

# Handling donor information

**A best practice guide for clinics**

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# Contents

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<b>About this guide</b>	<b>3</b>
<b>Collecting and sharing donor information</b>	<b>4</b>
What information can be disclosed?	4
Why is good donor information important?	4
What donor information should the clinic collect?	5
What donor information should be shared with patients?	5
<b>Handling identifying information</b>	<b>6</b>
What constitutes identifying information?	6
What should I do if identifying information is included in the donor's pen portrait and goodwill message?	7
How do I redact donor information?	7
<b>Example of a redacted message</b>	<b>10</b>
<b>Case study</b>	<b>11</b>
Collecting and using donor information at Complete Fertility Centre (CFC), Southampton	11

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# About this guide

This guide has been created for UK fertility clinics providing donor conception treatment to patients.

Individuals born through donor conception are likely to have information needs extending many years beyond treatment. This includes the need to know how they can access important information provided by their donor/s, such as personal descriptions (pen portraits) or goodwill messages (messages written for any children born as a result of their donation).

Clinics play a vital role in supporting these information needs and, if good practice is followed, can make significant contributions to helping families involved in donor conception.

In addition, some donors may find it challenging to draft their pen portraits or goodwill messages and clinics should also support them through this process.

We have produced this best practice guide to provide clinics with:

- tips and examples of how to collect donor information, including personal descriptions (pen portraits) and goodwill messages
- our expectations about sharing this information with people seeking treatment
- information on how to redact donor information, where this proves necessary.

# Collecting and sharing donor information

## What information can be disclosed?

Donor-conceived people are entitled to request information from us about their donor, including medical and personal information.

Personal information could include the donor's personal description (pen portrait) or any message for children born using their donation (goodwill message). Donor-conceived 16-year olds can be given information that is non-identifying, whilst 18-year olds can also be given any identifying information too (provided they were conceived after donor anonymity was removed in April 2005 or their donor has re-registered as identifiable).

People embarking on donor conception treatment can also obtain non-identifying information from their clinic about the donor that they are planning to use in treatment.

As our [Code of Practice](#) says, clinics should share all non-identifying information about donors with people seeking treatment, whether they are selecting their donor or have already had successful treatment. If this information is requested, parents of donor-conceived people should be referred to us so that we can provide them with non-identifying information.

If the pen portrait and goodwill message contain information that could identify the donor, the identifying information will need to be removed by the clinic before releasing it to patients considering treatment.

Donor-conceived people who have reached the age of 18 will be given all available information that is held by us, including the full versions (if different) of the pen portrait and goodwill message (provided their donor is identifiable) as submitted to us by the clinic.

## Why is good donor information important?

There are many reasons why this information is valuable – both to patients and to any donor-conceived children they may have. For example:

- It is important for patients to have as much information as possible to help them choose the right donor and to avoid any unpleasant surprises about the donor after conception.
- Sharing information encourages parents to be open with their child(ren) about their origins and helps them when preparing to talk about it with them. Research suggests that it is better to tell a child about their donor-conceived status in early childhood.

“It is important to know something more about the man who potentially your child will meet and who could potentially have a place somewhere in the family. You want to know that it is safe.

“Our child will grow up to know why, as a couple, we needed this man's help and it would be good to know why he decided to help us. Having this sort of information will, I am certain, make creating our family in this way a more comfortable journey.”

**Amanda, a patient from Inverness who is seeking donor treatment.**

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## What donor information should the clinic collect?

The law relating to the anonymity of donors changed on the 1 April 2005, meaning that those who were conceived after this date can contact us for identifying information about their donor once they turn 18 years old.

Parents of donor conceived children can apply for non-identifying information about the donor and children are able to apply for this information when they reach 16 years old.

For clinics, this means that when registering an egg, sperm or embryo donor, you must collect a range of information, such as their age and medical history. You should also ask donors to write a personal description (pen portrait) of themselves and a goodwill message to any child born from their donation.

You should encourage donors to handwrite their pen portrait and goodwill message, if they are comfortable with this. They should also be written in a way that does not identify the donor (see 'steps to redacting information' on p. 7 for tips on what to avoid).

Some donors may find it difficult to write about themselves and may need your help. [Our website](#) has useful tips for donors on how to write these messages.

Donors should be encouraged to keep their contact details up to date with clinics and us, as if we receive a request from a donor-conceived adult, we will use their last known address to try to contact them before releasing their identifying details.

This gives donors the chance to access support and prepare to be contacted. It also means that donor-conceived people will have a better chance of contacting their donor if their details are up to date. We recommend that clinics give donors our email address so that they can get in touch at [Opening.TheRegister@hfea.gov.uk](mailto:Opening.TheRegister@hfea.gov.uk)

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## What donor information should be shared with patients?

All non-identifying donor information, including the goodwill message and pen portrait, should be offered to people seeking treatment as early as possible at the donor selection stage. Patients should be told that this information is available and that they can choose whether or not to see it before selecting a donor.

It is not acceptable to tell patients that this information will only be available from the HFEA after successful treatment, nor that it is only given to patients upon request, since they may not be aware that this information is available.

Patients may or may not be interested in seeing this information at this stage or may prefer to see it later (for example, once a pregnancy has been achieved – or once the donor-conceived child is born). Some patients may only be interested in seeing some, but not all of the information. Others may wish to see all available information right from the start. The decision about whether or not to access this information is a highly personal choice and one that all patients should be in a position to make.

# Handling identifying information

## What constitutes identifying information?

Identifying information is:

- information that would directly identify a specific individual (eg, name and address)
- any information that could result in that individual being identified indirectly as a result of linking it to other information provided and/or information that is already available in the public domain (eg, via the internet).
- Any photograph of the donor, either now or as a baby.

When looking at the risk of identification, it is important to think about whether it is reasonably likely that other recorded information, established facts and knowledge is available elsewhere that could be put together, to allow the donor to be identified.

There is no need to worry about identification risks that are very unlikely or merely hypothetical but it is important to bear in mind that the growth of online direct-to-consumer genetic testing databases and social networking, together with the development of increasingly powerful and sophisticated search engines, mean that sometimes the combination of just one or two pieces of specific and factual information linking a donor to a school, college, job or workplace at a specific point in time could result in their identification.

There is a growing market in DNA testing websites offering consumers the possibility of discovering more personal genetic information, often with a focus on health or ancestry information. Many of these services also offer opt-in 'matching' services to identify genetic links between people on the same company's database. Such services have the potential to reveal unexpected information about genetic relatedness, or the lack of a genetic connection between people.

Because very large numbers of people are now using these services and because many people also have a social media or online presence, it's possible that when DNA matches are made, and close genetic relatives have been identified via such sites, that directly or indirectly combining this information with other information may lead to identification of donors or donor-conceived people.

This could potentially include instances even when the donor or donor-conceived person is not themselves on such a database, if they have close genetic relatives on such a database.

It may be useful to refer patients or donors to the following support websites:

- [Donor Sibling Link](#)
- [Donor Conceived Register](#)
- [Donor Conception Network](#)
- [National Gamete Donation Trust/SEED](#)
- [British Association for Counselling and Psychotherapy](#)

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## What should I do if identifying information is included in the donor's pen portrait and goodwill message?

Although you should help the donor to give information which does not identify them, sometimes the donor can include information that could reveal their identity. This might be because the donor didn't want help with writing the pen portrait or goodwill message, so they inadvertently included identifying information, or because they did not wish to remove such information.

In these cases, the identifying elements need to be redacted – at least until a donor-conceived person has reached 18 and is seeking information about an identifiable donor.

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## How do I redact donor information?

When redacting pen portraits and goodwill messages, you should ensure that information that could result in the identification of the donor is removed, whilst balancing this with the need to share as much non-identifying information as possible.

We recognise that the real challenge for effective redaction of donor information arises from the fact that it often includes biographical information made up of a unique or distinctive set of variables. While none of these variables alone could identify a person, there is a risk that combinations of variables will give rise to a distinctive or unique profile which could allow the donor to be identified. The more distinctive or unusual the donor profile is, the greater the risk of donor identification.

However, it is often the case that the more unique a piece of information is, the more valuable it will be to an individual to receive. It is therefore important to think about what information will give a better insight into the kind of person the donor is, without leading to the donor's identification.

## Steps to redacting donor information

Following the steps below will help you to adopt a systematic approach, reducing the risk of identification whilst still enabling you to share valuable information with patients and donor-conceived children.

1. Redact direct identifiers such as names, addresses and dates of birth. Any photos of the donor from childhood or as an adult that are included in the goodwill message must be redacted.
2. Redact specific details that would greatly reduce the population from which a donor could be identified such as town of birth or school/university name.
3. Redact specific details that would allow indirect identification because of their unique or unusual nature (knowing that people will also have access to information about height, weight, eye colour, hair colour, skin colour, ethnicity and year and country of birth which could enable them to link this information together). A specific detail may be a specific award, achievement or unique hobby. For example, competing in the Commonwealth Games in 2006 – this piece of information on its own may not be identifying. However, if you know that the donor's main interest and skill is archery, she is 5' 8" and was born in 1980 in England then it wouldn't be difficult to find out which females competed on the archery team at the 2006 games who were 26 years of age.
4. Place of work and job title are also something that could be potentially identifiable, particularly when looking at them in relation to other information. Often in these situations there are a number of ways information could be redacted.

For example: "I work as a senior HR manager at Tesco supermarket" could be redacted in one of two ways as follows:

- "I work as a senior HR manager at <redacted> supermarket" (recommended) or
- "I work as a <redacted> at Tesco supermarket".

Consider what information might be more meaningful for a potential recipient to know, in this case possibly that their donor worked as an HR manager at a supermarket, rather than to simply know they worked at Tesco. This gives a more meaningful description of the donor's occupation.

However, often it will be necessary to redact a company or organisation's name if they aren't a massive employer. Similarly, some very common job titles like 'teacher' may not need redacting but others that are unusual, uncommon or unique, like the Chief Executive of a particular organisation, will need to be redacted.

In other cases, where both items of information are equally significant, redaction decisions may be more difficult.

For example: "I received a first-class degree in history from Oxford University" could be redacted in the following ways:

- "I received a first-class degree in history from <redacted> University" **or**
- "I received a <redacted> degree in <redacted> from Oxford University".

Deciding which of these redacted statements to disclose calls for a judgment to be made about which piece of information would give the applicant a better insight into the donor ie, to know that the donor was a history graduate or to know that the donor had studied at Oxford.

In making this judgment it would be relevant to consider whether, once obviously identifying information has been redacted, it is going to be necessary, in any event, to redact the reference to Oxford because this reference, together with information contained elsewhere in the redacted donor profile, could result in the indirect identification of the donor.

## Recognising what could be identifying information

Doing a Google search of key terms/words from the donor information can help inform you what data is potentially identifiable. Adding the word LinkedIn to the Google search can also bring up a donor's profile where they may have listed similar information and/or achievements. Doing these searches as country specific and non-country specific often bring up different information to help your decision.

Sometimes, however, there will be no obvious way of deciding which piece of information should be redacted and which piece of information should be disclosed as the significance of specific information for different individuals is often highly variable. It may therefore be useful to discuss your decision with colleagues to see whether they share your view.

In some cases, it may be that there is simply no right or wrong answer. If you are concerned, please contact the Opening the Register Team at [Opening.TheRegister@HFEA.GOV.UK](mailto:Opening.TheRegister@HFEA.GOV.UK), or the Donor Information Manager for advice.

In all cases, to avoid differences in redaction style (leading you to redact one thing and the HFEA redacting something different), please **always submit the redacted version of the donor information to us and the original version together**.


If you decide to email a goodwill message to a patient, we encourage you to use appropriate software such as Adobe, rather than redacting information on Word for example. This mitigates the risk of the donor conceived person finding out identifying information about their donor. When providing donor goodwill messages, always provide a physical copy along with any electronic copy that is sent.

## Overseas donors

Goodwill messages from overseas donors are often lengthy and hold a variety of identifying information, including information about their extended family, their year of birth, medical information etc. We

recommend that clinics contact the donor information team at [Opening.TheRegister@HFEA.GOV.UK](mailto:Opening.TheRegister@HFEA.GOV.UK) before sharing the donor profile so that we can assist you in carefully redacting it.

# Example of a redacted message

 This page is to be completed by the donor  
**PLEASE WRITE CLEARLY IN BLACK INK USING BLOCK CAPITALS**  
Donor Information (Page 4) Centre  Form D

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**PLEASE COMPLETE ELECTRONICALLY OR HANDWRITE**

27. The space below is provided for you to give a description of yourself as a person. This information may be passed to anyone born as a result of your donation, and to parents intending to talk to children about their origins. The type of information that might be helpful could include your education, achievements, values and life experiences. Try to imagine yourself as a donor conceived person, and think about what you might wish to know.

I WAS BORN IN [REDACTED] AUSTRALIA IN 1972. I HAVE [REDACTED] YOUNGER BROTHERS AND ONE [REDACTED] SISTER. MY BIOLOGICAL PARENTS SEPARATED WHEN I WAS [REDACTED] AND RE-MARRIED.

I COMPLETED SEWNDARY SCHOOL IN 1990 AND WENT ONTO STUDY A BACHELOR OF ARTS (SOCIAL SCIENCES), IN [REDACTED]. AFTER THIS I ENROLLED IN A BACHELOR OF SCIENCE ([REDACTED]) AND BEGAN WORK WITH A LOCAL PRIVATE PHYSIOTHERAPIST IN [REDACTED]. AFTER A YEAR OF WORKING IN THIS FIELD I REALISED I WANTED TO BE A PHYSIOTHERAPIST. I APPLIED AUSTRALIA-WIDE AND WAS ACCEPTED INTO THE UNIVERSITY OF [REDACTED].

I COMPLETED THIS DEGREE IN [REDACTED] AND PRACTISED IN [REDACTED], [REDACTED] UNTIL DEPARTING FOR THE U.K. IN [REDACTED]. NOT LONG AFTER ARRIVING IN THE U.K I MET MY SAME-SEX PARTNER. WE ENTERED INTO A CIVIL PARTNERSHIP IN [REDACTED] AND WENT THROUGH IVF TREATMENT USING THE SPERM OF A FRIEND; TO CONCEIVE OUR OWN CHILD. WE DECIDED TO PARTICIPATE IN THE EGG-SHARE PROGRAM TO GIVE ANOTHER COUPLE THE OPPORTUNITY OF CREATING YOU.

AT TIME OF WRITING THE OUTCOME OF OUR IVF TREATMENT IS UNKNOWN. DURING [REDACTED] WE PLAN TO RE-LOCATE TO [REDACTED], AUSTRALIA TO START A FAMILY LIFE.

Reference to age

Year

Name

Year

City

Timeframe

Town of birth

Number

Age

Name of degree (unusual)

Town

Town

Year

Year

Year

City

Please continue on additional pages as required (writing the same form number as above on each page)

# Case study

## Collecting and using donor information at Complete Fertility Centre (CFC), Southampton

CFC encourages donors to share as much non-identifying information about themselves as possible.

### Collecting information

Implications counselling is compulsory for all donors and recipients. From the very start of the screening process, CFC lets donors know what information will be shared with recipients and donor-conceived children.

During their counselling session, staff give all donors a blank copy of the HFEA donor information form as well as [information](#) and advice on what kind of information to provide: see the [HFEA website](#) for more information.

CFC asks donors to handwrite their goodwill message and pen portrait wherever possible and they have several weeks to complete their forms. Follow-up counselling sessions or support for completing the form is available at any time.

### Redacting information

Once the donor has completed their form, the Donor Coordinator reads it and redacts any identifying information.

Sometimes identifying information is obvious, eg, the donor may have signed off their goodwill message with their name. Other times identifying information can be more subtle, eg, an unusual occupation alongside the mention of a small town.

In these cases, staff do a quick 'Google test' to see if the donor can be easily traced. Any identifying information is redacted by covering with a white sticker and photocopying. The photocopy is available to recipients.

### Providing information to recipients

Recipients are provided with pages two to four (and any additional pages) of the redacted donor information form.

This includes information regarding ethnicity, medical history, family limit, existing children and physical characteristics. All this information is available for recipients to read at the time of choosing their donor. Once a recipient has made their decision, they are given a copy to keep.

### Why it works

- Donors are fully informed as to how their information is used and shared from the very start of the process.
- Donors receive lots of support and advice on providing the kind of information that is valued by donor-conceived children and adults.
- Recipients receive the greatest possible amount of information about their donor at the time of choosing.
- Recipients are able to provide donor information to their children from the earliest possible age.

