Opening the Register (OTR) request to the HFEA or via online commercial DNA testing (often in combination with other online information about you).

- Contact could happen via the HFEA.
- Contact could happen via you, the donor, or a genetic relative joining a consumer DNA testing network (23andMe, Ancestry etc).



What can a donor conceived person or their family find out about me?

Donor conceived people can request information about you, (including your name, last known address and date of birth), once they reach the age of 18, from the HFEA Opening the Register service.

Donor conceived people can request nonidentifying information about you (including medical information) from 16. Their parents can access this information at any time.



Donor conceived people may be able to access identifying information earlier if they are in touch with older siblings conceived from your donation(s) (information they would not be able to get from the HFEA until they are 18).

Donor conceived people may not wish to contact you or they may not know they are donor conceived and so may not make contact for that reason.



2

Online commercial DNA testing websites often enable their customers to 'match' with genetic relatives registered on their databases.

If you or your genetic relative(s) register with an online commercial DNA testing site, you may match with any people conceived from your donation who have also registered with that database. Social media can be used to discover further information about genetic relatives, including contact information.

It is possible for parents of donor conceived children, or donor conceived children themselves, to trace you via online commercial DNA testing before the child is eighteen.



What happens if someone asks the HFEA for my information?

You will be contacted by the HFEA (via the address details they hold for you) to let you know if a donor conceived person requests your contact details.

If your address details are incorrect, you will not be notified and a donor conceived person may attempt to contact you via a previous address.

Find out more about updating your address details (see HFEA website).



What information is available to you (the donor)?

1

You can find out if your donation was successful, how many children were born, the year of birth and sex of the donor conceived people resulting from your donation.

Find out more about updating your address details. (see HFEA website).

2

If you or your genetic relative(s) register with an online commercial DNA testing site, you may match with any donor conceived children who have also registered with that database.



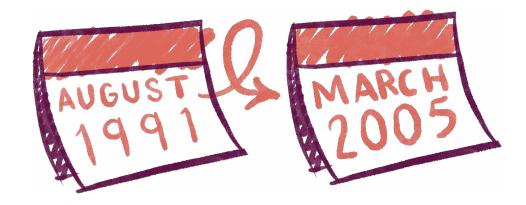
For further information please visit https://www.hfea.gov.uk/donation/

* If you are a sperm donor who has donated outside of a licensed clinic, you may or may not be identifiable via any information you have shared with your recipients or any intermediary. You may also be identifiable via commercial DNA testing websites (in combination with social media platforms) (see information for 1991-2004 or pre-1991 donors).

If you donated between August 1991 and March 2005 (in a licensed UK clinic) your donation was anonymous

Your anonymity can be removed by...

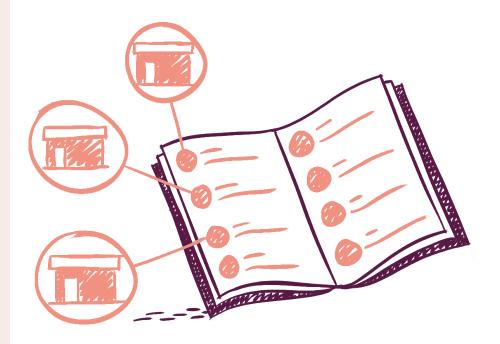
- You, the donor, removing your anonymity via the HFEA.
- You, the donor, or a genetic relative joining an online commercial DNA testing site (23andMe, Ancestry etc).



You, the donor, removing your anonymity via the HFEA...

The HFEA manages a register of all UK donor conceptions in licensed clinics since August 1991.

You can choose to remove your anonymity on the HFEA register and thus make yourself identifiable (via an Opening the Register request) to anyone aged 18 and over conceived from your donation. You will not be able to identify the donor conceived person unless they contact you.



It is your decision, whether and when to remove your anonymity but if you remove your anonymity you can't later choose to become anonymous again.

You can access support from a specialist professional before deciding to remove your anonymity.

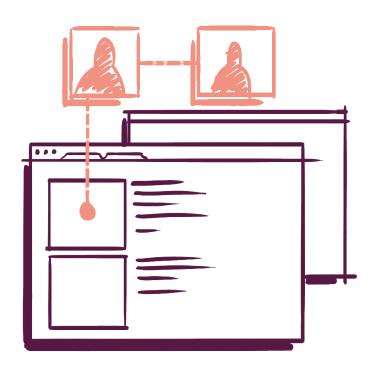


You, the donor, or a genetic relative joining an online commercial DNA testing site (23andMe, Ancestry etc).

Online commercial DNA testing websites often enable their customers to 'match' with genetic relatives registered on their databases.

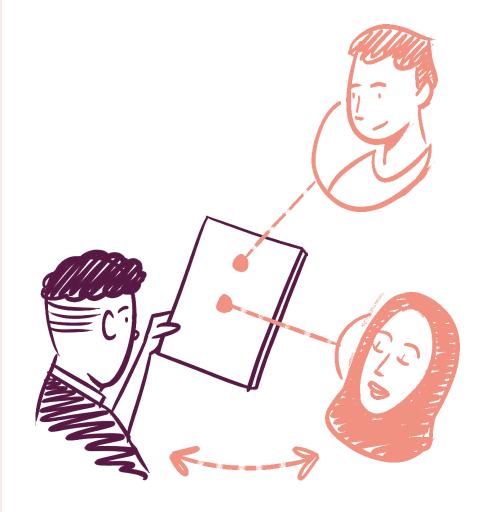
If you or your genetic relative(s) register with an online commercial DNA testing site, you may match with any people conceived from your donation who have also registered with that site. Typical costs for commercial DNA testing are between £80-100 approx.

The existence of online DNA testing and matching services means that anonymity removal is not necessarily up to you.



Donor conceived people might not know about their conception. Even if you register with the HFEA as non-anonymous they might not be looking for you.

Donor conceived people may find you, their donor, through an indirect match with one of your relatives registered on an online commercial DNA testing site (even if you haven't registered yourself).



For further information on becoming an identifiable donor:

https://www.hfea.gov.uk/donation/donors/remove-your-donor-anonymity/

If your donation was before August 1991 your donation was anonymous

Your anonymity can be removed by...

Registering directly with the Donor Conceived Register (DCR) held by The Liverpool Women's Hospital NHS foundation Trust

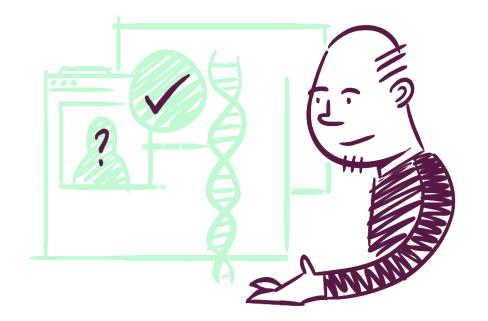
You or a genetic relative joining an online commercial DNA testing site (23andMe, Ancestry etc).



Registering directly with the DCR

The DCR is a database of donors and donor conceived people who have voluntarily joined the database to find possible genetic matches

You will need to voluntarily provide a DNA test in order to find possible matches on the database



You have access to support from a specialist professional during the process (before deciding to remove your anonymity, if there is no match and mediation if there is a match)

The database has approximately 500 registrants

The database is free to join. There is a cost for the DNA test (current fee in July 2023 is £95).

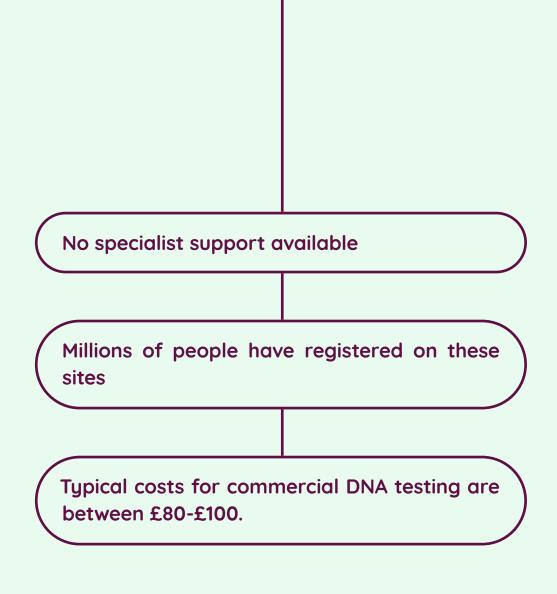


You or a genetic relative joining an online commercial DNA testing site' - (23andMe, Ancestry etc).

Donor conceived people may identify you through an indirect match with one of your relatives registered on these sites.

Donor conceived people on these sites might not know that they were donor conceived.







For further information please contact:

Donorconceivedregister@lwh.nhsuk 01517024339

https://www.liverpoolwomens.nhs.uk/our-services/donor-conceived-register-dcr/

Support group:

https://www.donorconceivedregister.co.uk/

For those who have donated at any time....

You may have further questions about how you could be identified and/or how you can prepare for the possibility of contact.

Other leaflets in this series explain the things you may wish to consider when preparing for contact e.g. the implications for you and your family and the reasons why donor conceived people may wish to trace their donor.

Some organisations who can provide further information and support to donors include:

- BICA: The British Infertility Counselling Association: https://www.bica.net/
- The Donor Conceived Register: https://www.donorconceivedregister.co.uk/
- The Donor Conception Network: https://dcnetwork.org/

The development of this resource was funded by an UKRI ESRC Impact Accelerator Award (University of Manchester).

The resource was developed in 2022-2023 by a team of professionals across a number of organisations: Joanne Adams, Nina Barnsley, Laura Bridgens, Meenakshi Choudhary, Helen Clarke, Roy Davis, Debbie Evans, Lucy Frith, Leah Gilman, Debbie Howe, Jackson Kirkman-Brown, Patricia Lambert, Charles Lister, Kevin McEleny, Petra Nordqvist, Angela Pericleous-Smith, Caroline Spencer, Caroline Redhead and Wayne Vessey.

Illustrations and design by James Huyton of Burograph Ltd.















