7. Connections you might (not) make

Mandatory and voluntary registers

Previous studies that have looked at how donor-conceived persons search for information and make contact with donors and donor siblings have mostly based their results on online surveys and had only few qualitative dimensions. A large part of them recruited their participants from the DSR, an American-based voluntary register with a worldwide membership (see section 1.2). Unlike the countries where I conducted my research, the US has no official policies on donor anonymity and the release of information (Johnson 2013: 64). Any attempts to establish connections in a context where formal registers are in place have been studied less thoroughly.[1] This is arguably also related to the fact that access to information is usually only granted when people reach a certain age. Even though some countries have long had specific regulations in place that grant the donor-conceived access to information, the first generation conceived after these laws came into effect was, in previous studies, simply not old enough to actually request information. In this chapter, I attempt to close some research gaps by mostly focusing on the situation in the UK where the way in which donor information is managed is marked by a high degree of formal control. The UK has various donor information registers that are established, managed and/or funded by government authorities. In contrast, a central register established by a government body was only put in place in Germany in 2018. As it only registers treatments that took place after its establishment, a formalised register was hence not available to any of my German research contacts. Since my interviews with those who were conceived in the UK offer an unprecedented opportunity to explore official infrastructures, their experiences will be examined in great detail. However, I will repeatedly make references to the interviews I conducted in Germany in order to bring out certain aspects more clearly. I have decided against dedicating a separate chapter to the experiences of my German interviewees who (often unsuccessfully) tried to obtain information through doctors and clinics. Since this experience often contributed to people ordering a

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[1] An exception is the work that has been conducted on UKDL (see for example Crawshaw and Marshall 2008; van den Akker et al. 2015; Crawshaw et al. 2016).

DNA test as soon as they knew genetic databases existed, I address this particularity of their experience within my analysis of DNA testing (chapter 8).

Even with central registers, there may still be several 'gaps' which are not covered by a mandatory infrastructure. They do not contain information on previous treatments and persons conceived prior to the establishment of a register; they are usually subject to a minimum age for release of information; and the nature of the information that is available may not correspond to what parents and donor-conceived persons would like to receive. Voluntary registers are commonly seen as a solution to this problem (Millbank 2014a: 225). In the UK, there are various voluntary registers that try to close these gaps and also enable contact to be established between donor-conceived half-siblings: firstly, donors who donated after the establishment of the HFEA, but before 2005, can remove their anonymity. Secondly, donor-conceived persons conceived after 1991 can contact their donor siblings through a voluntary sibling register administered by the HFEA. Lastly, those who donated before 1991, or were conceived with donated gametes, can network through a voluntary register (see also section 1.1).

These officially endorsed ways of obtaining information about a donor and/or donor sibling will be discussed in the following six sections. In this chapter, I am thus investigating specific ways in which answers to the question "Where do I come from?" can be found. In doing so, I examine not only how formal and voluntary registers work technically, and how anonymity is made or imagined here, but also what kind of hopes, expectations and uncertainties they give rise to. I suggest that many of the hopes and uncertainties discussed in this chapter are related to the fact that especially voluntary registers usually require the donor-conceived to do more than just apply for information. Instead, they have to 'enter' the infrastructure themselves, without knowing for sure that they will establish connections. They have to "put themselves out there" in order to find someone who might be 'out there'.

Overall, in this chapter I will explore how anonymity is negotiated at the intersection of regulations, infrastructures and practices, and how expectations, hopes and uncertainties are managed, maintained and shifted by various actors. First, I will focus on the central HFEA register and the non-identifying information that some of my British interlocutors could request. I am particularly interested in how the HFEA tries to manage both information and expectations. I then analyse how information was marked as either non-identifying or identifying. In the next section, I examine how people who had received non-identifying information assessed its significance. On a more general level, I will also look at what the donor-conceived that I interviewed in both countries wanted to know about their donor, before going on to discuss the hopes and uncertainties created in the UK by the possibility of anonymity removal. In the following section, I will not only examine the voluntary donor sibling register in the UK but also discuss donor sibling relations again on a more general level. In the last part of this chapter, I will discuss the register that is aimed at those who were conceived or have donated in the UK before 1991.

It should be noted that due to my research design, I cannot cover all the different groups of donor-conceived persons that exist in the UK, all of which have different possibilities in terms of what information they can access and at what time. Since I only interviewed people who were already 18, I did not talk to anyone who was conceived after 2005 and knew for sure that they would be able to obtain identifying information about their donor. The first generation conceived after 2005 has not yet reached the minimum age at which this information can be requested. This will be the case for the first time in 2023. Although I will briefly raise the question of whether the situation of those conceived after the law was changed is significantly different in terms of uncertainties, this clearly is a topic that requires further research.

7.1 Opening the register: Managing information and expectations

In the UK, information about donors and fertility treatments involving donated gametes is stored in a central electronic database managed by the HFEA. Information about donors is submitted electronically by sperm banks and/or clinics who are obliged to register the donors that they recruit or whose gametes they import. Some documents, such as voluntary "pen portraits" and "goodwill messages", were still submitted by post when I interviewed an HFEA official in September 2016. A programme aimed at making the data submissions fully electronic had already been launched (HFEA 2017b). Parents, children and donors who want to obtain information can submit applications to the HFEA to "open the register" (usually shortened to OTR). In this section I will first recapitulate who can obtain what information and summarise how the number of applications has developed over recent years. Following from that, I will describe how the process of "opening the register" was carried out and how information and expectations were managed by the HFEA.

Parents can at any time apply for non-identifying donor-information and find out whether their child has any donor siblings (which is not a statutory requirement); but may never receive identifying details about a donor. Donors can request information about the number, gender and year of birth of any children conceived with their gametes (with access being statutory). They cannot receive identifying information about the offspring (or recipients). Donor-conceived persons can find out non-identifying information about their donor and donor siblings once they are 16, and they may request identifying donor information and join the voluntary sibling register once they are 18. Since those conceived after the amendment to the law that came into force in 2005 will not be 18 until 2023, identifying information has so far only been released if donors who donated between 1991 and 2005 voluntarily removed their anonymity.

The annual OTR report for 2018 (HFEA 2019a) shows that there has been an increase in enquires over the years. In total, 310 requests had been made in 2018, with 75 applications having been submitted from donor-conceived persons. In comparison, there were significantly fewer enquiries in 2010. That year, 123 applications had been submitted, with only five OTR requests having been made by donor-conceived persons. The number of enquiries from parents (from 76 in 2010, to 106 in 2018) and donors (from 36 in 2010, to 127 in 2018) has also increased (HFEA 2019a).[2] According to the OTR report for 2018 (ibid.), this increase is related to the increase of treatments involving donated gametes and higher disclosure rates. Besides, the report also states that according to anecdotal information conveyed to the HFEA from applicants, the recent "rise in popularity of commercial direct-to-consumer DNA testing websites has also added to the rise in applications" (ibid.). These anecdotes are not described further but are likely about donor-conceived persons who have only learnt of their origins through registration with a DNA database.[3]

The central register is only accessible to HFEA employees who need to access it as part of their work, such as those on the OTR team. I had not signed a confidentiality agreement before interviewing Donor Information Manager Emma Wheeler, whom I met at the very beginning of my research, which was why I was not allowed to see the actual register. As the head of the small OTR team, which at the time of my research consisted of only two people, Emma Wheeler's main task was to manage and coordinate all OTR requests from donor-conceived persons, parents and donors. Since I was not allowed to see the register itself, Emma Wheeler instead explained to me step-by-step how the HFEA handled an application from a donor-conceived person. While I had assumed that retrieving information would be a simple matter of entering a name and pressing a button, it turned out to be a much more complex process, which I describe in the following paragraph.

In order to obtain information from the central register, applicants have to submit or present a proof of identity (for example a passport or a copy of an identity

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[2] The first children who had been conceived after the establishment of the HFEA turned 18 in May 2010 (HFEA 2012). It was not until 2009 that the minimum age for accessing non-identifying information was reduced from 18 to 16. The amendments made to the HFE Act in 2008, which came into force in 2009, also "reaffirmed the existing policy of giving parents non-identifying information so that they could share it with their child" (Nuffield Council on Bioethics 2013: 24).

[3] See also the concluding chapter of this book and the section on "#DNAmatters" for a brief discussion of how the HFEA reacts to the changes brought about by genetic testing.

document certified by a solicitor) and a proof of address (such as a pay slip).[4] As a general rule, the HFEA never discloses information that has not been specifically requested by the applicant. When requesting information, applicants must therefore indicate what type of information they wish to receive (e.g. information about a donor, but no information about donor-conceived half-siblings, or vice versa). At the time of my research in the UK, applications could only be submitted by post. In the meantime, this can also be done online. Upon receipt of an application, the HFEA officers will verify the accuracy of the application, make copies of the identity documents, and return them to the applicant. All requests are then electronically recorded in a case management system and must be processed within 20 working days. The resulting deadlines are what structures the OTR team's working days, as they define what tasks they have to perform on a given day. The OTR team will access the electronic register and obtain the requested information in a complex, multi-level process: to begin with, the applicant's birth mother is looked up on the register. Once this information has been retrieved from the database, an electronic form with information about the outcome of the treatment that led to the applicant's birth is retrieved. The outcome form then links to the corresponding treatment form, which in turn contains information about the clinic where the donor was originally registered, as well as the donor code. This code can then be used to look up the donor on the register. The next step is to run a report for each donor, listing all treatments and outcomes that relate to them. The OTR team will then interrogate the report to ensure the accuracy of the information. If the clinic where the donor was originally registered is still open, an HFEA employee will ask them to run an anonymous version of the report that the OTR team created. When this review process is complete, the information about the donor is translated into a new table and/or photocopied and sent to the applicant.

As my research progressed and repeatedly confronted me with the emotionally charged stories of my interviewees, some of whom had received information from the HFEA, this emotionality always struck me as being very different from the highly regulated nature of the procedure by which information was retrieved from the register. Both the elaborate and highly regulated process and the kind of information that was released seemed to be at odds with the repeatedly expressed desire to "know where you come from". My immediate thought was that the limited donor information in particular would probably not be what the applicants hoped for. My first impression would turn out to be correct in the course of my research. This expectation also seemed to be shared by Emma Wheeler. As someone who not only managed the process of releasing register information but also answered calls and emails from applicants, she was sometimes confronted with people who were

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[4] Two of my interviewees went in person to the HFEA office in London to present their documents to an HFEA officer who then made copies and certified them.

disappointed by the nature and amount of information they had received from the HFEA. Like everyone else in the OTR team, she had been required to have basic training in counselling to help her deal with such situations. Emma Wheeler noted that she could understand the applicants' disappointment, but also pointed out that the HFEA was trying to prevent unrealistic expectations. She explained that disappointment was especially experienced by those

> Emma Wheeler: "[...] that were conceived in the 1990s when the information collected about donors was very limited. So, when we provide them with the information it's disappointing. Although, to be fair, on our website we try very hard to manage people's expectations and explain that in this time-period very little information is collected, in this time-period a bit more was collected, so for them to sort of mentally prepare themselves for the fact that they might not receive everything they hope to receive. We've got leaflets and things as well. But that can be disappointing ... if people understandably want to know more about their origins and we can only provide them with their donor's height, weight, eye colour, skin colour, occupation at the time of donation, very limited information ... so that's probably a big cause of disappointment."

The HFEA website, various brochures and application forms contain numerous notes to alert potential applicants that the outcome of an application might not necessarily meet their expectations. One document where this is the case is the application form with which the donor-conceived can request information about their donor and donor siblings (HFEA 2016). On the form, the applicant is asked to

> "Bear in mind that different donors will have provided different amounts of personal information so it's possible that you will receive less information than you would like, or what you get could be very different from what you expect. You may have more or fewer donor-conceived genetic siblings than you expected or you may have none." (HFEA 2016)

Applicants are also made aware of the possibility that both their donor and their donor siblings may have lives, attitudes and opinions that differ considerably from their own. They are advised to carefully consider the implications of their request and are encouraged to talk to a counsellor. When Klotz did her fieldwork in the UK in 2010, the HFEA had not yet received any requests from donor-conceived persons (2014: 178). However, the HFEA already had detailed instructions for the Authority's employees on how to react in case of a call from someone who wanted to receive information from the register. These instructions are very similar to the note included on the above-mentioned application form.[5] Klotz concludes that "within formal

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[5] Klotz (2014: 180) cites the following passage from the 2010 standard internal operating procedures: "Obtaining information from the HFEA Register may raise some unexpected emo-

administrative procedures they [the HFEA] tried to actively manage the constitutive force of the information they were dealing with" (2014: 180). While the HFEA "was trying to anticipate kinship knowledge as constitutive information" (ibid.), it also "brought the notion of choice back" (ibid.) by recommending that people think carefully through the possible implications of accessing information. Several years and actual requests from donor-conceived persons later, the strategy of the HFEA does not seem to have changed too much. As I will show in this chapter, the management of expectations regarding the information that people could obtain and find proved to be an important concern for donor-conceived persons in both countries. Not being able to predict the outcome of their search, many felt they had to manage or dampen their expectations.

7.2 Guidelines, judgment, googling: The de-identification of information

Since all my interlocutors from the UK (as well as from Germany) had been conceived before 2005, none of them had a legal right to obtain information about the identity of their donor from the HFEA register. All they could do was wait for the donor to voluntarily "remove" his/her anonymity; the "removal" will be examined later on in this chapter (section 7.4). Upwards of 24,000 people were conceived with donated gametes between 1991 and 2005. They are entitled to what the HFEA refers to as "non-identifying information", although the HFEA already collected and stored identifying information during this period (Wincott and Crawshaw 2006: 56). Six of my interlocutors fell into this category, with one person (Amber Jones) not having submitted an application to the HFEA (and not intending to do so).[6] Before discussing the views of those of my interviewees who were entitled to non-identifying information in the next section, I will first discuss why it is not possible to know the exact percentage of people who are interested in receiving information about their donor and/or making contact with their donor siblings. I will then discuss the origins and development of "non-identifying" information within the context of donor conception in the UK. Finally, I will examine how the distinction between identifying and non-identifying information was made and what kind of person it creates.

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tions and you may wish to talk the decision through with someone before submitting a formal application. You may also wish to seek professional counselling or similar services, on the implications of accessing information from the HFEA."

[6] Tamara Haste had not made a request either. Since she and her two younger sisters had been conceived with sperm from the same donor, they had decided together that Becca Haste would do the application for them.

Looking at official statistics, one might actually get the impression that only few people are interested in receiving information about their donor. According to an HFEA report from 2017, there were a total of 177 requests from donor-conceived persons between 2010 and 2016 (HFEA 2017b). The number of people who access information is significantly smaller than the number of people who are entitled to information: in 2016, 20,500 of those conceived after 1991 were already old enough to request "non-identifying" information. More than 4000 were already 18 and could thus obtain "identifying" donor information if their donor re-registered (ibid.).[7] Thus, up to and including 2016, less than one percent of those who could have obtained information had requested it from the HFEA. Likewise, the proportion of those who are interested in their donor siblings seems to be rather small: according to the above-cited meeting paper, 137 donor-conceived people had joined the HFEA's voluntary sibling register since it had launched in 2010 (HFEA 2017b). The register can be joined by those who have donor siblings and are 18 or older – which means that of those who were eligible, only a small proportion had joined.[8] However, nothing is known about how many people even know that they were conceived with donated gametes. The percentage of people who request information and/or join the sibling register might be much higher if calculated on the basis of the number of people who know about the circumstances of their conception – but there is no way to know how large this group is. Precise statements about how many people are interested in their donor and/or donor siblings can hardly be made for Germany either. Media reports often state that there are about 100,000 donor-conceived persons in Germany. This number is also mentioned by Spenderkinder on the front page of the organisation's website, citing an article written by one of the pioneers of sperm donation in Germany (Katzorke 2008). However, since an official donor register has only existed for a short time, I would argue that it is more or less impossible to judge how accurate this figure is.[9] While most of my British and German interlocutors were interested in their genetic origins and connections, it is also impossible to know the total percentage of people who are interested in their donor and/or donor siblings. It might well be that those who want information and contact are over-represented both in my sample and in the public debate.

The Report issued by the Warnock Committee suggested not only that recipient parents should be open with their children about the use of donated gametes

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[7] More recent OTR reports do not contain information on the number of those who were entitled to receive information.

[8] It should be noted, however, that the report does not indicate how many donor-conceived persons have donor siblings.

[9] Moreover, it is not possible to check whether Spenderkinder really has 200 members; and even if this is the case, it is again not possible to know whether this is a large or small proportion of those who know they are donor-conceived.

but also that "on reaching the age of eighteen the child should have access to the basic information about the donor's ethnic origin and genetic health" (1984: 24–25). However, the Warnock Report did not specify what the authors meant by "basic information", and the legislation that largely followed its recommendations did not specify this either. The task of determining what information should be classified as "basic" and could be released to donor offspring without compromising the donor's anonymity was instead assigned to the HFEA. In 1992, the HFEA described such information as

> "[…] the minimum necessary to allow the Authority to answer questions from children born as a consequence of treatment services about their genetic background […]. Great importance was given to the design of the data collection system to avoid unnecessary intrusion into the personal lives of patients and donors, and to avoid unnecessary cost to centres and to the Authority." (HFEA 1992: 23, cited in Blyth 2004: 237)

This formulation suggests that the welfare of the child did not significantly figure into the HFEA's decision-making process when the scope and content of the "basic information" that had to be collected by those registering a donor was determined. The collection and provision of information was instead framed in terms that foregrounded and prioritised the autonomy and privacy of recipient parents and donors as well as the smooth, undisturbed running of clinical facilities and the HFEA. The information was initially limited to basic descriptive categories such as height, weight, hair and eye colour, occupation and whether a donor already had children. Both the type and the quality of the donor information collected were anything but uniform (Blyth 2004: 237), which was also reflected in my material. Those who had obtained non-identifying information from the HFEA received documents that differed not only in form but also with regards to the content that had been captured.[10] The form sent to Lindsay Billington (figure 3) contained, for example, a brief "clinic description" of her donor, which was not included in the replies that others had received.[11] Standardisation was implemented only in response to the Ministry of Health's 2001 consultation on the release of donor information (Blyth 2015).[12]

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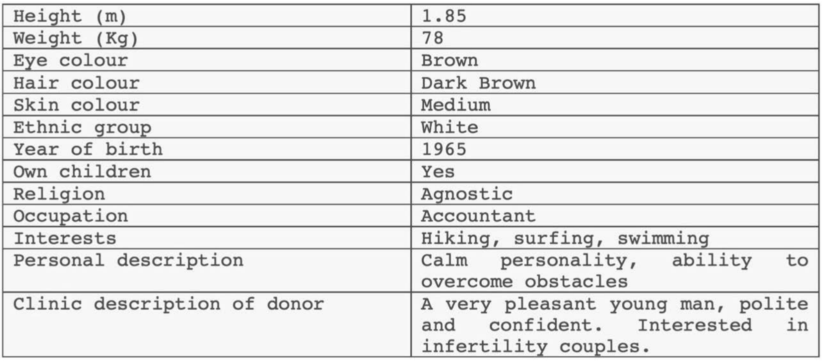
[10] Those of my interviewees who had applied for information had received a typewritten form without a handwritten part, a photocopy of a hand-filled and fully transcribed form, or a typewritten form along with a shorter handwritten paragraph.

[11] Although Lindsay gave me permission to use a photograph of her original document, I decided against it. In the table shown in this chapter (figure 3), I kept the original categories but changed the answers. In my opinion, it might be possible to identify the donor by combining the information provided to her by the HFEA.

[12] This consultation also provided a basis for the establishment of the voluntary register and for the law that eventually limited anonymity (Blyth 2015).

Figure 3: Non-identifying donor information, received by Lindsay Billington



Height (m)	1.85
Weight (Kg)	78
Eye colour	Brown
Hair colour	Dark Brown
Skin colour	Medium
Ethnic group	White
Year of birth	1965
Own children	Yes
Religion	Agnostic
Occupation	Accountant
Interests	Hiking, surfing, swimming
Personal description	Calm personality, ability to overcome obstacles
Clinic description of donor	A very pleasant young man, polite and confident. Interested in infertility couples.

Source: author/replica

Those who had requested information from the HFEA had been conceived in the 1990s and were between 18 and 23 years old when I interviewed them. There would have been a greater difference regarding the information that people received if I had also spoken to people who had been conceived since the beginning of the 2000s. From then on, the information collected about a donor had become not only standardised but also more extensive. Donors can now choose to leave a handwritten "goodwill message" to all children born as a result of their donation and may give a personal description of themselves, also known as a "pen portrait" (Gilman and Nordqvist 2018: 322). Writing these texts is voluntary, and it does not seem to be the case that all donors write them. A survey conducted in 2007 and 2008 found that some clinics reported that more than three-quarters of all donors provided "later life information" (Crawshaw and Dally 2012: 82), while other clinics stated that less than a quarter chose to do so (Crawshaw and Dally 2012: 85).[13] Although clinics may try to keep messages and portraits non-identifying from the outset by issuing guidelines on how to write these texts and instructing donors not to include identifying information (see for example Manchester University NHS Foundation Trust 2013), donors can theoretically incorporate information that would be classified as identifying. Since parents may request these additional texts, but are only allowed access to non-identifying information, messages and portraits must be edited, or,

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[13] Whereas writing pen portraits and goodwill messages is currently still optional, Crawshaw and Dally suggest that this may have to change: "Given the growing evidence of the importance of such information to donor offspring and their parents, the time may come when completion of good quality later life information by donors becomes a statutory requirement." (2012: 88)

as Emma Wheeler referred to it, "redacted" before being sent to those requesting information.[14] According to Emma Wheeler, one of the difficulties with the redaction process was that conflicting interests had to be considered:

> Emma Wheeler: "It's a balance between providing as much information as possible but also protecting that donor's confidentiality and not revealing their identity inadvertently with certain details that on a Google-search will bring them up in combination with everything else that [the applicants] are getting."

Although the redaction of donor information was about hiding information that could lead to the identification of a person, this process contained knowledge (or at least assumptions) about those who seek such information. Emma Wheeler and her colleagues assumed that the applicants would try to find the anonymous donors using the search engine Google. As I will show in this chapter, their assumptions were indeed correct for some of my interviewees.

Knowing from my own ethnographic research that effectively anonymising interlocutors, without omitting important contextual information, is not always an easy task, I was immediately struck when Emma Wheeler spoke of the need to edit voluntary personal messages and descriptions. For this reason, I asked her if there were any specific guidelines on how to redact these texts. She stated that while there were indeed some things that were regulated and "clear", there were other cases where "things are less clear", and more difficult. Although the HFEA had issued a redaction guideline for clinics, the OTR team and clinic staff sometimes had to rely on "common sense".[15] Emma Wheeler pointed out that personal names always had to be edited out and "blocked out in black", but noted that city names were already more difficult: mentioning the name of a tiny village had much more identifying power than saying that someone was born in a large city like London. The same applied to the profession of a donor: while saying that a sperm donor was a teacher might not reveal his identity yet, a rare military rank, or, as Emma Wheeler laughingly commented, the fact that a donor was the Prime Minister, would be a

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[14] At the time of my research in the UK (September 2016 – January 2017), those with donors that had written goodwill messages and pen portraits were not yet of age, as this option has only existed since the 2000s. For this reason, no unredacted messages had yet been released to donor-conceived persons, who can only receive identifying information once they are 18 years old. An unredacted version of all texts is kept on the register after information has been given to parents.

[15] Redaction can take place not only at the HFEA but also in fertility clinics, as they may be involved in the process of releasing information to prospective parents. However, Emma Wheeler pointed out that clinics did not always follow the HFEA's recommendation, which was to provide patients with as much information as possible. If clinics were only willing to provide very limited information, then the information had to be redacted by the HFEA's OTR team before being given to recipients.

very different matter. Redaction was not always simple but instead a complex process that combined a number of different elements and skills:

> Emma Wheeler: "There's some thought and judgement that goes into it, plus some common sense and plus some basic ground rules, we don't include names, so if someone says they've got a sister called June, a brother called Harry, we'll say they've got a sister and a brother, but we'll take out the names of those people because also sometimes you need to think about, particularly if it's egg donation, that the patient and the donor may have been attending the same clinic and if it's a clinic in a small area the likelihood that they might know of each other or certain unique things about them. In one message someone had written, 'I had a very unique group of pets, of animals', it wasn't just a dog and a cat, they were some very strange animals, and they'd given the names of all of their animals and the numbers, and that combined with other personal information they'd given about themselves just made things a little bit tricky. So, it's a bit of a mix, we've got some redaction guidance and guidelines and then a bit of judgement and a bit of googling."

The fact the OTR staff redacted information from databases with the help of unformalised knowledge underlines that knowledge is not always formalised; it can also be more implicit. Since oocyte donation, unlike clinical sperm donation, does not necessarily involve frozen gametes (see footnote no. 6 in the introduction), it is not unlikely that the ova donor and the recipient come from the same area. In the case of the egg donor/pet owner that Emma Wheeler had mentioned, knowledge about the place of treatment, which might also be the place of donation, was linked to information from the register. A redaction process was complete once the donor would no longer appear as a search result on Google with the information that would be given to the applicant. The execution of this task was determined not only by guidelines but also by social practices and the use of online infrastructures.

The aim of the complex, multi-step redaction process is the generation of an account that contains as much information about the donor as possible without revealing the donor's identity. Similar dynamics are at play in the marketing of donor profiles, as anthropologist Ayeshah Émon (2017) found in her ethnographic study of American cryobanks. Two of the banks she visited chose to share a wide range of donor information with recipients, for example the results of "personality, social behavior, and lifestyle-related tests" (2017: 14). Émon notes that the information obtained from these tests "had to be managed in a way that made each donor unique enough to be distinguishable from other donors, yet not so unique as to be identifiable" (ibid.). Frois argues in her study of Alcoholics Anonymous and other self-help groups (section 1.3) that one of anonymity's features is precisely its ability to "allow[…] the person to become indistinguishable" (2009: 153). Against this background, I suggest that the concept of non-identifying information is always something that must perform a balancing act and is inherently ambivalent: donors are supposed to become somewhat imaginable but have to stay unidentifiable. They have to become reasonably concrete so that their profiles will be distinguishable from other profiles, but have to remain vague enough for the donors to remain anonymous. Although some information is released, the donor is not supposed to fully become "a discrete, singular and bounded unit" (Konrad 2005a: 129), which is how persons are conceptualised in Euro-American thinking. A donor should hence only become a person to some extent.

7.3 Non-identifying information and "knowing the donor as a person"

Although my interlocutors only had a statutory right to obtain non-identifying information, the HFEA register does contain information that is considered identifying by the Authority (name, date of birth, last known address), even for those who donated before the law was changed in 2005. There is thus a significant difference between those who were conceived after the establishment of the HFEA and those who were conceived before 1991, as the latter group cannot know for certain whether there are any documents about their donor left at all. In contrast, those conceived between 1991 and 2005 are faced with the situation of the identifying information being on the register without being accessible for them.[16] In the first part of this chapter, I will first discuss how my interviewees felt about not being able to access everything that was on the central database. I will then go into more detail about what donor-conceived persons in both countries wanted to know about their donor, and why the non-identifying information was not felt, at least by most, to be sufficient to "know the donor as a person".

The thought of not being able to access all register information was clearly an upsetting one for 18-year-old university student Jade Foster, who had applied for information and was still waiting for the HFEA's reply letter when I met her. Jade struck me as particularly well informed about the national and international laws on gamete donation and donor anonymity, and she mentioned that she had used

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[16] However, not all donor-conceived persons may be aware of the discrepancy between the stored information and the information they have received. This thought occurred to me when Tamara Haste mentioned that she was not sure if her donor had even provided any identifying information at all. She added that it was uncomfortable to think that his identifying information might have been there, but that she and her sisters were not able to receive it. I was unsure how to react, as I did not want to exacerbate her sense of frustration. After making sure that I would not spread false information, I mentioned in a later email that the identifying donor information was indeed on the register. She replied that this made the whole situation "all the more frustrating" and added that she could not understand why information had been collected if no one ever intended to pass it on to the donor offspring.

the library of her university to read up on research on donor conception. In the interview, she spoke with an angry voice about the situation in the UK and about what she perceived to be an unfair system:

> Jade Foster: "It just angers me that they have the information, the HFEA have *all* of the identifying information of the donors, but they just are legally bound not to give it to me, they give me a piece a paper, it might have a hair colour and eye colour and height. But *they've got the file*, they've got names and addresses, and it's *there*, but *I can't have it!*"
> Amelie Baumann: "And they have it."
> Jade Foster: "Yeah, it's not that it doesn't exist, it's not that the there is no identifying information, it's just that I'm not allowed access to it."

Jade's resentment hints at a feature that may also characterise donor registers in other jurisdictions: they have more information stored in them than the donor-conceived themselves may be able to obtain. Registers like the ones managed by the HFEA do not store trivial information, but rather information that has a constitutive effect, and information that is conceptualised as pertaining to intimate matters enters a public infrastructure. However, due to the legal situation, it is not accessible to those who want to access it. In this sense, not only conception and kinship are dispersed (Strathern 1995) but also control over information. Parents might choose to tell their children that they are donor-conceived; their children might then choose to request information about the person whose gametes were used to conceive them. However, as it is the case with those conceived in the 'in-between period' from 1991 to 2005, they are not entirely free to decide which information they receive in the end.

While non-identifying information was, as noted earlier, supposed "to allow the Authority to answer questions" (HFEA 1992: 23, cited in Blyth 2004: 237), my research suggests that it may actually have a reverse effect, as it may raise new questions that cannot be answered purely on the basis of the information provided by the HFEA. This was the case for Lindsay Billington, who decided to request information just a few days after her parents had told her about the circumstances of her conception. She completed and submitted the application, and soon received the HFEA's reply letter, which contained both non-identifying information about her donor (see figure 3 in section 7.2) and information about her donor siblings. She had only learnt of the possibility of obtaining information from the register after contacting the clinic where she had been conceived. They had referred her to the HFEA. Others had usually learnt about the HFEA through searching for information online.

Although Lindsay had decided to apply for the information almost immediately, she had not been able to open the letter straight away: "When you open it, you don't really know what to expect, and I did have it sat in an envelope for quite a while before I opened it." Lindsay, who had tears in her eyes for much of our conversation, was noticeably disappointed and angry about the behaviour of her parents, who had told their relatives and friends about her origins a long time ago, but had only told their daughter after her twenty-first birthday (section 6.1). I was therefore interested in whether the way she felt had changed with the receipt of the letter. Lindsay described that she had ambivalent feelings about the information she had received:

> Lindsay Billington: "I think it gave me a bit more insight, obviously, because I could sort of have a vision of what he looks like. And it told me his interests, but you just think well that was 20 years ago, things change, people's interests change, so although I had an idea of what he was like then, it's like, well, what is he like now? So, it did help because you get this image, but you think, well, that image that I've got in my head is 20 years old now. And so you're still trying to piece together what he would look like now, and what his interests are now, and he was an accountant, did he get any promotion, did he work up, has he retired now, so there's lots of answers, it helped answering some questions, but then it opened the door to other questions that you can't find out."

When I asked Lindsay what kind of questions she would like to ask her donor, she said, somewhat embarrassed, "It just seems like silly questions, like what did his mom and dad do as a job, and where do they live, what's he doing now, what are his children doing, just things like that, just to get an idea of who this man is." Similar to what others told me, she mentioned that she wanted to "know him as a person [...] get some idea of what he's like, and what his personality is".

More than two decades had passed since her donor had donated, and Lindsay therefore assumed that at least some of the HFEA information was likely to be outdated. Instead of giving her an impression of what her donor was like now, the letter only allowed her to develop a sense of what he had been like in the past. As the non-identifying information released by the HFEA is not updated once it is collected and entered into the register, it provides a temporally fixed image of a more or less isolated donor who has no history and very few, if any, social relations.[17] However, most of my interviewees in both countries wanted to get to know their donor in his historical/temporal and family context. They were interested in finding out how his life had been like before and after the donation. It was mainly information about the upbringing of the donor and his parents in which many people, regardless of when and where they were conceived, had a great interest. Some referred to his parents as their "grandparents" or "genetic grandparents" and

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[17] The replies my interlocutors received contained information about whether the donor already had children at the time of the donation, but no other information about family relationships.

expressed an interest in meeting them. However, information about them is not included in the information provided by the HFEA.

The interest the donor-conceived expressed in the donor's life and upbringing, which was often summarised as "knowing him as a person", suggests a notion of personhood for which temporality and relationality are central elements. Similar to the frequently mentioned desire to "know where you come from" that I explored in section 5.1, their interest in the donor's family relationships indicates that one can indeed "find aspects of nonbounded and less individualistic personhood" (Carsten 2004: 87) in a Euro-American context, as Konrad also observed in her study of British ova donors and recipients (2005a). The desire to learn more about how the life of the donor developed before and after the donation indicates that this relationality is believed to be something that can only be understood in a temporal context. Knowing about kinship connections "locates a person in time and place" (Edwards 1999: 81); knowing how and where one's relatives live locates these kin persons "in time and place" in relation to the donor-conceived. It seems questionable whether the problem of unanswered questions will change significantly with the current legislation that provides access to identifying information for those conceived after 2005. Donors are currently under no legal obligation to respond to their offspring's request for contact or further information, although they have agreed to their identifying information being released to their offspring. This also applies to those who voluntarily remove their anonymity, as they are not obliged to meet up with their donor-conceived offspring.[18]

While others stressed that they wanted to "know the donor as a person", this was exactly what 20-year-old university student Amber Jones wanted to avoid. As someone who had been conceived in the UK in the 1990s, she would have been entitled to information from the HFEA register. However, in the interview with her, it quickly turned out that Amber was unaware of the legal situation and had no interest at all in her donor. In contrast to other donor-conceived persons that I interviewed, she stated that she had always known about the circumstances of her conception. She could not remember a specific disclosure conversation at all but had vague memories of how her parents had told her younger brother, who had been conceived with sperm from a different donor. Amber had recently joined the DCN, where her father had been a member for a long time. She believed that the majority of society did not know very much about donor conception and had decided to join the DCN "to kind of talk about it and stuff like that". At the same time, she also mentioned that she was "not really worried about meeting people and talking about the experiences" and therefore did not plan to attend any DCN meetings. Since she herself had always known about her origins and knew no one

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[18] A study published in 2016 suggests that egg donors donating under current UK regulations are happy to be contacted by children born as a result of their donation (Graham et al. 2016).

who did not, Amber seemed to see the interview as an opportunity to gain insight into very different experiences, and she asked me several times what other people had told me.

While others felt that they did not yet know who the donor was because of the limited scope and content of the non-identifying information, Amber feared that she would in fact be forced see her donor "like a person" if she received this information. I had mentioned that the non-identifying information she would be able to obtain would for example include information about the donor's profession, whereupon Amber commented that she was not interested in finding out anything

> Amber Jones: "[…] because it makes it more real, makes it like a person rather than just kind of like a far-removed donor, a bit of science kind of thing, it makes it more human, and then I don't want a relationship, I don't want to see him as a person, if that makes sense because I'm sure he's got a family, or he could have been a student that needed the money, but I don't want to know that, I don't want to know why this person decided to donate and stuff like that because it could change my view of myself maybe, I don't know."
> Amelie Baumann: "If you knew his reasons for donating or if you knew him as a person?"
> Amber Jones: "Both. If I knew his reason to donate would be because he wanted to help someone have a family, I wouldn't mind knowing that. But if I knew he was short of money, I'd rather not know that kind of thing. And I guess it's the fear of knowing that. […] If I could be a 100 percent sure they donated because they wanted to help someone have a family, and now they had their own family, that would be nice to know. But it's the risk that it's not like that and they're not a very nice person or I don't agree with their morals or how they're living or what they're doing. But actually, they're biologically related to me. I wouldn't like that kind of thing."

While others felt that they needed different and more information to know who their donor really was, Amber feared that even non-identifying information would 'force' her to think of her donor "as a person". She seemed to be worried about the potential consequences that knowing him might have for her, and therefore chose not to know. Amber feared that her self-image would suffer if she learnt something about the donor that she would find negative. Strathern's argument that "knowing about one's kin is also knowing about oneself" (2005: 69) seems particularly apt here. Especially Amber's insistence on not wanting to know *and* not wanting to have a relationship can be seen as epitomising the constitutive nature of kinship knowledge.

While for Amber not-knowing was the 'safer' and therefore preferred state, for many others it was the opposite. They wanted answers to their questions no matter what exactly they would find out. The donor's motivation in particular was one reason why Amber preferred not to know, whereas it was something many of my interviewees explicitly mentioned when talking about what they wanted to find out. The reply letter Lindsay had received from the HFEA contained information about her donor's reasons for donating, but even she wanted to ask the donor in person. While the question of the donor's motivation kept coming up in most interviews, the reasons why one's parents had decided to have children were rarely discussed, even though most of my interviewees knew why their parents had decided to use donor gametes. Having children as a married couple seemed to be a given for my interviewees, who often mentioned how long their parents had been married before they decided to undergo treatment. Commenting on the importance of "conjugal companionship", Strathern (1995: 351) argues that in Euro-American kinship, "the core of the family was constituted in the procreative act of the conjugal pair in such a way that the child's biogenetic closeness to its parents endorsed the nurturing closeness of the conjugal couple" (ibid.). In contrast, donor conception has brought a distant person into the procreative act. Donors as "new [procreative] actors associated with reproductive medicine create a field of relationships that does not overlap in any simple way with familial ones" (ibid.). While it may require little to no explanation to have children in and through "the nurturing closeness of the conjugal couple" (ibid.), the involvement of a distant procreator has the potential to raise more questions, as "there is uncertainty about what relationship the act of donation as such creates" (Strathern 1992: 149). This uncertainty is particularly evident in the frequently asked question about a donor's motivation.

As mentioned earlier, combining different pieces of information and checking whether they would reveal the donor's name in a Google search was a strategy used by the HFEA to check whether a donor had been successfully anonymised. In particular, this approach was inspired by an idea of how applicants would try to find their donor. These ideas did indeed correspond to the actual (or intended) practices of my interviewees. Using Google to search for her donor was the intention of Jade, who had not yet received any donor information. Although she hoped that it would turn out that her donor had removed his anonymity, she was already thinking about how to proceed if it turned out that he was still anonymous:

> Jade Foster: "I think if he had [removed his anonymity] it would be good because at least I'd have all the information, and I think I would contact him. I just want to know who he is as a person, what he looks like, how he acts. Nothing more than that really. But if it's just anonymous information I probably will do my best to search in other ways, depending on what information's available and whether it's enough to do some googling."

Access to online infrastructures such as search engines like Google did not necessarily lead to an extensive detective-like search that only ended when the donor was identified. Occasionally browsing or, to take up a notion from section 5.4, "scanning" the Internet instead of systematically searching for clues was sometimes all people did. Especially looking for pictures of people who matched the information of the HFEA could be both an attempt to counter the feeling of hopelessness and an expression of it. This was the case for Becca Haste, who had obtained non-identifying information about her and her sisters' donor. I will elaborate on their story later on in this chapter (section 7.5). According to the HFEA letter, their donor was a photographer. Becca, who was noticeably frustrated, commented that "apart from googling photographers in the UK who are about the same age as him and seeing if any of them look like us, I don't think there's anything else that I can actually do". In Becca's case, searching for images of her donor and scanning them for similarities seemed to intensify her frustration and anger.

Overall, the information my interviewees had received from the HFEA was rather limited compared to what those conceived later on would be able to receive, at least if their donors had written a pen portrait and goodwill message. Against this background, it may seem questionable whether the more limited non-identifying information would be sufficient to identify a donor. Having said this, some of the donor profiles that my interviewees showed me or described to me seemed to be rather specific and unique, and I sometimes wondered if it might be possible to identify the donors with a clever use of Google. Since some donors had, according to the HFEA information, very specific professions or uncommon hobbies, I came to suspect that persons with detective-like skills might be able to find the donor even with such limited information. However, it is important here to distinguish between what would be theoretically feasible, and what the majority was willing or are able to do. Not all of my interlocutors were willing or able to invest a lot of time and effort into a search, although those who wanted to know more felt that they did *have to try* and find the donor and/or donor siblings. The feeling of having to try was particular prevalent in the way my interlocutors approached commercial genetic testing (section 8.3).

7.4 "I might never find out": Removing anonymity, re-moving uncertainty

One possible regulation proposed as a solution for those who want information to which they are not entitled under current legislation is the voluntary removal of anonymity for donors. Similar to the "end of anonymity" that is supposedly caused by genetic testing (see introduction of chapter 8), the term "removal" suggests that something that used to be complete at a certain point in time is changed or eliminated. However, the mere existence of a central register, in which data is stored, illustrates that donor anonymity has always been partial. In the UK, those who donated after 1991 but before 2005 are given the opportunity to remove their anonymity and make themselves identifiable to the donor-conceived, who are then able to receive identifying information in case they apply for it. They cannot know in advance whether their donor is identifiable or not. This contrasts with the approach taken in the State of Victoria in Australia, where anonymity has been removed retrospectively for all donors (section 3.5). According to an HFEA meeting paper, 182 donors had removed their anonymity by the end of 2018, and 14 requests for identifying information on donors who had made themselves identifiable had been made by then (HFEA 2019a). None of my interviewees had a donor who, at the time of the interview or later on, had decided to become identifiable. All of them had indicated on their initial application to the HFEA that they wished to receive both non-identifying donor information as well as identifying information in case it was available. In this section, I will first analyse why voluntary removal created a challenging situation for my interviewees. I will then briefly touch upon calls for eliminating this uncertainty, before discussing the connection between hope and uncertainty on a more general level.

The possibility of removing anonymity can result in donor-conceived persons receiving identifying information years after their initial requests. Since the HFEA does not contact past applicants if donors remove their anonymity after their application has already been processed, they receive a reference number in their reply letter. This code enables past applicants to check on the HFEA website whether a donor has in the meantime decided to become identifiable; they cannot, however, obtain identifying information directly from the website. Although they cannot contribute to the donor becoming identifiable, they have to remain active and check the website, if they want to retain the chance to find their donor. However, they have no guarantee that their donor will ever decide to become identifiable. While the receipt of non-identifying information can lead to a person having more questions than answers, a sense of uncertainty can also be heightened by the mere knowledge that donors might at some point remove their anonymity, but that they might just as well choose to remain anonymous.[19]

The extent to which voluntary anonymity removal can create uncertainty became clear in Lindsay Billington's way of dealing with this option that past donors have. It was discouraging for Lindsay to find out that her donor was still anonymous and to face the possibility that she might never know who he was. This potential "never" was created by a set of formal regulations and infrastructures. In Lindsay's case, her search for the donor quickly came to a temporary halt:

> Lindsay Billington: "I just did some investigations myself, but when it came through that he wasn't registered, I just was a bit disheartened, I thought, 'I know

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[19] One potential source of uncertainty has however been eliminated: donors who have removed their anonymity cannot re-instate it later on.

> now I'm ready to find a bit of information out, and then I might never find it out.' It was hard to deal with that, you know, I might never know. That's some of the reason why I've sort of blocked it out for the last two years, I don't want to get infatuated with it, when I might never find out."

Lindsay had already started having psychological counselling sessions some time ago, as she had been struggling with anxiety for a long time. It was the counselling that had recently "brought it to the forefront" of her mind. Her counselling sessions had made her realise that "maybe now is the right time to do it", and she was hoping that finding out more might help with her anxiety. Lindsay had decided to try and find out something about the extent to which the possibility of removing anonymity was known among former donors, as she wanted to avoid developing an obsessive and unhealthy hope: "If he doesn't think he can do it, he might never do it, you need to know [about anonymity removal] to be able to do it, so I'm going to start looking into all the changes, [...] just to see how well known it is in the donor community that they can re-register." Lindsay's plan to find out how well known the possibility of anonymity removal was can be seen as an attempt to make an uncertain future at least a little more predictable. The hope of still finding her donor was 'justified' if she could realistically assume that he was aware of this option. At the same time, she felt that she had to prepare for a possible future in which the donor would remain anonymous. Therefore, she tried to manage and dampen her hope.

The authors of the Nuffield Report (2013) argued that the state should take a more active role with regard to re-registration. A public campaign aimed at raising awareness both for the possibility of re-registration and for the DCR, which would also raise general awareness of donor conception, was suggested as an alternative to removing anonymity for all donors (and not giving them a choice as to whether or not they want to become identifiable) and to contacting past donors directly (2013: 132–133). The HFEA's Code of Practice (HFEA 2019b) contains a similar approach. According to the Code, fertility clinics and centres should play an active, yet passive role: "The centre should inform anonymous donors seeking information about children resulting from their donation that they have the right to re-register as identifiable, if they wish." (2019b: 125) The possibility of re-registration is introduced as something that potential registrants should only be made aware of when they make inquiries by themselves; it is not supposed to be something that clinics should actively promote by directly contacting past donors.[20]

The voluntary removal of anonymity creates a situation where people can have some hope that they might find their donor, but they cannot be certain that they

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[20] In contrast, law scholar Jenni Millbank suggests that formal voluntary registers should take on a more active role, contacting potential registrants directly and offering them counselling as well as mediated contact (2014a: 223).

will find someone. Not knowing turns into possibly never knowing. The relationship between hope and uncertainty is explored by Mattingly (2010) in her ethnographic study of African-American families with chronically ill children. Mattingly argues that "to hope is to be reminded of what is not and what might never be" (2010: 3), which is why hope can be a "paradoxical temporal practice" (ibid.). It always points towards a future that, in the moment of hoping, can only be imagined (2010: 15). As such, hope and uncertainty are inseparable: "Hope lives in an uncertain place, in a kind of temporal lobby." (Ibid.) It is not merely "passively received but actively cultivated" (2010: 4) and constitutes a practice that "is immensely influenced by […] political and economic conditions" (2010: 34). I suggest that for those conceived between the establishment of the HFEA and 2005, the possibility of anonymity removal can turn into a "temporal lobby". The donor might still be anonymous, but the hope that the donor might one day be found via the official HFEA register is kept alive through the regulations that enable donors to remove their anonymity. Remaining too hopeful can be an exhausting experience, which is why it may become necessary to manage hope if one wants to avoid getting "infatuated with it", as Lindsay put it. In the case of donor-conceived persons who know that their donors could decide to re-register, their hope is inextricably linked to, created by and limited by formal regulations and infrastructures. The meaning and nature of hope has also been explored by Sarah Franklin (1997) in her ethnographic analysis of IVF. Franklin argues that the hope that IVF gives to those experiencing infertility "is double-edged, both enabling women to continue and dis-abling them from reaching an endpoint of treatment" (1997: 192). I will return to the ambiguous nature of hope in my exploration of commercial genetic testing (chapter 8), where I will draw on Franklin's work more extensively to explore the hopes and uncertainties created by this technology.

7.5 (In)voluntary siblings: searching and hoping for lateral kinship ties

In the UK, the voluntary register Donor Sibling Link (DSL) gives those conceived after 1991 the possibility of getting in touch with offspring conceived with gametes from the same donor, but only if both register and agree to be put in contact. The DSL was set up following the 2008 amendments to the HFE Act (Blyth and

Frith 2015: 142).[21] According to HFEA meeting papers, 193 registrants had joined the DSL up until the end of 2018 (HFEA 2019a).[22] The first sibling match had been made in 2015; with ten more matches having been facilitated since then (ibid.).[23] While the creation of the DSL might suggest that the importance of lateral ties is being recognised by official authorities, Gilman and Nordqvist (2018) argue that parliamentary debates and HFEA working papers mostly focus on the need of the donor-conceived to know their donor. According to Gilman and Nordqvist, "there has been much less debate and discussion regarding the significance of these lateral ties" (2018: 329). They see this imbalance as being related to and expressive of "the particular significance attributed to knowing one's origins in Euro-American kinship systems" (ibid.) that does not provide for "an established cultural narrative about the significance of knowledge about lateral connections" (ibid.). Those of my interviewees who had already made such connections and found donor siblings (via genetic testing) by the time that I met them had mostly done so only within a few months or weeks before the interview, and several people found someone via a DNA database after I had already interviewed them. The material discussed in this section thus speaks more to the process of searching and hoping for donor siblings and less to how people live these relations. I will first discuss what makes the DSL an interesting object of study compared to other registers that have been the focus of research so far. Drawing on material from the UK and Germany, I will also analyse on a more general level what attracted people to the making of lateral ties and explore why having "too many" donor siblings was seen as problematic. With the

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[21] Prior to the establishment of the DSL, parents had been able to obtain donor codes from clinics, which they could then use to network with other families who had children conceived with gametes from the same donor. However, the practice of releasing codes to parents, which was supported by the HFEA from 2004 to 2009, was eventually discontinued following a review of the policy. The review found several operational problems. For example, the same code was assigned to different donors registered by different clinics (Millbank 2014a: 232).

[22] In her analysis of formal voluntary registers in the UK and Australia, Millbank argues that such registers are currently "dramatically underutilized, with low rates of registration and few matches made" (2014a: 249). According to Millbank, formal registers like the DSL "offer the hope of contact and information sharing, but very little prospect of its realization" (ibid.). When she published her article, the DSL had 44 registrants and no matches yet (2014a: 232). While 44 registrants does indeed seem like a small amount of registrants, I would argue that describing the DSL as "underutilized" is somewhat misleading: since it is not known how many people even know about the circumstances of their conception, it is not possible to know whether 44 registrants (or 193 in 2018; HFEA 2019a) represent a small or large proportion of those who are donor-conceived *and* know about their donor-conceived origins (see also section 7.2 for a discussion of what is statistically known about donor conception).

[23] The number of people who have joined the DSL shows a steady growth compared to the 105 registrants (and four matches) reported by Emma Wheeler when I interviewed her in September 2016.

search for donor siblings, new hopes and expectations, as well as uncertainties are created. At the same time, I will show that the donor does not completely take a back seat when people search for and eventually meet their donor-conceived half-siblings.

In the case of the donor-conceived, their kinship is "dispersed" (Strathern 1995). Their donor might have 'assisted' numerous couples and/or single women, resulting in donor siblings born and raised in different families. Siblingship can therefore become dispersed as well. Due to the dispersed nature of their conception, the donor-conceived trace their connection to each other through a procreative actor who is distant from those who have raised them. Donor siblings are different from step-siblings who are not genetically related, but who grow up together, and not the same as half-siblings who are genetically related via a parent and not a donor (Edwards 2013: 286). Previous research on donor siblings has shown that they might establish connections not only between donor-conceived persons but also between their dispersed families. Such networks can involve the donor as well. This phenomenon has been explored by Hertz and Nelson in their recent and detailed sociological study of *Random Families* (2019), a term they use for "families who just happened to have selected the same donor out of the available donor pool" (2019: 8) without having any sort of pre-existing relationship.[24] *Random Families* is unique in its depth and in terms of the variety of sibling networks that were studied, which is something I cannot achieve within the scope of this book.

Nevertheless, I believe that even a shorter exploration of donor siblings can offer valuable insights: Hertz and Nelson conducted their study in the US, thus in a context where assisted reproduction is mostly unregulated. The networks they portray were established via privately run registers such as the DSR. An informal register like the DSR allows parents to sign up and contact families when their children are still minors, which might be seen as an advantage by recipients.[25] In

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[24] The empirical part of their book consists of an exploration of five different networks that vary in terms of composition, age of children, type of donor and intensity of contact. Hertz and Nelson argue that "each of these networks creates opportunities to make meaning out of connections that begin when parents with no pre-existing relationship with each other happen to purchase vials of sperm from the same donor" (2019: 3–4).

[25] This was the case for Jessica Robertson, a donor-conceived person from the UK. Jessica was trying to get pregnant with donor sperm and had already undergone IVF treatment at a British clinic with sperm from their local sperm bank. She had also tried at-home-DI with sperm she had ordered online from a Danish cryobank. This was considerably cheaper than another round of IVF in the UK. In addition, conceiving with the sperm she had bought online would have another advantage: Jessica had previously browsed the DSR and discovered that other families who already had children from the Danish donor had registered. Her family would not have to wait until the child was 18 to establish contact with the child's donor siblings: "There would be the option there to make contact with siblings as early as I wanted."

contrast, the DSL is a voluntary yet formal register that is run by the HFEA in a context where assisted reproduction is highly regulated, offering a chance to study the impact of regulations on the facilitation and forging of new kin connections. The DSL can only be joined by the donor-conceived themselves. In order to join the DSL, applicants have to fill out an application form and indicate which contact details (email address, phone number, address) the HFEA may pass on to any donor siblings on the register, and how they prefer to be contacted.[26] While anonymous donors who have removed their anonymity cannot undo their registration, DSL registrants can have their data deleted from the register at any time. The OTR team mediates initial contact in the case of a match, whereas contact established via the DSR is unmediated.[27]

With an official register like the DSL, donor-conceived siblingship is not only dispersed but also *delayed* by official regulations on age minimums. "Delayed siblingship" is a term I borrow from Chantal Collard and Shireen Kashmeri (2011) and their study of emerging forms of siblingship among families participating in embryo donation, or, in the words of a 'pro-life' organisation organising them, "embryo adoption". Though embryo donation or adoption, "extra embryos" (Roberts 2007) that are not used in an IVF or ICSI treatment can be placed into another family, resulting in full genetic siblings growing up in different families. Unlike other programs, the organisation that Collard and Kashmeri studied offers "open adoptions", with placing and adopting families receiving information about each other.[28] They found that it was usually "left to the child to activate, or not, the sibling relationship later in life" (2011: 320). "Delayed siblingship" (2011) can be a strategy employed by parents to protect their families from any destabilising effects that sibling relationships might have, as these relationships "suggest […] the

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[26] Potential applicants to the DSL are encouraged to first inquire via the central HFEA register for information on whether they have any donor siblings. They can choose to receive information about number of siblings, their gender, and year of birth.

[27] The HFEA itself does not offer psychosocial support in case of a match. Since 2016, a number of free counselling sessions were offered to donors, parents and donor-conceived persons via PAC-UK, an organisation that provides post-adoption support services. The contract with PAC-UK ended in April 2019 and was then awarded to the Hewitt Fertility Centre, the clinic that took over the DCR (HFEA 2019a).

[28] According to Nightlight Christian Adoptions, which is the organisation that Collard and Kashmeri (2011) studied, "[o]pen adoption encompasses a wide spectrum of contact. It does not mean that you meet, exchange last names or other identifying information, but does mean that families select each other through a letter, biographies, and photos. In most cases, you will know each other's first names and state of residence. […] By virtue of having this information about the other family, all our adoptions are considered open." (Nightlight Christian Adoptions, n.d.). The practice of "open donation", as practiced by Nightlight, differs from the practice of donor conception with gametes from known donors, who usually agree to become donors because they are friends with the recipients (Goldberg and Allen 2013).

randomness of embryo selection in transplantation" (2011: 317). In the case of the DSL, siblingship is delayed, as the donor-conceived cannot join the register prior to their eighteenth birthday. Someone with younger donor siblings might have to wait for several years before getting in touch with others even becomes a possibility. This was the case for Jade Foster, who did not know yet whether she had any donor-conceived half-siblings at all since she had not yet received the register information. The HFEA's reply, which she obtained shortly after the interview, stated that she had nine siblings that had been conceived with sperm from the same donor who was still anonymous. The table containing information about her donor siblings stated their year of birth and revealed that most of them were not yet 18. This meant that Jade would not be able to get to know them for at least a couple of years. As I discuss below, she was very interested in meeting her donor siblings (see also section 5.4), which is why this was a disappointment for her.

Siblings are thought to be "related laterally and equally" (Edwards 2013: 289). Although cryopreservation of embryos and gametes can change the presumed temporal order, as it may result in siblings that were conceived at the same time, but whose birthdays are years or decades apart, they are imagined to be similar in terms of age and interests.[29] Contact with donor siblings was often imagined to be less problematic than contact with the donor precisely because they were imagined as being similar to oneself, which epitomises Strathern's point about similarities being central for the way in which relations are made (Strathern 2018). For those who at some point in their lives had learnt of the circumstances of their conception, the information that they had an unknown donor had initially been at the forefront of their thinking. This was the information that their parents had given them in the initial 'disclosure talk'. However, many had quickly associated this with the possibility that they might have donor siblings. While people often emphasised that identifying the donor was only or mainly about receiving knowledge (section 3.5), almost all of my interlocutors wished not only to find their donor-conceived siblings but also to contact and possibly meet them. This was the case for Jade. Although the thought of being related to someone she already knew and did not like made her nervous (section 5.4), the thought of having donor siblings excited her:

> Jade Foster: [speaking about what the letter from the HFEA might contain] "I want siblings, but I don't know if there are going to be any."
> Amelie Baumann: "Do you think you would want to try and get in contact with them?"
> Jade Foster: "Yes. Yeah, I think just to find out, I don't know, I would want to see

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[29] If a couple has more embryos than they decide to implant in one cycle, the remaining embryos can be frozen in order to be thawed and implanted at a later time, possibly in another patient (Collard and Kashmeri 2011: 318).

> the similarities, see what I share with them. Fill in the missing pieces I guess."
> Amelie Baumann: "Have you thought about what kind of relationship you would want to have with them?"
> Jade Foster: "I don't know because I guess we're going to be a similar age and possibly have similar interests. So kind of like a friendship but a weird friendship, and also it would be nice to have people who share the same experience because I don't know anyone else except my younger brother who's donor-conceived, so it would be nice to have someone to talk to who understands."

The reasons Jade gave for wanting to find donor siblings were voiced by many of my interviewees in both countries: firstly, they wanted to achieve a sense of completeness. Even though donor siblings do not constitute a direct link to the donor, "scanning" them and identifying similarities was seen as a way to draw conclusions about the anonymous donor (see also section 5.4 for a discussion of the "scanning for similarities"). In this sense, "lateral ties do help re-create an absent forbearer" (Hertz and Nelson 2019: 69). My interlocutors tended to reason that if a donor sibling shared one of their characteristic traits, this similarity could be interpreted as a sign that this trait was inherited from the donor. Donors were thus conceptualised as being dispersed in their donor-conceived offspring. Secondly, finding donor siblings was seen as an opportunity to connect with people who were also donor-conceived. Many people mentioned, like Jade, that apart from the sibling they had grown up with, they did not know anyone else who shared the same 'fate'. The prospect of finding siblings with whom they were not only genetically related, but who would also share the experience of being donor-conceived, was one of the main reasons why my interviewees decided to look for donor siblings.

The 'weirdness' that Jade attributed to future relationships with donor siblings indicates that they confuse categories that shape the way people think about relationships. While kinship and siblingship are commonly seen as being ascribed, friendship is believed to be voluntary (van der Geest 2013: 51). However, such a schematic distinction does not bore out ethnographically (van der Geest 2013: 67) and does not map onto how relations with donor siblings come into being. While their shared genetic heritage can be said to exist independently of their decisions, it is only through their desire to connect with donor-conceived half-brothers and half-sisters that their sibling relationship is activated (Edwards 2015). They are connected through "a kinship link that is both involuntary […] and entirely voluntary" (Edwards 2013: 289).

Although the desire to find donors siblings who are similar to oneself underlines that siblingship is commonly seen "as being emblematic of similarity, equality and unity" (Carsten 2013: 147), my interviewees themselves mostly believed or expected that their relationship would not match a conventional sibling relationship. This was a point made by Sabrina Frey from Germany. She had grown up as an only child and had found several donor siblings via FTDNA (see section 5.3): "I've always wanted to have siblings, but I just know that I don't know that feeling of having a sister or a brother. I don't think I can develop that anymore, so it's just going to be a friendship." She and others envisaged the relationship they would have with donor siblings as a valuable friendship that could 'manage' without the experience of a shared childhood, but that would nevertheless be different from a regular friendship. In contrast to regular friends, donor siblings are linked by shared substance and the shared experience of being donor-conceived.

Donor siblings are unlike genetic half-siblings who grow up in the same family. They do not have a relationship that has been forged through a shared childhood, which was why Sabrina did not expect to develop a conventional sibling bond with her donor-conceived half-sisters. Since donor siblings do not have a shared past and a connection that has grown over time, the link to them can be imagined as one that does not come with any responsibilities. Building and maintaining a relationship with a donor sibling was commonly seen as a matter of choice instead of obligation. This supports Sjaak van der Geest's (2013) point about siblingship/kinship and friendship not being logically separable into matters of obligation and choice. Melanie Weber's way of thinking about the donor-conceived half-siblings she might find illustrates this point. The policewoman from Germany stated that she was actually not too interested in her donor: on the one hand, she wanted to find him because she felt that "there are some points in my life and in my personality structure and character that make me think, where does that come from?" On the other hand, not knowing him did not seem to bother her too much. She enjoyed being a new mother (section 5.4) and maintained a close relationship with her father. She also pointed out that in her opinion, sperm played a smaller role than ova in the development of a child. Melanie laughingly commented that "a sperm cell is only a sperm cell", whereas she felt that everything related to motherhood played a bigger role.

While she did not care much about her unknown donor and also considered it unlikely to ever find him, she stated that she was very interested in any donor siblings she might have. According to Melanie, her husband, who was in the room from time to time during the interview and looked after their little daughter, could not understand why she was interested in them at all. He feared that they would only be interested in their money. While Melanie herself usually found it hard to trust others, she had a good feeling about future contact with donor siblings ever since she had joined Spenderkinder's mailing list and started exchanging messages with other members. Nevertheless, Melanie was relaxed about the possibility that contrary to her expectations, contact might be unpleasant:

> Melanie Weber: "Of course it sometimes crosses my mind that there might be a sibling that I might not even want to get to know. Because I don't like his character

> or because we're not on the same page, anything is possible. After all, that's how it is in real life [*im wahren Leben*] as well, but I really don't assume that that's the case. I also told him [her husband] that when I exchange messages with [members of] Spenderkinder, they are all really intelligent. […] And even if that's the case, I don't have to keep in touch with them when I meet him or her and we realise, 'It was nice that we got to know each other, we're siblings, but you know what, I can't stand you at all', well then you can always say, 'Ok, I've gotten to know you, but don't get mad at me, I don't like you', or something like that."

The term "in real life" suggests that she regarded the relationship with her donor siblings as something that would not correspond to how she was connected to her sister, with whom she had grown up "in real life". Since her sister did not look like her at all, which her husband 'demonstrated' by handing me a framed family photograph, Melanie assumed that she probably had a different donor than her. According to Melanie, her sibling's character traits had always been very different from the rest of the family, making her sister feel "like an alien". Nevertheless, she did not question their relationship at all and seemed to have a close relationship not only with her parents but also with her sister. In contrast, Melanie did not feel like she would be obliged to keep in touch with a donor sibling whom she had not yet met "in real life". Most of my interviewees were, similar to Melanie, very interested in finding donor siblings and rather optimistic about the outcome of such an encounter. Nevertheless, the relationship with them was conceptualised as something that did not have to be maintained if one's donor-conceived half-sibling would turn out to be unlikable. Likability was commonly seen as a prerequisite for ongoing contact, which is similar to the findings from Hertz and Nelson (2019). They argue that "likeability and finding a basis for connection" (2019: 221) are essential for the formation of strong and lasting bonds between children conceived with gametes from the same donor. Expectations and imaginaries about contact and relationships with donor siblings were predominantly positive, and my interlocutors clearly expected to like their donor siblings – because they expected to be like them.

In general, they tended to be less interested in the children who had been conceived *and* raised by their donor. They referred to them as the donor's "own children". Although they were genetically related to them, their relationship was marked by difference, as they did not share the experience of being donor-conceived. Under certain circumstances, however, these half-brothers and half-sisters could also become the focus of their interest. This was the case with 21-year-old Jacob Moore, who, along with Amber Jones, was the only one of my interviewees who had grown up knowing about the circumstances of his conception. He was the only egg-donor-conceived person that I interviewed. Jacob was close to finishing his science-oriented master's degree when I met him in a coffee shop close to the university building where he was studying that day. In contrast to Amber, who occasionally spoke about the circumstances of her conception at home, Jacob mentioned that he had never had a profound or even casual conversation with his parents about it. He believed that this was related not only to him being still very young when his parents told him but also to the fact that there simply was not anything he wanted to talk about: "Mostly because I didn't really have anything I wanted to discuss, I was a very nerdy child, I understood all the science background of it, so I was just like, 'Oh well this makes perfect sense to me.' And I didn't really pursue it any further."

What struck me when talking to him was that answering questions with "I don't know" clearly did not bother him at all which distinguished him from almost every other person I interviewed. For example, he did not know why his parents had chosen ova donation (he assumed that his mother had had "some kind of illness" but could not remember the details) and did not know whether his parents had told anybody else about their fertility treatment (he mentioned that he "wouldn't be surprised if people knew", but added that he also "wouldn't be surprised if they didn't know"). He also did not know why his parents had chosen to tell him (he assumed that his parents probably "did some research into it" but mentioned that "they could have also just decided to wing it and just make it up as they go along"). Questions that others attached a great deal of importance to were not relevant to him. Answering one of my questions with "I don't know" was mostly uncomfortable to others. It seemed to remind them of conversations they could not have with their parents, who often did not openly talk about the topics my interviewees wanted to know more about. In contrast, Jacob did not seem to mind not knowing, and he even mentioned that he had pretty much forgotten that he was donor-conceived in his teenage-years.

Jacob had only started to properly think about the circumstances of his conception and "deal […] with it as an adult" when he read an article about IVF and "discovered" the possibility that he might have donor-conceived half-siblings, which he had previously not been aware of. Since he was an only child, he felt that this "might be worth pursuing". When he applied to the HFEA to find out whether he had any donor siblings, he had also asked for information about his donor "just to find out". While for others the anonymous donor was in the foreground from or at least in the beginning, Jacob's request for donor information had only followed from his interest in any donor siblings he might have. Finding out that he did not have any donor-conceived half-siblings had not surprised him, and he commented that "it's obviously much rarer to have them with egg donations as opposed to sperm donations".[30] Furthermore, he was not disappointed when he found out that his egg

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[30] Sperm cells are continuously produced within the testicles, while egg cells are already present at birth. The number of oocytes a person has is thus finite. Besides, eggs are more

donor was still anonymous. Jacob mentioned that he had no great hopes that she would ever remove her anonymity because “she donated under the impression that it would be anonymous forever”. However, he remembered being taken aback by learning that his donor had already had her own children at the time of her donation:

> Jacob Moore: “So I was expecting there to be no donor-conceived siblings, but I hadn’t thought about the possibility that I had half-siblings that weren’t donor-conceived. So that was a bit of a shock to me. It’s mostly weird for me because they are probably in their 20s, I think they probably live around the [part of the country where he lived] of England, so I could well run into them. But it’s a bit weird to walk up to people and be like, ‘Hi, nice to meet you. Was your mom born in 1961?’ […] So that was a bit of a shock to me. But I can’t find out anything else.”

Similar to those who expected to have donor siblings, or already knew that they had some, he imagined his genetic half-siblings to be of a similar age to him. Besides, he suspected that they lived rather close to where he had grown up. Jacob could not connect with them via the DSL, as they were not egg-donor-conceived.[31] Due to the anonymity of his donor, of whom he only knew the year of birth and a few other details, he could not identify these half-siblings. Given Jacob’s calm, sober nature, I found it particularly striking that the discovery of these lateral connections had shocked him. His sibling network had expanded in an unexpected direction, with half-sisters and/or half-brothers for whom his anonymous donor was a parent.

The story of Tamara Haste and her younger sister Becca Haste was fundamentally different from the experience of Jacob Moore, although all of them were conceived in the UK in the 1990s. The two sisters, together with Becca’s twin Emily (whom I did not interview), only learnt of the circumstances of their conception when the twins were 18 and Tamara was 20.[32] They had found out via the HFEA

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difficult to separate from the body: while egg donation requires hormonal stimulation and surgical extraction, sperm can be produced by masturbation; and while one egg donation cycle might produce approximately ten to 20 eggs, one ejaculation can produce millions of sperm cells. Therefore, a sperm donor is likely to have more donor offspring than an egg donor, and a person conceived with donated sperm is likely to have more donor siblings than a person conceived with donated ova.

[31] Even if his donor’s children were conceived with donor sperm and could join the DSL, they would not be matched with Jacob Moore, but only with those who have the same sperm donor.

[32] Like Jacob Moore, Tamara Haste had also learnt about my research through the DCN. Tamara had immediately offered to put me in touch with her sisters, which I had gladly accepted. Whereas I met Becca Haste shortly after meeting Tamara, Becca’s twin sister Emily Haste was abroad at the time of my research, and I was not able to interview her.

that they had, as Tamara had put it in her first email, “a lot of donor-conceived siblings out there”. During a walk with their dog on New Year’s Eve, their mother had told them about the circumstances of their conception. By this time, they had had almost no contact for several years with the person they thought was their father, and Tamara did not call him “father” or “dad”, but “the man”. Almost two years had passed since this initial conversation. Their mother still found it very difficult to talk about everything, as she seemed to blame herself for the pain that not knowing who the donor was had caused her daughters. She had also told them that they had been conceived with sperm from the same donor. As I mentioned in section 6.3, some of my interviewees were glad that they did not have the same donor as their sibling, as they felt that this gave them more freedom in their search. However, both Tamara and Becca were relieved about the fact that they all had the same donor, as it meant that no one would feel excluded from their search and/or sibling group. Tamara mentioned that they would be “sort of stuck on our own” in their search if they did not have the same donor. She also felt that it would be “more dividing” if one of them managed to find her donor while the others did not. Her sister Becca in turn suspected that Tamara “would probably feel a bit isolated” from her and Emily if the twins had a different donor.

Shortly after they had been told by their mother that they were donor-conceived, Becca had applied to the HFEA for information about their donor and donor siblings on behalf of the three sisters. Although finding out that they were donor-conceived had been, according to Becca, “quite a shock”, they had become interested in their donor siblings pretty soon after that. Becca commented that “we started to realise, if we’re donor-conceived, wouldn’t that mean that we have half-brothers and sisters. I think it was always something that we knew we wanted to find out.” Tamara mentioned that the HFEA application form they had to fill in “warns you a lot through it, ‘We warn you that it’s likely there will be no siblings, and like maybe one or two’”. For this reason, they “weren’t expecting anything and it came back and it said that we had 28”, which meant that in total, 31 children had been conceived with their donor’s sperm. Finding out that they had 28 unknown donor-conceived half-siblings had been an overwhelming experience for Tamara, who also explained that she had wanted to find their donor siblings “because they were part of that experience and my new identity as a donor-conceived person”.

> Tamara Haste: “I read a news article where it was this big thing because they found out a donor had fathered 34 children. I was like, well, we’re only three less than that, there’s still 31 of us. Apparently, the norm is like five maybe, if that. And there’s 31 of us, that’s just *mad*. And just because you don’t know, you start imagining all these possibilities. And you think that nothing is unlikely, these siblings could be anyone or anything.”
> Amelie Baumann: “And anywhere, I guess.”

> Tamara Haste: "Yeah, some could be dead, some could be in prison, some could have their own children, some could be famous and could be literally anything, it's just mind-boggling."

Knowing that they had 28 donor siblings was also an overwhelming thought for her sister Becca, who commented that they had enough siblings "to fill an entire classroom". Tamara and Becca were the only ones among my research contacts who knew that they had a double-digit number of donor siblings, and their fear of potentially entering an incestuous relationship with a donor-conceived half-brother seemed to be caused by their large number of siblings. While the topic of incest was rarely brought up by others, the thought of unknowingly falling in love with one of her half-brothers worried Tamara: "That's probably really silly, but an actual concern of mine is that [laughs] I'm going to marry my half-brother." Her younger sister Becca told me that "there's a chance I could be biologically related to them [her future partner], I think that's terrifying. Like also the fact that there's 31 one of us in total, being siblings, what if I met my sibling and they didn't know about it?" The thought of potentially having 'too many' donor siblings that might even be scattered all over the world also upset those who did not talk about incest. One of my interviewees from Germany, for example, had just found out that 'her' doctor's sperm bank had in the past shipped sperm to other European countries. She commented that the thought of having donor siblings all over Europe bothered her, as it made everything "too diffuse".

Donors who supposedly have many or too many offspring are repeatedly made the subject of media reports that are characterised by a mixture of fascination and horror.[33] The question of how many children or donor siblings are too many has been subject to policy debates and regulation. Different countries have set different limits on the number of children that can be conceived with gametes from one donor or families that may use the same anonymised source (Nelson et al. 2016: 43–44), thus attempting to control and regulate 'sibling dispersion'. In the UK, a donor can be used for up to ten families (Millbank 2014b: 327). In Germany, an association of sperm banks, reproductive medicine professionals and fertility clinics has set themselves a limit of 15 children per donor (Hammel et al. 2006: 172), which is however not a legally binding regulation.

While avoiding incest and making contact between donor siblings easier are the official policy rationales for numerical limits (Millbank 2014b: 336), I suggest that the discomfort that having a lot of donor siblings evoked, regardless of what

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[33] An article that was published online, addressing an American reality-TV-show, was entitled "The Trouble With Fathering 114 Kids: A suitor on *The Bachelorette* says he is a sperm donor with 114 kids - is that too many?" (Zhang 2019, emphasis in original) The author notes, "DNA tests and online registries have also revealed cases in which single donors have produced 50, 100, even 189 biological children" (ibid.).

exactly was considered to be 'too many', is also related to a fear of donor siblings dissolving individuality. As such, the fears that having too many donor-conceived half-siblings evoke are similar to the fears commonly evoked by cloning and clones. These fears have been discussed by Franklin (2007) in her monograph *Dolly Mixtures*. She argues that 'clone sheep' Dolly has "simultaneous connotations of duplicity and singularity" (2007: 29). Dolly is both a replicant that is "diminished by lack of a proper genealogy – and thus identity, substance, or origin" (2007: 26), and a previously "impossible animal" (2007: 27).[34] Although Dolly is special and unique, the clone has long been "an abject embodiment of a particular kind of genealogical shame" (2007: 26), as it is identical with its progenitor, and thus considered to be "a fake, a derivative, a copy, or a mere replicant" (ibid.)

I suggest that the dispersed nature of donor siblingship was perceived to be something that involves the danger of turning an individual into a multiple or "mere replicant". Similar to the irritation that the feeling of being too similar to one's donor could cause (section 5.3), having too many donor siblings could be experienced as a threat to individuality. It is arguably not coincidental that on the flyer created for the workshop held at the thirtieth anniversary of the CRC, which had been organised by donor-conceived persons (section 3.1; see also figure 1), the question "What if they have hundreds of siblings?" is followed by "What if money changed hands to create them?" (International Social Service 2019). The fear of being a commodity, of "being made to order or copied" (Franklin 2007: 204) is also the fear of not having one's rights respected by those who, according to donor-conceived activists, serve parents and the 'fertility industry'. The fear attached to the clone or copy is thus also a fear "of loss, devaluation, and worthlessness" (ibid.) Being part of a mass of siblings that has been "made to order" epitomises such fears.

Overall, donor siblings can serve as "a reminder of the unexpected and unpredictable means in which kinship can be ignited through desire, will and intention" (Edwards 2013: 291). They are a prime example for kinship being a dynamic process instead of a static structure. The unpredictability of relationships, which can lead to disappointment when they do not develop as hoped for, was particularly evident for two of my interlocutors who had made contact with some of their donor siblings some time ago. Given the small numbers of registrants and the even smaller number of matches, I was not expecting to meet someone who had found a donor sibling via the DSL. As a result, I was surprised when Tamara told me that they had found a donor-conceived half-sister and a half-brother via the voluntary register. Becca was the one who had gone through the formal process of applying for information and joining the DSL on behalf of the siblings. She soon received a call from the HFEA, informing her that one of their 28 donor siblings had registered.

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[34] Dolly, the first mammal to be cloned from an adult cell, was born in Scotland in 1996.

The HFEA then contacted their donor-conceived half-sister who agreed to be put in contact with them, and Tamara and her sisters soon sent her a first email. It tuned out that their newfound donor sibling also had a brother who had been conceived with sperm from the same donor. The two of them had been raised in a different country, and still lived abroad.

However, their donor siblings stopped replying to their messages after some time, despite initially mentioning that they were excited and happy about finding them and interested in meeting up. Both Tamara and Becca seemed to be sad and upset about this development, with Tamara commenting that she could not understand why her half-sister had registered with the DSL if she was not interested in maintaining contact. While they all had initially decided to activate their connection, their donor siblings apparently did not reciprocate their desire for an active relationship, which was what Tamara and her sisters had hoped for. For example, Becca told me that if they met any more people via the DSL, she would "love to become really close to them because at the end of the day, they're our siblings". The relationship between Tamara, Becca, Emily and their donor siblings had been mediated through formal infrastructures that are set in place and managed via official regulations. However, their experience suggests that the way in which a relationship unfolds cannot be regulated. One can only speculate about why their donor siblings broke off contact at some point. While some of the donor-conceived might see these unprecedented or "wayward relations" (Klotz 2016) as an exciting "area to interpret relatedness in new ways" (Klotz 2016: 45), this "lack of established social roles to which they can conform" (ibid.) might also be overwhelming for others.

7.6 Matching probabilities: Voluntary registers and DNA testing

A gap highlighted by law scholar Jenni Millbank (2014a) is that formal registers exclude conceptions that occurred prior to their establishment. In the UK, the voluntary register DCR, which is funded by the Department of Health, attempts to close this gap. Those who were conceived or donated before 1991 and who wish to join the DCR can either do so by only providing contact details and information about their conception or donation, or by also opting to submit a saliva sample that is then tested by a laboratory at King's College in London and added to the register's own DNA database. Since late 2019, the DCR is run by the Hewitt Fertility Centre at Liverpool Women's Hospital. The Hewitt Fertility Centre also offers counselling sessions, the first two of which are free, to registrants.[35] In the following section, I

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[35] During the time of my research in the UK, the DCR was still run by the National Gamete Donation Trust (NGDT), a charity established to raise awareness for gamete donation which has since then been renamed Seed Trust (www.seedtrust.org.uk, last accessed May 28, 2020).

will focus on the DNA register and introduce the type of testing that it uses. I will then elaborate on some of the studies from the social sciences that critically examine this testing technology and its use and interpretation in forensics. This body of work highlights that, contrary to how DNA testing is perceived in the public and legal domain, it cannot be a "truth machine" (Lynch et al. 2008) that eliminates any kind of uncertainty. Finally, I will discuss how my interviewees felt about the register and why it was seen as something that had to be joined, regardless of the chances of success.

Given the absence of an official register before 1991, exact estimates about the number of people who were conceived with donated gametes before the establishment of the HFEA and are eligible to join the DCR are hard to make.[36] Besides, it is equally difficult to estimate the number of people who know that they are donor-conceived and might be interested in joining. One can therefore not easily say whether the 172 donor-conceived registrants that the DCR's predecessor had in late 2012 (van den Akker et al. 2015: 113) represent a large amount of all donor-conceived people or not (see also the discussion in section 7.2 about what is known statistically about donor conception).[37] Since secrecy was still a prevailing norm in the 1980s, it seems reasonable to assume that a large part of those conceived during that period do not know about their donor-conceived origins, which significantly reduces the pool of potential registrants. Apart from a voluntary register run by the social work organisation Fiom in the Netherlands,[38] the DCR is the only DNA-based voluntary register that is government-funded (van den Akker et al. 2015: 112; Bolt et al. 2019). In contrast to commercial databases such as Ancestry,[39] the DNA sample (a mouth swab) for the DCR's DNA register has to be taken by a licensed medical professional. Registrants are charged 95 pounds (100 at the time of my research in the UK) for joining the DNA database. Apart from that, the DCR is free of charge. Registrants are also invited to join a hidden Facebook group that is only

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In April 2017, the HFEA took over responsibility for the DCR from the Department of Health after the Department had halted its funding for the register. It continued to be run by the NGDT (HFEA 2017a). An invitation to tender was put out by the HFEA in November 2017 (HFEA 2018c). Since a new provider had not been found when the contract with the NGDT ended on 31 March 2019, the register then went on a hiatus before the contract was awarded to the Hewitt Fertility Centre.

[36] Konrad states that, according to information from the Department of Health, 12,000 people were conceived with donated gametes before the establishment of the HFEA (2005a: 9). Konrad herself points out that this number "is only an estimate" (ibid.), as there is no central database for pre-1991 treatments.

[37] In late 2012, UKDL had 248 registrants in total (van den Akker et al. 2015: 113). A former donor and DCR registrant told me that the register had about 300 donor-conceived members when I interviewed him in September 2016.

[38] www.fiom.nl (last accessed May 28, 2020).

[39] www.ancestry.com (last accessed May 28, 2020).

open to DCR members, where an invitation to participate in my study was posted. In the following section I will introduce the type of DNA testing used by the laboratory that analyses the DCR's samples, which is different from the type of testing used by the commercial databases discussed in the next chapter. I have deliberately kept this part as short as possible and have included more detailed explanations in the footnotes.

DNA, short for Deoxyribonucleic Acid, stores genetic information, with the totality of nuclear DNA in a cell making up the genome. DNA consists of four nucleotide bases that are abbreviated with their first letter respectively: adenine (A), guanine (G), thymine (T) and cytosine (C) (TallBear 2013: 40). The kind of DNA test used by the lab commissioned by the DCR is called Short Tandem Repeat (STR) test. This test uses a certain number of genetic markers. Such a marker is a specific DNA sequence that has a known location on a chromosome, which is a molecule that contains the majority of DNA.[40] As a child will definitely inherit one STR value (number of times a sequence such as GATA is repeated) from each person that contributes a gamete (TallBear 2013: 88–89), STR tests are reliable for paternity testing. Sperm donor-offspring relations can therefore be determined with a high degree of accuracy with such a test.[41] However, STR tests are not as accurate if they are used to prove a sibling relationship,[42] and labs conducting STR tests have to rely on statistical equations that calculate the frequency of a given value in a population in order to determine how likely it is that two persons are siblings (Klotz 2014: 272–273).[43] Interpreting test results and deciding what can be classified as a "match" between genetic half-siblings can be a complicated matter, and the DCR

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[40] Chromosomes come in pairs, with one part being passed on from each person that has contributed a gamete. They are numbered 1–22, with the "sex chromosome" constituting the twenty-third pair. A STR test looks at how often a segment of DNA is repeated at a particular location on the chromosome and compares the results to that of another person. A STR might for example contain a certain number of repeats of "GATA"; while "GATA" might be repeated five times on chromosome no. 5 of one person, another person might have 16 repeats on the same chromosome.

[41] If a child has values 1 and 2 at a given marker, then he/she will definitely have received a 1 from one person and a 2 from the other; if a sperm donor has values 3 and 4 at that location, the child was not conceived with his gametes.

[42] The values that siblings have at a given marker might not match up. Child A might have values 1 and 2, whereas child B might have values 3 and 4. At first glance it would seem that they are not related at all. However, if their father has the values 1 and 3 at the marker in question, then each child could by chance inherit a different value. For this reason, a sibling relationship (as well as other relationships between, for example, grandparent and grandchild) cannot be proven with the same certainty as a parent-child relationship.

[43] Whereas each possible value will be carried by millions of individuals, some variants are less common than others. If two persons match on a variant that is rare, they are much more likely to be related than if they are merely matched on a common variant.

was undergoing a process of upgrading its genetic database by retesting existing samples at the time of my research in order to strengthen the accuracy of its testing. Since detecting actual sibling relationships is not a straightforward task, it has already occurred that a match had to be declared as invalid when new data was added to the database (Pryer 2010; Klotz 2014: 272). Individualising a person's DNA profile and matching it with another profile can only ever be probabilistic (Butler 2015). Increasing the number of genetic markers can increase the probability that a detected match is an actual match instead of a "false positive" one. Nevertheless, an increase of testing points will not change the fact that tests work with probabilities that can get lower or higher. The interpretation of results always has a certain degree of uncertainty to it.

The specific type of DNA testing employed by the DCR is also used in forensics (Lynch et al. 2008), where genetic testing is commonly ascribed an "allegedly unlimited evidential power" (Amorim 2012: 259). It is mostly seen as "an almost failsafe way to identify individuals and to match traces found at crime scenes with a suspect's [DNA] profile" (Heinemann et al. 2012: 249) and is therefore "considered to be the new gold standard of forensic science" (Aronson 2007: 6). However, scholars from the social sciences have long offered a much more critical perspective on the kind of results that genetic testing can yield. Their perspective destabilises the almost unquestionable certainty attributed to DNA testing (Heinemann et al. 2012). It has also been argued that "a high probability that the trace has indeed been left by the suspect is not the same thing as absolute certainty" (Kruse 2010: 86). While technical improvements might have managed to remove certain "sources of uncertainty" (Lynch et al. 2008: 233), these sources have also "been made more obscure" (ibid.) by administrative and bureaucratic developments (see Aronson 2007 for an analysis of the early history of DNA testing).

Due to the specific nature of the results of STR tests, the DCR's predecessor UKDL had in the past not spoken of "matches". They had instead opted to use the word "link" which was also part of the register's name ("UK Donor Link"; Crawshaw et al. 2016: 376). Various publications on UKDL point out that the results of DNA tests are inherently uncertain, and that testing necessarily has to operate with levels of probability (see for example Crawshaw and Marshall 2008: 236; van den Akker et al. 2015: 118–119; Crawshaw et al. 2016: 388). The Hewitt Fertility Centre, which manages the DCR, seems to be guided by these works and primarily uses the word "link" on its website.[44]

Those of my interviewees who had joined the DCR pointed out that the register was not sufficiently known among potential registrants, and that a lack of funds prevented this from being changed. Elizabeth Chapman, for example, had in the

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[44] www.liverpoolwomens.nhs.uk/our-services/donor-conceived-register-dcr/ (last accessed May 28, 2021).

past agreed to be interviewed for a newspaper article on donor conception with the aim of promoting the DCR. She had done so in the hope that it might encourage past donors to come forward and register, and that parents might be encouraged to tell their adult children about their origins. When I interviewed her, however, she did not hold any hopes regarding the DCR, as she felt that "nobody's putting money in, nobody's encouraging at all". Besides, she believed that the kind of DNA testing used by the DCR was "old-fashioned", compared to what modern commercial testing services had to offer. In general, those of my interviewees who were registered with the DCR did not seem to have much hope that they would ever find a donor sibling or their donor via the register. Given the small number of matches, their doubts do not seem unreasonable: according to an HFEA meeting paper from November 2018, around five people are matched per year (HFEA 2018b).

Similar to Elizabeth, Jessica Robertson felt that it was "a shame" that the register was not more widely known. Jessica was trying to get pregnant with donor sperm and had already completed two rounds of IVF at a UK clinic, with the first cycle resulting in a pregnancy that she lost early on. As part of her treatment, Jessica had had counselling sessions during which she had mentioned to the counsellor that she herself was donor-conceived. The counsellor had then told her about the DCN and the DCR. Jessica had joined both organisations in the same week, noting that she would have done so earlier if she had known of their existence. She had also decided to add her DNA to the DCR's database. However, her saliva sample had not been processed even one year after she had had her DNA sample taken. Like others (see the last paragraph of section 6.4), Jessica was convinced that many men were "very slightly curious, or even really quite curious about what happened with their donations, whether there are children". Since she feared that past donors probably did not know that there was something "they can do about it", she felt that the DCR should receive more publicity. However, she was not very hopeful that this was going to happen: "There's no funding for it, even to carry on doing what it's doing at the moment, let alone advertise." When I asked her about her motivation for joining the DCR, Jessica commented she had felt compelled to join the register as soon as she knew it existed:

> Jessica Robertson: "I'm not going to go to the lengths that some people go to, and they're trawling through university yearbooks, looking at photos from medical students that look like them, I think that's a bit ridiculous. But because this was an easy thing to do, and it was 100 pounds or something, it wasn't a huge amount of money … I couldn't not join. And it's not that I'm desperate to find my donor or genetic half-siblings, it's that … knowing that I *can* put myself out there … I can't not [do it]."

While Jessica felt that she had to "put [herself] out there", she rejected "ridiculous", 'excessive' methods such as going through old yearbooks. Since it is often assumed that sperm donors were recruited among medical students, these books are sometimes used by the donor-conceived to find pictures and names of former students (Cushing 2010). While new technologies create new possibilities to access and connect information, the practice of going through yearbooks demonstrates that the "infrastructuring" (chapter 8) of information is in itself not a new phenomenon. However, this was not a path that Jessica wanted to take. While she may not have taken absolutely every opportunity available to her, she had done everything she could *reasonably* do. She had not only tried to find the donor and her donor siblings, but she had also made sure that she could be found by others.

With a DNA register such as the DCR's database, it is not only about requesting information. Instead, they require the donor-conceived to "put themselves out there" and enter a position where others can find them. Commercial DNA testing introduces new possibilities for the donor-conceived to "put themselves out there", although buying a test was not solely agency-driven (section 8.3). Having to take advantage of the opportunities that existed did emerge as a recurring motif in many narratives, particularly with regards to commercial genetic testing. This technology, the work that people put into it, and the hopes it evoked, will be explored in the next chapter.

7.7 Recapitulation

While in Germany there has only been a national register in place since 2018, in which information on treatments and donors is stored centrally, such an infrastructure has existed in the UK since 1991. However, since the law was only amended in 2005, without the change being retrospective, those conceived after the establishment of the HFEA but before 2005 are only legally entitled to what the Authority classifies as "non-identifying information". For this reason, the HFEA and the clinics that recruit and register donors have a redaction process in place to remove potentially identifying information from what is released to an applicant. Those who are responsible for the redaction process rely not only on formal guidelines but also on their ideas about what those who receive the information might possibly do with it. Redaction is particularly relevant for more recent donors, as they may choose to write voluntary "goodwill messages" and "pen portraits" that might include identifying details about them. In contrast, the information that my interlocutors received was more limited and mostly restricted to a few descriptive categories. It was anticipated by the HFEA, as the institution that manages and releases the information, that applicants would be disappointed by this, and the Authority's attempt to manage expectations was something that ran through many HFEA texts and documents. The assumption that questions will remain open for those conceived in the 1990s turned out to be correct for the people I interviewed.

The non-identifying information that they were able to obtain was generally described as not sufficient to "know the donor as a person". This was a phrase that many people in both the UK and Germany used when describing what they wanted to know about their donor. They were particularly interested in learning about the donor's family and how his life had developed and changed after the donation.

Especially the latter wish can often not be fulfilled with the register information, which is recorded at a certain point in time. The management of expectations did not stop once people had received their reply letter from the HFEA. Although their donors were still anonymous, new regulations make it possible for them to remove their anonymity. However, this is not something that donor-conceived persons can count on with certainty. The voluntary removal of anonymity thus has the potential to create both hope and uncertainty, with the donor-conceived knowing that they might receive identifying information, but that they might just as well not receive anything. There is also uncertainty regarding the possibility of coming into contact with donor siblings. Although the HFEA offers a separate sibling register, this database is based on voluntary registration, and registrants cannot be certain that they will find someone. Those that I interviewed in the UK and Germany generally had a great interest in their donor siblings. Contact with them was seen as an opportunity to learn more about the donor. In contrast, most people were less interested in the donor's "own children" who do not share the experience of being donor-conceived, and who cannot be contacted through the HFEA. While many expected relationships with donor siblings to be positive, the experience of two sisters I interviewed in the UK indicates that such expectations might not always be fulfilled.

Apart from the uncertainty with regards to the various options and registers managed and/or offered by the HFEA, there are also uncertainties with regards to the voluntary register DCR. It has its own DNA database that is intended to enable those conceived before 1991 to find their donors and donor siblings. With the type of DNA test used for "matching" or "linking", which is also used in forensics, it is not possible to identify with certainty a genetic relationship between donor siblings. Furthermore, my interviewees who had registered with the DCR did not seem to be very hopeful about their own chances of getting a match, as they did not believe that the register was widely known about. Nevertheless, it was seen as a possibility to "put yourself out there" and was perceived as an opportunity that had to be taken.