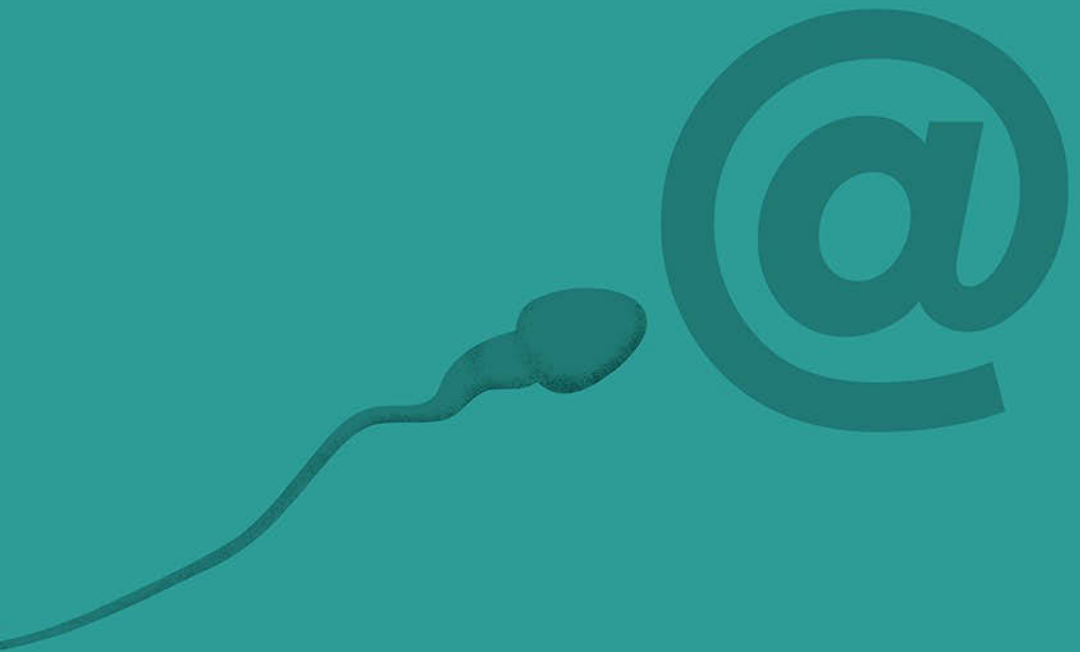


Amelie Baumann

# BECOMING DONOR-CONCEIVED

The Transformation of Anonymity  
in Gamete Donation



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[transcript]

Amelie Baumann  
Becoming Donor-Conceived

**body cultures**

*This book is dedicated to my grandmother, Leni Hitz,  
for her unwavering support and encouragement.*

**Amelie Baumann** is a postdoctoral researcher at Freie Universität Berlin, where she is an associated member of the Collaborative Research Centre “Affective Societies”. She completed her doctorate in cultural anthropology at the University of Bremen in 2020 and was part of the interdisciplinary research project “Reconfiguring Anonymity”, funded by the Volkswagen Foundation. Her research focuses on medical anthropology, the anthropology of ageing and kinship studies.

Amelie Baumann

## **Becoming Donor-Conceived**

The Transformation of Anonymity in Gamete Donation

**[transcript]**

This publication was submitted to the doctoral committee Dr. phil. of the University of Bremen as a dissertation.

Examiners: Prof. Dr. Michi Knecht, Prof. Dr. Jeanette Edwards

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## Introduction

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I am a retrained left-hander. Are you left-handed?

Dear former #spermdonors, we would like to get to know you. Please get in touch!

#searchforpersons #whoareyou

#showyourself #donorchildren

#searchmission #Berlin

#yourspermmasaname #donorconceived

#unknownfather #childrensrights

#righttoknowyourorigins

*Spenderkinder, Instagram post, March 2020*

A few weeks before submitting my PhD thesis, I came across an interesting and significant development with regard to my research interests. The German association Spenderkinder (literally “donor children”) published a press release, the content of which I wanted to mention. Spenderkinder is an advocacy group comprised of donor-conceived persons. When researching the transformation of anonymity in gamete donation, I found ten of my interviewees from among this very group.<sup>1</sup> Many of them had mentioned that German doctors, clinics and sperm banks failed to provide them with information about their anonymous sperm donors. While some were told that all documents had been destroyed, others were told that since donors had been guaranteed anonymity, no documents could be released. In my research I investigated, among other things, the means the donor-conceived use to obtain information in such situations. With the project described in the press release, a new search strategy was added to the repertoire, and an existing one was expanded. Spenderkinder announced that they would launch a social media campaign in March 2020 (Spenderkinder 2020b). Using the slogan and hashtag #zeigedich (“show yourself”), they would post incomplete pictures of members on Twitter, Instagram and Facebook in the following weeks.<sup>2</sup> According to a board

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1 [www.spenderkinder.de](http://www.spenderkinder.de) (last accessed May 23, 2021).

2 A hashtag is a word or phrase preceded by the “hash” sign (#). Hashtags are mostly used on social media platforms such as Twitter and Instagram to mark a post, conversation, or “tweet”.

member quoted in the press release, these posts were intended to reach former donors: in recent years, the association repeatedly called on reproductive physicians, who previously assured donors of anonymity, to assume responsibility. Ultimately their efforts proved futile. Now Spenderkinder decided to address former donors directly; the press release detailed how the donor-conceived want a genetic father who both acknowledges his past as a donor and acknowledges his children. The press release claimed to mark the first time where so many donor-conceived persons appeared openly in a photograph. The association stated that in order to find their offspring, former donors should register with a commercial DNA database, which requires submission of a saliva sample. These databases that facilitate genetic “matching” between registrants are mostly used by people interested in ancestry research and/or personalised genetic health reports. Since late 2011, members of Spenderkinder had been using one of these databases to identify genetic half-siblings – those who had been conceived with sperm from the same donor but who had grown up in different families (also known as “donor siblings”). In order to identify a sperm donor, he does not necessarily have to be registered himself; instead, it is sometimes sufficient if one of his relatives has added their DNA to the database and is genetically “matched” with the donor-conceived. Spenderkinder is clearly aware of this, as they encourage not only donors, but also all other persons to take a test: “The more people register with DNA databases, the more chances donor children have of finding their genetic fathers through other relatives.” (Spenderkinder 2020b, author translation) A few days after the press release, the first part of the campaign went online.<sup>3</sup> The post shows one half of a person’s face and states their first name, the year and the city where they were conceived. The member is quoted with the following sentence and question: “I am a retrained left-hander. Are you left-handed?” On Instagram, the post is captioned as follows: “Dear former #spermdonors, we would like to get to know you. Please get in touch!” (Author translations) In addition to #zeigedich (“show yourself”) several other hashtags follow. These include #deinsamenhateinennamen (“your sperm has a name”), #werbistdu (“who are you”), and #kinderrechte (“children’s rights”).

While I do not know whether the campaign had its desired effect, its very existence is relevant to the developments and dynamics I am interested in: anonymity in gamete donation is in transformation, and the donor-conceived are part of this process. In this book I examine how those who were conceived with anonymously

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Hashtags serve among other things as a retrieval system: by clicking on any given hashtag, users will be shown all (publicly available) posts that are marked by the same keyword or phrase.

3 Before the first picture showing a member of the association was posted on Instagram on 3 March 2020, a few other pictures had already been posted, all of which fit the campaign’s message. For example, a picture of a cat was posted with the following caption: “I know my cat’s origins better than my own.” (Author translation)

donated gametes in the United Kingdom (UK) and Germany are (1) involved in, (2) drive and (3) shape this process of change that takes place at the intersection of practices, regulations, technologies, narratives and relations. I argue that being donor-conceived becomes a meaningful and powerful identification only through the complex intertwining of these various factors and not through someone else's decision to conceive with gametes from anonymised sources. Indeed the title of this book: *Becoming Donor-Conceived*, deliberately articulates the concept of the donor-conceived as active, rather than passive participants. João Biehl and Peter Locke describe "becoming" as a concept that "destabilizes the primacy of being and identity in the Western philosophical tradition" (2017: 8). As such, this concept fits the overall approach of my research because I do not pre-define or condemn anonymity as a threat to personal identity. Instead, I start from the assumption that anonymity is always socially productive (Bachmann et al. 2017), producing new identifications, imaginations, and forms of sociality. This book thus deals with the transformation of anonymity in two ways: on the one hand, I conceive of gamete donation as a concrete case study in which a transformation away from prescribed anonymity and towards a protected "right to know" can be observed. On the other hand, I am also interested in "[o]pening up anonymity" (Konrad 2005a: 241) and re-thinking it in a way that acknowledges the ways in which it can be inventive (Konrad 2005a: 242).

I am pursuing this twofold approach by focusing on a group of people who have only benefited to a limited extent from some of the legal changes that have occurred in recent years and decades. In both the UK and Germany, there has been a transformation in terms of the regulation of anonymity: in the UK, information on treatments involving donated gametes has been stored in a central register since 1991. However, only those conceived after 2005 can apply at the age of 18 for what the administering authority classifies as "identifying" donor information. By contrast, Germany established a similar infrastructure in 2018. Those conceived after 2018 will have access to "identifying" information at age 16. In both countries, the regulations only applied to treatments that took place after the respective laws came into force. Those who were already adults or had reached the respective minimum age at the time of my ethnographic research from 2016 to 2017, did not benefit directly from these registers – they had been conceived too early. I focus on these excluded individuals in this book. They all had donors who were supposed to remain anonymous, not only at the time of the donation and treatment, but also for posterity. This book provides a particularly unique perspective on anonymity, since in the case of my interlocutors, who were all 18 or older, anonymity had already 'come into play' at least nearly two decades before my research. In this book I investigate how these persons interpret, discuss and problematise anonymity, and how they perceive of the circumstances of their anonymous conception. I attend to the various ways in which people negotiate living with non-knowledge: knowing that

they have been conceived with donated gametes, but not knowing the identity of the donor. In doing so, I seek to explore how they access both formal and informal infrastructures to ‘overcome’ anonymity, attempt to enforce their “right to know” together with others and form new social relations and kin connections in that process. A central question explored here is how the donor-conceived themselves both contribute to and are involved in the transformation of anonymity. Particularly, I am interested not only in how they formulate their demands in a public arena, but also in how they address, reflect upon, and drive this change forward in less visible practices and more everyday considerations.

### Opening up anonymity

While countries such as Spain and the Czech Republic still mandate donor anonymity by law and remain as popular destinations for those deciding to pursue treatment with donated gametes abroad, both the UK and Germany have updated their stance. These two countries have moved away from permanent anonymity, which was either protected by law or clinically practiced, and moved toward the “right to know” of the donor-conceived. Some argue that these developments have “ended” anonymity. Furthermore, the “end of anonymity” has been proclaimed not only in view of the legal development but also because of the growth of commercial DNA databases (see for example Harper et al. 2016). However, this project begins with the assumption that the anonymity of gamete donors, like any other form of anonymity, is always partial and never complete. It never exists in absolute form (Erois 2009). Gamete donors are always anonymous only in relation to certain persons, at a certain time, and in certain situations. Anonymity is always relative and has neither a clearly defined end nor a definite beginning. For this reason, I do not set out to examine the “end of anonymity” in gamete donation. Instead, I explore its transformation.

Most of the people that I interviewed did not learn until adulthood that they were conceived with donated gametes, and many of them told me that their parents had been advised to keep the treatment a secret. While anonymity and secrecy are sometimes used synonymously in discussions about gamete donation, they are terms that refer to two different forms of non-knowledge: “At its most basic, anonymity is a mechanism for keeping the identity of the donor hidden whereas secrecy has to do with keeping the genealogical origins of the child hidden.” (Konrad 2005a: 173) The two need not appear together. For example, parents who conceived a child with an anonymous donation may decide to tell their child about the treatment, while not telling (and not being able to tell) their son or daughter who the donor is. Anonymity is also not the same as privacy, which can be described as “a function of which pieces of personal information are known *simpliciter*” (Ponesse

2013: 330, emphasis in original); while I might be close friends with my neighbour, I might not know that he is a sperm donor. This, I suggest, is an example of a privacy relation, i.e. I know my neighbour, but some information about him is hidden from me. Anonymity in turn pertains to different constellations. Once a child has been told that he/she has been conceived with donor sperm, he/she might still lack the information he/she would need to link his/her conception to the man whose sperm was used, and whom he/she might already know by name and in person. Similarly, a person might even have a donor profile with basic, or even more detailed, information, but might not know that the information is about someone they already know – even if said person was their neighbour. The donor's anonymity would be dissolved only if the offspring could manage to make that link.

While anonymity always has to do with “an absence of information” (Bachmann et al. 2017: 247), it is not always about namelessness, as its etymological roots might imply.<sup>4</sup> Neither is it necessarily about facelessness, although concealing one's face might indeed be a means to avoid identification through, for example, facial recognition systems. Instead, anonymity is always about “constellations of *partial* unknowability, invisibility and untrackability” (Bachmann et al. 2017: 243, emphasis added). The dissolution of anonymity, which is never a “yes” or “no” thing, is less about the amount of information that is available, and more about a “shift in associability, or linkability” (Ponessa 2013: 330). I therefore suggest that the transformation of anonymity in gamete donation is less about the amount of donor information that can be obtained through registers or DNA databases, and more about the fact that there are new ways to link information. With the advent of unprecedented means to make connections, it has become increasingly difficult to distinguish between potentially identifying and non-identifying information. The assumption that such a distinction is possible is fundamental to the practice of anonymous donation and also an essential precondition for a system of temporally limited anonymity. When donors are guaranteed anonymity, clinics or cryobanks promise them that they will remain anonymous – either indefinitely, or at least until information about them is released through an authority and in a regulated process. The certainty that a distinction can be made and that clinical or state authorities can control the process of storing, managing and releasing information is however increasingly challenged by the donor-conceived's attempts to make new links between pieces of information that were previously unconnected.

Anonymity is anything but “a monolithic concept and practice” (Konrad 2005a: 85), even though it tends to get treated this way in policy debates about gamete donation. Although it is different from other forms of not-knowing, it often occurs together with them, which is reflected in the questions that the donor-conceived

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4 “Anonymous” derives from the Greek “*anonumos*”, which means “without a name” (from *an* – “without”, and *onoma* – “name”) (Ponessa 2013: 325).

ask themselves and others. For them, it is often not only about finding out who the donor is, but also about knowing who else knew about the donor conception, and who should still be told (and how). While an essential part of this book and of my attempt to “open up anonymity” focuses on laws and infrastructures, an examination of these more minute considerations and everyday problematisations of not-knowing remains important to fully understand the transformation of anonymity.

## Changing donor conception

The fact that the majority of the people I interviewed did not grow up knowing they were conceived with donated gametes is not surprising given the history of donor conception. In the past, anonymity and secrecy were “the primary organising principles” (Bateman Novaes 1998: 111) of donor conception. For a long time, it was taken for granted that neither children nor parents should receive “identifying” donor information. Besides, physicians were of the opinion that children should not learn about the circumstances of their conception. Since “the use of a donor poses a cultural threat to patriarchal traditions” (Becker 2000: 134) and would ‘expose’ the infertility of the father, the usage of donated sperm in particular needed to be hidden and made invisible. The stigmatisation of infertility contributed to donor insemination (DI), the oldest form of gamete donation, evolving into a medical technique that had to be kept hidden and did not have the status of a regular confidential medical matter (Blyth 2012: 143).<sup>5</sup> Programmes and physicians organising the much newer practice of ova donation, especially in the United States (US), were less strict about donor anonymity (Almeling 2011: 35),<sup>6</sup> while sperm banks were adamant on concealing both the donation and the donor.

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5    DI involves the injection of donated sperm into the recipient’s vagina or uterus with a syringe. Fertilisation thus occurs inside the body.

6    With successful egg freezing and thawing being a relatively new technology (Robertson 2014), using unfrozen eggs from a known donor became relatively common, while sperm banks were adamant on concealing both the donation and the donor. Techniques for the viable cryopreservation of sperm have already existed since the 1950s. However, it was not until the 1980s that frozen sperm became “a significant part of reproductive medicine” (Swanson 2012: 272; see also Swanson 2014) as sperm banks, or “cryobanks”, that stored, sold and shipped frozen sperm started to emerge. The use of frozen semen became more widespread after the onset of the Aids crisis. Cryopreservation made it possible to retest sperm after a quarantine period and to ensure that the donor was HIV negative (Bateman Novaes 1998: 113). Besides, frozen sperm made it possible to rule out any contact between recipient and donor. The same type of ‘slow’ cryopreservation turned out to be unsuccessful when used with eggs, as the ice crystals that form during the freezing process damage the oocyte. This can be avoided by the much faster and newer process of “rapid vitrification” (Mandawala et al. 2016).

Choosing a sperm donor that resembled the father was a crucial step in this process: “The donor’s physical similarities to the social parent are important in that they pay lip service to the notion of biological continuity.” (Becker 2000: 152) If the child resembles his/her mother or father whose gametes are not involved in the child’s conception, then parents do not have to deviate from “the cultural ideology about biological parenthood” (ibid.). By “matching” recipient and donor according to physiognomic characteristics, parents were, and still are, enabled to present the child as a child that’s genetically related to them (Bergmann 2014: 156).<sup>7</sup> Particularly in cases where legal relationships between recipients, donors and children were unclear, concealing information was also often a question of preventing financial claims. Physicians wanted to protect donors against any inheritance claims that donor offspring might raise, which was another reason why parents were recommended not to tell their children (Daniels and Taylor 1993: 158) and forget about the treatment (Dempsey and Kelly 2017: 205). Furthermore, concealing information was also seen as a means to protect donor-conceived children from stigmatisation, and the view that “the child could gain nothing from knowing about the connection between his/her conception, the practice of masturbation and the status of illegitimacy” (Haimes 1998: 70) was dominating the practice of DI. Besides, it was assumed that anonymity also had a protective function with regard to emotions, and “knowledge of the donor’s identity was seen as being too emotionally troubling for both parents and for their children” (Richards 2016: 27).

Many of these views have changed radically within just a few decades. In psychosocial studies on donor conception, reference is repeatedly made to the importance that knowledge about the donor has for the “identity formation” of children. Secrecy is commonly interpreted as something that is detrimental to “family functioning”, and openness and the opportunity to learn the identity of the donor are seen as fundamental conditions for the well-being of the donor-conceived (Edwards 2018). In both the UK and Germany, groups of parents and families who have had children with the help of gamete donations and who are committed to early disclosure have formed (Klotz 2014). While children conceived with donated gametes used to be considered the successful outcome of a medical procedure (Haimes 1998), the view that their interests must come first has gained traction. This is also reflected in the way in which access to information is regulated by law: while both the UK and Germany now provide for donor-conceived people to have

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7 Matching has also been a central paradigm in adoption practices where it “made kinship through effort-filled social operations that simulated the appearance, stability, and authenticity that were assumed to be effortless products of nature” (Herman 2008: 121). It is important to note that matching and anonymity do not necessarily result in parents trying to conceal treatment with donated gametes, as the ethnographic work of Klotz (2014) on families who choose to disclose has shown.



access to “identifying” donor information from a certain age, the possibilities for parents and donors to find out more are more limited. The right to know is very much understood as a right of children to information about the donor, rather than, for example, a right of donors to obtain details about their donor-conceived offspring.

Demands for a right to know are also increasingly being voiced by the donor-conceived themselves, who join forces with those who share the same ‘fate’: they have begun to network with others nationally and internationally, especially online, exchanging stories, advice and experiences, talking about them in a public and political arena, while sometimes making themselves identifiable during that process. Policy debates validate their ‘authentic’ experiences and first-hand accounts. Often-times their descriptions, some of which are full of pain and speak of their absolute need to know their origins, are seen as proof that it is wrong to withhold knowledge from the donor-conceived. “Being donor-conceived” has clearly become a powerful identification and categorisation. Since the donor-conceived usually obtain little or no information about their donors and donor siblings from official authorities and physicians, they look for and create other ways to find out who their donor is and connect with other relatives, as exemplified by Spenderkinder’s social media campaign. As they want to find out where they come from and whom they are related to, they are looking for ways to overcome limitations of the knowledge they can obtain and the relations they can form.

Above all, the donor-conceived do not rely solely on officially endorsed means to obtain information. The social media campaign of Spenderkinder draws on existing infrastructure and practices that members and other donor-conceived persons were already using to obtain information about their donors at the time of the launch: the Internet is central to the process of DNA testing, with tests sold by websites for genetic genealogy having become a particularly popular search tool. Several of the people that I interviewed shared their stories with journalists, hoping that donors and half-siblings might decide to reach out when hearing or reading about them. Publicising their stories and utilising the different resources fundamentally changes the conditions for anonymity in gamete donation in that such activities shift who can receive, distribute, share, hide or reveal information. Overall, people conceived with donated gametes are no longer represented only by others. Instead, they have now become active themselves and try to assert their interests by representing themselves.

The donor-conceived, whose narratives are the focus of this book, activate the knowledge of their biogenetic connections in specific ways. Marilyn Strathern (1999c) coined the term “constitutive information” to capture the specific nature of knowledge about these relationships. She pointed out that “in Euro-American thinking, knowledge creates relationships: the relationships come into being when the knowledge does” (1999c: 78). Information about biogenetic connections is

information that cannot be “selected or rejected *as information*” (1999c: 77, emphasis in original). The connection that this knowledge creates cannot be undone: although it is possible for a person who finds out that they are donor-conceived to say that they want nothing to do with their donor, it is not possible for them to say that they are not related to their donor (although this might well be what they tell others). The people at the centre of this book, who for the most part had grown up without knowledge regarding the circumstances of their conception, experienced the dissolution of a connection that normally cannot be dissolved; they found out that they were not genetically related to their father.<sup>8</sup> Strathern argues in an earlier essay that as their conception was a dispersed one so too is their kinship (1995). She notes that the decision to conceive with donated gametes results in “a field of procreators whose relationship to one another and to the product of conception is contained in the act of conception itself and not in the family as such” (1995: 352). However, it is important to note that there are “variable ways in which kinship knowledge is constitutive of the self” (Carsten 2007: 422), and not everyone will do the same with knowledge about genetic connections and origins. For the people that I interviewed, “being donor-conceived” became an important identifier. This book explores how the activation of kinship knowledge, the making of new social relations, the using and repurposing of infrastructures, and a variety of other practices and politics allow people to actively *become* donor-conceived, rather than passively as a by-product of their parents’ decision to reproduce with donated gametes.

## Empirical basis and comparative angle

The main empirical basis of this book consists of interviews that I conducted between September 2016 and December 2017 with 24 persons who were conceived in the UK or Germany (UK n=13; Germany n=11) through clinically mediated and anonymous gamete donation (sperm n=23; ova n=1). All had grown up with parents who were living in heterosexual marriages at the time of treatment, which had taken place between the 1950s and 1990s, with the majority of people conceived in the 1970s and 1980s. Two persons stated that they had always known about the circumstances of their conception, while all others could remember a certain moment when they were told. A large number of them had learnt about it in adulthood, through their parents’ conscious decision to tell their children, or through an unplanned situation such as an argument. I found most of them through the mailing lists of advocacy groups and through interview appeals posted in online forums. In

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8 The only one of my interviewees who had been conceived with a donated oocyte had, according to his own statement, always known that he was donor-conceived (see section 7.5).

addition to the interviews with donor-conceived persons, I also met with a number of other actors and spoke, for example, to a former sperm donor and a “donor information manager” who worked for the central UK donor register.

I selected the UK and Germany as case studies because of their specific regulations concerning the collection, storage and release of donor information. My research in the two countries, coupled with interviewing individuals who were conceived under different legal and clinical regulations, provides a broad examination of a variety of different infrastructures and regulations. As my research developed it became clear that there are also differences in the way the donor-conceived organised their activism – a difference not readily apparent at the conception of my research. The comparative approach of my research is more visible in some chapters than in others. This is determined in each case by my material and the topics I examine in the respective chapters.

When I started my research in Germany after having returned from the UK in January 2017, I was often amazed at how similar the narratives of my British and German interviewees were. Indeed almost everyone talked about how important it was “to know where you come from”, stressed that openness was vital, and addressed the question of who knew about the donation and who should know about it. In her ethnography of anonymous ova donation in the UK, Monica Konrad notes that while “[i]t is always good to find exceptions during the course of research” (2005a: 21), in her own fieldwork, “sometimes the surprise would consist in the very consistency of the reply” (*ibid.*). I can certainly say the same about my research. The comparison between interviews I conducted in the UK and those I conducted in Germany, often led me to find more similarities than differences. In particular the narratives and micropolitics discussed, analysed and presented in chapters 5 and 6, are not as contrasting as other parts of this book in terms of differences between my British and German material. Still it should be noted that differences between individual cases do remain an axis of comparison throughout this book. It is important to note that I do not claim to produce statistically representative results, nor do I aim to make general statements about national differences beyond laws, infrastructures and activism. At no time do I intend to engage in a discussion on intrinsic British or German ‘mindsets’ and how that shapes policy. My approach to comparative work is based on the assumption that “objects of comparison are not representations of what one would find and bring back home from the field. [...] They are rather articulations of analogous properties or problematics – related to a whole range of motions, and effects.” (Niewöhner and Scheffer 2010: 11) They are not ‘out there’ to be discovered by the researcher, but instead “produced through *thickening* contextualisations” (Niewöhner and Scheffer 2010: 4, emphasis in original). The comparability created by “thick comparisons” (Niewöhner and Scheffer 2010) is always limited in nature (*ibid.*; see also Scheffer 2008), and my analysis takes these limitations into account.

## Overview of the book's chapters

Before I examine the transformation of anonymity in gamete donation using my own empirical material, I will present the central historical and theoretical reference points and perspectives of this book in chapter 1. First, I will present relevant background information on the development of the regulation of reproductive medicine and gamete donation in the UK and Germany. This will be accompanied by an overview of the current legal situation in terms of who can obtain what kind of information about the donor or offspring. I will then examine how donor conception in general and the donor-conceived in particular have been discussed in psychosocial research so far. It is particularly striking that reference is repeatedly made to the damage that anonymity and secrecy can have on “identity formation”. The way in which anonymity has been discussed in ethnographic research on blood donation, organ donation and other topics differs from this ‘identifying’ focus, and I will discuss some of these works after reviewing the existing psychosocial research. In this section, I will also elaborate on the particular contribution my work can make to ethnographic research on anonymity. Finally, I will discuss several ethnographic works that provide theoretical and empirical points of reference for the anthropological study of donor conception. While throughout this book I will draw on literature that has inspired me in order to discuss my own material, central debates, concepts, and approaches will be presented here in a concentrated form.

In chapter 2, I introduce my sample and explain the process of researching, analysing and writing. The groups and online forums through which I came into contact with donor-conceived persons are also the platforms the donor-conceived and/or recipient parents use to network with others. This chapter thus introduces some of the central infrastructures in my field. I will also discuss how the anonymisation and deanonimisation practices of my interviewees affected my own research and efforts to ensure confidentiality.

In chapters 3–8, I will discuss my own empirical material, making repeated references both to the work and concepts presented in chapter 1 and to other, mainly ethnographic, works. In chapter 3, I will examine the often invoked “right to know” not only on the basis of my own ethnographic research but also by looking at the international and national discourses that shape the debates and demands voiced by my interviewees. The right’s taken-for-grantedness and its seemingly ahistorical nature will be ‘opened up’ for ethnographic discussion. I will examine some of the particularly influential and frequently voiced arguments that the donor-conceived and their supporters use to fight for the right to know. Finally, I will look at a specific variation of the “right to know” debate, namely a call that the “right to be told” be legally enforced by including donor names and/or treatment details in official documents such as birth certificates.

In chapter 4, I will examine how the donor-conceived in the UK and Germany fought for their rights. Their activism was not limited to their struggle for the right to know. Instead, many chose to tell their story to journalists and thus made it available to a wider public because they also wanted to propagate a specific vision of the nature of the ideal family. For a few of those who were particularly active in the public and media, this was the conviction that “real families” must be genetically related to each other and that people had a right to know their “real parents”. Others believed that “good families” should be strengthened and that donor conception should therefore be normalised. Many characterised “good families” as only those families who openly dealt with the use of donated gametes. In addition to publicity strategies, this chapter focuses on the networking practices of the donor-conceived who join forces via the Internet with others who share the same ‘fate’. In the last part of the chapter, I will take a closer look at the association Spenderkinder that I already mentioned earlier. It plays a central but not uncontroversial role in Germany in terms of donor-conceived activism and the fight for the right to know.

After demands for a right to know and the activism of the donor-conceived were the focus of the first two empirically oriented chapters, chapter 5 takes a different perspective. Here I will examine on a micro-political level how temporal and relational dimensions of anonymity and (non-)knowledge about kinship are discussed and problematised. I interpret both the frequently expressed desire “to know where you come from” and the look back at what some of my interviewees had already intuitively known prior to being told as an expression of a desire for a continuous life. Continuity also emerged as a key mode of relating in many narratives, which was reflected in the way my interviewees imagined their anonymous donors. It was particularly striking that they were interested above all in what they had in common with their donor in terms of intellect and academic abilities. Any external similarities with not only the donor but also donor siblings played a greater role in a process I have termed “scanning”, namely the intense and oftentimes automatic search for similar features and characteristics in others.

Chapter 6 takes a similar approach to examining dimensions of anonymity and non-knowledge that tend to go unnoticed in discussions about the right to know. In particular, in this chapter I will discuss how the donor-conceived deal with the “kinship trouble” caused by their parents’ decision to share information about their conception with them and/or others. It was especially important for the donor-conceived not only to know who their donor was but also to find out who else knew about the circumstances of their conception. In addition to the oftentimes central question “Who knows what?”, I examine how my interviewees decided whom they themselves wanted to tell that they were donor-conceived. When deciding whether to reveal or conceal information about their origins, it was not only the otherwise dominant right to know that influenced their decision. Instead, they were very much guided by considerations of care and the desire not to cause relationship

difficulties. This manifested in the way my interviewees (1) managed and/or anticipated kinship trouble caused by siblings who had not yet been told, and (2) by the act of telling their own children that they, as their parents, were donor-conceived.

In chapter 7, I examine the various formal and officially endorsed registers available to the donor-conceived in the UK to obtain information about the donor and genetic half siblings. Several of these options are based on voluntary registration. Central to this chapter are not only the various ways of obtaining information, but also the management of expectations and hopes. Formal registers were not available to any of my German interviewees, all of whom were conceived before the central donor register was created in Germany. Likewise none of my British interlocutors were among those who had guaranteed access to the information that the authority that manages the central UK register considers to be “identifying”. The method used to distinguish between “identifying” information and “non-identifying” information will be examined in detail. In addition, I will consider and discuss all of my ethnographic material to evaluate what kind of knowledge my interviewees had in mind when they spoke of their desire to “know the donor as a person”. I will also refer to the interviews conducted in Germany in my exploration of “donor siblings”, which are half-siblings conceived with gametes from the same donor but raised in different families. In contrast to Germany, there is a formal register in the UK that allows the donor-conceived to get in touch with this type of sibling. Finally, I will discuss a voluntary register that utilises a certain type of DNA testing in order to establish links between those who donated or were conceived in the UK prior to the establishment of any mandatory registers.

This type of genetic testing is different from the technology used in another type of DNA database that is popular amongst the donor-conceived in both the UK and Germany. The way in which they use the tests offered by commercial DNA databases, which sell their products online, has radically changed the conditions of anonymity in gamete donation and will be discussed in detail in chapter 8. First of all, I will explain how these tests work and how they differ from the technology presented in the previous chapter. I am especially interested in how kinship and ancestry are “measured” here, and how these measurements can be discussed and problematised from an anthropologically informed perspective. I will then examine how some of my interviewees tried to identify their donors by linking the results of their DNA tests and utilising other online and offline searches in a complex process of “infrastructuring”. While not everyone was willing to go through such an elaborate search, most of the people that I met still felt like they had to at least try to find someone. “Having to try” was a central motif in many narratives when it came to DNA testing. In the last section of this chapter, I examine what happens when people unsuccessfully search for genetic relatives via DNA databases and are left to wait for more people to take a test.

In chapter 9, I will summarise and discuss the central arguments and findings of my work. As my research points to a dissolution of the boundary between non-identifying and identifying information, I will also look at whether, and if so how, those who traditionally had control over information react to these changed circumstances.

This book is a slightly revised and updated version of my PhD thesis at the University of Bremen. In addition to the general editing process, chapter 2 has been extended to include a more detailed discussion of the specific character of my sample composition, and of the motivation of my interviewees. Chapter 3 has been extended to include more information on the significance of specific international treaties in Germany. Moreover, I have slightly reworked this part of my thesis to further disentangle the “right to know”, which is a dense and multivalent concept, in light of the comments and questions from my examiners. A more detailed discussion on what is known statistically about gamete donation in the UK and Germany has been included in Chapter 7, and a brief discussion of what people do when their donor does not meet their expectations has been added to Chapter 8. Finally, the conclusion has been reworked to reflect these changes, and to include comments and suggestions made by my examiners and the other members of my doctoral defence committee.

# 1. Contextualising donor conception and anonymity

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DI as the oldest form of treatment with donated gametes is technically easy to perform. Its basic principles have not changed over the past decades. Sperm from a man who is not the patient's partner is produced by masturbation and is then transferred into the patient's uterus or vagina. Ideally, pregnancy occurs, and after nine months a child that, in the case of a heterosexual couple, is not genetically related to the man who is raising the child, is born. As simple as the process itself is, it has always fascinated, irritated and often horrified people. The same is true for technologically more complicated methods that might include the use of donated gametes: a long-cherished wish for a child and for the experience of parenthood may be fulfilled, which tends to be celebrated. At the same time, the use of donated gametes in particular causes discomfort, as it challenges established ideas about family, conception, and reproduction. While the practice of anonymising donors and keeping the donation a secret has often been seen as the solution to these challenges, today anonymity as well as secrecy are increasingly being criticised for being harmful for both children and families.

Before discussing my own empirical material in chapters 3–8, I will first present developments, debates and discourses that are relevant to my research. Thus, the following four sections serve to contextualise my own analysis. It should be noted that I do not conceive of “context” as something out there to be found. Instead, contexts are “sets of connections construed as relevant to someone, to something or to a particular problem” (Dilley 2002: 454). Trying to establish “a claim about context” (ibid.) will thus always remain a claim that is “socially and historically situated” (ibid.), and contexts remain “expandable” (ibid.). According to anthropologist Roy Dilley, “the best we can do is to look to the relations between knowledge, context and power that seem to fix some meanings and interpretations rather than others as pre-dominant or even hegemonic forms” (ibid.). As I will show in this chapter, a certain way of contextualising and interpreting anonymous gamete donations as a threat to identity has established itself as a dominant perspective. Thus, this chapter is not only designed to provide relevant background knowledge that helps to situate my material but is also a “context claim” that represents my attempt to



open up other approaches to the topic, namely by drawing on anthropological approaches to anonymity, donor conception, openness and disclosure.

I will first give an overview of how the regulation of reproductive technologies and donor conception has developed in the UK and Germany. Despite certain differences, it will become clear that in both countries the answer to the question of what kind of information the donor-conceived can obtain is not uniform. I will then discuss how anonymity and donor conception are situated in psychosocial research, which has produced a lot more studies on donor-conceived people than anthropology. In this section, I will discuss the empirical gaps that my ethnographic research fills and how my anthropological approach to anonymity in gamete donation differs from the focus on “identity formation” that dominates psychosocial studies. Subsequently, I will examine how anonymity has been ethnographically investigated to date, and what the particular strength of my material is in terms of ethnographically exploring anonymity. In the last part of this chapter I will focus on some of the anthropological research on kinship knowledge, donor conception and disclosure that has shaped my own approach to the topic. While throughout this book I will repeatedly refer to different ethnographies on these and other topics, in this section I will discuss in condensed form the concepts and theories that have been particularly pertinent to my own analysis.

## 1.1 Regulating donor conception

Inseminations with donor sperm had been carried out in both the UK and Germany long before the development of In-Vitro Fertilisation (IVF) (for early medical reports on DI, see Barton et al. 1945; Schaad 1972; Rose and Schaad 1974), and anonymity in donor conception had already been the subject of legal and ethical debates as early as the 1940s (Haimes 1998). However, reproductive technologies in general started to receive a lot more public as well as political attention following the birth of Louise Brown, the first person to be conceived via IVF.<sup>1</sup> While DI in itself does not create a completely new situation, as there have always been children who did not grow up with their genitor, IVF created something unprecedented: fertilisation outside the body. This made it necessary to find an appropriate way of dealing with extracorporeal embryos and egg cells. It should be noted that most of the people I interviewed were not conceived through IVF, but through DI. In fact, of those who were conceived at a time when IVF was already available to patients, only one

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1 IVF involves the surgical extraction of oocytes, which are monitored and fertilised in a laboratory. The resulting embryos are then transferred into the patient's uterus.

person stated that he was conceived through such treatment. I had not asked my interviewees about it, but he mentioned it on his own initiative.<sup>2</sup>

However, in both the UK and Germany the debates about the “unprecedented procreative possibilities” (Richardt 2003: 87) created through IVF also included discussions about the much older practice of DI and the anonymity of donors that was by then the clinical norm. While the British debates resulted in the establishment of a central donor register and strict regulation on embryo research, this was not the case in Germany. Embryo research remained prohibited and no such register was created. The debates on IVF thus had an influence on how information on donors was managed, which in turn had an effect on the way the donor-conceived can proceed in their search for information. I will discuss these debates briefly, focusing on how anonymity was debated by two specific commissions of inquiry that were set up in response to the development of IVF and the legal developments that followed, or did not follow, their recommendations. Furthermore, I will give an overview of the current situation with regard to access to donor information, before going into more detail in chapter 3 on how demands for a right to know influenced important changes in this domain. I will return to the topic of IVF in chapter 8 where I discuss commercial genetic testing and the phenomena of “having to try” DNA testing and “waiting for matches”, drawing on ethnographies of assisted conception (Franklin 1997; Throsby 2004).

The new procreative possibilities include in particular the donation of oocytes and the implantation of an embryo that was not created with an oocyte from the woman gestating the foetus, which means that the “organic unity of the fetus and the mother can no longer be assumed” (Martin 1989: 20). Prior to IVF, it was only fatherhood that was thought to be intrinsically uncertain (Strathern 1992: 148). With IVF, motherhood was no longer certain either. Besides, ‘surplus’ embryos that were not used in an IVF cycle could be used in embryological research, and embryos could be created specifically for that purpose (Richardt 2003: 87). In addition, the further development of cryopreservation methods made it increasingly possible to store and transport gametes and embryos. It became necessary to find a way of dealing with these new cryopreserved entities.<sup>3</sup>

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2 Only Jacob Moore from the UK, who was conceived with a donor egg and who had always known about the circumstances of his conception, mentioned that he was conceived via IVF, which is arguably not surprising given the differences between treatment involving donor sperm and donor ova. In the case of egg donation, the donated egg cells are fertilised in a Petri dish and then transferred into the recipient’s uterus, whereas treatment with donor sperm does not have to involve IVF. In fact, it was Jacob’s interest in IVF that sparked his interest in his genetic half-siblings and in his anonymous donor (see section 7.5).

3 Those of my interviewees who had been conceived in the 1970s to mid-1980s usually told me that, according to the information given to their parents, they had been conceived with ‘fresh’, unfrozen sperm. In the case of unfrozen semen, the donation was often made shortly

The first birth resulting from an IVF treatment “was seen to create not only a new kind of reproductive choice but a legal vacuum surrounding its use, as well as an immediate practical imperative to produce regulation” (Franklin and Roberts 2006: 40). In the UK, the government reacted to these challenges by setting up a committee of inquiry in 1982, 14 years after DI had become available on the National Health Service (NHS) (Frith 2001: 820). When the inquiry was set up, anonymity and secrecy had already dominated the much-criticised practice for several decades.<sup>4</sup> The committee was led by philosopher Mary Warnock and laid the foundation for what has been described as “the world’s most comprehensive legislation on human reproduction and embryology” (Franklin and Roberts 2006: 41). The so-called “Warnock Committee”, which published its report in 1984, managed to “establish[...] a pattern that has prevailed ever since in Britain” (Franklin and Roberts 2006: 3) regarding the regulation of reproductive and genetic technologies, namely to “*achieve workable and sustainable policy*” (Franklin and Roberts 2006: 5, emphasis in original).<sup>5</sup>

The Warnock Committee endorsed the practice of gamete donation and recommended that a child conceived with donated gametes “*should in law be treated as*

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before the insemination took place. Patients and donors were likely to be in close physical proximity of each other at some point. A German gynaecologist told me that in his practice, they sometimes ran into each other on the stairs. To avoid this, he started working with cryopreserved sperm in the 1980s.

- 4 In response to “a growing public and professional debate” (Richards 2016: 15) that followed early medical reports on donor conception in the UK, the Archbishop of Canterbury had already commissioned a report on DI in 1946. The report, which was published in 1948, argued that the method should be banned by law (Daniels and Taylor 1993: 156). DI was rejected for religious and moral reasons: masturbation, as a way of obtaining sperm, was considered a sin. Both secrecy and disclosure were seen as harmful (Haimes 1998: 57). Although DI was subsequently not banned by the government, “negative attitudes [...] made the practice rather more secretive and under the counter during the late 1940s and 1950s” (Richards 2016: 16). The Peel Committee came to a different conclusion (Peel Report 1973). It had been set up by the British Medical Association to examine matters of artificial insemination and accepted DI “as appropriate medical practice” (Richards 2016: 23). While there was no mention of whether a child should be told or not, the authors of the report seemed to take the importance of anonymity for granted: “In order to preserve anonymity it would be necessary for information about donors sent by the frozen-semen banks to accredited centres or to private practitioners to be in coded form [...]” (Peel Report 1973: 5)
- 5 The Committee not only discussed the views of its members but also considered evidence submitted or presented by organisations working in the field of human reproduction, as well as by individuals such as adoption researchers. Apart from this evidence, it also received almost 700 submissions from the public (Warnock Committee 1984: 95; see also the introduction of chapter 4, where I mention a submission made by a donor-conceived person). However, it is unclear how this evidence, which was never published, shaped the final recommendations (Cavaliere 2017: 3).

*the legitimate child of its mother and her husband*" (1984: 23–24, emphasis in original). By contrast, an "AID child", as it is referred to in the report (with AID standing for "Artificial Insemination by Donor"), was previously regarded as illegitimate. Although the husband was registered as the father, this was officially considered an offence, and "the problems with legal paternity contributed to the desire to keep the practice secret" (Frith 2001: 820).

At that time, the anonymity of the donor had a protective function, as it prevented the donor from being forced to assume parental responsibilities and the husband from being displaced as the legal parent (*ibid.*). The Warnock Committee also believed that anonymity would protect several other vital interests: not only would it give "legal protection to the donor, but it would also have the effect of minimising the invasion of the third party into the family" (1984: 25). At the same time, the Committee argued "that it is wrong to deceive children about their origins" (1984: 21) and that secrets were harmful to family relationships (*ibid.*). Nevertheless, it suggested that parents should only be given limited information about the donor. Only "basic facts [...] such as his ethnic group and his genetic health" (1984: 24) were to be recorded and be given to recipients. Members of the Committee did not want "to encourage parents to seek donors with specific characteristics in the hope of producing a particular type of child" (Richards 2016: 29). Additionally, the Committee recommended for such "basic" information to be made available to the child at the age of 18 and stored in a central register (1984: 82).

The Human Fertilisation and Embryology Act (HFE Act) from 1990 largely followed the recommendations of the Warnock Report.<sup>6</sup> Apart from donor conception, it also regulates fertility treatment that does not involve donated gametes, research on embryos,<sup>7</sup> as well as storage of gametes and embryos. The HFE Act provided for the establishment of the Human Fertilisation and Embryology Authority (HFEA), an executive, non-departmental public body that began its work on 1 August 1991.<sup>8</sup> The HFEA primarily functions as a licensing authority that oversees all centres and clinics that collect, store and use human gametes and embryos

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6 A voluntary regulatory body called Interim Licensing Authority (previously Voluntary Licensing Authority) had been established in 1985 by the Medical Research Council and the Royal Society of Obstetricians and Gynaecologists. However, it did not cover treatment with donated gametes unless it involved IVF or gamete intra-fallopian transfer (Blyth 2004: 227), a procedure that involves placing eggs and sperm in one of the Fallopian tubes. The Interim Licensing Authority remained active until the HFEA was established.

7 Research on embryos is limited to a maximum period of 14 days after their creation.

8 From now on I will only use 1991 in this book instead of the full date when referring to the date which divides the donor-conceived into two groups in terms of what they can find out about their donor. The same applies to 1 April 2005, the date from which donor anonymity was limited in time. When I refer to the period between 1991 and 2005, I mean, strictly speaking, the period between 1 August 1991 and 31 March 2005.

(Franklin and Roberts 2006: 61). From the very beginning it also had the task of keeping a register with information on all donors and treatments involving donated gametes. The HFE Act permitted “the government to issue regulations authorizing the disclosure of [...] information relating to the donor to an individual who was conceived following donor treatment and who has reached the age of 18” (Blyth 2004: 235). However, it did not include regulations concerning the release of information (*ibid.*). Although sperm donation had already been practised for several decades at this point, it was not until the HFE Act came into effect that gamete donation was legitimised in the UK. The Act provided that in the case of DI, the mother’s husband or partner would be registered as the legal father, while the donor remained anonymous. The legitimisation thus occurred under conditions that upheld the ideal of the nuclear and heteronormative two-parent-family. In this sense, anonymity can be described as a mechanism that “helps to preserve as many as possible of the conventional features of the family by setting a barrier around the unit” (Haimes 1990: 169).<sup>9</sup>

Following extensive campaigning by a working group within the British Association of Social Workers (BASW) that had been formed in the wake of the Warnock Report (Wincott and Crawshaw 2006), a government consultation (section 3.4), and a court case that involved a donor-conceived adult and a donor-conceived child (section 3.2), the law was eventually amended in 2004. The change was announced “on the basis that a child’s right to learn its genetic inheritance out-weighed the donor’s right to privacy” (Thomson 2008: 114). The 2002 court case in particular will be discussed in more detail in section 3.2 when I explore and analyse one of the most omnipresent topics of my research, namely the right to know. With effect from 1 April 2005, persons conceived after that date have the possibility to obtain identifying information (name, date of birth, last known address) about their

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9    The extent to which the HFE Act can be interpreted “as a strong moral statement of the importance of the nuclear family” (Sheldon 2005: 527) is particularly evident in the “need for a father clause”. The 1990 Act (section 13(5)) stated that “a woman shall not be provided with treatment services unless account has been taken of the welfare of the child who may be born as a result of the treatment (including the need of that child for a father)”. While the Act did not explicitly state that single women and lesbian couples should not have access to treatment, this provision gave clinics a basis for refusing them treatment. The Act was updated in 2008, and “need for a father” was replaced with “need for supportive parenting” (see also Blyth 2015 for a more detailed discussion of this development). Female partners are now registered as legal parents, alongside the gestating mother. Although these changes might seem revolutionary at first, a traditional “two parent model retains a grip on the law” (McCandless and Sheldon 2010a: 191). The law still adheres to the view that it is best for children to be raised by two parents that are in a sexual relationship; “what changes is the necessity that one of the two must be a father” (McCandless and Sheldon 2010b: 209).

donor from the age of 18. In addition, they can obtain non-identifying information (such as physical description, year and country of birth, ethnicity, whether a donor had children at the time of donation, marital status) from the age of 16.<sup>10</sup> At that age they can also receive basic information about their donor siblings (number of children, year of birth, gender). Parents are given access to non-identifying information about the donor and any children conceived with gametes from the same donor. In UK policy documents, the importance of this information is framed “as significant to recipients in their role as parents (or potential parents) of donor-conceived children and not as directly meaningful to themselves” (Gilman and Nordqvist 2018: 324). Whereas provision of information to parents is not a statutory requirement, donors do have a statutory right to obtain non-identifying information about any children born from their donation but may never receive identifying information. It has been argued that disclosure of information to donors is “framed as means of ensuring that openness *about* donors is successful and that any implied disruption it might cause to their families is minimized” (Gilman and Nordqvist 2018: 326, emphasis in original). Openness is thus organised in very specific ways in UK policy, and priority is given to “information sharing about donors with their donor-conceived offspring” (Gilman and Nordqvist 2018: 318).

The HFEA also manages a voluntary sibling register that was set up in 2008 (Blyth and Frith 2015: 142). It enables those who join it to make contact with their donor siblings. Besides, those who donated after 1991, but before 2005 can choose to re-register with the HFEA and make themselves identifiable to any offspring who request information; otherwise, those conceived during that time can only obtain non-identifying information. They can also join the voluntary sibling register at the age of 18. Furthermore, those who were conceived or who donated before the establishment of the HFEA can join the voluntary Donor Conceived Register (DCR). It receives its funding from the Department of Health and facilitates DNA “linking” or “matching” between donor-conceived adults and donors, as well as between donor siblings (who are not eligible to join the voluntary HFEA sibling register). These different registers will be discussed in detail in chapter 7.

In Germany, the debates on IVF, the regulation of reproductive technologies and donor anonymity took a very different course. When IVF was developed, anonymous and secret donations were the clinical norm, albeit not being mandated by law. In 1970, the *Ärztetag*, the annual meeting of the German Medical Association, declared DI to be a practice that was not in violation of the professional code of physicians (Bundesärztekammer 1970), thus overturning its 1959

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10 Initially, the minimum age for accessing non-identifying information was 18 (Blyth et al. 2009: 209).

decision.<sup>11</sup> Prior to 1970, physicians who performed the treatment risked losing their medical license, even though DI was not illegal.<sup>12</sup> However, the 1970 *Ärztetag* also declared that it did not recommend the practice as such, as it was still fraught with too many legal problems, such as the issue of maintenance claims. Although DI was liberalised to a certain extent after 1970, anonymity and secrecy therefore remained dominant. In 1984, two years after the first German ‘IVF baby’ was born, the Federal Ministries of Justice and of Research and Technology appointed a committee of inquiry chaired by former Constitutional Court president Ernst Benda. With regard to donor anonymity, the recommendations issued by the so-called “Benda Commission” (“*Benda-Kommission*” in German) differed from the Warnock Report. It was considered wrong for sperm donors to remain anonymous: “Knowledge of one’s own origins is of considerable importance for establishing identity and thus for personality development.” (Benda-Kommission 1985: 14, author translation) The Benda Commission recommended that the law should be amended to require that the donor’s personal details be documented and presented to the child on request from the age of 16. However, its recommendations were not translated into law. In contrast to the UK, where information on donors was stored in a central register managed by the authority that also regulates embryo research, no such infrastructure was established in Germany.<sup>13</sup> I suggest this has to do with the fact that the German debates on embryo research were very different from those in the UK.

In her comparative analysis of the embryological research debate in the UK and Germany, Nicole Richardt argues that permitting “even a limited amount of embryological research was perceived as entering onto a slippery slope that might lead to a population policy like that of Nazi Germany” (2003: 110), with all political

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- 11    Due to legal uncertainties, German university clinics discontinued their DI programs in 1984 (Katzorke 2008: 17). Little is known about how DI was organised and regulated in the former German Democratic Republic (GDR). According to publications from the 1980s (Graf and Glander 1980; Günther 1987), donors were supposed to remain anonymous, and information on DI was documented in a central register. Those of my interviewees who had been conceived in the GDR pointed out that, to their regret, the whereabouts of this register are unknown.
- 12    In 1959, the *Ärztetag* had decided that inseminations with donor sperm were to be rejected on moral grounds and constituted a violation of the code of medical ethics (Katzorke 2008: 17).
- 13    Information about IVF treatments is stored in the German IVF register, which was created in 1982. However, information on the use of donor semen is not recorded in it. In contrast to the German donor register, its status remains uncertain (Kadi and Wiesing 2016: 682). While it was initially designed as “a voluntary association between IVF centers” (*ibid.*), the IVF register was later on recognised by the professional guidelines of the German Medical Association. However, it is currently lacking this kind of formal recognition and clinics are not required to submit data.

parties opposing Preimplantation Genetic Diagnosis (PGD) as well (ibid.). It is interesting to note that the Benda Commission had in fact “allowed for the possibility of high-priority research on embryos” (Jasanoff 2007: 162). While the Benda Report made clear recommendations on embryo research, what followed was not consensus but “years of conflict” (Herrmann 2009: 131) between government officials at the federal and state level, medical professionals and public actors (ibid.). In parliamentary debates and expert commissions, discussions focused primarily on the question of whether embryos inside and outside the body should be given the same level of protection as humans that were already born (Knecht and Liebsch 2019: 103). By contrast, in the UK research on embryos was framed “in terms of progress rather than opening Pandora’s box” (Richardt 2003: 108). In the end, conservative forces won in Germany. The Embryo Protection Act (*Embryonenschutzgesetz*; ESchG 1990) that was passed in 1990 did prohibit all forms of embryological research and PGD. Egg donation continues to be prohibited under the Act, resulting in Germans travelling abroad for treatment with donated ova (Bergmann 2014). The discursive creation of the pre-embryo that was not yet a proper embryo in the UK, “together with a less traumatic eugenics experience than Germany’s” (Richardt 2003: 106) resulted in a UK law on embryological research that was “diametrically opposed” (Richardt 2003: 88) to the German regulation. While Warnock pursued “a strategy that is based not on absolute values of right and wrong but on the “bottom line” of deliberation within an established legislative system” (Franklin and Roberts 2006: 3), the German debate still seems to be more geared towards finding limits that are reflective of what is right and wrong in an absolute sense.

In the absence of a register and comprehensive regulation of DI, the decision as to what kind of information on donors was collected, how it was stored, and to whom it was made available, continued to be largely taken by the medical profession. German physicians in particular remained “gatekeepers” (Bateman Novaes 1998: 106) to a greater extent than their British colleagues, especially with regard to access to donor information. Anonymity was still the clinical norm. With the implementation of the European Union Tissue Directive (ETD) into German law within the Tissue Law (*Gewebegesetz*; *GewebeG* 2007) and through the Transplantation Act (*Transplantationsgesetz*; TPG 2007), the power that physicians exerted over information was only somewhat curtailed in 2007. While the law generally provided for anonymity, sperm donation was treated as an exception. The Transplantation Act stated that in the case of sperm donation, “the right of the child to know its own origins” (TPG 1997 §14 (3), author translation) had to prevail. However, it was still not regulated how and at what time information should be made available. Some



clinics began to store donor information with a notary so that children would be able to access it later in life.<sup>14</sup>

Following the implementation of the ETD, doctors were obliged to keep clinical records including donor information for at least 30 years. Previously, these documents had been destroyed in many clinics after ten years, with donor-conceived activists arguing that physicians should have ensured a longer storage period already prior to that (Spenderkinder 2016d).<sup>15</sup> The extension of the mandatory storage period made it possible, at least theoretically, for adult donor-conceived persons to obtain information about their donor. While in some clinics the new regulation was only applied to treatments that took place after 2007, in other treatment centres records that were already ten years old at that time were also kept. For this reason, some clinics and sperm banks state that they no longer have records for treatments that took place before 1997.<sup>16</sup> Even for treatments that took place after 2007, it is not always easy to obtain information about a donor, as the release of information was not clearly regulated.<sup>17</sup> Overall, the Tissue Law can be described as having “tipped the scales in Germany from a de facto anonymity in sperm donation practices to a still fragile and not very clearly defined form of non-anonymity” (Klotz and Knecht 2012: 293).

A more far-reaching limitation of the power of the medical profession was implemented ten years later. In 2017, the Sperm Donor Register Act (*Samenspenderregistergesetz*; SaRegG 2017) was passed. A central national register began its work one year later. It is managed by the Federal Institute for Drugs and Medical Devices (*Bundesinstitut für Arzneimittel und Medizinprodukte*).<sup>18</sup> At the same time, the Civil Code was adapted, and sperm donors can no longer become the legal fathers of

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14 The practice of storing information with a notary was described to me in personal communication by Claudia Brügge, the head of the German organisation DI-Netz (“DI network”). The practice is also recounted through Zypries and Zeeb (2014).

15 Spenderkinder argues that since the 1960s, it was already accepted by legal scholars and courts that there was a right to know. In addition, the association argues that the code of medical ethics provided that documents should be kept longer if it was deemed necessary.

16 This was reported to me by several of my German interviewees who had contacted the clinics where they had been conceived. They had been told that there were no records left for treatments that took place prior to 1997.

17 In 2017, for example, a couple whose child had been conceived after 2007 only received identifying donor information after they won a lawsuit against a sperm bank (Amtsgericht Wedding 2017). In contrast, a German lawyer told me that a sperm bank had immediately released information when he contacted them on behalf of a client whose child had been conceived before 2007.

18 The register was previously managed by the German Institute for Medical Documentation and Information (*Deutsches Institut für Medizinische Dokumentation und Information*), whose major functional units were merged with the Federal Institute for Drugs and Medical Devices in May 2020.

donor-conceived children, and can no longer be made liable for child support. This was theoretically possible before that but never happened. Those conceived with donor sperm after 1 July 2018 will in the future be able to request identifying information about their donor, which has to be stored for 110 years, from their sixteenth birthday. In contrast to the UK, donors cannot directly apply for information about the children conceived with their donation. However, they are informed when information about a birth resulting from treatment with their semen is registered. They can thus indirectly draw conclusions about how many children were conceived through their donations. A special feature of the German law is that prior to the child's sixteenth birthday, parents as his/her legal guardians can also receive identifying information and may request it right after the birth of their child. Once their children are 16 years old, only the children themselves can access information. No data on past treatments were included in the register, as was also the case for the HFEA register. Thus, it is not an institution from which my interviewees themselves could directly benefit, even though it was seen as positive that it would be made easier for "future generations", as my interviewee Sabrina Frey put it, to obtain information. In contrast to the UK, there is currently no sibling register, which has been criticised by donor-conceived activists (Spenderkinder 2017b) and others (Brügge and Thorn 2017).

In summary, it can be said that the regulation of gamete donation and anonymity has developed differently in the UK and Germany. In the UK, following the discussions sparked by IVF, a central donor register was created, which is managed by the authority that oversees embryo research. However, donor anonymity was only limited years later. In Germany, research that involves embryos remained banned. It was not until 2018 that a central donor register was established. In contrast to the UK, donor anonymity was limited from the outset of the register's creation. Despite these differences, one thing is nevertheless similar: in both countries, the answer to the question of what information the donor-conceived can obtain through formal infrastructures is not simple. Jeanette Edwards argues that due to the various changes in legislation and because of the various voluntary registers, "the situation in the UK of what donor-conceived people can know about their donor, and when, is uneven and complicated" (2015: 102). In Germany, the situation appears to be uneven mainly because decisions on how information should be stored and released have long been made by doctors and sperm banks, without them being supervised by an authority like the HFEA. As Maren Klotz points out in her ethnographic exploration of gamete donation in both countries, "the under-regulation of sperm donation in Germany made its clinical management highly idiosyncratic" (2014: 110).

In Germany, this unevenness also applies to those who were conceived in the 1980s or earlier. While clinics in the UK were not obliged to store information in an accessible form indefinitely before 1991 (Edwards 2015: 102), it remains contro-

versial whether doctors in Germany were required to permanently store information, with donor-conceived activists arguing that anonymity was never legal and that doctors should not have destroyed any records. This has led to several donor-conceived persons suing clinics and doctors, which is not an option for those conceived in the UK.<sup>19</sup> However, neither my German interviewees nor my British ones are among those who have (easily enforceable) official means at their disposal to access identifying information about their donor. For this reason, many of them turn to other means to find their donor or donor siblings. Commercial DNA databases are of particular importance here and will be discussed in detail in chapter 8.

## 1.2 'Identifying' current research practices and themes

In her analysis of the psychosocial scholarship on surrogate motherhood, anthropologist Elly Teman (2008), who has herself conducted some of the first ethnographic research on surrogacy (2010), argues that it “collectively represents a cultural text on the norms and values of Western culture and reveals how Western cultural assumptions impact scientific research” (2008: 1105). In particular, she suggests that traditional assumptions about motherhood and the uneasiness with surrogacy that these assumptions evoke have had an influence on “research goals, methods and conclusions of the scarce empirical scholarship on this topic” (ibid.). Teman (2008: 1110) quotes anthropologist Margaret Lock, who called for anthropologists to “trouble” and “monitor concepts and categories” (2001: 483) used in other disciplines as if they were “universally objective” (ibid.). I find Teman's perspective on psychosocial research enlightening, as the majority of studies on donor conception in general and donor-conceived persons in particular are psychosocial in nature as well. An analysis of the existing research that oftentimes focuses on the connection between having information and “identity formation” shows that scientific knowledge does not emerge from a vacuum. It always “comes from somewhere” (Krebbekx et al. 2017: 639). It is produced through an interplay of various factors, instead of being something that is waiting ‘out there’ to be discovered by researchers. Scientific practices “do not take place outside social contexts, but are shaped by it, and also shape them in return” (ibid.). In this overview I will first discuss the empirical basis of a large part of the psychosocial studies on donor conception. I will then summarise some of these studies in relation to the topics that are most frequently addressed in them. Finally, I will discuss what points of reference these studies provide for my own approach.

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19 See for example a 2014 blog post from Spenderkinder (2014a) for a case that was lost and another entry from 2017 (Spenderkinder 2017a) for a case where several donor-conceived persons succeeded.

A large part of the studies that focus on donor conception – be it parents (Freeman et al. 2009), donor-conceived persons (Jadva et al. 2009; Beeson et al. 2011; Hertz et al. 2013; Nelson et al. 2013; Slutsky et al. 2016; Persaud et al. 2017), or donors (Jadva et al. 2011; Daniels et al. 2012; Hertz et al. 2015; Nelson and Hertz 2017) – have recruited participants from an informal voluntary register called the Donor Sibling Registry (DSR), an American online platform with a worldwide membership.<sup>20</sup> The DSR was founded by Wendy Kramer, who is listed as a co-author on the majority of publications, and her donor-conceived son. What started as a Yahoo group in 2010 with the aim of enabling networking and exchange between parents, their donor-conceived children and donors, has evolved into a non-profit organisation that not only has an online-based register but also frequently collaborates with academic researchers. I argue that the involvement of institutions like the DSR in research and the mixture of scientific studies with concrete calls for actions, which marks a large part of the research, point towards a reconfigured understanding of who can contribute to scientific knowledge.

This transformation has already been explored by other anthropologists. Commenting on the lobbying work of the Donor Conception Network (DCN),<sup>21</sup> a British interest group set up by parents who have conceived with donated gametes, which has been explored in detail by Klotz (2014), Edwards (2018: 160–162) takes up the work of Michael Gibbons, Helga Nowotny and colleagues (Gibbons et al. 1994; Nowotny et al. 2001). In their theoretical work, they explore what they perceived as a shift in the dominant mode of knowledge production. They argue that the new mode of knowledge production was “socially distributed, application-oriented, trans-disciplinary, and subject to multiple accountabilities” (Nowotny et al. 2003: 179). In contrast, the previously dominant mode was “characterized by the hegemony of theoretical or, at any rate, experimental science” (ibid.), by disciplines that remained strictly separated, and by scientists and universities that worked outside of society. They argue that knowledge is now “generated within a context of application” (Nowotny et al. 2003: 186) and by “research communities [that] now have open frontiers – which has allowed many new kinds of ‘knowledge’ organizations [...] to join the research game” (Nowotny et al. 2003: 187). I suggest that organisations like the DSR have succeeded in joining “the research game”. Besides, “the reconfiguration of what constitutes expertise” (Edwards 2018: 161) is also noticeable in Germany, where the organisation Spenderkinder in particular is now invited to government hearings on reproductive technologies (section 4.4).

Since the DSR is different from the formal registers I examined in my own empirical work (chapter 7), I will briefly summarise its special features. It has been

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20 [www.donorsiblingregistry.com](http://www.donorsiblingregistry.com) (last accessed March 28, 2021).

21 [www.dcnetwork.org](http://www.dcnetwork.org) (last accessed March 28, 2020).

argued that it “has perhaps the most comprehensive eligibility criteria of any service” (Crawshaw et al. 2015: 75), as it can be joined by offspring, parents, and donors as well as “family members of all parties directly affected” (ibid.), whereas the UK’s sibling register can only be joined by the adult donor-conceived themselves (section 7.5). Parents can register their children at an early age with their donor’s code if they want to use the DSR to network with other families. Although there is no precise information on the composition of the membership, various studies and information available on the website suggest that parents make up the majority of the membership.<sup>22</sup> Single mothers and lesbian couples seem to be the most active in terms of connecting with families whose children were conceived with gametes from the same donor. New DSR members usually register with the code assigned to each donor, which is a common practice in the US, but not in fertility clinics and sperm banks in the UK and Germany.<sup>23</sup> The donor codes are used to facilitate “matches” between users who have registered with the same code. It is striking that “the identification numbers that dissociated men from their gametes are being used to connect the children conceived from their gametes” (Hertz and Mattes 2011: 1135), which has been described as an “ironic twist” (ibid.). A mechanism designed to separate donors from their gametes and to sever all ties between recipients, donors and offspring is now being used to create unprecedented connections. According to its website, the DSR had almost 75,000 members in May 2021, and more than 20,000 offspring had been connected with their donor siblings and/or donor. Overall, the DSR can be said to “promote[...] the idea that it is socially enriching and satisfies natural curiosity [...] to get in touch online or even form closer relationships” (Klotz 2014: 270).

While the majority of studies conducted with DSR registrants and/or members’ children consist of online-based surveys that usually contained closed and open-

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22 DSR members do not have to provide any information about their family type. However, questions about, for example, marital status are usually part of research surveys. According to the website ([https://donorsiblingregistry.com/our-members#background\\_on\\_members](https://donorsiblingregistry.com/our-members#background_on_members), last accessed May 31, 2021), it is estimated that 49 % of members are single mothers by choice; 33 % are LGBTQ families; and 17 % are heterosexual couples (or were conceived by them).

23 While visitors can browse the register, only registered and fee-paying members can contact other members. The only DSR registrant I interviewed pointed out that the DSR might possibly have more members from the UK than one might think: a former donor I met through the voluntary register DCR mentioned that he had joined the DSR because “a lot of UK people who haven’t found our register go there”. Since I did not try to find interviewees via the DSR, I did not follow up on this. According to those of my interviewees who had joined the DCR, the register was indeed not very well known (section 7.6). Although it seems unlikely to me that someone interested in their donor and/or donor siblings would find the DSR but not the DCR when looking for information, I would not rule out the possibility that my interviewee was right, as the DSR is a lot more present in the media than the DCR.

ended questions, two recent studies (Slutsky et al. 2016; Persaud et al. 2017) built their analysis upon the results of face-to-face interviews conducted with adolescents (aged 12–19) whose mothers were members of the DSR, and who had been conceived with anonymous sperm donations. In both articles, the parent-child relationship is portrayed as laying the foundation for how donor-conceived persons think and feel about the circumstances of their conception. Slutsky et al. argue that those adolescents who are “securely attached” (2016: 206) were most likely to engage in the “sometimes challenging task of exploring donor conception” (ibid.) and express curiosity in their unknown donor. They conclude that the study’s findings “suggest that the valence of the parent-child relationship influences the adolescents’ appraisal of their donor conception within the context of their growing sense of identity” (2016: 207). Being open with the child and within the “wider emotional context of the family” (ibid.) are portrayed as the factors that enable the donor-conceived to “positively integrat[e] donor conception into a coherent sense of identity” (2016: 203). The connection between the desire to find out more and a secure identity is also central to the second article (Persaud et al. 2017), which examines adolescents’ experiences of contact with donor siblings. Persaud et al. argue that their desire to meet them was motivated by the desire to learn more about the donor and themselves. They suggest that finding similarities between them and their donor siblings allowed them to develop “a better sense of their genetic background and identity” (2017: 20).

While these studies focus on openness, contact with donor siblings and the respective connection with identity, Scheib et al. (2017) explore the link between “identity formation” and temporally limited anonymity. The persons interviewed for their study were all conceived with sperm from The Sperm Bank of California (TSBC), which has offered an “Identity-Release® Program” with donors whose identifying information the donor-conceived can request at the age of 18 since 1983. The TSBC stopped offering anonymous donations altogether in 2016. Nowadays, the term “identity release” is often used for donors whose information can be “released” to their offspring, usually when they reach a certain age (see for example Graham et al. 2016 and Hertz et al. 2015). Although the term “release” has positive connotations, and is associated with freedom and development, it is also used to refer to the dangerous release of toxic substances.<sup>24</sup> While the TSBC presents openness and identifiability as having a positive impact on individuals and families, the term “identity release” also frames donor information as something that can have profound consequences for those who request it. This is similar to the

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24 See for example anthropologist Kim Fortun (2001, 2009) on the “Toxic Release Inventory”, a publicly available database about information on the release of chemicals by industry groups and federal facilities. It was established in the US in the aftermath of the Bhopal disaster (see also section 3.5 for a discussion of environmental “right to know” debates).

way in which HFEA texts, which do not speak of “identity-release donors”, “depict accessing information as a ‘big decision’ with profound emotional consequences” (Gilman and Nordqvist 2018: 322; see also section 7.1).

Similar to the DSR, the TSBC has long been involved in academic research. Since 2000, its research activities and programs are headed by research psychologist Joanna Scheib from UC Davis. She has written and co-authored numerous widely cited articles that primarily focus on the TSBC’s “Identity-Release® Program”, lesbian and single mothers and more recently on contact between families with children conceived with sperm from the same donor (for example Scheib et al. 2005; Goldberg and Scheib 2015; Goldberg and Scheib 2016). Those interviewed for the 2017 article were all adult offspring conceived with sperm from identity-release donors, which are referred to as “open-identity donors” in the paper (Scheib et al. 2017). About a third had already requested identifying donor information, which had first become available in 2001 when the first eligible donor-conceived person turned 18. Scheib et al. argue that those who requested identifying information “hoped for an expanded sense of their identity” (2017: 492) as part of a “process of identity formation [that] seemed important for their sense of belonging” (ibid.).

Identity, its formation and the factors that can disrupt it are also at the forefront of the studies that did not find their participants through the DSR or the TSBC. In general, there seems to be a consensus that being told late in life, in combination with not being able to access donor information, results in what psychologist Maggie Kirkman describes as “a fractured sense of identity” (2004: 15) in her qualitative narrative study of recipients, donors and donor offspring from several different countries. This also applies to one of the first studies on the experiences of donor-conceived persons, which was published in 2000. Amanda Turner and Adrian Coyle found that their study participants (from the UK, USA, Canada and Australia), who were sent a semi-structured questionnaire via email and post, “expressed a need and a right to know who their donor fathers are and, if possible, to have some sort of relationship with them” (2000: 2050). None of them had a legal right to obtain identifying donor information. Turner and Coyle argue that providing them with non-identifying information is not “sufficient to meet their identity needs” (ibid.) and that not being able to know “their full genetic history posed a threat to their identity” (ibid.).

In a later study consisting of interviews of people aged 19–29, raised by lesbian parents and conceived with known donors in the US, Abbie Goldberg and Katherine Allen found that their participants tended to become more interested in their donor as they grew older (2013: 327). They argue that this is “indicative of a turning point in their identity, emerging as they were coming of age, in late adolescence or young adulthood” (ibid.). In contrast to this study, for which semi-structured telephone interviews were conducted, clinical psychologist Astrid In-dekeu and bioethicist Kristien Hens (2019) conducted focus group interviews with

twelve donor-conceived persons from Belgium (n=11) and the Netherlands (n=1). All were “born under a legal system of donor anonymity and an atmosphere of secrecy” (2019: 20). Those who were raised by heterosexual couples had not been told until adolescence or adulthood. Indekeu and Hens seem to both relativise and simultaneously emphasise the importance of genetic information: “How we think about genes is [...] shaped by the societal, professional and political discourse on the topic. But it is also undeniable that genes are the biological building blocks of a human being and are linked to resemblance and identity.” (2019: 34) In an online questionnaire-based study that was conducted with registrants of the voluntary pre-1991 register in the UK, van den Akker et al. found that donor-conceived participants had a “lowered collective identity” (2015: 119), which they describe as a “concept referring to a belief that one shares characteristics with a group of others” (ibid.). They interpret this finding as indicating that “belongingness is critical to identity” (2015: 120).

Apart from the “identity effects” of donor conception and/or anonymity, studies oftentimes address the effects of secrecy, openness and disclosure on the wellbeing, or “functioning”, of entire families. This was already the case for the studies conducted by professor of sociology Robert Snowden and his colleagues (Snowden et al. 1983, 1985), who were among the first to conduct empirical research with recipient parents in the UK.<sup>25</sup> Their interlocutors had been treated by Margaret Jackson, one of the “main protagonists of DI provision” (Blyth 2004: 226; see also Jackson 1957), with sperm from anonymous donors. Snowden and his colleagues argued that the stress caused by trying to keep the use of donated sperm and male infertility a secret aggravated the overall burden placed on couples undergoing fertility treatment (Snowden et al. 1985: 60). They believed that couples should be helped to gain a different understanding of male infertility rather than to be encouraged to keep it hidden from their child, while at the same time advocating donor anonymity.<sup>26</sup> Their studies contributed to donor conception coming “more fully on to the public agenda” (Haimes 1998: 59) in the UK, with other non-medical professionals becoming involved in the field as well (ibid.).

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25 A study similar to the ones conducted by Snowden and his colleagues was not carried out in Germany. However, their book *Artificial Reproduction* (1983) was translated into German by Professor of Dermatology Walter Krause (Snowden et al. 1985). The fact that a book on DI, which was back then still conceptualised as a treatment for male infertility, was translated by a dermatologist is linked to the history of andrology in Germany. In contrast to clinics in other countries, where andrology developed as a urological sub-discipline, the majority of German andrology clinics emerged as a subfield of dermatology in the 1950s (Kampf 2013: 25).

26 Snowden argued in 1984 that “there would seem to be good reason for maintaining the anonymity of the donor” (1984: 262), as identifiability might result in “conflicting emotional ties between the family of the recipient and the family of the donor” (ibid.).



The benefits of early disclosure in particular are addressed by Blake et al. (2010) in a study conducted as part of a longitudinal research of families created with the help of reproductive technologies in the UK. They interviewed both parents who had told their 7-year-old children that they were donor-conceived and children who already knew about the circumstances of their conception. All but one child (who had a known egg donor) had been conceived with anonymous donations. According to the authors, a great “majority of children responded to disclosure in a neutral way, or had no reaction at all” (2010: 2533). They argue, however, that those who decide to disclose should keep in mind “that disclosure is an ongoing process” (ibid.) and that children’s understanding of donor conception is likely to evolve as they get older. In a follow-up study of the disclosure decisions of families in the UK, all of whom had children conceived via anonymous DI, Tabitha Freeman and Susan Golombok (2012) found that non-disclosure did not necessarily result in weaker family relationships. However, they point out that “observations of positive functioning in non-disclosed families must be weighed against the risk of accidental disclosure in later life and the potentially negative outcomes associated with this” (2012: 201). This mirrors the results of an earlier European study (Golombok et al. 2002). Freeman and Golombok also highlight the “positive functioning in disclosed families” (2012: 201) and argue that openness “does not appear to create significant difficulties in family functioning and child psychological adjustment” (2012: 202). Disclosure is thus advocated not on the grounds of a right to know, but rather on pragmatic terms that nevertheless promote a specific ideal, namely that of the harmonious family whose members do not keep secrets.

Comments about identity and the damage that anonymity and secrecy could cause to it were abundant in the interviews I conducted. My interviewees frequently mentioned that they experienced an “identity crisis” when they found out that they were donor-conceived, had started to “lose identity”, and emphasised that “knowing where you come from” was essential for a child’s “identity formation”. While I take the theorising of my research contacts seriously, I suggest that an epistemological and analytical distance to their statements is necessary to avoid a mere replication of their descriptions. I contextualise the stories of my interviewees and make them an object of ethnographic investigation. This means that I interpret neither anonymity nor secrecy as inherently dangerous to individuals and families, and that I also interpret “identity” differently than the psychosocial studies I have presented. Their authors seem to conceive of identity as something that is primarily formed in childhood and that can be shaken by new, unexpected information about one’s origins and by the impossibility of getting to know the donor. Following Strathern and her concept of “constitutive information” (1999c), I conceive of information about the circumstances of a person’s conception, the use of gametes and the donor as something that *constitutes* identity. It is the “cul-

tural coupling with identity” (1999c: 68) that makes information about a donor “a particular kind of knowledge” (ibid.).

It should be noted that Strathern otherwise tends to avoid the term “identity”. In a recent interview with sociologist Joanna Latimer, Strathern argues that it is “one of those incredibly loaded Euro-American concepts that made its use for analytical purposes really suspect” (Strathern and Latimer 2019: 490).<sup>27</sup> She has written elsewhere (2017) about how identity was “invented”: “It is to the scientific and philosophical innovations of the European seventeenth century that we owe the concept ‘identity’.” (2017: 20) It is “applied to the self-sameness of persons quite as much as of things” (ibid.). I share Strathern’s concerns, especially given the extent to which the concept is used in psychosocial studies and by my interviewees themselves, even though I do not avoid the term completely. I speak, for example, of the wish to know “the identity of the donor”, whereby I mean a condition in which identifying information is not disconnected from a donor. By contrast, anonymity means that “identifying information is dis-associated from a person or simply vanishes” (Bachmann et al. 2017: 249).

This short overview of psychosocial studies also shows that there are several research gaps in terms of who is studied and what methods are employed.<sup>28</sup> I will explain the methods I used and my research process in chapter 2. Much of the existing research on donor-conceived persons has recruited its participants through voluntary registers (DSR and TSBC), with the majority of them having been conceived in the US, where reproductive technologies are largely unregulated. There are relatively few studies that focus on Europe and donor-conceived adults instead of children, and, apart from Klotz (2016), no ethnographic explorations.<sup>29</sup> In this

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27 Strathern uses the term “Euro-American/Euro-Americans” “to summon those whose cosmologies were formed by the religious and rationalist upheavals of the seventeenth and eighteenth centuries across Northern Europe, creating present-day America in their wake” (2005: 163). Furthermore, she argues that “Euro-American influence [...] has global spread” (ibid.). It is thus not confined to Europe and North America. Strathern argues that this “hybrid [term] is preferable to the monolithic ‘Western’” (1992: 11), although it seems that “Euro-American” is in fact often used as a substitute for “Western” (Bergmann 2014: 27). While I do use the term “Euro-American”, I am aware of the fact that it can be “a hindrance when attached to particular populations and real lives” (Edwards 2008: 7) and might, similar to the term “Western”, again be too monolithic. If one takes into account the law “as a site in which certain kinship understandings are crystallised” (ibid.), it becomes clear that significant differences exist between the countries where I conducted research: for example, ova donation is permitted in the UK but not in Germany.

28 See Canzi et al. (2019) for a systematic review of studies conducted about donor-conceived persons.

29 Drawing on ethnographic interviews conducted with two donor-conceived adults in the UK, ongoing contact with a member of Spenderkinder and a worldwide newsgroup, Klotz explored “wayward relations” (2016), which she defines as the “searches and relationships be-

book I investigate the narratives of donor-conceived persons from countries where gamete donation and anonymity were regulated differently and with varying degrees of formal control exerted by official authorities and/or physicians. While previous research on how the donor-conceived access information and come into contact with the donor and/or donor siblings has mainly focused on voluntary and informal registers, in this book I will look at a whole range of possibilities, including formal and informal infrastructures (chapter 7) as well as “subversive uses of genetic testing” (Klotz 2016: 52) (chapter 8). I will thus explore the transformation of anonymity at the intersection of various regulations and infrastructures, while also focusing on social practices and relations. I examine not only how the donor-conceived form connections with anonymous and/or identified genetic relatives but also how they form new relationships with each other.

By “[o]pening up anonymity” (Konrad 2005a: 241) and other forms of non-knowledge, instead of focusing on its consequences for “identity formation”, relational and temporal practices and questions of power and politics can be investigated. Since questions of anonymity in gamete donation and its effect on “identity formation” are morally charged, the following is usually forgotten: anonymity “is able to function to both good *and* bad ends” (Ponessa 2013: 322, emphasis in original). Anonymity is notably “tied to a fundamental set of values associated with the European enlightenment: *liberté, égalité* and *fraternité*” (Bachmann et al. 2017: 245), as it may ensure freedom from surveillance, guard against the establishment of hierarchies by removing certain social categories from a person and enable new forms of collaboration. At the same time, it may also “promote the promulgation of hate speech” (Ponessa 2013: 321) and has the potential to “create a special sort of license to perform moral transgressions we might otherwise resist” (Ponessa 2013: 322). The multifaceted nature of anonymity and the many different ways in which anonymity can be socially productive (Bachmann et al. 2017) have been explored in various ethnographies that deal explicitly or implicitly with anonymity in a variety of contexts. A small but ethnographically rich selection of these works will be presented in the next section.

### 1.3 Situating anonymity

In my exploration of anonymity in gamete donation, I start from the assumption that anonymity is always something that is situated (Bachmann et al. 2017: 243). In this section, I will discuss a couple of ethnographies that have explored situated

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tween persons connected through the chance allocation of a sperm donor through a fertility clinic” (2016: 45).

anonymity in a variety of different fields, namely Monica Konrad's work on ova donation (2005a), Jacob Copeman's exploration of blood donation (2009), the work of Lesley Sharp (2006) and Margaret Lock (2002) on organ donation, several explorations of the lesser-known practice of breast milk donation (notably Cevese 2015), and Catarina Frois's (2009) inquiry into self-help groups. Of course, this small selection of topics does not cover all fields in which anonymity has been explored. It leaves out, for example, studies that have looked at anonymity in the virtual world. Gabriella Coleman's work on the activist online network Anonymous (Coleman 2014) is of particular importance here. I have chosen to focus on ethnographies of the donation of ova, blood, organs and breast milk in order to show how differently the importance of knowledge, and thus the meaning of anonymity, is negotiated in relation to the origin of bodily substances and fluids. I have included the work of Frois (2009), as her study of self-help groups is one of the few that deals with anonymity in physical interactions, illustrating that anonymity does not have to equal facelessness.

An ethnography that is arguably path-breaking not only for the study of anonymity but also for ethnographies of gamete donation is Konrad's *Nameless Relations* (2005a; see also Baumann 2017 for a more detailed review). Konrad conducted ethnographic research on anonymous ova donation in the mid-1990s in three English fertility clinics, interviewing both donors and recipients who could not receive identifying information about each other. Since the women remain mutually anonymous, recipients cannot make reciprocal return gifts, and the "principle of balance" (2005a: 41) is thus blocked. However, Konrad shows that anonymity can be explored as a form of sociality: despite never meeting up in person, donors and recipients establish "relations of non-relations" (2005a: 49). While they cannot make reciprocal counter-returns, Konrad suggests that "in anonymous sociality relations of non-relations are mediated by the (non) knowledge of transilience" (2005a: 242). "Transilience" describes an abrupt change or leap from one thing or state to another. Konrad argues that "the substance of transilient relations is made from the anticipation of a future, as yet unknown, kinship whose processual activation sometimes may span several years" (2005a: 49). Since donors and recipients cannot know each other, transilient relations are imaginary and marked by "a sense of intimacy at a distance" (2005a: 98). Konrad suggests that they are 'killed off' by actual physical encounters (2005a: 214). While a donor cannot know neither the identity of the ova recipient, nor the outcome of her donation, she can compensate a lack of knowledge "by the continuous work of transilience that keeps ties alive as imagined relations" (2005a: 115). I will return to Konrad and her idea of "active not-knowing" (2005a: 170) in section 5.4.

A work that picks up and expands Konrad's ideas is Copeman's ethnography *Veins of Devotion* (2009), in which he investigates blood donation in India. Since public campaigns aimed at raising awareness for voluntary blood donation have not

yet been very successful, religious movements have become important providers of voluntary blood donations throughout the country (2009: 3). Donations at “record-breaking ‘mass’ or ‘mega’ blood donation camps” (2009: 105) are voluntary, unremunerated and anonymous and therefore differ considerably from a system that is based on paid donations and replacement donations.<sup>30</sup> Copeman’s work on donation camps staged by devotional orders, which attract thousands of people, shows “that anonymity need not be synonymous with alienation and passivity but may rather provide a kind of imaginative canvas for novel ideational maneuvers” (2009: 10). In particular, Copeman argues that the ideology of national integration is “recreated and reasserted” (2009: 150) through large-scale camps where organisers often attempt to gather people from diverse backgrounds (2009: 158–159). Taking up Konrad’s concept of transilience, he suggests that blood donation camps can be seen as “the basis of a “national transilience”: the enactment of threadlike imaginative extensions across diverse plurality as the folding of different constituencies into a single social field” (2009: 165). He gives the example of a Muslim donor who imagines his donation to transgress the boundaries of religion and caste and quotes him as saying that his donation is “for the integration of people” (ibid.). Copeman’s work thus shows, like Konrad’s study, that “anonymity can open up new spaces of ideation and relational reckoning” (2009: 11). *Veins of Devotion* and *Nameless Relations* both demonstrate that anonymity is not asocial, and that it can in fact be a form of sociality.

In organ donation, anonymity has long been regarded as something that protects both donor kin and recipient: on the one hand, it is perceived as something that enables the relatives of the deceased donor to mourn peacefully, without being disturbed by recipients who might try to contact them. On the other hand, it is seen as a mechanism that ensures that recipients do not identify themselves with donors and feel even more guilt than they already do after being given the chance to live on through someone else’s death (Sharp 2006: 106). It is striking that, as I have shown in section 1.1, anonymity in gamete donation was also previously seen as a protective mechanism before a far-reaching change occurred. A transformation can also be observed in organ donation. In *Strange Harvest*, her ethnographic study of organ donation in the US, Sharp argues that there have been “radical shifts in the ways that cadaveric organ donors are described and, ultimately, imagined in the transplant arena” (2006: 105). One of these shifts is “the recent challenge mounted by numerous donor kin against the assumption that the anonymity of donors is crucial to organ transfer’s success” (2006: 106). Since the idea that “transplanted organs can retain the life essence of their donors” (2006: 4) is central for the way

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30    A “replacement donor” is a friend or relative of the recipient who donates blood in order to replace the blood used in a treatment, ensuring that the clinic or bank has a consistent supply of stored blood.

in which donations are understood in the US, not being able to know who received the organs of a loved one can be experienced as detrimental.

While encounters between donor kin and recipients used to mainly happen by chance, Sharp argues there has been “a dramatic shift from renegade acts of personal contact to more carefully, and professionally, orchestrated encounters” (2006: 180). Organ procurement agencies and transplant units have started to rethink and reshape their policies on anonymity (2006: 106). As part of this transformation, communication between the different parties has become bureaucratised. Special communication coordinators mediate the exchange of anonymous letters, which they might edit before passing them on (2006: 179). While protocols and guidelines make a meeting more likely, they also mean that the final decision to make contact lies with coordinators who decide “on a case-by-case basis whether personal encounters should occur” (ibid.). Sharp does not explain how coordinators proceed with the editing of the letters and, above all, what information they classify as identifying and thus decide to edit out. An editing process is also carried out at the HFEA, as officers have to review donor information before sending it to those applicants who are not entitled to identifying details. As I will show in my discussion of the HFEA’s “redaction process” (section 7.2), the decision as to whether information is considered to be identifying or not is determined by a variety of factors and practices.

Another ethnographic account of organ donation that addresses the question of anonymity is Lock’s monograph *Twice Dead* (2002). Lock argues that ideas about a donor ‘living on’ in the recipient individualise donation, which “encourage[s] anthropomorphization and fantasies about personality changes” (2002: 372). Donor kin worry about the whereabouts of the donated organ and the identity of the donor, having no chance “to come to terms with the finality of death” (ibid.). Lock suggests that this increases resistance to donation in North America. Her ethnographic research in Japan opens up a particularly interesting perspective on anonymity, as she observed a similar kind of resistance in the Asian country. The reluctance to donate, however, had other reasons. In contrast to American donor kin, “Japanese families do not fantasize about individual transcendence of death but rather worry whether recipients will treat their relatives’ organs with due respect.” (Ibid.) However, Lock found that many Japanese would still prefer a donation from an anonymous donor, who has consented to the donation, to a living donor transplantation from a known relative (2002: 334). Lock argues that in a society such as Japan that is “bonded through networks of reciprocity and exchange” (ibid.), the “burden of reciprocity” (2002: 335) that comes with a living donation can be unbearable. Receiving an organ from an anonymous donor is ascribed a protective function, as anonymity makes reciprocal exchanges impossible from the outset. It is thus not a matter of fending off future difficulties that may

arise from contact with donor kin, which is a main reason why gamete donors are anonymised, but of not burdening existing relationships.

Anonymity can also have a protective function for self-help groups where it may be crucial for creating equal relationships between members. In *The Anonymous Society* (Frois 2009), an ethnographic study of Alcoholics Anonymous, Narcotics Anonymous and Families Anonymous in Portugal, Frois argues that in these groups, anonymity is “used to minimize and level out [social and cultural] differences” (2009: 158). While it might seem strange to speak of anonymity in a situation where people meet face-to-face in an offline environment, Frois found that “it is anonymity that the members speak of and it is in fact anonymity that they want to preserve” (2009: 174). According to Frois, anonymity in self-help groups has inside and outside dimensions to it (2009: 156): on the one hand, anonymity is important for the relationships within the group, as participants do not have to reveal anything about themselves apart from their condition or problem. On the other hand, it is a protection from the outside world that might stigmatise those who attend (2009: 161–163). Frois concludes that anonymity constitutes “a method for managing revelation and concealment” (2009: 174). These two processes “imply a tension which is fundamental in member’s lives: revealing or hiding *where, to whom and why*” (2009: 175, emphases in original).

Frois found that only few people allowed the inside and outside of a group to overlap (2009: 176), although she observed that members would sometimes “establish preferential relationships with a few others, to whom they reveal information omitted so far” (2009: 164). Frois does not go into detail about situations where it may be important or desirable for members to reveal their identity, arguably because she believes that anonymity breaches, despite being common, “cannot be generalized” (2009: 165). The question of with whom one should share information was repeatedly addressed by the persons I interviewed. They frequently asked themselves whether to tell friends and relatives about the circumstances of their conception (sections 6.2–6.4). It was thus not about sharing information that would reveal the identity of the person in question, whose name their friends and relatives knew; the information would however identify them *as donor-conceived*. It should be noted that anonymity could be “a method for managing revelation and concealment” (2009: 174) in my field as well. Some of my interviewees would choose to appear in the media anonymously (section 4.2) or worry a great deal about how I anonymised them (see for example Timothy Parsons in section 6.1), as they did not want others to find out they were donor-conceived.

While remaining anonymous was considered necessary by my interviewees in certain situations, it was clear to the majority of them that the anonymity of gamete donors had to be rejected. If you do not know the donor’s identity, they reasoned, you do not know where you come from. In their way of conceptualising kinship, knowing the identity of the donor is important because the donated gametes have

created an indissoluble link between them and their donor. As Strathern points out, “it is not the case worldwide that the foundation of relationships is held to rest in [...] biogenetic facts” (1995: 349). There are many different ways of creating and ‘doing kinship’, which has implications for the type of knowledge that is considered important. Depending on from where kin ties originate, it may not (or at least not only) be knowledge about those involved in one’s biogenetic conception that is important. This becomes evident in the practice of human breast milk donation and banking and the way the anonymised nature of breast milk is, at least by some, problematised. Similar to banks working with donated blood, human milk banks are “dedicated to the collection, processing and distribution of a disembodied human fluid as a medical therapeutic” (Swanson 2014: 165). Donated milk becomes “anonymous, movable, mixable, and, above all, it is totally detached from the provider” (Cevese 2015: 102), before being used to feed premature babies whose mothers do not yet have their own milk (Carroll 2015: 173).

In her ethnographic study of milk banking in an Italian neonatal intensive care unit, Rosella Cevese (2015) found that immigrant Moroccan women were often-times reluctant to donate milk or accept donated milk for their children. Cevese argues that the practice of milk banking can be said to “challenge[...] the rules of milk kinship” (2015: 108). Milk kinship can be described “as a strategy of managing social relations by limiting or creating milk ties” (2015: 107). It is a kinship relation created through breastfeeding that is acknowledged by Islamic law as a form of kinship (Altorki 1980). Milk kinship remains socially important in the Middle East despite the practice of shared breastfeeding having declined (Clarke 2007). It turns a woman who breastfeeds a child she has not birthed into his/her “milk mother”, the children into the woman’s “milk sons” or “milk daughters”, and those who have been nursed from the same woman into “milk siblings” (Parkes 2005). Milk kinship is something that is “not created by chance, but it is managed by important social rules” (Cevese 2015: 103–104), which is why not being able to trace the origins or whereabouts of breast milk may be perceived as problematic. Cevese cites a young mother, who had chosen not to donate her surplus milk: “I have to know the baby who would suck my milk, because he would become my “milk son” and [her daughter’s] “milk brother.” Who knows if one day in the future they will get married...!” (2015: 100)<sup>31</sup> Cevese found that Italian women, despite “consider[ing] breastmilk

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31 Whereas donating and procuring milk through banks is a regulated process, in the case of informal milk sharing, recipients and donors tend to make their decisions about what rules to follow on a case-by-case basis (Falls 2017: 58). In her ethnographic study *White Gold*, anthropologist Susan Falls (2017) highlights that a new way of organising informal milk sharing has emerged. Parents are increasingly connecting with each other via online platforms (2017: 54). Falls found that the kind of donor information recipients wanted to receive and the type of connection they wanted to form with a donor did vary. While some parents used screening forms provided by some platforms, others relied on their personal impression and on



as a precious and nourishing substance” (2015: 104), did not share these concerns and were not worried about the identity of a milk donor and recipient. For them, breast milk was not a substance that creates kinship ties.

In this book I take up some of the themes and questions raised in the works discussed in this section. Inspired by Konrad (2005a) and Copeman (2009), I examine imaginations and imaginary relations in the context of anonymous gamete donation. Like Sharp’s study (2006), my research deals with an area in which far-reaching transformations have occurred in relation to anonymity. A particular strength of my empirical material and the added value it brings to ethnographic research on anonymity is, I suggest, the fact that it opens up a very specific temporal perspective. In the case of my interviewees, all of whom were adults who had been conceived with anonymous donations, anonymity had already ‘come into play’ nearly two or more decades ago. In the years since their parents had undergone treatment, the conditions for donor anonymity have changed radically. This change has less to do with formerly private information about donors being publicly accessible, and more with new ways of linking information becoming available. For the most part, the parents had not intended to tell their children about the donation at all. According to my interviewees, many had been advised by doctors to keep the anonymous donation a secret. Thus, many of the phenomena I discuss in this book are unintended developments. If everything had gone the way it was often planned at the time of treatment and conception, the people I interviewed would not know about the anonymous nature of their conception. Even if they are the desired result of the treatment, they are still an unintended development in terms of the knowledge they have.

The transformation of anonymity in gamete donation has various dimensions to it and is influenced by various factors, some of which have been taken up by the works presented in this section. Of central importance in my research are infrastructures. They are, I suggest, also central to Copeman’s work on blood donation (2009), although he does not use the term when analysing donation camps. Important infrastructures in my field of research are not only formal and voluntary donor and sibling registers but also commercial DNA databases. Commenting on some of the early anthropological studies on infrastructures, which highlighted “that infrastructure is a fundamentally relational concept” (Star and Ruhleder 1996: 113; see also Star 1999: 380), Sandra Calkins notes that the term has been applied to variety of entities: “Whatever arrangement of technologies, procedures, and people

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inquiring the donor’s medical information (2017: 59); and while some parents chose to have frozen milk shipped to them, others decided to only collect the milk in face-to-face meetings to form a better impression of the donors (2017: 62). Personal contact could be completely avoided when a third party such as a doula organised the donation (2017: 59). However, this does not seem to be a common variant, or at least is not described in detail by Falls.

was solid enough to facilitate a set of organized practices was called infrastructure in relation to that very practice.” (2016: 178) In her study of gold mining in Sudan, Calkins uses the term “infrastructuring” to attend to “the always incomplete process of making infrastructure and the continuous work at integrating, cutting, and maintaining relations between heterogeneous elements” (2016: 188). The shift in focus from infrastructure to infrastructuring can be described as “an analytical measure that shifts attention from structure to process” (Baker et al. 2018). I use the term in chapter 8 when examining the ways in which the donor-conceived use online genetic databases. Instead of postulating the “end of anonymity”, I argue that a complex process of infrastructuring information, which involves these technologies, changes what can be known and by whom.

The question of how anonymity and the release of information is regulated is, for example, explored by Sharp (2006) who found that contact between organ recipients and donor kin is increasingly subject to bureaucratic procedures. The question of regulation is particularly important in my field of research where, unlike in other fields, claims to a “right to know” are formulated by specific groups. Konrad’s (2005a) ethnographic research on ova donation took place at a time when donations in the UK were still permanently anonymous by law. She already noted back then that many of those who advocate a fundamental right to know of the donor-conceived “have turned to legal instruments in an attempt to press their case” (2005a: 36). Since special significance is ascribed to knowledge about genetic origins, discussions about anonymity in gamete donation are morally and emotionally charged. This is particularly evident in the discussions about a “human right to know” (section 3.1). The demands that the donor-conceived make are often demands that concern the regulation of information. They demand that the donor’s identity be known and claim that the state has a duty to ensure and, if necessary, enforce disclosure by including information in official documents (section 3.6). This book also examines the networks that the donor-conceived form in order to enforce their claims and the role the Internet plays in this (sections 4.3 and 4.4)

## 1.4 Knowing kinship

While there are relatively few ethnographies that explicitly deal with anonymity, the situation is different when it comes to relationships: “If there is one story that anthropology has always told well, it is the story of relationships.” (Klotz 2016: 45) This seems to be particularly true for kinship. However, the nature of the story has changed significantly over time. While in the past kinship was seen as a solid structure, today it seems almost banal among anthropologists to say that it is something that is done, and that *doing kinship* should be the focus of attention. I thus draw on the scholarly tradition of the so-called “new kinship studies” (e.g. Carsten 2004;

Edwards 2000; Franklin 1997; Strathern 1992, 2005; Weston 1991) that have explored how kinship is done in a particular setting.<sup>32</sup> Central to this body of work is the recognition that procreation through heterosexual reproduction is not the only way in which kin relations can be made, which is also illustrated by the work on milk kinship I mentioned in the previous section. Knowledge of the alleged “facts of life” is not as important everywhere as it is in the countries where I have conducted research. However, it certainly is “foundational to personal identity” (Strathern 1999c: 68) for the people included in this study. Since kinship knowledge “forms (‘constitutes’) what [people] know about themselves” (ibid.), it cannot be rejected once it has been discovered, even if it is considered irrelevant or unpleasant. Its “cultural coupling with identity” (ibid.), for which Strathern coined the term “constitutive information” (1999c), has an immediate social effect (1999c: 77). It is always more than knowledge about relationships: “knowing something about one’s kin is also knowing something about yourself” (ibid.).

For people who discover that they were conceived with donated gametes, the social relationship with the woman or man who raised them, and to whom they are not genetically related, does not necessarily have to change. They might still see them as a family member and call them their “mother” or “father”, which was the case for the majority of my interviewees (section 6.4). They might also choose not to pursue an active social relationship with their donor. This goes to show that Euro-American kinship “cannot be confined or delimited by the scientific facts about conception or birth” (Edwards 2015: 106).<sup>33</sup> It is also “forged over time” (ibid.). Nevertheless, the donor-conceived cannot maintain that they are genetically related to their parent (although this might of course be what they tell others whom they do not want to know). While finding out that they are donor-conceived might not necessarily lead to a breakdown of their social relationships, it does constitute what they know about themselves.

As Klotz points out, “there actually has been little empirical engagement with the concept of kinship-knowledge as constitutive information” (2014: 53). Apart from her own work, which I will introduce shortly, the concept has been discussed mainly by Janet Carsten (2007). In this book I will repeatedly refer to some of her research on adoption reunions, in which she does actually not yet use the concept (2000b, 2004). Drawing on her own previous work and on other ethnographic research of not only adoption but also prenatal testing and ova donation, Carsten examines “what people *do* with the information they acquire, and the different ways

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32 Two edited volumes that have shaped my approach to the topic are *Relative Values: Reconfiguring Kinship Studies* (Franklin and McKinnon 2001) and *Cultures of Relatedness: New Approaches to the Study of Kinship* (Carsten 2000a).

33 The way in which “[k]inship is also forged over time” (Edwards 2015: 106) has for example been examined in anthropological studies of adoption (e.g. Howell 2006).

in which they may deploy it” (2007: 405, emphasis in original). While Strathern focused her analysis on reproductive technologies, Carsten argues that there are multiple examples in the literature that illustrate her idea about kinship knowledge being constitutive of identity (2007: 407–408). Based on her own research on adoption, Carsten also points out that “acquiring information about origins” (2007: 416) can be a means “to reassert agency over past events” (ibid.). Constitutive information is thus not only about personal identity but also about agency. Lastly, Carsten found that despite not being able to outright refuse information, adoptees and others can nevertheless manage information by attempting to control “the destabilizing force of new kinship information” (2007: 421), for example by not telling their own children that they had met their birth parents. Such tendencies can also be observed among the donor-conceived persons I interviewed. It was striking that when thinking about who should be told, the right to know and norms of honesty and transparency were less important than considerations of care and the desire to avoid “kinship trouble” (chapter 6).

Klotz herself focuses on such “tactics of active management” (2014: 54) in her study of British and German families that chose to tell their donor-conceived children about the circumstances of their conception. She borrows a term from management and organisational theory, namely “knowledge-management”, “to refer to these active processes in families, clinics, regulation, and interest group activism” (ibid.). The term connotes not only practices but also the involvement of “material and immaterial information infrastructures” (2014: 55). Instead of pointing towards “a growing currency to genetics/genomics within different social arenas” (2014: 338), her findings are indicative of “the rise of transparency as moral imperative for various forms of information-sharing and as a framework to manage problems” (2014: 340). When transparency becomes “infused with an explicit moral judgment” (2014: 341), non-disclosure becomes equated with lying (2014: 213–217), and “inequalities in knowledge distribution” (2014: 218) are viewed as “something to be avoided” (ibid.). She found that parents managed kinship knowledge through a variety of strategies, for example by advocating a certain terminology and not referring to the donor as “biological father” and using special ‘disclosure books’ to tell their child early on (see also section 6.4). She also observed a “subversion of official regimes of knowledge-management” (2014: 349) through voluntary registers and DNA testing. This aspect of knowledge-management in particular is taken up in this book and especially in my analysis of genetic databases (chapter 8), which have grown considerably in terms of their membership base since Klotz conducted her fieldwork.

Commenting on UK debates on disclosure, Edwards notes that calls for openness promote a particular vision of family life, namely “a family that flourishes on open communication and honesty between parents and their children and one where relations of equal and individual rights rather than authority or hierarchy

are preferred” (2018: 157). She argues that this “push to more openness and transparency in donor conception is informed less by the practices that go on within actual families, [...] and more by a particular politics and value in specific forms of family relationships” (2018: 167). The kinship relations that are valued are those that are completely “see-through” (2018). This was also the case for the people I interviewed. While some believed that “real families” were only those whose members were genetically related to each other (section 4.1), the vast majority of people emphasised that what mattered most was openness and honesty (section 4.2). “Good families” were those that were “see-through”. According to Edwards, calls for openness that denigrate anything other than early and full disclosure are “of a piece with calls for more transparency and openness in many spheres of personal and political life in the first decades of the twenty-first century” (2018: 166). Parents who have conceived with donated gametes and seek to keep the treatment secret because they fear being stigmatised by their community are considered not only improper parents but also improper citizens. Edwards concludes that the ideology of the transparent family “allow[s] some rather than others to belong unproblematically to the state in which they reside” (2018: 169). She argues that anthropologists “need to remain alert as to what and who gets invisibilized” (ibid.) when there is “a moral imperative to disclose” (2018: 167).

The testimonies of the donor-conceived carry weight in discussions on disclosure and donation. Drawing on her experience as a member of the Nuffield Council on Bioethics working party on disclosure and donor conception, and its consultation exercise where donor-conceived persons testified,<sup>34</sup> Edwards points out that

“The firsthand account of the “directly involved” legitimates emergent authority with authenticity. In the case of the debate on disclosure and donor conception, the strong and compelling voice of donor-conceived adults backed by supporters, including social workers and counselors, is powerful. It is not easy to gainsay an account of the personal experience of hurt and betrayal – put powerfully and idiomatically to the working party as a “life screwed up” – caused through not being told something that is then generalized as a deliberate conspiracy to withhold

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34 In 2012, the Nuffield Council on Bioethics, a UK-based independent charitable body, commissioned a report on information sharing in donor conception: “At stake was the question of whether donor-conceived offspring should always be told the means of their conception so they can know, at some point, the identity of their donor.” (Edwards 2018: 156) In preparation for its report, which was published in 2013, the Council launched a consultation exercise and conducted several “factfinding sessions” with representatives from various organisations as well as individuals, such as donor-conceived persons, recipient parents, donors, medical professionals, and researchers. In addition, the Council also issued a “call for evidence” that allowed organisations and members of the public to submit replies.

information. It is relatively easier to condone the idea that “the establishment” conspires to keep its workings hidden.” (Edwards 2018: 161)

An example for the authority ascribed to the donor-conceived and their ‘authentic’ stories can be found in an article authored by family law commentator and practitioner Andrew Bainham (2008) in which he argues for a reform of birth registration.<sup>35</sup> Bainham refers to the testimonies of two donor-conceived persons who presented to the committee on the Human Tissue and Embryos Draft Bill, which eventually resulted in the 2008 amendments to the HFE Act. Both of them argued that the state had to protect and enforce their right to know. Bainham maintains that these views should be taken “extremely seriously. They are not based on academic theorising but on direct personal experience.” (2008: 465) The question arises as to what this means for anthropologists (Edwards 2018: 161). Apart from pointing out “that there are different ways in which flourishing kin relations are forged” (ibid.), researchers might also argue “that it is not axiomatic that a healthy “self-identity” correlates with knowing one’s biological parents” (ibid.). However, I suspect that Edwards is right in assuming that such arguments might lead to anthropologists being “accused of complicity: complicity in allowing a parlous state of affairs to continue” (ibid.).

Apart from Strathern’s notion of constitutive information, I also draw on her 1995 essay “Displacing Knowledge: Technology and the Consequences for Kinship” and the predictions or “extrapolations” she formulates.<sup>36</sup> Fundamental to her analysis is the assumption that procreation and reproduction are different. She describes reproduction as the process that “refers both to the biological aspects of producing new children and to the perpetuation of aspects of personal identity over time” (1995: 347). She notes elsewhere that “a reproduction always shows its relationship to the original: the old entity is present in new form” (1999b: 209). In contrast, “Procreation refers to the generative moment, to the act of begetting [...] Offspring may be implied, but nothing about their similarity to the original.” (1999b: 210) Strathern argues that in contrast to procreation and “the process of conception and birth” (1995: 347), “reproduction cannot occur in the absence of a certain kind of knowledge about the identity of others” (1995: 354). An anonymous donor might thus be involved in the procreation of a child, but not in his/her reproduction (ibid.).

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35 The connection between authenticity and authority is laid down in the etymological origins of the term. It derives from the Greek word “*authentēs*”, which can mean both “one who acts with authority” and “made by one’s own hand” (Bendix 1997: 14).

36 Strathern argues that since “cultural analysis is always after the event” (1995: 346), these predictions are also “commentary on current practices” (ibid.).

Strathern's first extrapolation concerns the displacement of the family.<sup>37</sup> Previously, "both the mother and the father were responsible for the production and reproduction of the child" (Cadoret 2008: 82). While "procreation was once a symbol of reproductive continuity" (Strathern 1995: 354), the creation and reproduction of a child no longer coincide when the child is conceived with donated gametes. Strathern notes that while previously it was caretaking roles that could be assumed by several persons, reproductive technologies have resulted in the dispersion of something else: "In some of the current facilities offered by assisted conception, it is the range of those involved in procreation itself that has become dispersed." (1995: 352) There is a plethora of procreators that include those who need assistance to conceive, and those who offer assistance. While it is the couple that reproduces the child, "the kinship is dispersed" (*ibid.*).

Strathern argues that apart from the dispersion of kinship and its separation from the family, assisted reproductive technologies also lead to the displacement of reproduction, with identity becoming part of the procreative instead of reproductive process (1995: 360). She suggests that the more knowledge people have of "the complexity of genetic makeup" (1995: 356) and "of the likelihood of disorders being transmitted and the more accurate the tracing of genetic components, the less necessary it becomes to know the identity of the parent (1995: 356–357; see also Strathern 1992: 178). Strathern argues that while dispersed conception leads to dispersed kinship, the separation of reproduction from procreation creates a paradoxical situation: "'more' kinship does not necessarily lead to 'more' relatives" (1995: 353).

While Strathern's prediction about the dispersion of kinship seems immediately plausible, the second extrapolation is somewhat puzzling at first: it seems that donor-conceived persons are very keen to know the identity of the donor after all. This applies at least to the majority of my interviewees.<sup>38</sup> It should be noted that the desire to have a complete medical history seemed to play a minor role in the search for a donor for most of the people I have talked to (section 6.4), although I have no evidence to suggest that this has anything to do with people being able to directly 'access' their genome. However, the growing popularity of "ethnicity estimates" offered by commercial DNA databases, which promise to show registrants where they "really come from" (section 8.1), might be seen as confirming Strathern's argument: "Questions that the individual person once asked of him- or herself

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37 It is important to note that Strathern does not argue that the (nuclear) family would disappear, but "that there is more to kinship than family life" (1995: 351).

38 See section 7.2 for a discussion of why it is difficult, if not impossible, to make precise statements about how large the proportion of those who want to know more really is.

about origin and links need no longer be asked of kinship when they can be asked of the individual's genome." (Strathern 1992: 178)<sup>39</sup>

Strathern herself does actually note that "in personal and social terms it may matter considerably to individuals to know who their genetic parents are" (1995: 356). This is what Victoria Grace and Ken Daniels (2007) argue in their study of New Zealand parents that conceived with DI. They claim that Strathern's predictive account is problematic because "it is frequently the case that offspring who know that half their genes come from an unknown donor in fact do want to find out about this inheritance" (2007: 707). Grace and Daniels conclude that the separation of reproduction and procreation is not that definite and suggest that "procreation will always contain the seeds of social relatedness" (2007: 708). However, I suggest that their criticism falls short, as it fails to take into account an important part of Strathern's argument:

"[...] while the procreative act is constitutive of kinship in a biogenetic sense, making that knowledge explicit makes more not less evident the fact that the social relationship is contingent. [...] Arguments about individuals' right to know based on their rights to knowledge about themselves are arguments for knowing about the individual rather than about the kinsperson. So while kinship in Euro-American thinking may be predicated on the facts of life, learning more about the facts of life will not, these days, necessarily tell us more about kinship." (Strathern 1995: 360)

More explicit biogenetic knowledge does not contribute to "knowledge about persons as kin" (Carsten 2007: 411), but to "knowledge about individual personhood" (*ibid.*). This, I suggest, is particularly evident in discussions about the right of the donor-conceived to know *about themselves* (chapter 3). The fact that a right to know is often formulated today does not refute but rather confirms Strathern's prediction about the separation of reproduction and procreation.

While knowledge about biogenetic relationships is constitutive, it does not necessarily have to be socially activated. As Strathern points out,

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39 In addition, 23andMe and other companies also offer genetic health tests (see also the introduction of chapter 6 for a discussion of genetic "right to know" debates). The popularity of such tests seems to support Strathern's argument, although it should be noted that none of the people I interviewed seemed to be very interested in genetic health tests. Tamara Haste, who had signed up with 23andMe to find her donor, told me that she had actually decided against the optional genetic health test that the company offers because her donor was still anonymous: "I thought if I do find out there's something terrible, it's not like I have any reference point, I'd just be lost knowing this information, so I clicked that I didn't want to know." Tamara mentioned that she might have decided differently "if he was around".



Euro-American kinship always made it possible for one to be related without activating the relationship. [...] When a kin relationship is activated, it is of course acted upon either because what was already known provides the basis for social interaction (as in the way kin select those they keep up with) or else because what was not before known becomes so (and the person with the knowledge has to act on it in some way, even if only to resolve not to do anything more with the knowledge)." (1995: 354)

For my research project I mainly interviewed people who only found out about the circumstances of their conception in adulthood. They activated kinship knowledge because something that had not been known before had become known. The activation of knowledge is particularly evident in the searches for donor siblings. While one might argue that these relatives exist regardless of whether they are discovered or not, searching for siblings that have been conceived with gametes from the same donor "is geared towards igniting a spark that would otherwise lay dormant, inactive and non-sociable" (Edwards 2015: 110). I argue that the donor-conceived activate knowledge about the circumstances of their dispersed conception through a variety of factors. While they might be said to exist regardless of whether or not they know, or care, about their donor-conceived origins, it is through the activation of knowledge that they *become* donor-conceived. The ways in which people activate kinship knowledge and become donor-conceived will be explored in the empirically oriented chapters (3–8).

## 2. Research and analysis

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Studying anonymity ethnographically can be challenging. The difficulties that may arise during research and/or writing are related to how anonymity is evaluated in a particular field. This becomes clear in Frois's work on self-help groups in Portugal (2009). Frois found that anonymity was "the *sine qua non* condition demanded by members before deciding if they are going to be part of one of these groups" (2009: 149, emphasis in original). It is therefore not surprising that anonymity was the only condition that members imposed on her research. They wanted to remain unrecognised by her general readership and prevent others within the group from recognising their personal stories. Frois therefore gave participants pseudonyms and changed or omitted other details, while "still trying as far as possible not to compromise the content of the information provided" (2009: 15).

While these are not in themselves unusual demands or measures, it was also Frois's methodological approach that was shaped by the purpose anonymity has in the groups she studied. For example, Frois was not allowed to record conversations during group meetings, but only formal interviews and could not take notes while interviewing (ibid.). The challenges Frois faced had to do with the fact that anonymity was perceived as a necessary protection by members of self-help groups (section 1.3). By contrast, in my own research difficulties as well as opportunities arose from the fact that donor anonymity was viewed extremely critically by most of my interviewees. Many of them seemed to see my work as an opportunity to share their opinions with a wider audience. Finding research contacts was therefore easier than I had expected. While their critique also created challenges for my research, which I will discuss in more detail in this chapter, ethnography nevertheless is a suitable means of exploring anonymity. Certain aspects of what the donor-conceived think about anonymous donors could have been investigated by means of a questionnaire. However, questionnaires only "work well to elicit responses about which respondents are confident and, above all, certain" (Franklin and Roberts 2006: 82), since they "rely on people *knowing what they think*" (Franklin and Roberts 2006: 81, emphasis in original). For a question such as "Should donors be anonymous?", a questionnaire would probably have worked better than it would

have for a more complex question, such as what kind of donor information people want to receive.

In this chapter I will first give an overview of the people I have interviewed in the UK and Germany. In addition, I will go into more detail about how the media strategies of the donor-conceived have affected the taken-for-granted practice of anonymisation in my work. Afterwards I will describe how I found my interviewees, introducing some of the online infrastructures and groups that are important in my field. I will also briefly address a specific problem I encountered while doing research in the UK as an employee at a German university. I will then give an overview of the process of data collection before elaborating on how I analysed my data, how I put results into written form, and how I represent my findings and the people I either interviewed or that somehow figured into my research.

## 2.1 Sample composition and (re)negotiating anonymity

From September 2016 to December 2017, I interviewed 24 donor-conceived persons (UK  $n=13$ ; Germany  $n=11$ ) whose parents had undergone treatment with anonymously donated gametes in a clinically controlled setting in either the UK or Germany. All but one egg-donor-conceived person from the UK had been conceived with anonymously donated sperm. My interviewees ranged in age from 18 to early 60s, with the majority of them being in their mid-30s to early 40s. About one third of them had been conceived in the 1990s. Apart from one person who had been born in the 1950s, the rest of my interviewees had been born as a result of a treatment that took place from the mid-1970s to the late 1980s. Due to the “culture of secrecy” (Klotz 2016: 46) that has historically dominated gamete donation, it is not unreasonable to assume that it is probably “rare that they [the donor-conceived] would know of their donor conception in the first place” (*ibid.*). Therefore, I was rather surprised when I started to get contacted mainly by people who told me in their first email that they had been conceived in the 1980s or 1970s. I had assumed that more younger people would reach out to me, simply because it seemed more likely that they knew about the circumstances of their conception. I cannot answer with certainty why only a few people who were conceived in the 1990s did contact me, although a theory voiced by those of my interviewees involved in advocacy work might shed some light on this: they were of the opinion that many of the donor-conceived did not become interested in their donor until their mid-20s, as this was usually the age when people joined their groups. Many believed that this had to do with people starting to have children at this age and, as a result, developing a stronger interest in their genetic origins. Some of the people I interviewed also reported how their own interest in their donor had only emerged over time. They usually mentioned that they had become more interested when something

important in their own family life changed (section 6.4). This might indicate that an interview about donor conception becomes interesting for many only at a certain point in their lives. I would also suggest that it may not have been an appealing idea for younger people to talk to someone older than them, especially because they knew that the interview would address issues that are often coded as private and that are perhaps more likely to be discussed with friends of the same age.

For both countries, there are reports from doctors who performed inseminations with donor sperm decades ago (for example Barton et al. 1945; Schaad 1972; Rose and Schaad 1974), which indicates that there might be significantly more donor-conceived persons aged 60 and older than my sample of donor-conceived persons might suggest. However, probably only a small percentage knows about the circumstances of their conception. Since there was still variation in terms of when people had been conceived, and because I had interviewed people from the UK and Germany, I was still able to examine a particularly wide range of experiences in relation to the infrastructures they used in their search for information. The people I interviewed differed especially with regards to the officially endorsed means and registers available to them.

The people I met also differed in how long they had known they were donor-conceived and regarding the age at which they had been told. Most of them did not grow up knowing they were donor-conceived. One person had known for about ten months at the time of the interview, others for several years or even decades, and two of my British interviewees told me they had always known. Those who could remember a specific moment in which they were told had either found out in unplanned situations, or because their parents had planned and decided, for various reasons, to tell them. A few of my interviewees also mentioned that they had provoked the disclosure talk, for example by confronting their parents with the results of a secret paternity test (section 5.2), although no one claimed to have suspected that they were donor-conceived. All of them had been born to heterosexual parents who were married at the time of the treatment. A different sample composition in terms of family background might have resulted in me meeting more people who had learnt about the circumstances of their conception in early childhood. High levels of disclosure have been found among families of single women, lesbian couples (Frith et al. 2018: 191), and gay fathers who had children via egg donation and surrogacy (Dempsey and Kelly 2017: 208). Due to the absence of someone who could easily be identified as a “father” or “mother”, these parents cannot easily “display their family as a biogenetic family” (Frith et al. 2018: 198).

Moreover, the findings of previous studies (for example Klotz 2014) indicate that those who do not conform to the ideal of the heterosexual family are at the forefront of promoting openness and the child’s right to know. As lesbian/gay couples and single women are generally perceived as being beyond the boundaries of what a “real” family is, their families are being looked at more critically. They may

therefore be more concerned than heterosexual couples to practice “see-through kinship” (Edwards 2018) and to ensure that their children have access to information about the donor (Sullivan 2004). For them, openness might also constitute a way to break up heterosexual and bi-parental family norms rather than it being solely a practical matter (Klotz 2014: 320). Since lesbian couples and single women have in the past mostly been excluded from access to reproductive technologies and notably clinical DI, I was arguably less likely to meet someone who had been clinically conceived within a two-mother or single-mother family.<sup>1</sup> I chose not to specifically recruit additional interviewees who grew up in families led by lesbian and gay couples or single women, as I conducted more interviews than I had anticipated. While my sample lacks diversity in terms of family background, the people I interviewed differed significantly in how they positioned themselves in relation to heteronormative family norms, with some of them having very conservative views (section 4.1). However, I found that there was much more talk of “good” and “open” families, and people did not necessarily believe that “good families” had to be genetically related to each other (section 4.2).

Exactly one quarter (six out of 24) of the donor-conceived persons I interviewed were men. This sample composition almost mirrors the response rate of a study conducted with registrants of UK Donor Link (UKDL), the former voluntary register in the UK (Frith et al. 2018). 77 percent of those who participated in the questionnaire-based study were women, which reflects the overall composition of the register’s membership in terms of gender (Frith et al. 2018: 191). In their overview of studies conducted with donor-conceived persons, Blyth et al. (2012: 773) point out that the majority of them had more female than male participants. The predominance of female individuals in my sample also seems to reflect what I was told by

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1    In the UK, single women and lesbian couples mostly did not have access to NHS-funded treatment until 2008 when the HFE Act was amended and no longer included the “need for a father” clause. A few private clinics did specifically target at least the lesbian community already prior to that (Klotz 2014: 111). Access to reproductive technologies for those who are not in heterosexual relationships was still highly uneven in Germany at the time of my empirical research. Since physicians considered it more likely that children of single women and lesbian couples would sue donors and/or physicians for maintenance, the German Medical Association had in the past advised doctors to treat only heterosexual married couples (Bundesärztekammer 2006). This passage is not part of their 2018 guidelines (Bundesärztekammer 2018). After the Sperm Donor Register Act came into force in July 2018, the number of clinics that treat lesbian couples has increased: whereas in the past lesbian couples often had to resort to clinics abroad because German clinics did not treat them, today they are offered treatment with donor sperm in most parts of the country (Hammel 2020: 35). For single women, on the other hand, it is still not easy to receive treatment with donor sperm at a German clinic. Despite the legal changes in Germany, only a few German fertility clinics treat single women. Doctors still seem to be afraid of maintenance claims and/or worried about the welfare of a child growing up with only one parent (ibid.).

one of my interviewees about Facebook groups created for and by donor-conceived persons (section 4.3): according to Elizabeth Chapman, whom I interviewed in the UK, they had far more female than male members.<sup>2</sup> The role and importance of gender in the creation of and participation in similar networks has been explored by Rosanna Hertz and Margaret K. Nelson (2019). They analysed different types of donor sibling networks in the US, the members of which often maintained online contact for example via Facebook groups. Hertz and Nelson found that girls were “more likely to play an active part in maintaining a large network itself” (2019: 200). They suggest that the higher involvement of girls in these networks has to do with gendered expectations: “Gender role expectations are notable for emphasizing that women are more inclined to acquire social skills that facilitate interaction.” (2019: 270) Since relations and feelings are coded as female concerns and competencies, it seems likely that women are more inclined to engage in donor sibling networks and online groups, and also more inclined to participate in research that explores issues pertaining to social relations. Moreover, reproduction is also widely seen as something that is a female responsibility (Baumeister-Frenzel et al. 2010: 84). This might be another reason why more women than men did contact me.

My sample of donor-conceived persons was very homogenous in terms of education, with most people having earned a university degree. Those who were under 30 were mostly either still studying or had completed their studies just before I met them. Moreover, all of my interviewees were white, and based on what I learnt about their lives, I would describe all of them as belonging to the middle class. It should be noted that I did not systematically collect data on the persons I interviewed in terms of education and other socioeconomic characteristics, as this was not a quantitative study where such information would have been considered relevant. However, many mentioned their academic degrees and successes especially when talking about the talents and characteristics they thought might have been passed on to them from their donor (section 5.3). When particular characteristics of my interviewees are relevant to my analysis, for example with regard to their profession, education or family life, I mention them when introducing individual persons in more detail. Again, I want to emphasise that my interlocutors are a very specific group among all donor-conceived persons. Most of them had only learnt about the circumstances of their conception as grown-ups, wanted to find their donor, and were actively searching for information about their genetic origins. Many of them publicly advocated for the rights of the donor-conceived, and it was obvious that “being donor-conceived” had become a central part of their life. Especially those who spoke frequently with journalists tended to be highly eloquent

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2 In a later email, Elizabeth Chapman told me that she had posted information about my project in a closed Facebook group in order to specifically motivate more men to participate. As far as I know, none of the men I interviewed had found out about my project via this post.

and had the means to make themselves heard. It is in this light that the following chapters (3–8), in which I present and discuss my own empirical material, have to be understood.

In addition to donor-conceived persons, I also interviewed an HFEA officer who was working with the central UK donor register to better understand the Authority's way of handling data, processing requests of donor-conceived applicants and releasing information. The officer was also in charge of the voluntary donor sibling register. Moreover, I collected a large amount HFEA documents, which she either sent me or which I found on the Authority's website. These included application forms and numerous meeting papers. Besides, I interviewed a former donor who volunteered for the voluntary UK register DCR, a German physician who had been working with donor sperm since the late 1970s, and the head of a German sperm bank. Through these interviews I was able to gain valuable insights into how donations had been organised in the past, how they had changed over the past three decades, and how donor anonymity had been (re)negotiated at different points in time. I also interviewed Marilyn Crawshaw, an internationally renowned expert on donor registers from the UK, and Claudia Brügge, one of the founders of the German advocacy group DI-Netz ("donor insemination network").<sup>3</sup> Through the interview with Marilyn Crawshaw I got much background information on the UK's voluntary register and on the lobbying for the right to know of a group of social workers within the BASW. I drew a lot of data on interest groups and their activism in Germany from the interview with Claudia Brügge, who also provided important insights into the way clinical management of donor information has changed in recent years and the challenges parents are faced with, for example when trying to secure access to information for their children. I was also invited to attend parts of a meeting that brought together several DI-Netz families, and where I had informal conversations with couples who had all decided to tell their donor-conceived children at an early age. Given their highly unique expert status, both Marilyn Crawshaw and Claudia Brügge have given consent not to be anonymised. Any direct quotes have been authorised by them. The same applies to Joanna Rose, a donor-conceived person from the UK. She was involved in the court case that helped change the law in the UK (section 3.2). It is almost impossible to write about the 2002 verdict without mentioning her, especially since her surname is mentioned in the court ruling (EWHC 2002).

Joanna Rose was not the only one of my donor-conceived interviewees who had already told her story in a public arena. In fact, half of them had already spoken to a journalist at least once, were preparing to do so when I met them, or chose to contact one after I had already interviewed them. Some had also taken part in government consultations. I had not specifically looked for people who had experience

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3    [www.di-netz.de](http://www.di-netz.de) (last accessed March 28, 2020).

with the media or politics, nor had I tried to contact donor-conceived persons after I had seen them on television (TV) or read about them in a newspaper article. From the beginning, I had planned to do research on anonymity in gamete donation and especially on how the donor-conceived are involved in its transformation. However, I had not anticipated that the phenomena and practices I would investigate would ultimately present me with challenges in terms of anonymisation. I suggest that given my research interests, this chapter would be missing the point if I were to simply note that I anonymised my interlocutors for reasons of confidentiality, although this was indeed part of what I decided to do.

It is important to note that not all of the people I interviewed chose to appear in the media with their real names. Some of those who had decided to conceal their identity told me that they would actually prefer to use their real names and were hoping or planning to do so in the future (see for example David Weber in section 4.2). In addition, some were using different strategies simultaneously: they appeared under their full name at a public event and were announced in the program, again by their name, as representatives of a specific organisation, but used a pseudonym, an apparent nickname or their real first name in online forums or blogs. For someone who knew them, it was arguably not particularly difficult to link the various pseudonyms and stories to one particular person. I certainly managed to do so after I had interviewed them. I discovered several articles and blog entries of or about people who had been pseudonymised, but which I could still assign to a person I had interviewed. I therefore do not consider it impossible that readers of this book, who are familiar with some of the articles and TV documentaries that feature my interviewees, might recognise some of the stories that I tell in the following chapters. At the same time, someone who is not familiar with donor conception and the stories circulating in the media and on the Internet will not recognise the people I interviewed. Nevertheless, the challenge remains the same: even if people remain nameless in public, their stories can oftentimes be connected.

Given the extent to which reproductive technologies and donor-conceived persons are mediatised, using pseudonyms and changing or omitting personal details seems necessary to me, although I am aware that I cannot control anonymity. Moreover, the consequences of mentioning people by their real names can hardly be estimated, neither by me nor by my interviewees themselves. In addition, from an analytical point of view, it is arguably problematic to name some persons by their real names, while continuing to anonymise others. Due to their different visibility in the text, non-anonymised persons might be perceived as more meaningful and more 'authentic', which I wanted to avoid as much as possible. Besides, I did not want to be perceived as a Public Relations (PR) officer for the people I interviewed by the readers of this book, which I assume might have happened if I had chosen



to only interview those who would agree to have their real names revealed.<sup>4</sup> The question of anonymisation seemed particularly tricky to me in the case of those who had decided to make themselves identifiable after the interview I had conducted with them, but before the completion and publication of my PhD thesis. I suspected that they may have told me things that they might have been more reticent about if they had already known then that they would make their stories public.<sup>5</sup> I decided to contact those I knew had gone public, and from whose interview I quote, to address the situation and to point out that it was more difficult for me to ensure confidentiality under these changed conditions. I also sent them those excerpts from my PhD thesis in which I explicitly referred to the interview I conducted with them. Nobody insisted that I should not use their interview, or that I should change more details about them.

Overall, my work illustrates that there are ethical and epistemological questions regarding anonymity that need to be renegotiated, rather than offering concrete solutions. The fact that anonymity and ethnography are not always compatible has also been discussed by other researchers, even though the subject still seems to receive relatively little attention.<sup>6</sup> Based on what I was told by other anthropologists, I would nevertheless argue that those who do research on other, less mediated topics might experience similar difficulties, especially since the assurance of anonymity is often a condition for obtaining both funding and access in the field. I suggest that given the transformation of anonymity and the blurring of the boundary between identifying and non-identifying information, ethnographers will need to renegotiate the practice of anonymisation which has long been taken for granted.<sup>7</sup>

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4 As I discuss in section 2.3, some of my donor-conceived interlocutors did in fact seem to see me as someone who would advocate for their needs and rights at an academic level.

5 Besides, some of those I pseudonymised might decide to make themselves identifiable much later.

6 Notable exceptions are Stein (2010) and Duclos (2017).

7 My thoughts on this topic are based on numerous discussions I had with the other members of the *Reconfiguring Anonymity* project, some of whom encountered similar challenges during their work. Based on our discussions within the project group, Michi Knecht and I organised a roundtable entitled "(Re-)negotiating anonymity in ethnographic" research at the 2019 conference of the German Anthropological Association. Through the participants' short statements and numerous comments of the audience, it became clear that many had encountered challenging situations in their work with regard to the anonymisation of persons and organisations. It became particularly evident that the topic should be dealt with more intensively in teaching.

## 2.2 Online recruitment for offline research

In her ethnography of anonymous ova donation in the UK, Konrad states that when she conducted her fieldwork in the mid-1990s, “donors and recipients were not easy populations to meet” (2005a: 22), mostly because they “did not pre-exist the researcher as cohesive groups” (ibid.). Konrad therefore had to “make these ‘communities’ appear” (ibid.), which she managed to do by approaching clinical teams at fertility clinics who then agreed to put her in contact with donors and recipients. My own research, which I conducted more than 20 years later, began under completely different conditions. Unlike Konrad, I was able to enter my field largely by directly contacting the groups that the donor-conceived themselves and/or gamete recipients have founded. While this did not mean that access did not have to be negotiated, the gatekeepers were different from the medical professionals Konrad encountered during her fieldwork. The various alliances that have formed since she conducted her study made it a lot easier to find donor-conceived persons than it would have been ten or 20 years ago. Since the Internet is of central importance for the donor-conceived, who use it to network with each other and search for their donors and donor siblings, trying to find people online turned out to be an effective strategy. Finding interviewees online would have been less effective in the past: not only because specific interest groups and their online forums were still in their infancy, but also because having access to the Internet was less common. Internet usage rates are high in both the UK and Germany and are close to 100 percent for people in their 30s and 40s. In contrast, the proportion of Internet users over 65 is significantly smaller (Office for National Statistics 2019; Statistisches Bundesamt 2020), which might be another reason why I talked to only one person who was in her 60s. People of that age are less likely to be involved in online groups and forums where they could have found out about my study.

The donor-conceived are organised differently in the two countries where I conducted my research. Searching for research contacts in Germany was therefore different from searching in the UK. Besides, my respective approach was similar to what people from both countries told me about their ways of obtaining information and making connections: similar to my interviewees in Germany, who would oftentimes tell me that they went online and straight away landed on the homepage of Spenderkinder (section 4.4), I had come across the association’s website early on. Although Spenderkinder has its own homepage, I had actually first gotten in touch with them after emailing Donor Offspring Europe, a European umbrella organisation that consists of several advocacy groups from various countries.<sup>8</sup> A member

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8 In addition to Spenderkinder, the website lists organisations from France, Belgium and the Netherlands as members ([www.donoroffspring.eu](http://www.donoroffspring.eu), last accessed May 26, 2021). The website occasionally publishes news that are relevant to donor-conceived persons on an international

of Spenderkinder replied and offered to distribute information about my study via their internal mailing list. After an initial phone call, emailing back and forth several times, and her suggesting specific changes to my study information which pertained to my presentation of the legal situation, it was sent out twice several months apart. Like the information sheet that I used in the UK, it stated the purpose of my research project and who was funding it; details about the interview and the kind of topics it would cover; what I would do with the data; and information about my academic background. All in all, I interviewed ten persons who were either only part of the mailing list or also members of Spenderkinder. Since membership to the mailing list is restricted – only those who are donor-conceived are able to join – access to members was thus enabled but also controlled by certain gatekeepers on whose support I was dependent. Given the extent to which information about my study was circulated online, it is all the more significant that no one conceived in Germany contacted me because they had discovered information about my project somewhere else than through the mailing list of Spenderkinder. If donor-conceived persons from Germany want to network with others, the association seems to be their central and often only platform for doing so.

Apart from Spenderkinder, I also had gotten in contact with the German association DI-Netz. I had been told by Claudia Brügge that there were several families in the association whose children were already 18 or older and who could therefore be potential participants for my research. Here too, my study information was distributed online. However, no one contacted me after this email, although I do not know whether the information was sent directly to the adult children or first to their parents. In the end, I interviewed one son of a member of DI-Netz. I had previously met her at an event. As her son indicated during the interview that he had the possibility to obtain identifying information about his donor but chose not to make use of it, I did not include the interview with him in the detailed coding process. I had previously assumed that his donor was still anonymous. Nevertheless, the interview did contribute to the interpretative framework of my research. In the UK, I interviewed another person who was not interested in her donor and some of her statements were very similar to his (unlike him, however, she had chosen to contact me on her own initiative). Besides, the way the interview with the German student had been arranged was in itself an interesting and revealing moment in my research. Since Spenderkinder largely dominates public reporting in Germany on the topic of donor conception, the young man's mother seemed anxious to provide an empirical counterpoint in my research.

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level, such as information about the workshop held at the celebration of the thirtieth anniversary of the UN Convention on the Rights of the Child that I mention in section 3.1 (Donor Offspring Europe 2019).

As there is no organisation similar to Spenderkinder in the UK, I had to make use of a variety of organisations and platforms when trying to find British interviewees. This mirrored the way in which my British interlocutors would often-times join several groups and online forums when searching for information. I first contacted the interest group DCN. The DCN advocates early disclosure, organises workshops and annual conventions, and offers a wide range of advice materials on the topic of disclosure. I interviewed a total of six donor-conceived adult members of the DCN. In addition, one person offered to put me in contact with her sister, who was also donor-conceived and agreed to meet with me. Since the DCN is committed to early disclosure, I was surprised to learn that only two of the members I interviewed had grown up knowing how they were conceived. I was equally surprised to learn that some of them were very critical of gamete donation per se (and not only of the way in which it has been regulated in the past), while the DCN is working to increase social acceptance of the practice. The people I interviewed had mostly joined the DCN because they were searching for a way to get in touch with others who were donor-conceived, or because they were looking for more information about donor conception. They did not necessarily support the goals of the DCN, although they too often emphasised the importance of early disclosure.

While I found almost half of my British interviewees via the DCN, I had initially not assumed that contacting the organisation would even be a means to get in touch with donor-conceived persons, as I had pictured the DCN mainly as an association of parents. However, I did still send them an email, hoping for more background information that might be relevant for my research. After sending them some general information about my project, I was told that I could also submit a project proposal to the DCN's research panel. If accepted, information about my study would be sent to the donor-conceived adult members. In order to receive approval, I had to fill out a detailed checklist. Among other things, I had to indicate whether I had already received ethical approval for my research. Since it is not common practice for anthropologists working at German universities to obtain an institutional ethical approval, I explained that I was nevertheless committed to the obligations laid down in the ethics guidelines of professional organisations. Fortunately, the DCN's panel did not raise any objections and did not ask me to submit an application for a formal ethical review, which would certainly have slowed down the research process. As international funding organisations increasingly require applicants to obtain certified ethical approval, there is an ongoing debate in German anthropology on whether ethics review boards should be used more frequently. For reasons of space, I cannot comment on this debate in detail. Nevertheless, I would like to briefly argue that while a certain institutionalisation of the process, as is already common in other countries, may be helpful in terms of applying for funding, publishing, and making research contacts, it is not the only and arguably not the ideal way to foster ethical conduct. Given the specificity of ethnographic

research, which involves close and often ongoing contact with interviewees during which unexpected developments can occur, researchers are required to remain flexible throughout the entire research process. A formal, one-time ethical review might hamper such flexibility. I suggest that apart from thinking about how to respond to the demands for ethical review by establishing institutional processes, there should be a debate, especially at the level of teaching, about how to make research ethical (see von Unger et al. 2016 for a similar argument).

Apart from the internal mailing lists of Spenderkinder, DI-Netz and the DCN, information about my project had also been distributed online in ways that I could not always follow and observe (which also applies to the mailing lists, as I am not a member of the respective organisations). As I will explain in more detail in section 4.3, donor-conceived persons increasingly network on an international level in closed and partly secret online groups, many of which are on Facebook. I knew that information about my study had been posted on the secret Facebook group of the DCR, the UK's voluntary register, after I had contacted the organisation. Two donor-conceived persons contacted me after seeing the post, and I also interviewed a former donor who was registered. In addition, several people I interviewed and donor-conceived activists from the US, with whom I had been in email contact, offered to post information about my study in various networks. Since I was not able to join their groups and forums myself, I was not able to follow the exact course of this 'online snowballing'. The lack of control that is characteristic of the fieldwork experience (Pratt 1986: 38) sometimes felt uncomfortable, especially when I was once told in an interview that I had been discussed online (section 4.3). Another person contacted me after reading the call for participants I posted on Anonymous Us, a website created by an American donor-conceived activist.<sup>9</sup> Besides, I had met a person who had been conceived in the UK through an open Yahoo group. The group's moderator had replied to my email, explaining that the group was mostly inactive, as most of the discussions were now on Facebook. Nevertheless, he agreed to an interview and later gave my contact details to another person, whom I also

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9 Anonymous Us ([www.anonymousus.org](http://www.anonymousus.org), last accessed April 09, 2020) is an interesting example of how complex and varied anonymity can be negotiated. It is described on its website as an "online story collective on reproductive technology and family separation themes" (Anonymous Us, n.d.). Readers can post short stories about their personal experiences with donor conception and gamete donation, which have to be approved by the organisers before they can be published. The donor-conceived founder of the website, who is very critical of donor conception and anonymity, offered me to publish a short piece about my project after I had contacted her via email. While my post included my contact information, those submitting personal stories are normally asked not to use identifying information in their texts, all of which are published anonymously. According to the website, this approach was chosen because it allows people to speak openly about their experiences.

interviewed and who put me in touch with one of her donor-conceived friends as well.

### 2.3 Overview of data collection

The fact that I had searched for and found interviewees online meant that my research was not limited to one geographical location. Although my interviewees belonged to the same online groups and forums, they lived in different parts of the UK and Germany. In the UK I was only contacted by people living in England, even though this was not a selection criterion for me. The dispersed nature of my sample meant that interviews in both countries usually involved long train journeys and oftentimes overnight stays. I also conducted one interview via Skype with a person who lived in Australia but had been conceived in the UK. Most of the people were very accommodating when I contacted them to arrange the details of an interview. Some even offered to come to another city for an interview if they lived particularly far away. However, all interviews took place in the cities or villages where my interviewees lived, worked and/or studied, usually in their homes or in a café. The length of an interview varied from one hour to four hours, with the majority of interviews being around the two-hour mark. I spent much more time than that with many people, and we usually talked for a long time after I had already turned off my recording device. Only then did some of them mention things they did not think were important and therefore had not brought up during the actual interview, but which helped me to understand the recorded conversation better.

I taped and transcribed all interviews apart from two where permission to record was not granted. In both cases, I took more notes than usual during the interview and wrote down as much as possible from memory afterwards. I suspect that for various reasons both persons did not trust me at first, although neither of them explained in detail why they did not agree to a recording.<sup>10</sup> In addition to transcripts, I kept notes on all encounters, which I attempted to write down as soon as possible after an interview. They included descriptions of details that would get lost if I was to only rely on the transcript, such as notes on what we talked about before and after the interview; a description of the places we met up in; notes on any objects that people showed me; and notes on how I felt during and after an

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10 I was not given consent to record by the doctor I interviewed. Shortly before the interview, he had been sued by a donor-conceived person. He seemed anxious to stay out of more trouble and, at least in the beginning, seemed to think of me as a kind of 'spy' from Spenderkinder. Besides that, one donor-conceived person did not want to be recorded either. He mistrusted researchers, believing that they ignored the dangers of donor conception. He was the only person who seemed uncomfortable during the interview and only became more relaxed afterwards.

interview. These first notes also included reflections about themes that seemed to be emerging from an interview and that I wanted to explore more. I found myself often coming back to these notes as my analysis progressed. Although my analytical framework kept evolving, these first ideas often turned out to be important analytical resources.

Especially those who were very critical of donor conception per se and/or the way it has been conducted and regulated in the past (i.e. with the principles of anonymity and secrecy) seemed to see my work as a possibility to make their opinions visible in an academic and public arena. Several people seemed to be interested in my study because they hoped that their story and the fact that it would be included in my PhD thesis would warn others of gamete donation, anonymity and secrecy, and a few explicitly mentioned that this was their reason for participating. While my intention was not to 'give voice' to the donor-conceived, and act as an academic 'PR officer', but to explore how they constitute themselves as a powerful political and public voice (chapter 4), it was sometimes apparent that I was seen as a mouthpiece for the concerns and demands of the donor-conceived. In these cases, I did not seem to be perceived much differently from a journalist (and a lot of my interviewees had already had contact with journalists). For others, the interview seemed to be more like a welcomed opportunity to reflect on what had changed in their lives since they found out they were donor-conceived. They would sometimes ask if they could receive a copy of the transcript because they felt that they had summarised their feelings and opinions particularly well. Even though people had different reasons for talking to me and teaching me what "being donor-conceived" meant to them, I would argue that telling one's story in the context of an interview *and* having it listened to was always part of the process of "becoming donor-conceived". As I will show in the empirically oriented chapters of this book, being able to (re)frame and (re)construct one's story – as a matter of rights and as a continuous whole – was an essential part of becoming donor-conceived; and by listening to their stories, I became a part of this process.<sup>11</sup>

While I was rarely asked how I felt about the topics I was doing research on, many people were interested in hearing what others had told me. This was especially the case for those of my British interlocutors who were not involved in an active exchange with others, while my German interviewees were all in contact with other members of Spenderkinder and/or the mailing list. Although I did not share any identifying information, I did answer their more general questions, such as whether others had found donor siblings or their donor. Since several people had never met anyone who was also donor-conceived, they seemed to view me as a kind

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11 See also section 5.1 for a discussion of the ways in which telling stories, and being listened to, can act as an "assertion of agency over one's own past" (Carsten 2000b: 698).

of interesting link to a community they had not yet joined.<sup>12</sup> Furthermore, those who were still studying, had just finished their studies and/or were thinking about applying for a PhD position were often curious about my academic experiences.

Originally, I had planned to conduct more than one interview with each person in order to enable a more processual analysis of the way in which people form new networks and kin relations, and to trace the transformation of anonymity over a longer period of time. However, this proved to be challenging due to the tight timeframe of my doctoral research project, and I eventually decided against it. Nevertheless, even without follow-up interviews, processes of transformation were noticeable during the time of my research. For example, as I will explain in chapter 8, the DNA databases used by the donor-conceived grew enormously during and after I conducted my empirical research. Although I did not conduct any formal follow-up interviews, I arranged to meet with two of my British interviewees when I returned to the UK for a conference in 2018. In the meantime, one of them had managed to identify her donor, and we talked at length about the growth of DNA databases. I also met some of the people I interviewed in Germany at various events, such as a two-day conference on legal and ethical challenges in reproductive medicine. This gave me an insight into their public engagement and interaction with other stakeholders. Furthermore, I remained in email and phone contact with the majority of people. I usually emailed them with follow-up questions, and many of my interviewees replied to me with very detailed answers. While I had no further contact with a few people who did not respond to the emails I sent them after an interview, I kept close contact with others. Some of them also contacted me occasionally on their own initiative, for example when they had found a donor sibling, or to inquire how far I had progressed with my work and when I would publish.

In the first email people sent me, they usually mentioned when and where they had been conceived and when they had been told. After describing my study and answering any questions that people had, I started an interview in many cases by asking them to tell me more about the circumstances in which they found out. This usually led to detailed accounts that went far beyond the mere description of the disclosure situation. Often these initial answers already contained many of the

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12 This is reminiscent of Konrad's experience of becoming "a potential link-person" (2005a: 23) between mutually anonymous ova donors and recipients. Even if she suspected that she had met a donor-recipient 'pair', she chose not to divulge any information to her interviewees. She thus "respected and worked within the parameters of the system" (2005a: 24). Likewise, I never indicated my hunch that one of my interlocutors might be a donor sibling of someone else I had interviewed. Since most of them had already done a DNA test, the probability that I met donor-conceived half-siblings who did not know they were related is very low.



topics that came up again and again later in the interview. I found that these ‘finding-out-narratives’, similar to “coming-out-narratives” (Weston 1991: 15) of lesbians and gays, had “the advantage of representing a category meaningful to [research] participants themselves” (ibid.). My interviewees would tell these stories not only when being interviewed by me but also when joining new groups and networks (see section 4.3 for international networks and Facebook groups, and 4.4 for the German association Spenderkinder). Therefore, they constituted a useful “point of departure” (Weston 1991: 15) in many interviews.

Apart from this first question, my interview manual covered topics such as how people reflected on their anonymous origins; how openly they dealt with the information; their opinion on the legal regulation of anonymity and gamete donation; what meaning they attributed to genetic and social connections; and whether, why and how they searched for their donor and/or donor siblings. My guide evolved over the course of my research as new topics emerged from the interviews I had already conducted. At the same time, I tried to let my research contacts steer the conversation and address the topics they wanted to bring up. I thus followed the idea that ethnographic research “relies on the assumption that we may not know what the important questions are, or why, or how to ask them” (Franklin and Roberts 2006: 82) and that researchers should attempt “to remove as many limits as possible from a potential response” (ibid.). While this worked well in most cases, there were occasions when responses were very brief, for example when I asked a question that had an obvious answer, at least in the eyes of my interviewees. I usually tried to minimise my own role in the interviews; in these situations, however, I tried to elicit more detailed answers. In particular, I found that mentioning specific examples from previous interviews or other sources often led to detailed comments, especially if people disagreed with what others had told me. They would then usually explain their own views in a more detailed way. In the interview passages that I quote, I mention if and how an answer was prompted by certain questions or comments on my part.

In addition to conducting interviews, I attended several events that dealt in various ways with reproductive technologies. These included two ‘fertility fairs’, one in the UK and one in Germany, which were attended by couples and singles. Both events brought together clinics and sperm/egg banks from several countries as well as various interest groups and were very useful for establishing research contacts. In both cases, exhibitors participated from countries where reproductive technologies are regulated differently, where more and different techniques are allowed than in the UK and Germany, and where different regulations on donor anonymity apply. This also gave me an interesting insight into how these dimensions play a role in the marketing of treatment options and were for example addressed in the

brochures of the different exhibitors.<sup>13</sup> Apart from transcripts, notes on interviews and any events that I attended, I also kept notes on conversations and encounters I had outside of an ‘official’ research context. When I talked about my project, it often happened that friends, acquaintances and sometimes even strangers told me about their own experiences with infertility and their reproductive family secrets. Especially the questions I was asked were often particularly insightful, as they made the empirical material that I was already familiar with more unfamiliar again. They also helped me to understand how the donor-conceived are imagined by others. In section 3.5, I refer explicitly to a question I was asked particularly often, namely whether my interviewees were looking for their donors because they were interested in their money.

## 2.4 Analysis, writing and representation

The analysis of my material was not a process that took place separately from conducting the interviews. Instead, I already began analysing my data and in particular the narratives of the donor-conceived by taking notes during and after a conversation, which in turn influenced the outstanding interviews, for example in relation to the questions I asked, and continued analysing throughout the actual writing process. In my analysis I always started from the assumption that narratives are neither straightforward reflections of an objective reality, nor “descriptive free-for-alls” (Gubrium and Holstein 2008: 250). Instead, they are constituted through “the interplay between experience, storying practices, descriptive resources, purposes at hand, audiences, and the environments that condition storytelling” (ibid.). They are always “more than a chronological sequence of events” (Ochs and Capps 1996: 25). By forging different elements into a structured plot, narratives create order and coherence, which in turn empowers those who tell them (Becker 1997) and turns isolated actions into an unfolding, intelligible history. Anthropologist Cheryl Mattingly suggests that a narrative is more than “a kind of artifact (a text) or a genre of speech act” (2010: 44). She argues that “we locate ourselves in unfolding stories that inform our commitments about what is possible and desirable” (2010: 43) through an ongoing “narrative work” (2010: 49) that is shaped through “culturally shaped narrative expectations” (ibid.). I will explore the “narrative work” of my interviewees in more detail in chapter 5. The expectation of continuity, which was part of this work, shaped how people made sense of being donor-conceived, and will be explored throughout this book.

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13 For example, some cryobanks advertised on their posters and brochures that they offer future parents a particularly wide range of donors and that recipients can choose between anonymous and non-anonymous ones.

The transcription of the interviews I conducted, during which I spent hour after hour with my material, listening and re-listening to stories, was part of the analysis process. All transcripts were imported into the MAXQDA software for qualitative data analysis. Once they were imported, I reread all interviews and began coding them, using codes that evolved from my research questions and from the material itself. Although I found the software helpful in keeping all interviews in one place, in my experience there is also the danger that a ‘flood’ of codes can break the interview into tiny pieces, which in turn can lead to the overall context being lost. For this reason, I wrote short ‘condensations’ for ten interviews, aiming to record the main points that were not necessarily succinctly formulated in a specific passage. I selected the interviews for which I wrote these texts on the basis of the topics that had been particularly striking up to that point of the research, and which seemed to be particularly present in these interviews.<sup>14</sup> These were first and foremost the right to know, which was a particularly prominent theme; the search for origins; the frequently evoked connection between “identity formation” and knowledge; the search for relatives and information; and openness, transparency, as well as the toxicity of secrets. I examined the selected interviews primarily on the basis of the following questions: what in the interview is more than a code? What does a specific interview stand for? How am I positioned by this person? From whom or what do they distance themselves? What gets problematised? What narrative patterns and metaphors are used?

Only after completing the first ‘loose’ coding step and writing condensed reports on ten interviews did I move on to a more detailed coding phase. In doing so, I was guided by the model developed by Emerson et al. who suggest coding data in a two-step process consisting of open and focused coding as a way to find “concepts that are grounded in and reflect intimate familiarity with the setting or events under study” (1995: 166). They draw on Grounded Theory approaches but combine them with more reflexive elements. Grounded Theory as a qualitative research paradigm aims to develop theories that are ‘grounded’ in data (Glaser and Strauss 2010). The researcher is supposed to discover theories by leaving behind any preconceived ideas that did not originate from the data itself. Emerson et al. (1995) argue that such an approach is problematic, as it depicts data analysis as an autonomous process with neat boundaries. They argue that it should rather be seen as something that is pervasive throughout the entire research process (1995: 143–144). Emerson et al. suggest that instead of trying to ‘mine’ for theories ‘hidden’ in the data, ethnographers should think of analysis as the act of “creating what is there by constantly thinking about the import of previously recorded

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14 I wrote ‘condensations’ for the following persons: Lindsay Billington, Elizabeth Chapman, Sabrina Frey, Nadine Fuchs, Alexandra Gerstner, Tamara Haste, Sarah Holmes, Amber Jones, Timothy Parsons and David Winkler.

events and meanings” (1995: 168). This approach is more reflective than traditional Grounded Theory and allows for immersion in the data as well as an analytically distanced position (Klotz 2014: 75). This process was not just divided into two steps, but something I repeated over and over again. After I had already started writing, I kept going back to my material and moved from an open coding phase to a more fine-grained analysis, and then back to writing.

Writing my doctoral dissertation was thus very much part of the analysis and not something that I started only after I had completed the coding. Especially when working on my empirically oriented chapters, I continuously refined some ideas, discarded others, and linked my material to new concepts that I had discovered in the literature, or to those that I had already read about long ago. For example, while I knew early on that I would write something on DNA databases, it was only later that I developed the idea of thinking through my material on genetic testing with literature on IVF (sections 8.3 and 8.4), although I had read the relevant ethnographies early on. When writing, I was, at least after completing the first drafts, less concerned with mentioning every person in every chapter, but rather with making my main arguments clear, and this book more readable, through a detailed discussion of selected examples.<sup>15</sup> I sometimes decided to develop several points using examples from one particular interview instead of mentioning as many interviewees as possible. Most of the people I mention particularly frequently are among those whose interviews I have ‘condensed’, although here too I mention some more than others. A few people are rarely or not at all mentioned by name, which does not mean that their stories were less important for my analysis, less interesting or less complex.

As is customary in ethnography, I ‘cleaned’ interview passages that I included in the empirically oriented chapters, not only removing most filler words, such as “you know”, but also editing out incomplete sentence fragments and making grammatical adjustments. As Franklin and Roberts point out, these “decisions are far from straightforward” (2006: 91). They describe this strategy as a form of “textual etiquette” that has the aim of “present[ing] the speakers faithfully but also courteously and respectfully” (ibid.). Although I have cleaned the quotes, I have tried to preserve their original character as much as possible. Since people told their stories at specific moments in time, I chose to use the past tense when presenting ethnographic material, thus avoiding the “ethnographic present” (Fabian 1983) that “locates the other in a time order different from that of the speaking subject” (Pratt 1986: 33). While others have argued that ethnography constitutes a “written truth in the historical moment and must, therefore, be constructed in the ethnographic

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15 In the beginning, I had tried to include as many examples as possible, precisely because I did not want to leave out any of the people who had shared their stories with me. However, this had resulted in overlong chapters, which in turn had prompted me to edit out many sections.

present” (Hastrup 1990: 57), or that the use of the present tense sustains the immediacy of ethnographic research (Borneman 2015: 28), the past tense seemed more appropriate to me, as people’s lives did not remain frozen in time. The dynamic nature of my field will become particularly evident in chapter 8, when I discuss the growth of commercial DNA databases.

I assigned first names and surnames to all interviewees. In doing so, I follow anthropologist Kath Weston who has argued that “introducing strangers by given names alone paradoxically conveys a sense of intimacy while subtly withholding individuality, respect, and full adult status from research participants” (1991: 31). For reasons of readability, and because the relationship with interviewees is a dialogical one and differs from the way I position myself in relation to other researchers whose works I cite, I mostly use first names when writing about individual persons in more detail. By doing so, I lose “the different nuances of distance and closeness in address available in the German language but not in English” (Borneman 2015: 28). Most of the people I interviewed in Germany addressed me with the formal “*Sie*” and my surname (“*Frau Baumann*”), while a few of those who were similar to me in terms of age would offer me to switch to the informal “*Du*” right after I had met them. We subsequently addressed each other with our first names. Addressing them by their given names without them bringing it up first would have been inappropriate, as it would have pushed them into a linguistic closeness that they did not necessarily want to have, thus running counter to my aim of letting them lead the interview process. The use of the polite “*Sie*” in a situation where people shared intimate details of their lives, which they would normally probably only share with people they have known for a long time, underlines that interviews “transgress conventional social boundaries between the public and the private, mixing the domain of personal experience with that of professional activity” (Franklin and Roberts 2006: 89). This was particularly noticeable and also challenging in situations where people shared stories that were upsetting for them and brought back painful memories, even though I only entered their lives for a short time. Nevertheless, they too seemed determined to tell their stories, and I continued to feel impressed by their openness.

As Klotz points out, the kinship terms that people use “imply certain relationships and positionings concerning the nature in – or of – kinship” (2014: 77), and different terms have “different emotive and legal connotations” (ibid.). My interviewees themselves used various terminologies and sometimes switched between different terms during an interview (see for example Melanie Weber in section 5.4). For example, some talked about searching for their “donor”, but occasionally used the term “genetic father”. Others strictly refused to use the term “donor” at all, arguing that money had been exchanged for sperm, and instead just spoke of their “father”. While I analyse their terminology (see section 4.4 for a discussion of the German term “*Spenderkind*”, and section 6.4 for an analysis of statements such

as “dad is still dad”), I myself use the terms “father”, “mother” and “sibling/sister/brother” for those “taking on classical kin positions” (Klotz 2014: 77) within family relationships. I speak of “donors”, “offspring/donor offspring” and “donor siblings” when referring to those related through clinical gamete donation. While those whom I refer to as “mother” and “father” can be said to “produce” the child, donors assist them (Strathern 1995). Strathern suggests that “for Euro-Americans it is virtually impossible to talk of a parent in a human context without evoking the idea of potential social relations” (1992: 3), when the social relationships between the child and its procreators is in fact contingent (Strathern 1995). For this reason, I do not use the term “genetic parent”. I do not use the term “social father/social parent” either, which was used very little by my interviewees themselves, as I do not want to imply that the absence or presence of a genetic link determines how people parent.

I do use the term “donor-conceived” when referring to people conceived with donated sperm or ova.<sup>16</sup> This is the term commonly used in academic publications and chosen by many of my British interviewees as a self-designation, despite many people arguing that a gamete donor did not “donate”, but earn money.<sup>17</sup> However, a variety of labels has been used in the past. In an early medical report, the term “donated child” (Barton et al. 1945: 41) was used, whereas the Warnock Report spoke of the “AID child” (Warnock Committee 1984). Erica Haimes suggested the term “people conceived by DI”, arguing that it not only “situates this group in relation to the practice of DI rather than to any other party” (1998: 54), but also “follows the trend of favouring phrases such as ‘People with AIDS’ and ‘people with disabilities’, which are more open-ended and which place the person first before qualifying him/her as a particular type of person” (ibid.). The question of what people conceived with donated gametes should be called is still very controversial in Germany. I will elaborate on this debate and the contested term “*Spenderkind*” in section 4.4. In general, I would caution against any attempt to find a ‘neutral’ term. As Haimes noted, “the choice of one label over others does not resolve the debate: it simply establishes another claim” (ibid.). Although the term “donor-conceived” has become commonly used and accepted in English, one could of course object that it is too narrow; after all, my interviewees might also be described as “parent-raised”. Given the importance that most of them attached to the parent who had raised but not conceived them, I guess that they would not object to such a term. Besides, all of them were also conceived with one gamete that did not originate from a donor and might even

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16 I also use the term “donor-conceived half-sibling/sister/brother”. In Euro-American kinship, “half relatives” are those that are “connected by substance through one avenue rather than two” (Edwards 1999: 69).

17 It is also one of the hashtags Spenderkinder uses in their social media campaign (see the introductory chapter).

be described as “parent-conceived”. Since my research was after all about donor conception, I chose to foreground the “donor” aspect of their conception through my choice of words. Finally, I would argue that it is precisely the fact that they were conceived with donated gametes that people emphasise when they try to enforce their right to know and fight anonymity. Therefore, they do qualify themselves, at least in certain situations, as a particular kind of person. They *become* donor-conceived and turn “being donor-conceived” into a powerful identification, without denying that they are also something or someone else, for example the parent of their own children (section 6.4).

### 3. The right to know

#### Arguments, histories, debates

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One topic that came up again and again in the vast majority of interviews, yet was rarely discussed in more detail, was the right to know. The anonymity of donors was rejected, as it made it impossible for the donor-conceived to exercise their right to know their donor. The view that there is a right to know seems to have gained acceptance in the legislation of the countries where I have conducted my research. In both the UK and Germany, donor-conceived persons are now granted by law the right to access information about their donor at a certain age, namely information that is classified as identifying. This has replaced a system of legally protected donor anonymity in the UK, and a system of anonymity, which, albeit never being mandated legally, was nevertheless common practice in Germany. The change was carried out differently in the two countries, although a closer look reveals that both in the UK and in Germany court cases involving donor-conceived persons played an important role. The people I interviewed were all born and conceived before the respective regulations that temporally limited anonymity came into force. Their possibilities to obtain information about their donor through official channels were therefore either limited, or more or less non-existent. Although they are not necessarily among those who can easily access information, or perhaps precisely because of this, the right to know was always present in the interviews I conducted. Overall, it seemed to have the status of an unquestionable, taken-for-granted ideal, and was presented as an entity without context or history.

In this chapter I try to break down the apparent unquestionability of this right by asking about its history and its links to other international and national discourses and developments, and by examining my own ethnographic material with regard to how exactly the right to know was discussed. As will become clear in the following pages, the “right to know” is a concept that has multiple interpretations, applications and meanings. It is not only about a right “to know where you come from”; it is also about a right “to know one’s identity”. Furthermore, donor-conceived persons also talked about their right “to just know” and their right to find out and/or be told about their origins, while in jurisprudence the right “to know one’s descent” is discussed. In this chapter, I will discuss these different aspects,



which are sometimes mixed together, especially in the accounts of the donor-conceived. In this way, it will become clear that the “right to know” is not only a morally charged concept, but also has a complex legal history.

First, I will approach the issue from an international perspective and examine the international treaties often invoked by opponents of donor anonymity. Subsequently, I will discuss how international legislation has affected a court case in the UK that was of particular importance for the development of the legal regulation of gamete donation, and the shift towards temporally limited anonymity. When discussing the development in Germany, I will go a little further historically, and trace how the contexts in and for which knowledge about descent was considered relevant and worthy of legal protection have changed. I will then go on to discuss a particular line of argumentation of the advocates of the right to know one’s donor, namely references to and comparisons with adoption. In the following section, I will examine a different argument, namely the frequently expressed demand that the donor-conceived should have the right to decide whether they want to access information. I will then examine debates about a right to be told which were oftentimes linked with discussions about enforced disclosure. In particular, requests to record the name of the donor or information about the use of donated gametes in official documents were discussed at the time of my research as possible ways to ensure that the donor-conceived would find out in any case. Like all empirically oriented chapters, this chapter ends with a recapitulation of the individual sections and their main arguments.

### **3.1 International human rights law and the right to know**

It has been argued that the right to know, and more specifically the right of children to know their genetic origins, is “substantially reinforced by international human rights law” (Fortin 2009: 470). My aim is not to investigate whether this is correct or not, as I do not intend to develop a legal argument. Instead, I intend to show how the notion that one has a right to information about one’s origins has been reflected in international law, its interpretation and application. I will begin by examining the ways in which the reference to human rights has become a powerful narrative resource, and how the development of human rights is related to certain political developments and notions of personhood. I will then have a closer look at two particular treaties, and how they are mobilised by the opponents of anonymity in gamete donation. This in turn will illustrate an argument made by anthropologist Kim Fortun: “Law does more than codify, regulate and control; it also catalyzes and transmutes, provoking cascading social and cultural effects [...]” (2009: 146)

In conversations with those who advocated the right to know in the UK, it was striking that they repeatedly spoke of the human right to know and in part invoked

international treaties as well. Elizabeth Chapman, for example, believed that all donor-conceived persons, regardless of when they had been conceived, should be given access to information, commenting that “if you look at the United Nations Charter on the Rights of the Child, every child has a right to its own identity”. Regarding anonymity as a violation of the right to know was presented as something that is supported by internationally recognised legal agreements instead of by merely personal beliefs or emotions. One’s anger about not being able to access information could be explained as a reaction to the violation of a fundamental human right. At the same time, the reference to human rights agreements is more than just an attempt to justify one’s opinion to outsiders. By invoking human rights, one’s own demands are not only raised to a legally higher level but are also given a morally higher status that cannot and must not be questioned. If it is considered a human right to have knowledge about one’s origins, then the destruction or withholding of information about a gamete donor is a serious violation of personal integrity that is protected by international law. The discourse on human rights is also employed in other highly contested areas. In a study on the public debate on reproductive technologies in Poland, sociologist Elżbieta Korolczuk shows how conservative forces employ “the modern semantics of human rights [...] to reshape the way in which persons are understood by authorities and the public” (2016: 130). Fertilised eggs and embryos are constructed as political subjects whose human rights are violated when they are for example frozen. Korolczuk argues that employing “the rhetoric of human rights allows the opponents of reproductive technologies to claim that their opposition is motivated by medical facts and human rights standards, and not religious beliefs” (ibid.).

While international law was traditionally focused on relations between states, the development of human rights documents has meant “that not only states but also individuals are considered to have rights and responsibilities under international law” (Merry 2006: 104). The internationalisation of law is tied to movements that take place on a transnational level, such as the development of new political systems that link together several states (Merry 2006: 110). It was notably the end of World War II and the subsequent political developments that changed the legal landscape and advanced the development of international legal frameworks, human rights documents and institutions (Merry 2006: 104), making these rights “one of the most globalised political values of our times” (Wilson 1997: 1). Human rights law is tied to a notion of the person that is marked by “autonomy, choice, and bodily integrity” (Merry 2006: 109), which are hallmarks of “the Western sense of the self as a bounded, coherent, internal depth” (Sadjadi 2019: 112), as opposed to other systems of law that might focus on commitment or mutual obligations. Human rights have two distinct qualities to them: on the one hand, they are “investing the subject with the dignity of choice (between multiple options)” (Strathern 2005: 130). On the other hand, human rights can be thought of as “fitting an anonymous entity

abstracted from all social contexts bar one (common humanity)” (ibid.). Although international law aspires to be universal, it “exists alongside and above domestic law” (Merry 2006: 100), which can shape its contents, and also acts as a basis for arrangements on an international level. International law and the domestic laws of nation states are an interwoven field, and not strictly separated (ibid.). Therefore, a closer look at regulations that are effective beyond the national level can afford insights into national legislative processes and developments as well, even if the rules put down in writing cannot be forced upon a sovereign state by a central authority (ibid.). It is particularly striking that the treaties and articles to which opponents of anonymity repeatedly refer in their arguments are not rooted in a concern for DI.

International human rights law in form of the European Convention on Human Rights (ECHR), which was drafted in 1950 and came into force three years later, did play a major role in a 2002 ruling of the England and Wales High Court (EWHC) that contributed to the ‘lifting’ of anonymity. I will elaborate on this verdict in the next section (3.2). It has been argued that the ECHR, which was created five years after World War II, “is primarily concerned with curtailing the powers of totalitarian states and fascist regimes” (van der Sloot 2015: 27). In particular, the need “to avoid a future reoccurrence of the racial restrictions of the right to marriage” (Diggelmann and Cleis 2014: 453) as well as “forced regimentation of children and young persons” (ibid.) through totalitarian regimes influenced the drafting of Article 8, which provides a right to respect for one’s “private and family life, his home and his correspondence” (ECHR 1950). The ECHR also provided for the establishment of the European Court of Human Rights (ECtHR). Its final decisions are binding for all signatory states (Archard 2015: 109), and the view that “the right to identity, and hence to know one’s origins, belongs to the inner core of the right to respect of one’s private life” (Besson 2007: 151) seems to be gaining ground within the ECtHR.

While the ideal of privacy can be evoked to maintain or establish donor anonymity, the importance attributed to private life is increasingly evoked to argue against donor anonymity by those who oppose it, which is what happened in the UK as well (section 3.2). In the past, the need to protect the privacy of donors, recipients and children has often been cited as a reason for the anonymity of gamete donation (Blyth and Farrand 2004: 92). It was assumed that anonymity was necessary to prevent donors from interfering in the life of the recipients’ family, and that parents and children should be prevented from imposing themselves on the donors. In contrast, anonymity today is rather understood, with reference to the ECHR, as something that violates and restricts the private lives of the donor-conceived. The recent shift seems to be connected with a modified understanding of privacy, which illustrates that “privacy is spoken of in many ways today” (de Zeeuw 2017: 263). I suggest that conceiving of anonymity as something

that protects the privacy of donors and recipients is related to “[s]tatic notions of privacy” (ibid.). In contrast to more dynamic conceptualisations, these static notions “construe it as the state of being private and the right to privacy as each person’s right to be *let* or even *left* alone, to live undisturbed and in absolute independence from others” (ibid., emphases in original). A more dynamic and social account that does not conceptualise social interaction as the antidote to privacy seems to have become more prevalent, with the focus having shifted from privacy *per se* to private life.<sup>1</sup>

In the UK, the ECHR was incorporated into domestic law in 1998 under the Human Rights Act (HRA), meaning that citizens can bring human rights cases to court directly in the UK. Even before the HRA came into force in 2000, 1989 had already seen a much-noticed ECtHR ruling in the Gaskin-case, which had nothing to do with anonymous gamete donation (ECtHR 1989). The ruling in the Gaskin-case “was subsequently analogised with the question of accessing biological origins across Europe” (Blauwhoff 2009: 383). It has been described as a watershed decision (ibid.) that had a “tremendous importance for the progressive international and national recognition of individuals’ interest in knowing the truth about their genetic descent as a fundamental right” (Blauwhoff 2008: 99). The case had been brought in front of the ECtHR by an adoptee from the UK who already knew who his birth parents were (Marshall 2009: 127). He had applied to the Liverpool City Council for his case records, as he considered it crucial to find out more about his past in order to overcome traumatic childhood memories (Blauwhoff 2009: 65). The ECtHR ruled that the UK government, by denying the applicant access to records, had breached Article 8 of the ECHR. According to the verdict, the court was of the opinion that “respect for private life requires that everyone should be able to establish details of their identity as individual human beings and that in principle they should not be obstructed by the authorities from obtaining such very basic information without specific justification” (ECtHR 1989: paragraph 39). The verdict also states that “the information compiled and maintained by the local authority [in Liverpool] related to the applicant’s basic identity” (ibid.). Although the ECHR “does not guarantee the right to know one’s origins expressly” (Besson 2007: 142), it has been argued in the legal literature that it is “an essential part of the respect of

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1 It should be noted that a shift in terms of emphasis and conceptualisation might not necessarily be what the committee that drafted Article 8 had in mind. In their examination of the Article’s development, legal scholars Oliver Diggelmann and Maria Nicole Cleis argue that there is no documented discussion on “the use of the terms ‘privacy’ and ‘private life’ and the change of meaning thereby implied” (2014: 457). They suggest that the two terms were used as synonyms for each other but point out that the very first draft already contained the term “private life” instead of “privacy” (ibid.).

private life and has been derived by the ECtHR directly from Article 8 ECHR since 1989” (ibid.).

Another particularly prominent international treaty that is said to protect the right to know is the United Nations (UN) Convention on the Rights of the Child (CRC) (UN General Assembly 1989) which opened for signature in 1989 and came into force in 1990. The CRC has been described as “the first human rights treaty expressly to recognise a right to identity” (Freeman 1996: 283). In contrast to the ECHR, the CRC did not provide for the establishment of a separate international court. The UN itself is an institution that is “based on the ideal of universal standards that all countries can meet” (Montgomery 2001: 81) which is linked to the idea that there are “certain inalienable rights that apply to everyone by virtue of their humanity” (ibid.). Currently 196 countries are parties to the CRC, including every member state of the UN except the US, which has signed the treaty, but never ratified it.<sup>2</sup> Article 1 of the CRC defines a child as “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier” (UN General Assembly 1989). The CRC is based on a specific, yet standardised model of childhood, which might not necessarily match with how childhood is understood elsewhere (Montgomery 2001: 83; Howell 2006: 167). The Convention and its conceptualisation of childhood are based in particular on the assumption that childhood and adulthood are separate.<sup>3</sup> Despite its specific background, the treaty is “premised upon the notion that concepts such as human rights or children’s rights are not negotiable at the local level” (Montgomery 2001: 82).

Human rights law as formulated in the CRC has become a key means of justifying legislation amendments that have led to the establishment of temporally

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2    By signing the treaty, a state declares that it intends to implement its contents into national law. However, it is not yet a legally binding contract. It is only through ratification that the signing parties “commit themselves to protecting and ensuring children’s rights and developing actions and policies to promote the best interests of the child” (Clark 2012: 625). Ratification thus obliges states to make any necessary adjustments to their national legislation (Fischer 2012: 45). Critical voices have highlighted that “many signatory states pay no more than lip service to the Convention” (Archard 2015: 109) which has been explained with “the absence of an international court to which cases alleging breaches of the CRC could be brought” (ibid.).

3    The idea that children and adults are different is historically relatively new, with the separation taking place gradually since the sixteenth century when children were still very much “considered to be small adults” (Hart 1991: 53). In contrast, Euro-American societies have increasingly come to recognise that “childhood is the ‘not-yet-ness’ of adulthood” (Archard 2015: 48). Although childhood is thought to be fundamentally different from adulthood, it is nevertheless considered to be “a stage or state of incompetence relative to adulthood” (Archard 2015: 43). It is very much seen as a developmental stage (Archard 2015: 44–48). This means that children are no longer seen as “small adults”, but as future adults instead (Brennan 2014).

limited anonymity and calls for further changes, as permanent anonymity is said to violate especially Article 7 and 8 (Ravelingien and Pennings 2013: 33; Lyons 2018). Article 7(1) provides that a child “shall be registered immediately after birth” (UN General Assembly 1989) and “shall have [...] as far as possible, the right to know and be cared for by his or her parents” (ibid.). Article 8(1) states that a child has the right “to preserve his or her identity, including [...] family relations as recognized by law without unlawful interference” (ibid.). Article 8(2) provides that states have the duty to assist a child in “re-establishing speedily his or her identity” if the child has been “illegally deprived of some or all of the elements of his or her identity” (ibid.). It is important to note that neither of the two articles were inspired by a concern to protect the rights of those conceived through DI. Instead, Article 7 originated from the need to address the problem of statelessness (Fortin 2009: 470), while Article 8 was a response to crimes of child abduction that had been committed by the Argentinian military regime (Freeman 1996: 283).<sup>4</sup>

It has been argued that the child’s “right to know and be cared for by his or her parents” is largely contingent on the exact definition of a “parent” (Blyth 1998: 240). The CRC itself does not provide a clear definition of what a parent is. The authors of the United Nations International Children’s Emergency Fund (UNICEF) Implementation Handbook for the CRC argue that “the definition of parents includes genetic parents (for medical reasons alone this knowledge is of increasing importance to the child) and birth parents” (Hodgkin and Newell 2007: 105, emphasis in original), which they define as “the mother who gave birth and the father who claimed paternity through partnership with the mother at the time of birth (or whatever the social definition of father is within the culture [...])” (Hodgkin and Newell 2007: 105–106). They then add that the “psychological parent – those who cared for the child for significant periods during infancy and childhood – should also logically be included” (Hodgkin and Newell 2007: 106), as all these different sets of parents are connected to the identity of the child (ibid.).

In the UK, the HFE Act established in 1990 that a gamete donor would not be regarded as the legal parent of a child born as a result of a donation. The UK declared upon ratification of the CRC that it intended “to restrict definition of the term ‘parents’ to persons who are treated as such in law” (Blyth and Farrand 2004: 94). According to Blyth and Farrand, “it may [therefore] be argued that Article 7 has no relevance to donor anonymity in the UK” (ibid.). A similar argument could be developed for the new German law, as the Sperm Donor Register Act from 2017

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4 See also Arditti 1999 and Goddard 2018 for a detailed discussions of the activism of the Grandmothers of the Plaza de Mayo (*Asociación Civil Abuelas de Plaza de Mayo*), an Argentinian human rights organisation that aims to promote the search for and recovery of children abducted during the military regime. Article 8 is largely the result of the lobbying of the Grandmothers.

provides that donors cannot be determined as legal fathers by the donor-conceived. In contrast, the Austrian legislation that allows donor-conceived persons to access information about the donor at the age of 14, which is younger than the minimum age requirements set in place in other jurisdictions, can in part be attributed to the Austrian government's way of interpreting Article 7 of the CRC as prohibiting donor anonymity (Blyth 1998: 241).

While neither Article 7 and 8, nor any other articles of the CRC are rooted in an attempt to reform donor conception, a group of donor-conceived and surrogacy-born persons from several countries did in fact participate at a workshop held at the celebration for the thirtieth anniversary of the CRC. This workshop, held in a centre of international law and politics, epitomises the authority attributed to 'authentic' experiences and the first-hand account of the donor-conceived, making it a particular striking example of donor-conceived activism. The session, which took place in November 2019 in Geneva, was entitled "The Development of Biotechnology and the Concept of the Child". It was organised by Sonia Allan, a public health, law and policy researcher who has worked on donor conception (see for example Allan 2017), and Stephanie Raeymaekers, a donor-conceived activist from the organisation Donorkinderen, the Belgian equivalent to the German association Spenderkinder.<sup>5</sup>

On the flyer announcing the workshop (figure 1), a number of questions are printed next to the picture of a newborn baby and a note that states "Discount – Right for Sale".<sup>6</sup> These include "What if this child doesn't know their biological parent(s)?" and "What if they have hundreds of siblings?" (See also section 7.5, where I discuss the fear of having "too many" donor siblings) These and other questions are followed by the invitation to the workshop: "Join us to hear from people who have lived these experiences." (International Social Service 2019) The workshop included several presentations of donor-conceived persons. Some of them made direct references to the CRC and the articles they saw as protecting the right to know.<sup>7</sup> According to a blog post written by the organisers and one of the presenters, they "were met with rapturous applause and a standing ovation by the audience, several of whom had been moved to tears by the stories" (Allan et al. 2020).

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5    [www.donorkinderen.com](http://www.donorkinderen.com) (last accessed May 27, 2020).

6    Interestingly, the flyer looks very similar to the poster of the "Fertility Show" I attended in the UK. This type of event is often criticised by donor-conceived activists and others who are critical of the commercial nature of such events. The Fertility Show's poster also showed a newborn baby and was strikingly similar to the flyer in terms of colour. I do not know whether these similarities were intentional.

7    Videos of their speeches are available on the website of Donorkinderen ([www.donorkinderen.com/united-nations-2019](http://www.donorkinderen.com/united-nations-2019), last accessed May 23, 2021).

Figure 1: Flyer of the workshop held at the 30<sup>th</sup> anniversary of the CRC

## Donor Conception and Surrogacy

Session organised by Sonia Allan OAM and Stephanie Raeymaekers and presented by surrogacy born and donor-conceived people.

19 November 2019 - 11.20am - 12noon

30th anniversary of the CRC celebrations: Room XXI - Palais des Nations

<https://reg.unog.ch/event/28741>

**What if this child doesn't know their biological parent(s)?**

**What if they are at risk of a medical condition, they know nothing about?**

**What if they have hundreds of siblings?**

**What if money changed hands to create them?**

**Join us to hear from people who have lived these experiences.**



Source: International Social Service 2019



### 3.2 (Inter)national law, private lives and the need for information in the UK

By the time the issue of donor anonymity was debated in the EWHC in 2002, the HRA had already been established in the UK. Before the HRA had come into force, family law had already moved towards the view that the right to know was central to a child's welfare, notably in paternity disputes (Wallbank 2004). In 2002, a case was brought to the EWHC by Joanna Rose, who had been conceived with anonymous donor sperm before the establishment of the HFEA, and a six-year-old girl (referred to as "EM" in the verdict) conceived after 1991, who was represented by her parents (EWHC 2002). They were both represented in court by the human rights non-governmental organisation Liberty and argued under the HRA Act that they had a right to non-identifying information. Additionally, they sought the establishment of a voluntary contact register. This court case, the verdict and the assessment of one of the applicants of the significance of the judgement will be discussed in this section. The verdict is indicative of the idealisation of openness, and also acted as a catalyst for further change.

Article 8 of the ECHR, the right to respect for private and family life, was invoked in support of Rose's and EM's claims. It was also argued that Article 14, which prohibits discrimination, was engaged, as there should be no legal difference neither between adoptees (who were granted access to information about their birth parents already back then) and the donor-conceived, nor between those conceived before and after the establishment of the HFEA. The verdict quotes Rose, who describes not having her full "genealogical picture [as] very distressing" (EWHC 2002: paragraph 7), and who states that the "need to discover this information" is "a central feature of my life, along with the need for recognition for this" (*ibid.*). According to the verdict, EM's parents had always been open with their daughter about how she was conceived. The verdict, however, states that her mother "feels strongly that she is prevented from being open with her daughter because of current legislation" (EWHC 2002: paragraph 13). A causal link is thus established between the extent to which openness can be practiced and the availability of information. In their analysis of UK policies and texts on gamete donation, Leah Gilman and Petra Nordqvist argue that since "the ideology of openness" (2018: 330) is pervasive, "increased availability of information is often viewed as inherently positive" (*ibid.*). I suggest that the 2002 ruling can be interpreted as being indicative of this ideology. It is not just parents' willingness to be open that is deemed important for the child's wellbeing and healthy family relationships but also having information (see also Edwards 2018: 167).

A consultation exercise had already been launched by the UK Department of Health in late 2001, after the commencement of the case, "to determine how non-identifying information should be handled and whether and how anonymity should

be lifted” (Wincott and Crawshaw 2006: 67). In the EWHC case, Justice Scott Baker, who had been a member of the Warnock Committee, argued that the “line between identifying and non-identifying information is not [...] an easy line to draw” (EWHC 2002: paragraph 39), and that in coming to his conclusion, he felt it was necessary to “look at the concept of information about donors regardless of whether it falls on the identifying or non-identifying side of the line” (ibid.). The EWHC decided that Article 8 was indeed “engaged both with regard to identifying and non-identifying information” (EWHC 2002: paragraph 46), although the judge emphasised that the court did not want to address the question of whether or not donor anonymity constituted an actual breach of the ECHR. Justice Baker also stated that he found it

“[...] entirely understandable that A.I.D. children should wish to know about their origins and in particular to learn what they can about their biological father or, in the case of egg donation, their biological mother. The extent to which this matters will vary from individual to individual. In some instances, as in the case of the Claimant Joanna Rose, the information will be of massive importance. I do not find this at all surprising bearing in mind the lessons that have been learnt from adoption. A human being is a human being whatever the circumstances of his conception and an A.I.D. child is entitled to establish a picture of his identity as much as anyone else. We live in a much more open society than even 20 years ago. Secrecy nowadays has to be justified where previously it did not.” (EWHC 2002: paragraph 46)

In the statement, the link between having information and being able to form a complete identity is something that is presented as being self-evident and backed up by “the lessons learnt from adoption”, which is an argument that I will explore in more detail in section 3.4. The donor is conceived as a “biological parent who will inevitably have contributed to the identity of his child” (EWHC 2002: paragraph 48). Although the judge acknowledged that information about one’s origins might be more or less important depending on the individual in question, the need for information is interpreted as something that characterises humans as humans. Denying access to information to those who are donor-conceived was interpreted as an unfair and unjustified decision. The acknowledgment that claims to information were supported by Article 8 of the ECHR “made change virtually inevitable” (Fortin 2009: 470), especially since the Committee on the Rights of the Child, which monitors and reports on the implantation of the CRC, criticised British law for not enabling access to donor information a couple of months after the verdict (Blyth 2004: 239). A later hearing which could have determined whether there had indeed been a breach of Article 8 never took place, and two years later, the law was changed. When Melanie Johnson, the then public health minister, announced the change at the 2004 annual conference of the HFEA, she declared that she had “listened to

the views of donor-conceived people and they would like more information about their genetic origins – perhaps for themselves, perhaps for their children, perhaps because they feel the information belongs to them. That it is rightly theirs.” (Cited in Turkmendag 2012: 66)

While the court case is commonly portrayed as the event that “contributed to the decision to end donor anonymity” (Lister 2015), or even as the development that “brought about a ban on anonymous donations in the United Kingdom” (Bottone 2018), Joanna Rose, whom I interviewed in the UK, felt ambivalent about the changes her court case had brought about. Rose emphasised that she had initially wanted the EWHC to rule that their human rights had been violated instead of them being merely engaged. Rose, who strongly opposes donor conception, mentioned that she was embarrassed “by the misunderstanding that the issue is resolved” now that she had won her court case and by the commonly held idea that the best interests of the donor-conceived are protected by the law. She was proud of having been involved in a court case that had “established something in terms of a foothold”, but felt that “the surreptitious seeping of our rights” continued to go on as clinics in the UK would facilitate treatment with anonymously donated gametes by maintaining links with clinics in other countries and sending patients abroad, making “a mockery” of the British law.<sup>8</sup> Rose, who has a PhD from Queensland University of Technology (Rose 2009), hoped that the second part of the court

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8    A study published in 2015 (Hanefeld et al. 2015) found that for British patients who travelled abroad for medical procedures, “networks between providers in the UK and abroad (all resulting from informal connections) play an important role” (2015: 362) when choosing a clinic. I could not find any information about such connections on the websites of fertility clinics; assuming that these links are informal, this is arguably not surprising. However, I was told by a British couple who had conceived their child through egg donation that their British clinic had referred them to a specific clinic in another European country where patients did not have to wait for donor eggs. They told me that virtually all major UK clinics had links with fertility clinics abroad and gave me several concrete examples (that I could not verify). Whereas those of my interviewees who were critical of donor conception per se tended to foreground the desire to avoid national legislation on anonymity as a reason why people went abroad for treatment, research on the phenomenon of “cross-border fertility care” (Culley et al. 2011) paints a different, more nuanced picture. In their study of UK residents who had gone abroad for treatment, Culley et al. found that only ten % of those who had had treatment with donor gametes had gone abroad specifically to get an anonymous donor (2011: 2379). They argue that for the majority of those opting for treatment in countries where donors are guaranteed anonymity, having an anonymous donor “was simply an unavoidable corollary of having treatment in countries where donors were readily available and treatment accessible and affordable” (ibid.). Likewise, Hanefeld et al. (2015: 360) found that only one respondent out of nine had decided to go abroad for fertility treatment because of British regulations on anonymity. However, they suggest that this finding “must be seen in the context of our sample recruitment and self-selection, as patients seeking anonymity are likely to have been more reluctant to participate in a social research study” (ibid.).

case that would establish that their human rights had been violated would happen, believing that “much more needs to be done to protect our rights”. She was upset about the fact that donor conception was still being practiced, as the “lessons learnt from adoption” and other areas which she had explored in her PhD thesis (which is entitled “A Critical Analysis of Sperm Donation Practices: The Personal and Social Effects of Disrupting the Unity of Biological and Social Relatedness for the Offspring”) had shown that it resulted in major difficulties:

Joanna Rose: “I hope that all around the world, anonymity will be overturned legally. And we’ll be given rights, and that has seemed to happen with most groups of people this has been done to before, whether that’s adoptees, whether that’s Stolen Gen.<sup>9</sup> But the human cost of that type of experimentation, the amount of people that have to be hurt and the amount of effort those hurt people have to put in as a collective group is just phenomenal. That’s what my PhD was trying to say, you don’t need to do this experiment on the next group of people, you’ve already got the results, if you deprive people of knowledge and relationships with a genetic family as a means to somebody else’s ends, or even for child protection, that results in huge complexity and issues of loss, and issues of identity full stop, you know it.”

Rose also pointed out that “there are times when families need interventions that can result in separations and alienation of kin. However, this should be as a last resort and only for good reason such as child protection rather than for child production or any other spurious reason.”

These excerpts illustrate that Rose herself did not believe that her court case and the legal changes that followed had sufficiently protected or restored the rights of the donor-conceived. Her opinion was shared by other activists in the UK. I suggest that the case can nevertheless be seen as an example of donor-conceived activism reaching a public and legal arena, and as an instance of a human rights treaty finding a very particular local formulation and application. In addition, the ruling seems to have shaped the way donor-conceived persons in the UK feel and speak about donor anonymity. Even though my British interviewees did not explicitly refer to the 2002 verdict, it was striking that they repeatedly referred to their *human right to know*. A different kind of argumentation was prevalent in Germany where Spenderkinder argues that anonymous donations were never permitted by national law.

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9 The term “Stolen Gen”, short for “Stolen Generation”, is used for children of Australian and Torres Strait Islander descent who were forcefully removed from their families by Australian government officials as well as church missions from the beginning of the twentieth century up until the 1960s.

The question arises how the legal situation with regards to human rights in the UK will develop in the future now that the country has left the European Union, and how this might affect the way the right to know of the donor-conceived is (re)negotiated. In a policy paper published in July 2018, the government stated that the country was “committed to membership of the European Convention on Human Rights” (May 2018: 52). The Conservative Party had long pledged to replace the HRA with a British Bill of Rights (Conservative Party 2014), and it seems to have become likely that they might now move forward with their plans. At present, there are no indications that Brexit might result in any legal changes with regards to donor anonymity. It remains to be seen whether other narrative resources will be evoked in discussions about the regulation and management of donor information.

### 3.3 From maintenance claims to personality rights: The German debate

Germany is a particularly interesting case to study the right to know one’s descent. An examination of the development of this right, which is well documented in legal history, reveals that it underwent a profound transformation in the twentieth century. In particular, it was not always interpreted as something that was intended to secure important information for the individual’s “identity development”, which is how it is seen nowadays. I will trace this shift in the following section.

At the beginning of the twentieth century, the determination of descent was only a matter of establishing maintenance claims. It was thus not a question of supporting children in their “search for identity”. The newly created category of the so-called “pay fathers” (*Zahlväter*), who were only connected to their children born outside of marriage in monetary, but not in legal terms (Buske 2002: 323), expresses this particularly clearly. Whereas determining paternity used to be only relevant for maintenance claims, “the determination of the biological truth came to represent a value worth legal protection in itself” (Blauwhoff 2009: 102–103) as part of the racial ideology of the Nazi regime in the 1930s. The totalitarian regime’s increased interest in determining descent “reflected the racial segregationist and eugenic public policy objectives” (Blauwhoff 2009: 103). The determination of descent that was “*blutsgemäß*” (“according to blood”) was seen as something that, “in view of the German people’s interest in maintaining racial purity” (*ibid.*), was not

merely of private or familial, but of public interest.<sup>10</sup> A child's descent could from then on be determined even if no maintenance claims were in dispute (*ibid.*).

Although the Nazi regime ended in 1945 and democratic rule was reinstated, the law on descent remained largely unchanged. After the official renunciation of NS ideology, the legal status of descent that was “*blutsgemäß*” could theoretically have been restored to its pre-1933 status. However, the Federal Court of Justice (*Bundesgerichtshof*, BGH) essentially upheld the jurisdiction of the *Reichsgericht*, the former supreme criminal and civil court, even if racist Nazi ideology was officially rejected (Helms 1999: 41), and “the mere fact that much of the legislation had originated in a murky past was not in itself considered a sufficient reason to justify their deletion” (Blauwhoff 2009: 104). Discussions about descent law in post-war Germany revolved around “the necessity to cast the existent legislation into a radically different ideological mould which would be directed primarily towards the individual's identity rather than racist conceptions of national identity” (*ibid.*). By invoking the special position of the individual and the “personality right” (*Persönlichkeitsrecht*) of the illegitimate child in the legal literature as well as first court decisions (von Sethe 1995: 62), it became possible to essentially maintain the previous laws without reinstating Nazi regime argumentation. However, the legal discrimination of children born outside of marriage was by no means abolished, although the *Parlamentarischer Rat* (“parliamentary council”) had already instructed the legislator at that time to ensure legal equality of children born inside and outside of marriage.<sup>11</sup>

It was not until the 1960s that extensive changes were made to the law of descent, and children born inside and outside of marriage were given equal rights. It has been argued “that the legislator did not only have in mind the idea of promoting greater status equality, but also forestalled a child's right to know her or his genetic descent” (Blauwhoff 2009: 105). A 1969 law for the first time fully recognised the relationship between a child born outside of marriage and his/her father, and children were granted the right to have their descent established in court (Helms 1999: 43; Buske 2002: 345–347). However, the authorities wanted to avoid this unless no man recognised the child on his own initiative and thus became obliged to pay child support (Helms 1999: 44). The “swift determination of the parentage of all

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10 Since the racist Nazi regime claimed that there was a public interest in determining the origins of a child, the public prosecutor was given the right to challenge the child's legitimacy. This was only dropped in 1961 (Blauwhoff 2009: 105). Another result of the racist endeavour to keep Germany ‘pure’ were provisions that allowed persons to be compelled to undergo physical examinations, notably blood tests that could exclude paternity in some cases (Frank 1996). Such compulsory examinations are still legal today.

11 The *Parlamentarischer Rat* was the West German constituent assembly that convened from 1948 to 1949 in Bonn. It drafted and adopted the *Grundgesetz* (“basic law”) of the Federal Republic of Germany.

children born out of wedlock” (Blauwhoff 2009: 106) instead of helping a child with his/her “identity formation” seemed to be the main concern of the authorities.

The importance of securing a right to know for donor-conceived children was repeatedly the subject of legal discussions. Legal argumentation was oftentimes mixed with ethical considerations, and the moral standard by which DI was judged was clearly aligned with the ideal of the marital family (see for example Geiger 1960).<sup>12</sup> The right to know of the donor-conceived was already propagated by law scholars in the 1960s. However, the link between personal identity and knowledge was not always propagated as strongly as it was later on. A 1962 draft amendment to the penal code sought to prohibit DI altogether (Deutscher Bundestag 1962: 356–359). The anonymity of the donor was presented as a human rights violation, since the anonymously conceived child would not know who the father was (Deutscher Bundestag 1962: 357). The importance attributed to the figure of the father and to marital unity, rather than to the child’s interest in finding out about his/her origins, underlines the patriarchal and heteronormative orientation of the draft (see also Timm 2016 for a detailed discussion of the draft and its development).

The focus of the legal criticism seems to have shifted in the following period and was less directed towards the alleged threat to marriage posed by DI, and more towards the threat to the right to know posed by anonymity. For example, Jürgen Pasquay argued in his doctoral dissertation that DI should be rejected mainly if it deprived the child of the opportunity to find out about his/her origins (1968: 155–156), and in particular when the semen of different men was mixed (1968: 155). He was convinced that having this knowledge was a human right “because it is part of the essence of man to have a firm place in the stream of history, in the succession of generations, which can also be determined by blood [*blutsmäßig*]” (1968: 155–156, author translation). However, Pasquay suggested that donors should remain anonymous until a donor-conceived person reached the age of legal majority. He argued that such a restriction was necessary “in order to avoid contact between the couple and the child and the sperm donor for pedagogical reasons and in order to maintain marital harmony” (1968: 192, author translation). Pasquay therefore suggested to enter the donor’s name in the birth register and to grant the adult child a right to inspect the files (1968: 192–193).<sup>13</sup> The link between knowledge and

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12 Willi Geiger, who was a judge at the Federal Constitutional Court from 1951–1977, argued in 1960 that both heterologous and homologous insemination should be banned (Geiger 1960). He was convinced that treatment with donor sperm constituted a violation of human dignity and was not compatible with the nature of marriage (1960: 43). Geiger also argued that couples opting for treatment with the husband’s sperm could never be sure that no “extramarital” (*ehefremd*) sperm would be used (1960: 68).

13 A similar proposal was made by the author of another dissertation: Bartold Busse (1988) argued that permanent anonymity constituted a violation of the donor-conceived person’s

the “essence of man” is even more pronounced in the first legal monograph focusing on the right to know one’s descent (Kleineke 1976), the last chapter of which deals with anonymity and DI (Kleineke 1976: 288–305). Knowledge about one’s descent is described as an irreplaceable “means of recognising one’s own identity” (Kleineke 1976: 50, author translation).

Shortly before the Gaskin-case, the Federal Constitutional Court (*Bundesverfassungsgericht*, BVerfG) had already passed a “landmark judgment” (Blauwhoff 2009: 65) in 1989 – the same year that the CRC was adopted by the UN General Assembly – with regards to the right to know that further cemented the legal link between knowledge and identity. In TV, radio and newspaper reports on the subject of donor conception, it is often argued that there has been a right to know one’s origins since the 1989 court case. The association Spenderkinder frequently objects to such an interpretation, arguing that the court confirmed that there was a right to know instead of creating it. Through the verdict, the right to know became recognised by the highest German court.<sup>14</sup> It has been argued that the BVerfG “fulfilled its globally pioneering role” (Blauwhoff 2009: 110) by “acknowledging the right to know one’s genetic parentage as an aspect of the personality right, seemingly irrespective of a person’s status or the circumstances at birth” (*ibid.*). Although the case had nothing to do with DI or reproductive technologies in general, it has been argued that it “was decided in the context of academic and political debates about the relevance of a right to ascertain one’s genetic origin, particularly in relation to those born as a result of medically assisted procreation technology” (Dupré 2003: 84; see also Smid 1990 for a legal commentary published after the verdict).

A woman who wanted to challenge the legal presumption that her mother’s husband was her father had brought the case to court. She had known for a long time that the man who had raised her was not biologically related to her. Moreover, it was allegedly already known to her who her genitor was (Helms 1999: 46–47). However, her parents, who were in agreement with her plan, were still married and did not intend to separate. At that time, children born inside of marriage were generally only able to challenge the paternity of their legal father in the event of a divorce (Dupré 2003: 84). The court decided that this regulation constituted a breach of the Basic Law (*Grundgesetz*). Knowledge about origins was described as “offering the individual important points of reference [*Anknüpfungspunkte*] for understanding and

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right to know and was therefore unconstitutional. He claimed that the legislator was obliged to ensure that a person would have access to information upon reaching adulthood (1988: 195) and suggested that the donor’s name be noted in the register of births. In addition, he stressed that the legislator would have to oblige physicians to document and store the donors’ names (1988: 185–186).

14 According to legal scholar Tobias Helms, the verdict is significant because it was the first one to emphasise the “completely independent constitutional significance” (“*die völlig eigenständige verfassungsrechtliche Bedeutung*”; 1999: 46, author translation) of the right to know.



developing one's own individuality" (BVerfG 1989, author translation), and the court concluded that "the personality right encompasses the knowledge of one's own descent" (*ibid.*). Following the judgment, there was a debate, at least in the field of law, as to whether anonymous sperm donation was permitted (Starck 1989; Enders 1989). However, no change in law was implemented, and even after the implementation of the ETD in 2007 and the extension of the minimum storage period for donor records, there was still no regulation on how information should be made available to the donor-conceived (section 1.1).

While the UN Committee on the Rights of the Child had criticised the UK for not granting the donor-conceived access to information a couple of months after the 2002 court case, the anonymity of donors is not mentioned in any UN reports on Germany: for example, it is not discussed in the 2004 "Concluding Observations" (UN Committee on the Rights of the Child 2004).<sup>15</sup> Eric Blyth, a former Professor of Social Work at the University of Huddersfield and a member of the BASW's Project Group on Assisted Reproduction (PROGAR), points out that other countries had already been criticised by the Committee before 2002 for allowing anonymous gamete donation (2008: 162–163, note 36). Blyth argues that "since many more signatories of the UN Convention also endorse donor anonymity, the rationale for the Committee's selective approach is unclear" (*ibid.*).

In contrast to the UK, the ECHR does not seem to have played a decisive role in Germany either. The Convention has been incorporated into German law as an ordinary statute (Hoffmeister 2006: 724), and the rights contained in the ECHR "can be invoked in German courts like any other federal act of parliament" (Lock 2015). Both the ECHR and the decisions made by the ECtHR "serve as interpretative tools of German norms of a constitutional nature" (Hoffmeister 2006: 724). According to law scholar Tobias Lock, the Convention "does not play a huge role in German legal practice" (2015). He further points out that the ECHR "is not routinely referred to by German courts in fundamental rights cases as the constitutional guarantees suffice" (*ibid.*). Even though the legal literature on the right to know one's descent contains no evidence that the ECHR played an important role in Germany, it is noticeable that German publications addressing sperm donation nevertheless often refer to the ECHR – presumably to underline the importance of this right and of knowing one's origins (see for example Müller 2020: 102).

A major event in terms of fights for the right to know and donor-conceived activism occurred in 2013 when a donor-conceived person born in 1991 who was a member of Spenderkinder won a court case against the doctor who had treated her mother. The physician had claimed to have no treatment records left. The court

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15 All state parties must submit regular reports to the Committee on how the CRC is being implemented. After examining these reports, the Committee then publishes its concerns and recommendations in the form of "Concluding Observations".

ruled that he was not entitled to withhold any information that was obtainable. It was decided that the provision of information could only be considered impossible once extensive searches had been carried out by the clinic. Referring to the 1989 case, the court argued that the right to know one's descent was particularly worthy of protection. According to the verdict, "understanding and developing one's own individuality is closely connected with knowledge of the factors that are constitutive for it. These factors include, among others, descent." (OLG Hamm 2013, author translation) Another significant verdict came in 2015, when the Federal Court of Justice ruled that underage donor-conceived persons also had to be given information about their donor. The BGH gave reasons for its decision similar to those given in 2013: "One of the elements that can be of decisive importance for the personality development [*Entfaltung der Persönlichkeit*] is knowledge of one's own descent." (BGH 2015, author translation) In view of these two verdicts, it is not surprising that the Sperm Donor Register Act, which was passed in 2017, gives the donor-conceived (albeit only indirectly through their parents) the possibility to obtain donor information prior to their sixteenth birthday.

As this overview of the German history of the right to know one's descent shows, this right has not always been what is discussed and negotiated today. It is particularly striking that, at the beginning, it was purely a matter of maintenance claims, which were not intended to establish a legal or social relationship. It was only in the course of time that new arguments emerged, and the need for protection of personal identity as an argument against not having access to information came into play. The link between knowledge and personal development was repeatedly invoked in many of the interviews I conducted in the UK and Germany, and this will be evident at various points of this book. Since there was a need to know, my research contacts reasoned, there was a right to know. I suggest that, given the changes that the right to know one's descent has undergone and the emergence of human rights treaties after World War II, these claims must be understood as statements embedded in a specific historical context. Arguing that one has a right to know one's origins in order to form a firm identity would not have made any sense in the past. The frequently invoked connection between knowledge and the child's healthy development is a central component of a certain and particularly influential line of argumentation that will be explored in the next section.

### **3.4 Moving away from secrecy and anonymity: Lessons learnt from adoption**

Those who oppose anonymity and advocate a right to know oftentimes argue that one has to take into account the "lessons learnt from adoption" when regulating gamete donation. In the UK, these lessons were already brought up as early as

the 1970s. The practice of secrecy in DI was questioned by adoption researchers, without anonymity necessarily being debated. Joan Brandon and Jill Warner, for example, pointed out that adoptive parents are encouraged to tell their children about adoption, not least because “the child may find out in any case” (1977: 339). They argued that children should be told that they were conceived with donated sperm because they “need information concerning their origins” (1977: 340) and suggested that donor anonymity could be maintained even if children conceived with donated sperm were told about their origins (*ibid.*). The lessons that could and should be learnt from adoption are still evoked in today’s discussions and were also frequently touched upon by my interviewees. In the following I will first explore the analogy made between adoption and donor conception on a more general level, before discussing how these lessons were evoked by my interlocutors. Finally, I will briefly discuss one particular criticism of this analogy.

In her analysis of the comparison made by opponents of anonymity in gamete donation between closed adoption and anonymous donor conception, philosopher Kimberly Leighton examines what she calls the “Harm Claim” (2014: 241).<sup>16</sup> Leighton argues that this claim constitutes a core component of the “right to know” arguments against anonymous sperm and egg donation: those who argue this way maintain that not knowing one’s genetic origins is in itself a source of harm. In addition, it is argued that people have a right to be protected from such damage. It is assumed that a lack of information about origins is hazardous, regardless of why people do not have access to it. Opponents of anonymous donations argue that the donor-conceived might experience “genealogical bewilderment” (Sants 1964), a term originally used to describe the distress experienced by adoptees.<sup>17</sup> They argue that the regulation of gamete donation should be altered according to the policies governing adoption, which have increasingly moved away from secrecy and towards openness, and from closed adoptions towards open ones.

The analogy that is commonly made between donor conception and adoption illustrates that people commonly “draw on what they already know to order and make sense of the ramifications of NRT [new reproductive technologies]” (Edwards 1999: 67).<sup>18</sup> Anthropologist Marit Melhuus argues that this analogy only “works by making some aspects of adoption explicitly relevant, while others are silenced”

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16    A closed adoption is a form of adoption in which the birthparent(s) and adoptive parent(s) receive no or only very little information about each other. The records of the biological parent(s) are kept sealed and are not made available to the adoptee or the adoptive parent(s).

17    Psychologist Harold J. Sants argued that genealogical bewilderment could be experienced by any children that grew up with “*at least one unknown parent*” (1964: 133, emphasis in original).

18    In her analysis of reproductive technologies, law and kinship in Norway, Melhuus (2012) makes a similar point. She argues that in contrast to IVF and other methods, adoption “has a long legal history” (2012: 11). Since adoption is something Norwegians are likely to be familiar with, Melhuus suggests that it is “not surprising that this existing knowledge about the

(2012: 11). She argues that adoption and donor conception are not only “two very different ways of procreating” (ibid.), but that they are also “two very different ways of becoming someone’s child” (ibid.). Nevertheless, Melhuus and Signe Howell argue elsewhere that both adoption and assisted conception, including DI, are forms of “unnatural procreation” (2008). Commenting on Norwegian debates and legal developments concerning both practices, they point out that adoption “has been legally part of the public domain for almost a century” (2008: 158). They suggest that it “becomes (paradoxically) a natural model against which other forms of unnatural procreation are measured” (ibid.). The way in which adoption has become a “cultural model [...] through which assisted conception is interpreted and evaluated” (ibid.) was particularly evident in the UK, while references to adoption seem to have been made less often in policy debates in Germany (Thorn 2004).

Lessons that could be learnt from adoption have been explored by Marilyn Crawshaw, who has published extensively not only on adoption but also on donor conception and surrogacy (see for example Crawshaw 2002; Crawshaw and Marshall 2008; Crawshaw, Blyth et al. 2017; Crawshaw, Fronек et al. 2017), and whom I interviewed in the UK. Crawshaw was a Senior Lecturer in Social Work at the University of York and is the chair of PROGAR. The group’s origins date back to the early 1980s, when the BASW was invited to submit evidence to the Warnock Committee. After the Warnock Report (1984) had been issued, several initiatives within the association were brought together to set up the Warnock Report Project Group. Together with Elizabeth Wincott, the former chair of PROGAR, Crawshaw has authored an article that chronicles the advocacy work of social work professionals who lobbied for the right to know of the donor-conceived (Wincott and Crawshaw 2006). Wincott and Crawshaw describe the group’s creation in 1984 as the event that “commenced BASW’s lobby for the right of donor-conceived people to have parity with adopted people” (Wincott and Crawshaw 2006: 55). The name subsequently changed to PROGAR in 1988.<sup>19</sup>

Crawshaw herself has experience as a practicing social worker working with adoption as well. She had also been the national advisor to the voluntary register UKDL, the predecessor of the DCR. The register had been run by After Adoption Yorkshire, a post-adoption service, which later merged with a similar service to

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incorporation of non-biological children into the bosom of the family is mobilized to make sense of babies created as a result of ART [assisted reproductive technology]” (ibid.).

19 A particularly important event of the group’s lobbying for the right to know, which for reasons of space cannot be described here in full, was a conference that PROGAR hosted in 2002 after the government’s consultation exercise had already been launched in late 2001. At the event, Mary Warnock gave the keynote address and spoke out in favour of changing the law and limiting anonymity. According to Wincott and Crawshaw, the “announcement was an extremely important contribution to the consultation process” (2006: 68).

form a national organisation called PAC-UK.<sup>20</sup> In an article published in 2002, Crawshaw examined the results of a large-scale adoption study from the UK of over 400 adult adoptees and compared some of the findings to the results of some of the early studies on donor conception (for example Turner and Coyle 2000). Crawshaw argued that “both adopted people and donor offspring are brought up in families formed as a result of professional intervention, with the legal sanction of the state (adoption agencies and licensed assisted conception centres)” (2002: 6), and that in both types of family, “there is no genetic relationship to one or both parents” (ibid.). One of the lessons she pointed out to in the conclusion is that “professionals need to consider the possibility that some donor offspring will experience a normative urge for identity completion and seeking relationships, similar to that experienced by adopted people” (2002: 12).

When I interviewed her about her involvement with PROGAR and UKDL, Crawshaw pointed out that drawing on professional experience with adoption had not always been met with approval when PROGAR had lobbied for the law on donor anonymity to be changed.<sup>21</sup>

Marilyn Crawshaw: “Early on those of us who were lobbying for change, if we stood up in meetings, the HFEA annual conference or a BFS [British Fertility Society] meeting or all sorts of public spaces [...] you could reasonably expect that a lot of people in the room would be totally against what we were saying, thought that it was just appalling what we were saying. If those of us who had a background in adoption, if we ever mentioned adoption, it would be like a howl would go up, ‘This isn’t adoption’, and you would say that it’s not the same as adoption but there are transferable things. And you need to think about that because there is a whole body of experience, there is a body of research, there’s a whole lot of things there that you could make some use of.”

Whereas references to adoption used to be contested in policy work, it seemed to be a firmly established argument amongst my interviewees. Analogies to adoption as an area where the right to know one’s origins was already respected and protected by law were made by several of the donor-conceived persons that I interviewed. One of them was Jennifer Bunton, who had been conceived in the UK in the 1980s. When I interviewed her, I mentioned the report published by the Nuffield Council on Bioethics on disclosure and donor conception (2013). The report argues that “openness may or may not be beneficial, depending on the context” (2013: xx), al-

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20 [www.pac-uk.org](http://www.pac-uk.org) (last accessed February 27, 2021).

21 Wincott and Crawshaw also report on this experience in their article (2006). They point out that PROGAR’s lobbying work was made difficult by the fact that “references to adoption were roundly refuted as having no transferable messages of value” (2006: 61).

though in general a strong case for disclosure is made.<sup>22</sup> I asked Jennifer, who did not seem to be familiar with the report, about her opinion on this position. Like others with whom I discussed the report, she declined its validity straight away and referred to the “lessons learnt from adoption” to support her claims:

Jennifer Bunton: “I think the child always has a right to know they’re donor-conceived and that openness is vital, and as much information should be provided to that child as possible. We’ve moved away from trying to keep adoption a secret. We’ve realised the damage that that can do to adoptees, all the research shows that people should know, it is better for people to know and to know as much as possible. Rather than for it to be kept a secret. And the thing with donor conception is, you look at the numbers and there are thousands and thousands and thousands of people around the world that are donor-conceived, but nobody talks about it. People talk about being adopted, there’s a lot of research on adoption, it’s not as much of a taboo subject. Whereas donor conception is still taboo, it’s still a secretive industry. And that’s what it is, it’s an industry, and as far as I’m concerned, my biological father sold me in loose terms and my parents bought me, and the industry profited on that. So that’s how I see things.”

Her views seemed to be grounded in her own experience. Jennifer had already been told about the circumstances of her conception before her tenth birthday, when her already divorced parents spilled the truth during an argument. However, her parents had never been willing to talk about it until she started searching for her donor the year before I interviewed her. Jennifer was not the only person who had learnt of the circumstances of her conception in a situation that her parents had not planned. In many stories there was a clear contrast between the high value attributed to the right to know and what my interlocutors had told me about the way they had been told. Their parents seemed to have either spontaneously decided to tell their child or children, or they had revealed the truth during a family dispute. They seemed to have been guided not by their children’s right to know, but by the conditions that had prevailed in a particular situation.

References to adoption continue to be rejected in academic debates (see for example Pennings 2017). Leighton, whose exploration of the “Harm Claim” I mentioned in the beginning of this section, criticises the argument and taken-for-granted analogies to adoption and maintains that donor conception lacks the element of relinquishment that is central to the practice and experience of adoption. For Leighton, it is “the violence that comes from our belief in heredity” (2012: 89)

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22 The authors of the report argued that while family relationships will mostly benefit from disclosure, “openness about donor conception may potentially have the opposite effect, particularly where families created through donor conception come from communities where donor conception itself is not widely accepted” (Nuffield Council on Bioethics 2013: xx).

that should be the true cause for concern, not the anonymity of gamete donors. Leighton claims that the belief in the right to know frequently invoked in arguments against anonymous gamete donation is linked to a “fundamental heteronormative assumption” (2013: 54) according to which genetic relatedness is required in order to have a well-functioning family. I find Leighton’s detailed breakdown of the “right to know” argument illuminating, as it offers a close look at an oftentimes unexplained, but very dominant line of thought. However, my ethnographic material paints a more nuanced picture of the donor-conceived. It is especially Leighton’s claim that proponents of the right to know necessarily adhere to a heteronormative view of family-making that my conversations with donor-conceived persons seriously challenge. Overall, the narratives that I have collected suggest that the lived realities of people conceived with anonymously donated gametes are complex and far from uniform. That is not to say that heteronormative views were not present amongst the donor-conceived that I have encountered, and I will explore some of these views in section 4.1.

### **3.5 When you just want to know: Anonymity and the right to make a choice**

In case law and verdicts, the right to know is presented as something that protects the individual’s interests, notably in personal development and a “secure identity”. Information about the donor tends to be presented as something that a person definitely needs. It was striking that in many interviews, a different line of argumentation was part of people’s demands. What many interviewees emphasised was that the donor-conceived should be given a choice as to whether they want to access information about their donor or not, and that having an anonymous donor made it impossible for them to make use of this right to choose. The importance people ascribed to having a choice illustrates that “[c]hoice has become the privileged vantage from which to measure all action” (Strathern 1992: 36), and that individuals are “defined by the ‘innate’ capacity of ‘free choice’” (Cronin 2000: 279). The idea that rights protect choices is a standard account of what a right is (Brennan 2014: 32). Often, the demand to give the donor-conceived a choice was combined with the assertion that for them, it was only about knowledge and the possibility to access it, and not about unsolicited contact or financial demands. In the following, I will examine demands for a right to have a choice and discuss in particular how this was frequently linked to claims about not wanting to do anything ‘excessive’ with donor information.

The right to have a choice was highlighted by Sarah Holmes from the UK. As she had been conceived before the establishment of the HFEA, information about her donor had not been stored on the central register, and he had not been regis-

tered with the UK's voluntary contact register. However, in the meantime she had been matched with her donor's cousin on a commercial DNA testing site. When I interviewed her, I mentioned the law on retrospective removal of anonymity in the Australian state of Victoria that came into effect shortly after I had conducted my empirical research in the UK (Allan 2016).<sup>23</sup> While several of my interlocutors were critical of this development, Sarah felt that such a law would restore and respect the rights of the donor-conceived:

Sarah Holmes: "I think that's great. I think that it would recognise the human right of the child who didn't have any decision in this, and then it would be their choice. I'm not saying that every donor-conceived child needs or wants to make contact with their donor. What I'm saying is it's their right to have that choice. That's how I feel. And anonymous donation takes away that choice. And so I'm really pleased that in the UK we don't have anonymous donation anymore. But if that can be the world over that would be good."

Sarah talked about how those conceived with anonymously donated gametes were deprived of the opportunity to contact the donor. For Sarah herself, however, contact with her donor played a subordinate role. Through his cousin, she had learnt that her donor did not want contact with her. Since her donor did not want to be contacted by his offspring, his cousin had not revealed his name. However, he had given her some information about their family. Sarah mentioned that she was not surprised by his rejection and seemed satisfied to at least have information: "There's still a definite boundary around him being anonymous but I have that information about the family, I have that information about the genetic stuff, the medical history, I have some photographs. And it's really comforting to have that information."<sup>24</sup> Against this background, I would argue that the above-mentioned quote should not be understood as an insistence on a right to contact, but as an insistence on a right to information that can then be used to potentially make contact. For Sarah, this was not an ordinary right, but one that was particularly worth protecting due to its universal character. Furthermore, it is striking that Sarah,

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23 Previously, only those conceived after 1 January 1998 had been able to maintain identifying information about their donor when they turned 18. In February 2016, the state parliament of Victoria passed legislation that also enables those conceived before 1998 to access it (Allan 2016). The law came into force on 1 March 2017. I did not mention to Sarah Holmes that donors have a veto right. If they make use of this right, their donor-conceived offspring are prohibited from contacting them. If they do contact them, the law provides for a fine. However, donors cannot prevent that identifying information about them will be released if the donor-conceived apply for it.

24 A few months after I had interviewed her, Sarah managed to identify her donor with the information given to her by his cousin. Knowing that her donor did not want to have any contact with her, Sarah decided not to reach out to him.



who herself was in her 30s, spoke of the right of a donor-conceived child and not of an adult. Other people that I interviewed argued similarly. In particular, it was repeatedly pointed out that children should not be deprived of the possibility of requesting information later as adults. This line of reasoning is consistent with a contemporary understanding of children's rights. They are conceived of "primarily in terms of rights that protect the future choosers they may become" (Brennan 2014: 34), with children being conceptualised as future adults (see also section 3.1 for a discussion of the CRC and the specific understanding of childhood upon which it is based).

In contrast to Sarah, other people that I interviewed felt that retrospective legislation went too far in abandoning anonymity of the donors. They argued that past choices and decisions had to be respected, even if they felt it was at the expense of the donor-conceived. They believed that past donors should be given a choice as to whether they wanted to remain anonymous or not. Comments about the need to respect past decisions were viewed critically by others. In both the UK and Germany my interviewees frequently argued that contracts guaranteeing anonymity to donors were not valid because the donor-conceived themselves had, as Sarah had put it, "no decision in this", or because anonymity had never been legal in the first place. Especially those who had been involved in support and advocacy groups for a long time sometimes pointed out that others were still influenced by the opinions of others instead of insisting on their own rights. Some described how they themselves had undergone a gradual development in this regard and, unlike their younger selves, were now focused on their own needs and understood why anonymity was unjustifiable and wrong.

Although it was common for people to emphasise that parents should emotionally support their children in their decision to access information, nobody mentioned that the donor-conceived might need some form of support to be able to make such a choice. My interviewees seemed to be of the conviction that individuals would simply know what to do. They also repeatedly told me that they just wanted to know who their donor was – without necessarily wanting to 'do' anything with this information. A lot of people stressed that they were not interested in establishing a personal relationship with the donor. Timothy Parsons from the UK summed it up as follows: "It's not like you want a relationship with that person. It's not like you want to speak to them every day. You just want to know." Some felt that close contact would not be possible because they had not grown up with their donor, and they did not seem to be sad about it. Others mentioned that they had no interest in a personal connection and emphasised that they had a very close relationship with their parents. They were not looking to add a new relative to their family. But even they just wanted to know and believed that they had the right to just know their donor. The desire to "just know" who the donor was turned out to be a motif that kept recurring in many narratives. Since my interviewees considered

their wish for access to donor information to be modest and non-intrusive, holding on to anonymity was depicted as something that is not only wrong but also simply incomprehensible: if people “just want to know”, refusing their demands can be interpreted as even more unacceptable. Not giving them the information they want is seen not only as a violation of their rights, but also as morally reprehensible, because what they are asking for is perceived as very modest and harmless.

The importance that was ascribed to being able to exert a choice and just have information without ‘doing’ something with it marks the “right to know” discourse in donor conception as being very different from “right to know” discussions in a different context, namely environmental activism. It seems that the information that is to be accessed through the right to know one’s donor has a very different status than knowledge in the context of environmentalism. Environmental “right to know” initiatives have cultivated the crucial skill of “being able to critically read and strategically deploy” (Fortun 2009: 164) information instead of merely being able to access it. Demands for an environmental “right to know” legislation voiced by activists around the world were renewed and reinforced by the disastrous events happening in Bhopal, India. The chemical disaster that occurred in 1984, when a highly toxic substance leaked from a pesticide plant, resulting in thousands of deaths and injuries, led to a renewed push for legislation that granted the public access to information about hazardous substances and technologies. The disaster had been worsened by information not being properly circulated. In response to Bhopal, activists in India and elsewhere fought to establish an environmental “right to know” that would be enshrined in the legislation (Jasanoff 1988; Fortun 2001, 2009). However, it is not just having information that is considered important for the prevention of catastrophes like Bhopal. Information about hazardous chemical substances and toxic emissions is something that “animates rather than dictates activity, propelling people to recognize problems and identify points of intervention” (Fortun 2009: 149). In contrast, the question of how to effectively ‘use’ information about the donor is not addressed or even asked by those opposing anonymity. Instead, it is considered crucial to enable the donor-conceived to access and “just know” it. Knowledge about the donor is conceptualised as something that directly fulfils its purpose.

I suggest that the emphasis people oftentimes put on wanting to have the right to make a choice was also related to them wanting to avoid being seen as people that want to destroy the donors’ lives by tracking them down and turning up at their doorstep unannounced.<sup>25</sup> They were especially anxious to negate an image of

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25 Interestingly, some of those who opposed retrospective regulation or giving out information about donors that had been guaranteed anonymity believed that it could potentially disrupt the lives of donors: they argued that their donor offspring might decide to contact them against their will, which was precisely what others thought would not happen.

themselves as being motivated by financial concerns. In Germany, such assertions were arguably also related to the fact that until the Sperm Donor Register Act came into force in 2018, it was theoretically possible for a donor-conceived child to challenge the paternity of a legal father and then have the donor legally recognised as the father. This would have made the donor liable for paying maintenance (section 1.1). My German interviewees often argued that the possibility of making financial demands had to be excluded for past donations as well in order to free donors from the fear of contact. In both the UK and Germany, people seemed to be aware of the fact that sperm donation has received bad publicity: “Sperm donation has a history of rousing dystopian journalistic and artistic visions of how meetings or ensuing relationships between donors and children might look [...]” (Klotz 2016: 54)

Such tendencies can also be found in political discussions. Klotz analysed British parliamentary debates on the topic of donor anonymity and found that a distinctive “feature of the early regulatory discourse is the construction of an unreasonably demanding donor-conceived child” (2007: 84). The scenarios that were being evoked frequently focused on “the child attempting to benefit financially once its biogenetic kinship ties to the donor are laid open” (ibid.). This scenario in particular was something that I too was confronted with time and again. When I told acquaintances about my research and mentioned that, among other things, I was interested in how the donor-conceived searched for their donor, I was very often asked whether my interviewees were after their donor’s money. When I replied that this was not the case, and that people simply believed they had a right to know, I was usually told that a financial motivation could still not be ruled out. I suggest that similar to the way in which people made analogies to adoption, these ‘financial fears’ are another example of people drawing on what they already know about kinship to make sense of assisted reproduction. While many may not be familiar with donor conception, a larger proportion may have witnessed, for example, divorce, and financial disputes between former spouses. Familiarity with complex kinship situations is, I suggest, behind the dystopian visions of money-hungry donor-conceived persons.<sup>26</sup>

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26 They way in which people “express their concerns about technological developments in familiar idioms” (Carsten 2004: 30) was also reflected in the comments I got from friends and relatives on the topic of incest. When I told them about my research, many immediately mentioned, with horror, a possible meeting between donor siblings who begin a romantic relationship and have children without knowing they are related. The inhabitants of the small English town of Bacup, with whom Edwards talked about new reproductive technologies (2000), often mentioned such scenarios. Edwards concludes that this “preoccupation derives from a cultural understanding of the prior relatedness of those who share substance” (2000: 234). Besides, incest is a concept that “delimits who can donate gametes to whom and images a limit to technological intervention in reproduction” (ibid.). Interestingly, the danger of incest was rarely mentioned by my interviewees themselves (see section 7.5 for an excep-

### 3.6 The right to be told and the duty to disclose: Debating birth certificates

It has been argued that since children have a right to know about their origins, “there is a duty inhering in their parents not to deceive them about their true origins. And this duty extends to others [...]” (Freeman 1996: 290) Although those who are conceived with donated gametes in the UK or Germany now have a right to obtain information about their donor, there is currently no law prescribing or ensuring disclosure. My interviewees would oftentimes point out that the donor-conceived could not actually exercise their right to make a choice and know the donor unless they were told about the way they were conceived. The rights and autonomy of the individual, who is to be given the opportunity to decide freely by receiving information about its origins, are invoked to justify intervention by the state, whereas those who reject such interventions invoke the autonomy and rights of the family (Edwards 2018: 158). In this sense, “the same kinship ideology deployed in attempts to make the state responsible (to enforce disclosure) is also mobilized to exclude the state (to ensure family privacy)” (ibid.). It has been suggested that formally documenting the name of the donor, and/or information that treatment with donated gametes took place, in official documents could be a way to ensure disclosure. However, such proposals are not uncontested. In the last section of this chapter, I will explore these discussions, which constitute a surprisingly old part of the “right to know” debate.

Although my interlocutors felt that it was best for the donor-conceived to be told by their parents, some also believed that the state should take responsibility for ensuring that they would become aware of the circumstances of their conception. Recording information about the donor in official documents such as the birth certificate was seen as a particularly effective way of doing this and is advocated by activists in both countries. It was also seen as a means of increasing the willingness of parents to tell their children about the circumstances of their conception, thus ensuring higher disclosure rates.<sup>27</sup> The answer to the question of how many

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tion), possibly because the majority of them were already in a relationship and not worried about unknowingly falling in love with a donor sibling.

27 In Germany, an excerpt from the register of births (*Auszug aus dem Geburtenregister*) usually has to be presented if two persons intend to enter a civil marriage. In comparison, the actual birth certificate (*Geburtsurkunde*), which contains the names of the legal parents, has to be submitted much more frequently. In the UK, there are short birth certificates that only contain the child’s details, and long certificates that include both the child’s and the parents’ details. Parents are issued with a free copy of the short version when they register a birth. Its basic purpose is to provide evidence that a birth has occurred and has been registered. Reasons for obtaining long certificates, which are only issued upon request, include an application for marriage.

parents nowadays tell their children is a controversial one, on which there were different opinions in my field.<sup>28</sup> Some of those who believed that most parents still do not tell argued that the state should change this. Here, too, reference is made to adoption and the “lessons” that could and should be learnt from it. In both the UK and Germany, adoptees can obtain information about their birth parents through the respective system of birth registration.<sup>29</sup> Those advocating for a change in Germany also argue that the practice of giving adoptees access to information through birth registration has led to high disclosure rates among adoptive parents (Spenderkinder 2016b).<sup>30</sup> Although it is not yet very widespread, some jurisdictions have enacted laws to this effect. There has been a change in the law in Victoria, Australia. Since 2010, the law in Victoria requires that the birth certificates of the donor-conceived include an appendix stating that a person was conceived with donated gametes (Allan 2017: 93). A similar legislation has been enacted in Ireland (Allan 2016: 52). Besides, a British donor-conceived woman who had been conceived prior to the establishment of the HFEA had managed in 2014 to have the name of the man she thought was genetically related to her removed from her certificate and obtain a new one (McCandless 2017: 53). However, there has not yet been an actual change in the law, neither in the UK nor in Germany.

Demands for an adjustment of birth registration are not new. Already in the 1980s, the members of the Warnock Committee had debated how to deal with parents not telling their children about the circumstances of their conception. They feared that “there is a temptation for the couple to conceal the true situation” (1984: 26) and suggested that, in the case of donor-conceived children, their birth certificates should state “by donation” (*ibid.*; 37–38; 40–41). This proposal was not implemented in legislation, as such a regulation was believed to cause the child embarrassment (Frith 2001: 822). A possible change of the birth registration system had also been discussed in the run-up to the 2008 reform of the HFE Act (Bainham 2008). Donor-conceived activists appeared before the parliamentary committee that was consulting about the draft bill and stated that the current system was in

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28 A member of Spenderkinder told me, for example, that after talking to parents who had contacted the association, she was sure that far from all parents did tell. In contrast, Claudia Brügge mentioned the survey DI-Netz had conducted amongst German sperm banks and fertility clinics. Those who participated in their study estimated that about 70–80 % of all parents intended to disclose (Brügge and Simon 2017: 16).

29 In the case of an adoption within Germany, the adoptive parents are registered in a newly issued birth certificate. This does not change the entry in the birth register, which adoptees can view from the age of 16. In the UK, adoptive parents are also issued a new birth certificate once the adoption process has been completed. Adoptees can view their original certificate from the age of 18.

30 One of the central political demands of the German association Spenderkinder is to enter the name of the donor in the register of births (Spenderkinder 2016b).

need of a drastic reform. They held “the view that the current legislation sanctions deception in which the state is complicit and in which the identity rights of donor-conceived persons are officially stolen” (Bainham 2008: 464). However, this did not translate into any changes, although it has been argued that “the Government itself has accepted that the birth registration system as it affects donor-conceived persons needs to be kept under review” (*ibid.*; see also Blyth et al. 2009 for an overview of the arguments that were put forward by donor-conceived persons).

Against this backdrop, it is not surprising that the birth registration law had been raised for discussion during the consultation leading up to the announcement of the 13<sup>th</sup> Programme of Law Reform via the Law Commission of England and Wales (McCandless 2017: 53). Consultation for the Programme had been launched in July 2016 and ran until the end of October 2016. Despite being organised at very short notice in a large auditorium at the Institute of Child Health in London on a Monday evening in October 2016 by Progress Educational Trust (PET),<sup>31</sup> a charity aimed at raising awareness for genetic research and assisted conception, the event entitled “Birth Certificates and Assisted Reproduction: Setting the Record Straight?” was well attended. After arriving early, I could observe from the back of the room how the hall was gradually filling up with about 200 people. Among those present were several people I already knew by name (and picture) from their scientific publications and/or media reports, and I discovered representatives of the DCN, scientists and fertility counsellors in the audience. After introductory comments by the head of PET, the chair of the evening went on to further introduce the topic by quoting South African theologian and human rights activist Desmond Tutu, who had described the birth certificate as “a small little paper” (Plan International 2006: 4) that nevertheless “establishes who you are and gives access to the rights and the privileges, and the obligations, of citizenship” (*ibid.*).<sup>32</sup>

The six keynote speakers, who made short statements before engaging in a discussion with each other and answering questions from the audience, had different opinions about the purpose of a birth certificate and what information it should

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31 [www.progress.org.uk](http://www.progress.org.uk) (last accessed May 27, 2020).

32 The quote is taken from a speech Tutu held at the launch of Plan International’s birth registration campaign in 2005. International human rights organisations like Plan International are committed to increasing the proportion of children that are being registered right after birth. Their claims focus on Article 7 of the CRC and the right of a child “to be registered immediately after birth” (UN General Assembly 1989), which was formulated in response to the problem of stateless children (Fortin 2009: 470; see also Steiner 2003). In this context, a birth certificate is seen as a “ticket to citizenship [that] opens the door to the fulfilment of rights and to the privileges and services that a nation offers to its people” (Dow 1998: 5). In contrast, birth certificates can also be seen as a hallmark of the way in which states exercise their power: “The identification of citizens or subjects is as vital a function of modern statehood as establishing and policing territorial borders.” (Currah and Moore 2009: 113)

document.<sup>33</sup> Some of them were adamant that the main or sole purpose of the birth certificate was to establish legal parentage and not to document biological parenthood. Marilyn Crawshaw, the chair of PROGAR, contested this view. Crawshaw argued in her presentation that the meaning and purpose of birth certificates had only recently shifted from capturing biological parentage to documenting legal parentage. She also stressed that there was a whole parentage range and argued that the rights of those born through donor conception and surrogacy had to come first. As an alternative to the current birth registration system, she suggested changing all certificates to highlight their legal nature (see also PROGAR 2016). The donor-conceived speaker, who was a member of the DCN, told the audience that she had been informed about her origins at a young age. She expressed scepticism about whether including the donor's name or information about the use of donated gametes in official documents was a good way to encourage parents to be more open. She also stated that in her eyes, it was appropriate for the certificate to show the names of the two persons who had raised her. Despite the event, a project on birth registration was not included in the final programme of the Law Reform, which was launched in December 2017. It was argued that although "there is a case for reform to birth registration" (Law Commission 2017: 28), it was not one of the matters most in need of legal reform.

Those of my interlocutors who were sceptical or critical of a change usually had concerns about the consequences of changing the birth registration for their control over information. As I will show later on in this book, a major concern for my interviewees was to exert control over information by telling some people but not telling others (section 6.2). The issue of control was brought up by Amber Jones who had been conceived in the UK in the 1990s. She had always known that she was donor-conceived and had no interest in finding out anything about her donor. However, she felt that "everyone has a right to know" that they were donor-conceived and mentioned that "there are points in your life where you do need to know". For Amber, these moments were primarily medical appointments where, when being prescribed a particular drug, she was asked about the medical history of her parents. She herself had never had any problems explaining to doctors why she could not fully answer such questions. Amber stated that she was not bothered by it either since "as doctors they'll never let you take a risk that's too big". Nevertheless, she emphasised that it was important to know. Amber rejected the idea of including the donor's name on a birth certificate when I brought up the topic, but felt that a more "discreet" solution could be beneficial:

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33 Presentations were made by Crawshaw, a legal scholar, a British lawyer specialising in fertility and family law, the Development and International Programmes Director of an American fertility clinic, a donor-conceived person, and the founder of an American law firm specialising in family law and assisted reproduction.

Amber Jones: "I feel like it would just be so obvious when it's such a personal thing that I feel like you should have control of, so I don't agree with it [having the name on the certificate] but I think even if there was just a symbol or something like that, something discreet, you don't want to be made to feel different, because you're not different. You don't want your birth certificate to be a different colour and scream and tell everyone, 'Oh by the way, this is my family's situation', but I think that having it known could be a good thing, and then maybe it would prompt that people that don't tell their children do tell them because I do really think it's important."

Researchers have also suggested annotating birth certificates, albeit in a different way. Crawshaw, Blyth et al. make the following suggestion: "The format of all birth certificates regardless of whether or not the individual is donor-conceived or born following a surrogacy arrangement, is annotated to make clear that it is a certificate of legal parentage only [...]." (2017: 3) They suggest that upon applying "either for a birth record or to see if any additional information is available" (ibid.), the donor-conceived could then be referred to the HFEA where an application for register information could be made.<sup>34</sup> Crawshaw and her colleagues argue that such a procedure "safeguards privacy rights so that no-one other than the donor-conceived person or his/her legal parents will be able to access information disclosing the donor-conceived person's status" (Crawshaw, Blyth et al. 2017: 4). In Germany, too, in discussions about donor conception and birth registration the problem of reduced control over information is usually brought up.<sup>35</sup> However, given the growing idealisation of openness and calls for more transparency in donor conception (Klotz 2014; Edwards 2018), further developments with regard to the right to be told, enforced disclosure, and possibly changes to the system of birth registration, do not seem entirely unlikely.

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34 This was also the idea Crawshaw proposed at the PET event.

35 In 2016, the Green Party proposed that a note on the use of donor sperm should be entered in the birth register. The reason given was that such an entry would motivate parents to tell their children (Deutscher Bundestag 2016: 4). In a statement on the proposal, legal scholar Tobias Helms (2016) points out that such a practice would inevitably result in others finding out, as registrars would automatically gain knowledge about the use of donor sperm when registering a birth. Helms concludes that this makes including information about treatment with donor sperm in the birth register extremely delicate from a data protection point of view (2016: 10).



### 3.7 Recapitulation

International law and human rights agreements play a central role in the demands of those who speak out against donor anonymity. They represent a particularly powerful narrative resource through which critical opinions can be presented as not emotionally or religiously conditioned. It is particularly noteworthy that neither the ECHR nor the CRC, two prominent international treaties, explicitly refer to gamete donation or the right to know of the donor-conceived. Besides, the articles evoked by the opponents of anonymity do not have their origin in a concern about the effects of reproductive technologies on “identity formation”. Nevertheless, the ECHR, and in particular the right to private life, became a linchpin of the 2002 EWHC ruling, which led to the amendment of the law in the UK. In the verdict, knowledge about origins was described as being of importance for the formation of personal identity. In addition, the availability of information was considered to be something that enabled parents to be open with their children about the circumstances of their conception. I suggest that the verdict is both an expression and a catalyst of an idealisation of openness. Whereas the 2002 court case is commonly seen as a decisive event in the fight for the right to know, one of its donor-conceived protagonists believed that the issue was not yet resolved, arguing that it was still possible for parents to receive an anonymous donation, for example through treatment abroad.

While the connection between identity and knowledge, which was emphasised as a central issue in the EWHC ruling, is now also legally recognised in Germany, an overview of how the right to know one’s descent has changed over time shows that this was not always the case. Instead, knowledge about origins was initially something that was central to the enforcement of maintenance claims. This changed with the racist Nazi regime, and the law of descent remained largely unchanged after 1945. What changed were the arguments put forward to establish the right to know one’s descent: knowledge about origins was now interpreted as something that was important for the individual’s identity, whereas the Nazi regime had focused on national identity and “racial purity” (Blauwhoff 2009: 103). Even though there were legal debates on DI as early as the 1960s, it was not until 2013 that a landmark ruling was issued, after the special legal status of the right to know one’s descent had already been recognised by the highest German court in 1989.

In their demands to grant donor-conceived persons access to information, opponents of anonymity often refer to adoption. The comparison between adoptees and donor-conceived persons illustrates that people make sense of reproductive technologies by drawing on what they already know about complex kinship constellations. Apart from maintaining that knowledge about origins is essential for “identity formation”, many donor-conceived persons also argued that anonymity had to be abandoned because it made it impossible for people to exercise their

right to make a choice. This was often accompanied by the assertion that while they would choose to find out more about the donor, they would not interfere with his life in any way. I suggest that this was being said to fend off dystopian visions of donor-conceived persons destroying the donors' lives. Some people also argued that the state had a duty to ensure that this right would be respected. They believed that authorities should ensure and/or enforce disclosure, notably by including the donor's name or information about the use of donor gametes in official documents, such as birth registration certificates. While some were in favour of such changes, others critically noted that such a measure would limit their control over information.



## 4. Public stories and new networks

### Donor-conceived activism

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From the very beginning of my research, I was particularly interested in how the donor-conceived themselves intervene and participate in transformative processes by becoming politically active. A closer look at the literature reveals that donor-conceived activism is actually not a new phenomenon: according to the Warnock Report, an organisation called Donors' Offspring had submitted evidence to the Warnock Committee (1984: 96). Donors' Offspring was founded in 1981 by Candace Turner, a donor-conceived person from the US (Turner 1993), making it the earliest example of donor-conceived activism that I could find in the literature.<sup>1</sup> Turner described the group as “an educational and support organization for those connected with high tech conception” (1993: 197). She had apparently also developed a register “for exchanging information between genetic donors and their offspring” (ibid.).<sup>2</sup> None of my interviewees mentioned Turner or Donors' Offspring, and the group seems to have no online presence, although an address with a P.O. Box can be found online.<sup>3</sup> However, for the groups active today, to which many of my interviewees belonged, the Internet was of central importance. These groups provide opportunities to exchange information and compare experiences. At the same time, they offer a way to cope with the (offline) experience of not being understood by others, as people who have a similar story gather together in a safe virtual place.

Apart from this community-building function of stories, they were told not only in protected online spaces but also in public. These publicly shared narratives are powerful and culturally legible, as authenticity and thus authority is attributed to them. In turn, they can stimulate the production of more narratives. But in order for this process not to be suspended, new narratives must be produced again and

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1 According to Haines, the organisation was founded in 1982 (1998: 66).

2 Haines also mentions that Turner “provides a model bedtime story, to assist parents in telling a four-year-old child of his/her conception and suggests developments in the story as the child gets older” (1998: 66). She lists a publication that is entitled “A baby creation story” and authored by Turner as one of her references (1998: 75).

3 [www.donorchildren.com/resources](http://www.donorchildren.com/resources) (last accessed May 23, 2021).

again. I suggest that donor-conceived activism can be interpreted as an example of a recursive public; a term coined by anthropologist Christopher Kelty (2008) in his ethnographic study of free software. He defines a “recursive public” as follows: “A recursive public is a public that is constituted by a shared concern for maintaining the means of association through which they come together as a public.” (2008: 28) It is “*a public that is vitally concerned with the material and practical maintenance and modification of the technical, legal, practical, and conceptual means of its own existence as a public*” (2008: 3, emphasis in original; see also Nayar 2012 for an exploration of the making of recursive publics through narratives). Online-based communities play a central role in the production and dissemination of new narratives, and thus in the maintenance of the recursive public. However, the step into the media public sphere can be motivated differently. In the first two sections of this chapter I will examine two different motivations that are linked to different attitudes towards donor conception. In doing so, I will also address the question of what, in the eyes of my donor-conceived interviewees, constituted a “real” or “good” family. I will then go into more detail about the Internet communities in which donor-conceived people connect with others who also have a story to tell. In the last part of the chapter, I will discuss an organisation that is particularly important and significant for my research, and that contributes significantly to the maintenance of a recursive donor-conceived public in Germany.

#### 4.1 Seeing the truth, telling the truth: The fight for real families

A “hetero-bionormative” view of the nature of family, which Leighton (2013: 54) sees as the core of “right to know” arguments against anonymous donation (section 3.4), was neither the only nor the most common view among the donor-conceived persons I met. However, such views were expressed by at least some of my interviewees. They were very critical of gamete donation per se, arguing that the use of donated gametes – regardless of whether the donor was anonymous or not – always damages family life and “identity formation”. Although their views might be unusual, they were not exceptional. Nevertheless, it should be noted that the space I am giving to this analysis is not proportional to the number of people who held such opinions. As with other stories that I tell, evaluating them in terms of general representativity is not my aim. In view of the fact that there is no reliable information on how many donor-conceived persons there are in total (see section 7.2), this would arguably be an impossible task. Since I try to reflect the diversity in my field of research by including many different opinions rather than excluding those that seem rather unusual, I will discuss these more unusual views in more detail in this section, focusing mostly on the point of view of one particular person.

Those who saw donor conception as a dangerous interference with the natural order and structure of the family spoke very clearly and openly about their views at the public and political level, as they usually wanted to eliminate gamete donation, whether anonymous or not. This was especially the case for those of my British interlocutors who publicly opposed donor conception. They were involved in court cases, government consultations and campaigns, and told their stories to journalists and other researchers. Elizabeth Chapman from the UK was one of the harshest critics of donor conception that I met during my research. Since discovering more than two decades ago at the age of 40 that she had been conceived with donor sperm, she had been on a mission to raise public awareness of what she described as the overlooked dangers of gamete donation. She considered donor conception to be a human rights violation, as it prevented children from growing up with their “real parents”. Elizabeth, who lived an otherwise quiet life with her now retired husband in a picturesque little town, laughed and commented that she was, in a way, two persons, as “there was the Elizabeth that just was the wife and mother, and then there’s Elizabeth the donor-conceived offspring”.

The interview I conducted with Elizabeth took place the week after the PET event on birth certificates (section 3.6). When her husband Andrew came to us during our conversation with water and coffee, he mentioned that a Facebook group for donor-conceived persons in which they were both active, was “going mental”, as members were discussing the impending Law Reform, the programme of which had not yet been announced.<sup>4</sup> They all hoped that it would include a project on birth registration. Elizabeth herself mentioned her birth certificate before I could ask my very first question. Immediately after we settled in her living room, she began talking about her birth certificate in an agitated voice, angrily stressing that the document was a lie. She then jumped to her feet, hurried into the next room, and came back with a tin that contained not only her family’s birth certificates but also her marriage certificate. She showed me her documents and pointed out that her late stepfather was registered as her father on her marriage certificate. On her birth certificate, however, the name of her mother’s first husband, who had already died in her childhood, was registered. He was the one she had thought was her father and whose surname she had carried before her mother remarried. Since the names of the men registered as her father did not match, Elizabeth commented laughingly that she had already wondered whether her marriage to her husband was invalid.

However, this was not the reason why these documents bothered her. Instead, she was angry because she wanted a document that would reflect the truth about

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4 As far as I know, Andrew Chapman himself was not donor-conceived. The Facebook group he mentioned seemed to be open to close ‘allies’ of the donor-conceived. It is also possible that the two had a joint Facebook account.

her genetic origins. The way Elizabeth showed me her certificates is reminiscent of the adoptees in Carsten's study, who often referred to or even produced "mnemonic objects" (2000b: 692), such as personal letters and baby clothes, when being interviewed. Carsten argues that such "objects are often vivid and painful reminders of the missing threads of continuity between them" (2000b: 696). Like the adoptees in Carsten's study, who attached great importance to their own families and marriages, Elizabeth seemed very concerned about her "own connections in the present and future" (*ibid.*), which was reflected in the presence of framed family photographs throughout the entire ground floor. Her relationship with her children and grandchildren was close, and the "dense network of kin relations" (2000b: 688) that struck Carsten about her interlocutors seemed to characterise the lives of Elizabeth and her husband as well. The two had already known each other in adolescence, had been married for over 40 years, and were still connected by a noticeably affectionate relationship. While their own family life was marked by continuity and closeness, her birth certificate and its production in the interview served to show and prove the discontinuity caused by donor conception.

Appearing in the media with her story and her views was something she felt obliged to do, as she was firmly convinced that "people who can see the truth must tell the truth". Shortly after she learnt that she was donor-conceived, she contacted a major British daily newspaper: "I thought, 'This is wrong. People need to know about this.'" The editors had then reached out to her, and an article about her appeared shortly afterwards. In addition to speaking to journalists, Elizabeth had also participated in government consultations. Her lobbying work was not limited to the UK but also extended to an international level, and she had made several written statements for consultations in other countries. Speaking about the overlooked dangers of donor conception, Elizabeth pointed out that "people who've been adopted very often end up in prison, they're far more likely to be in prison than an ordinary member of the public. So, is there a higher proportion of us who have ended up on the wrong side of the law?" She then argued that this question was impossible to answer since most donor-conceived persons did not know how they had been conceived. Another UK critic of donor conception expressed a similar opinion and commented that researchers should investigate whether a large number of people conceived with donated sperm would end up in prison because of their identity problems.

While it was common for people to argue that "children need to know where they come from" to be happy and healthy, it was less common for people to argue that the donor-conceived were more susceptible to becoming criminal than the 'regular' citizen. Beliefs that donor-conceived persons are particularly susceptible to crime were rare and represented a more unusual form of criticism. However, I would argue that they are in fact based on an assumption held by the majority of the people that I interviewed: that a stable and healthy identity can only be developed if

children are given knowledge about their origins, with strict opponents of DI arguing that children must also grow up with their genetic and “real” parents. Moreover, I would argue that a moral and medical discourse on reproductive technologies that portrays those pursuing parenthood with the help of these technologies, as well as those offering them as selfish and immoral actors, also has the tendency to create a subcategory of children that are seen as inherently defect, and potentially even delinquent. Since donor conception is seen as inherently faulty, these children are seen as being outside of the community of proper citizens. The ‘crime critique’ in particular ties in with some of the findings of Korolczuk (2016), who has explored the ways in which reproductive technologies are ascribed a debilitating potential in public debates on reproductive technologies in Poland. Korolczuk shows how those opposing reproductive technologies oftentimes propagate the view that children conceived via IVF are more prone to physical and psychological impairments (2016: 131). She points out that “undermining the physical and mental health of children conceived with the use of reproductive technologies demonstrates that it is not only moral or religious values but national identity that is at stake” (ibid.). Referring to the stigmatisation of ‘IVF children’ in Poland, she argues that they “fall into the category of citizens, whose value is contested because of the alleged risks associated with their bodies” (ibid.).

What is of course striking and somewhat bewildering in the case of donor-conceived persons rejecting reproductive technologies and specifically donor conception is that they, at least indirectly, envisaged themselves as a threat to the community of those who were normal, healthy, and ‘naturally’ conceived, although all of them appeared to be law-abiding citizens. It was almost as if they saw themselves as a painful reminder that donor conception, which they perceived as an abomination, was still being practiced. For example, another activist from the UK commented that both donor conception and being donor-conceived were horrible. I could not help but thinking that he wished he did not exist, even though he seemed to live a life that, especially given his professional success, I would have assumed to be fulfilling. In contrast, others argued that because they themselves had been conceived via sperm donation, and were happy to be alive, they did not (and could not) reject the practice *per se*. Still others seemed to be bothered by such opinions, arguing that one did not have to approve of the circumstances of one’s conception in order to live a happy life, while those who, like Elizabeth, held these more unusual opinions would argue that it was being donor-conceived that prevented them from being happy in the first place.

At four hours, the interview with Elizabeth was one of the longest I conducted. Even though she had often spoken about her views, she seemed no less passionate about them. Towards the end of our conversation, I asked Elizabeth where she saw her own role in the discussion about donor conception in the future. She answered that she would “still do what I can now and again, but it has been a long time”.



Elizabeth added that she would be more likely to stay “behind the scenes” and encourage the next generation of donor-conceived persons, with whom she was in contact through various Facebook groups, to get involved. She felt that “it’s nice to be pro-active rather than to feel like a victim” and that “when you’re actually doing things, you feel less of a victim”. Although she stressed the active “doing” of things, and attributed a positive effect to it, she had at the same time a pessimistic opinion about the legal situation and its future development. She feared in particular that changing the law to allow same-sex couples to marry had been at the expense of the donor-conceived:

Elizabeth Chapman: “So there has to be donor conception and there has to be surrogacy to nourish their [same-sex couples’] right to have children. Our rights now have to be suppressed again. The rights of the donor-conceived have to be suppressed in order to fulfil the wishes of the adults. And I don’t think there will be any more changes in legislation.”

Elizabeth and others who opposed donor conception altogether and were publicly and politically active did not explicitly condemn gay and lesbian people for their sexuality. However, it was clear that many of them believed that a child should only be conceived in a heterosexual relationship. Donor-conceived activists also frequently voice such opinions on an international level. They repeatedly point out publicly that children with lesbian parents, or born to a single mother by choice, suffer from the absence of a father figure. An example of this is the Australian activist Millie Fontana. Fontana was conceived through sperm donation, grew up with two mothers, and is publicly very critical of same-sex parenting. She mentioned in an online article that “there is not a moment where I have looked back and thought that I did not crave that male stability and that father in my life” (Fontana 2017). If families with heterosexual parents are seen as the only valid family form, then homosexual and other couples, as well as singles, are automatically seen as unsuitable parents who cannot belong to the group of “real” families. However, one should keep in mind that “[i]t is but a short step from positioning lesbians and gay men somewhere beyond “the family” – unencumbered by relations of kinship, responsibility, or affection – to portraying them as a menace to family and society”, as Weston (1991: 23) points out. Following Weston, I would argue that even if people claim that they have no reservations about homosexuality ‘per se’, but only about gay and lesbian couples forming families through marriage and donor conception, such an opinion might lead to non-heterosexual couples being viewed as a threat to family life.

Weston’s work with gay and lesbian families who emphasise the importance of spending time together for the creation of permanent family bonds, and who have oftentimes been rejected by their families of origin because of their sexuality, is also important for showing that “blood is not intrinsically thicker than water” (1991: 24).

This proverb in particular was invoked by several of the opponents of donor conception that I interviewed. Elizabeth used a similar expression, stating that she had been connected to her donor by an “invisible umbilical cord”. For those who stressed the importance of growing up with one’s “real” family, genetic and biological connection equals permanence. Weston’s work offers a different perspective on the relationship between genetics, biology and permanence. It is “the possibility of being rejected by blood relatives for a lesbian or gay identity” (1991: 135) that shaped the meaning the people in her study attached to “family”, with rejection “undermining the permanence culturally attributed to blood ties while highlighting categories of choice and love” (ibid.). She points out elsewhere that biology is not inherently permanent: “In and of itself, nothing about “biological” connection implies permanence, much less ongoing relationship or solidarity.” (1995: 103) Weston argues that given the way in which cellular tissue is constantly renewed, “biological processes might just as easily constitute a signifier of change and flux rather than continuity and control” (ibid.). In comparison to what I was told in the UK, the criticism voiced by German activists often seemed more moderate. I suggest that this has to do with some of the politically active protagonists. For example, Spenderkinder was co-founded by a lawyer who seems to have established a certain line of argumentation – (past) anonymity as a violation of the law – among the members. The arguments, as far as the right to know is concerned, seemed to be more ‘sober’ and less emotional than the ones voiced by British activists. Nevertheless, I will point out in the last part of this chapter that argumentation and criticism based on the alleged permanence of biological connections was not absent from the German discourse either (section 4.4).

## 4.2 “Just one of many ways”: Taking a stand for normality

Not everyone I met in the UK or Germany rejected all forms of gamete donation, and even those who were critical or sceptical of conventional and commercial gamete donation did not necessarily agree that “real and good families must be genetically related” (Leighton 2013: 54). Instead, “good families” were usually defined as those whose members were open with each other. A few people had even taken on a kind of ambassadorial role. They wanted to convey to the public that donor conception was a normal way of creating a family. I will discuss the motivations and views of two people for whom this was the case in the following section. The examples I have chosen are rather unusual cases in some ways: the first person became a sperm donor himself, and the second person decided to get in touch with a journalist very early on precisely because she was not, unlike Elizabeth Chapman, hurt by finding out she was donor-conceived. It was more common for people to be ready for an interview only after a few months or years. Nevertheless, the way the

two donor-conceived persons portrayed in this section viewed openness as being vital for the donor-conceived and their families was in fact typical for the way “see-through kinship” (Edwards 2018) was idealised by the people I interviewed.

The extent to which openness was seen as the hallmark of a “good” family was particularly evident in the story of David Winkler, who was conceived in the former German Democratic Republic (GDR) in the early 1980s. Shortly before I met him, he had already been interviewed by a journalist for an upcoming article. In contrast to those who strictly rejected donor conception and went public to alert others to the dangers of the practice, David was pursuing a different goal with his media activities. He was concerned with publicly advocating the normalisation of reproductive medicine and non-traditional families. David was critical not only of anonymous donations but also of conventional “identity release” donors. In his opinion, it was essential for the healthy development of a child to know the identity of the donor and to get to know him personally, if desired, instead of having to wait until a certain age. This had shaped his own life in a special way. Shortly after he learnt of the circumstances of his conception, two of his closest friends, who were a lesbian couple, told him that they were planning on having a child. They mentioned that they were currently going through online catalogues of sperm banks to find a suitable donor. He then told them his story and shared with them his concerns about anonymous donors. Through the discussions they had afterwards, they came to the decision that David should be the sperm donor. The three friends had agreed that the child, who had not yet been born or conceived at the time of the interview, should grow up with the two women. Nevertheless, it was planned that David should always be a part of the child’s life and should also be recorded on the birth certificate. The trio had discussed their plans for a long time and believed, according to David, that “nothing can go wrong because there are no gaps” if everyone was as transparent and open as possible. While David’s insistence that children must know their donors could be seen as a confirmation of heteronormative assumptions about parenthood, “multiple parents question the centrality of the nuclear family” (Ryan-Flood 2005: 201).

David himself emphasised that he wanted to show through his life and his media activities that the type of family constellation in which a child grows up is irrelevant to the child’s well-being as long as there are people who care for him or her. In the first article for which he had been interviewed, his real name would not appear. Since David’s brother, who was also donor-conceived, did not yet know about the circumstances of his conception, David had asked to only be mentioned with a pseudonym. However, he hoped to be able to deal with the issue completely openly once all his intra-family issues had been sorted out. His reluctance to be pseudonymised in the article seemed to be symptomatic of his desire for openness and honesty. Not only did he want to deal openly with his own story, but also with the topic of donor conception in general. David therefore did not want to com-

ply with his parents' wish to keep the circumstances of his conception completely secret:

David Winkler: "Because I don't want to be part of such a lie or deception [...] these are not my fundamental beliefs and principles [*Lebensüberzeugungen und Maximen*], and I would continue to act as if we, the children, are some kind of flaw or taboo. And that's stupid, that doesn't feel good. And I don't think it makes much sense for society as a whole to continue to taboo it, you should simply open it up and normalise it completely. That's just one of many ways to have children."

While DI with a non-anonymous donor in particular was often considered a completely acceptable practice by my interviewees and, as David put it, "one of many ways to have children", other measures were often rejected because they were seen as too much of an intervention in the natural order of things. As with couples who undergo fertility treatment and refer to the naturalness of the method they have chosen (Knecht et al. 2011: 40–41), my interviewees often drew a line between what they saw as natural and unnatural, thereby normalising the circumstances of their own conception. They mentioned particularly frequently that they were critical of surrogacy, without me ever bringing it up. Often, the women I interviewed brought up their own pregnancies and claimed that they knew that pregnancy created a special bond between mother and foetus, arguing that the separation from the surrogate harmed the child. Interestingly, even Diana Kraft, whom I will introduce shortly and who was very positive about donor conception, drew a line between what she considered natural and normal and what she felt went "way too far". While Diana believed that sperm donation led to the birth of a normal human being, she saw surrogacy as something that was inherently dangerous. She raised this issue when I asked her whether she believed that the state or clinics should take responsibility for donor-conceived children learning about the circumstances of their conception. She explained that in her opinion, parents definitely had the greatest responsibility. Diana believed that clinics should ensure a careful donor selection process. In her opinion, the state should have the task of making sure that reasonable legal regulations existed. In particular, she felt that surrogacy should remain prohibited in Germany since "these nine months in a woman's belly, they just don't pass by without leaving a trace".

Apart from advocating for the normalisation of donor conception, David also wanted to 'put himself out there' to heighten his chances of finding donor siblings. For others, the idea of attracting the attention of donor siblings, and perhaps even the donor, was more of a desirable side effect of speaking to journalists. Especially those who appeared on TV hoped that they would be seen and contacted by donor siblings or even past donors. David, on the other hand, connected his public work more directly with the idea of finding donor siblings. He was convinced that most people had no idea how they had been conceived, and he suspected that even many

of those who knew and wanted to know more had not heard about genetic testing. David had found out that the doctor who had treated his mother was responsible for the conception of about 600 children, and he believed that talking to journalists was the only way to find his donor siblings who might be among those 600. He hoped that articles and reports might have the potential to reach parents and make them aware of the importance of telling their children, and that more people would take a DNA test once they were told about their origins: the more people knew they were donor-conceived and did a DNA test, the higher the chances of having a match. While others tended to hope that their own donor siblings or donor would contact them if they were seen in the media, David seemed to hope to increase the chances of all donor-conceived persons to find their relatives (see also section 8.4 for a discussion of his approach to “waiting for DNA/genetic matches”).

A strong desire to promote the social acceptance of donor conception was the main reason why Diana Kraft agreed to an interview for a German TV station just four weeks after she learnt of the circumstances of her conception. She was working in PR, and I got the impression that her job as a press spokesperson was probably the perfect kind of work for her: Diana seemed to be a very outgoing, open person who likes to talk to people. When she told me that we would only have an hour for the interview, as she had not been able to take the day off, I was initially worried that I might not be able to ask her everything I had written down. However, not only did she speak very quickly, but she also seemed to have no problem putting her thoughts into words, a skill she had probably cultivated in her PR work. Before the interview she had sent me a link to the documentary for which she had been interviewed, which mostly focused on German couples travelling abroad for fertility treatments. Diana stressed, both in the interview as well as in the documentary, that nothing had changed in her relationship with her parents since she and her brother learnt that they were donor-conceived. She told me that “for our very personal situation”, late disclosure had been the right thing, since she and her brother were “stable in the family of origin [*Herkunftsfamilie*] and in our own lives”. Diana was aware that others did not feel this way and, despite her own experience, was in favour of telling children as early as possible, “so that it’s just normal”. Together with her brother, she had quickly decided to bring the topic to “a normal level” so that they could talk about it openly with their parents: “Because I’m not willing to somehow make a bigger deal out of it than it actually is.” Finding out that she was donor-conceived had merely modified her story by introducing another “variant”, which had not resulted in any changes in her family relationships.

Nevertheless, Diana had been immediately curious about her donor and her donor siblings. She therefore began searching online for information and immediately came across Spenderkinder. I asked her how she had ended up on TV, and she told me that soon after she contacted the organisation and signed up for their mailing list, a journalist’s request was shared on the list. Since her mother telling

her the truth had not led to a breakdown in their relationship, Diana felt that her story might encourage other parents to be open with their children, although she emphasised that she did not have the time to become an activist. Her decision to contact the journalist was also motivated by her belief in the importance of promoting tolerance:

Diana Kraft: “That’s how it somehow came about, and I said to myself, the more this subject becomes public, the more normal it becomes, of course, so I’m trying very hard to take away this fear from people like my mother, that when they break this secret, everything is broken, it doesn’t necessarily have to be like that. And you also have to stand up for an open and tolerant society, and if you use yourself as an example, hello, I’m an exotic too, but look, [laughs] I’m completely normal, then maybe every step, every little piece of the puzzle somehow makes people a bit more open-minded and not as narrow-minded and intolerant. I thought, maybe that makes sense, and then I said to myself, yes, that’s actually a pretty good vehicle. And of course, perhaps a donor will get in touch. Or a half-brother and sister or whatever, when it gets aired. That didn’t work, but [laughs] it was worth a try.”

Both Diana and David made references in their stories to what they considered normal. For Diana, donor conception was something that results in normal children, and she had made it a normal topic of conversation with her brother. David emphasised that the treatment was “just one of many ways to have children” and a way to fulfil a deep desire for children, which he believed most people had. Such references to normality can help to create continuity in narratives (Polat 2018: 121). The fact that a donated gamete was involved in a person’s conception is interpreted as something that has no particular significance, neither for the individual nor for the family, and about which one can therefore speak openly and without fear. Openness and trivialisation are also normalisation practices that couples who use reproductive technologies resort to (Knecht et al. 2011). While not everyone decided to appear in the media, the importance of being open and the dangerous nature of family secrets were topics that kept appearing constantly in interviews. Secrecy was described as being harmful and “toxic” not only for healthy personal development but also for the creation of close family relationships. The insistence on the importance of disclosure contains a strong “message of inadequacy: the inadequacy, that is, of parents who do not tell their children how they were conceived” (Edwards 2018: 166). Good parents are only those who tell and continue talking about it.

### 4.3 The stories of others: Finding information, validation and community online

The majority of my interviewees only had little information about why their parents had decided on treatment with donated gametes, and why they had ended up at a specific clinic. Several people told me that their parents either refused to talk about the subject or that they themselves did not want to put their parents in unpleasant situations by asking questions. Those who knew a little more usually mentioned that their parents had been informed by doctors or nurses about the possibility of treatment with donor sperm and had also been referred to a particular clinic or physician. In other cases it seemed to have been more complicated. David Winkler had been told by his parents that they had only learnt “by detour and hearsay” about the few doctors who carried out DI in the former GDR back in the 1980s. They had managed to contact one of these physicians, who had then agreed to treat them. This is significantly different not only from the way in which patients inform themselves today but also from the way my interviewees themselves had found out more about donor conception and gamete donation.<sup>5</sup> Those who had learnt since the mid-2000s that they were donor-conceived, or were only more interested in it since that time, usually first turned to the Internet, or more precisely to Google, to get a first overview. Several of my interlocutors told me that they had done so almost immediately after finding out. Their desire to learn more about donor conception was often linked to a general feeling of confusion or disbelief. Especially those conceived in the 1970s or early 1980s usually commented that they had not even known that these treatment options had already existed back then, and they thus wanted to know more about DI in general. But even for them, the Internet was usually not only a way to get information but also a way to network with other people. The online-based communities that donor-conceived persons create and use to exchange and share information will be introduced in this section. I will discuss both what they meant to the people I interviewed and how they have changed over time. Finally, I will examine a special feature of many groups, namely their hidden and closed nature.

Online communities, and especially Facebook, had become an important part of Jennifer Bunton’s life, and of how she made sense of donor conception. Jen-

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5 Writing specifically about how those travelling abroad for treatment select their fertility clinic, Shenfield et al. note that in total, 41 % of European patients had used the Internet as a source of information (2010: 1364). There were considerable differences between the seven countries that they studied. While only a quarter (25.3 %) of Italian patients would frequently use the Internet, and instead relied more heavily on their doctor’s advice, almost three quarters of Swedish patients (73.6 %) as well the majority of those coming from Germany (65.0 %) and the UK (58.5 %) would cite the Internet as a frequently used source of information (2010: 1366).

nifer, who was in her mid-30s, had grown up in the UK and emigrated to Australia with her daughter several years ago. The interview with her was the only one I conducted via Skype. Jennifer, who had known about the circumstances of her conception since her childhood, only began to search for her donor a few months before I interviewed her. By her own admission, Jennifer had simply not been aware that there was anything she could do to find her donor. Instead, she had always accepted his anonymity silently until she came across an article about DNA testing on Facebook. Having always felt a very strong desire to find her “paternal family”, she immediately began looking online for more information, and commented that she had “just googled the hell out of donor conception”. Jennifer had joined not only the DCN, through which she had learnt of my research, but also the DCR and various Facebook groups. She explained that she had “found as many things as possible that I could be a part of or connect with” and that she had “just kind of tried to put myself out there”. Prior to that, she had never even heard of anyone else who was donor-conceived. For her, joining groups had been about

Jennifer Bunton: “[...] hearing other people’s stories, gaining hope from other people that had found matches [on DNA testing sites], being able to understand how all the DNA stuff works, trying to get my head around the different laws and legislations in different countries, and how there are people that are trying to change those things and make amendments to different things, I didn’t know any of that was going on in the world.”

Jennifer explained that although she knew very little about how donor conception and gamete donation were regulated, she felt she had “been accepted and been included into these things and into these groups and been a part of what’s going on”. In the meantime, she had already met up offline with a donor-conceived person whom she had met online and who lived only a few minutes away from her. With some others she had planned a meeting that would last several days, which was to take place a few weeks later in another Australian city. A person from a European country would also fly in for the occasion. The gathering was to be an opportunity to share personal experiences, and Jennifer hoped that it would help her understand “what’s going on a little bit more”.

Although she had only recently started to connect with others, her way of expressing herself was surprisingly similar to the rhetoric of my British interlocutors who had been involved in networking and lobbying for many years. As I mentioned in the last chapter (section 3.4), Jennifer referred to the “lessons learnt from adoption” when arguing for the right to know of the donor-conceived, which was a common argument among long-time activists. Jennifer also mentioned that “donor conception goes against a number of the UN Convention of Human Rights”, and that she could not understand why it was not yet banned. In contrast to others who primarily criticised anonymity and secrecy, it was clear that Jennifer was critical of



gamete donation per se, believing that it took away half of a child's family. However, like those of my interviewees who did not reject all forms of gamete donation, Jennifer also had an explicit problem with the way donations had been regulated in the past. When we talked about the retrospective removal of anonymity in Victoria (section 3.5), she stressed that she was in favour of the amendment and thought it should be worldwide, as the donor-conceived had "the right to know who they are and who their family is". Her idea of who belonged to the family of a donor-conceived person was very similar to what those who had been involved in activism for a long time imagined a "real" family to be like. Membership in the various groups had had an impact on her views and actions. Ever since she had come into contact with others who also rejected gamete donation, she had started to "express my feelings because I know that they are validated, and I know that they are real". Jennifer was thus able to interpret her views as something that was normal, rather than seeing herself as an extreme case. She could now formulate and justify her rejection in a way that legitimised her view, as she could present it as being in line with human rights law. Besides, she had gotten more information on DNA testing and read 'success stories', giving her the means to pursue her search and remain hopeful.

Similar to Jennifer, who by now was in contact with other donor-conceived people both online and offline, others told me that they had never met anyone else who was also donor-conceived before joining online platforms. This was especially brought up by my interviewees in the UK, who may have been members of an organisation like the DCN, but had not yet attended offline meetings, or interacted with other members online. Often, they were interested in meeting other donor-conceived persons to compare their own stories with those of others and to see how common their own experiences and opinions were. Some tried to get an overview by reading testimonies published online or by watching YouTube videos of donor-conceived persons. In Germany, on the other hand, all but one of my interviewees were on the mailing list of Spenderkinder, and they thus already had access to the narratives of other donor-conceived persons. In addition, almost all of them had closer contact with individual members with whom they were talking on the phone, writing emails, or meeting up in person. They would frequently comment that "what I found so common", or "it does appear quite common" when talking about their personal experiences and comparing them to what they had heard from others and observed online. They had the biographical comparison points that Tamara Haste from the UK, who was a DCN member, was mostly lacking. Apart from her sisters, she knew no one else who was donor-conceived. Commenting on the difficulties they faced when trying to talk to their mother, she mentioned that she did not "know how usual this is in terms of other donor-conceived people". She had not attended any DCN events yet but thought about doing so in the future, commenting that she would "love to speak to someone in that situation".

As I will explain in more detail in section 6.2, many of my interviewees talked about their experience of not being met with a lot of sympathy in their everyday offline lives and by the people close to them. They often felt that their rejection of anonymity and their interest in the donor was not understood by those who were not donor-conceived, which was often described as painful. They did not have to face this problem in online communities that were only for the donor-conceived. They could discuss their experiences without having to deal with the comments of 'uninformed' outsiders. The Internet could thus represent a kind of safe retreat space, which seemed particularly attractive to those who were critical of donor conception per se, as it provided them with a space where they could feel normal. A similar observation has been made by anthropologist Nurhak Polat in her ethnographic study of reproductive technologies and the activism of concerned groups in Turkey (2018). As part of her research, she examined online forums that are used by those considering or undergoing fertility treatment to get information, share their stories and engage with other users. Polat argues that their growing importance can be seen as a reaction to other sources of information being "confrontational, heterogeneous and fragmented" (2018: 200, author translation). For the women and men in her study, the Internet provided a safe haven where they did not have to expose themselves to the intrusive comments of others (2018: 217). The forums studied by Polat were semi-public spaces where, after registration, participants could decide for themselves how much they want to reveal about themselves (2018: 203). Polat herself could also register, follow discussions, and get in touch with users (2018: 69–71). This constitutes a crucial difference to my own research. As I will explain in more detail later, I was not able to participate in the groups myself, which apparently did not mean that my research and I were not discussed online.

The way people used the Internet to find information and connect with others was very different from what Elizabeth Chapman told me about the mid-1990s. At that time, she had learnt about the circumstances of her conception. Having Personal Computers (PCs) and access to the Internet was not yet common, and Elizabeth commented that donor conception in general was "still quite underground in a way". She could only get information about the clinic where she had been conceived and the legal situation through books from a local library and a bookstore that was located in a nearby university town. Elizabeth told me that she had immediately perceived the Internet as an opportunity to connect with others as it had gotten more common for people to have access to it. She also described how the ways and platforms of networking had changed over the years:

Elizabeth Chapman: "To begin with, there wasn't much on there about donor conception, and it was really only good for email, but then you had to know someone who had email. And not many ordinary people had home PCs, not when I first

started. A lot of the people I did connect with would do it in their lunch hour, on their work computer. [...] I became a member of the donor conception group of Australia, they were great, they were really supportive, they were really into donor-conceived rights and people finding their families. So that was handy.”

Amelie Baumann: “And you found them online?”

Elizabeth Chapman: “That was online, well, I could contact them online, but they would also send postal stuff as well. [...] A lot of stuff was still done by phone or post, but now of course everything has moved, a lot of it is on Facebook now, things are moving, so we’ve got lots of groups on Facebook, but it has revolutionised things, it has meant that we can discuss and chat and support one another, it’s great, it’s wonderful. I don’t know what we’d do without the Internet, to be honest.”

Elizabeth, who strongly opposed donor conception and all forms of reproductive technologies (section 4.1), described the friends she had made through her advocacy work and her involvement in online groups as “the only good thing about being donor-conceived”. She, too, had met several of them offline as well. For her, having been conceived with donated gametes was something that could unite people that were of different ages and might otherwise not meet:

Elizabeth Chapman: “Doesn’t matter how old you are, when you get with another donor-conceived person, and they start talking about how they feel and their search and whatever, you just have so much in common, so much empathy with each other that you bond. It’s unusual, it’s quite special, the friendships that we all have with one another [...] we encourage one another, and if somebody does something in the news, ‘Oh wow’, we’re all looking at it, we talk about it, there is a lot of camaraderie in the group. And that really does depend on the Internet.”

The groups she had joined had mostly been founded by donor-conceived persons themselves. The Yahoo group PCVAI (short for People Conceived Via Artificial Insemination; it was renamed into People Conceived Via Donor Insemination later on), for example, was founded in 2000 and was only open to those who were conceived with donated gametes.<sup>6</sup> It has been described as “[o]ne of the first networks to attempt linking donor-conceived people together” (Crawshaw et al. 2015: 74) and had 290 members in October 2019. In their “Group Description”, the moderators described PCVAI as “a haven for those who do not care to defend their feelings, attitudes or opinions”. Their aim was for “members to feel comfortable expressing strong opinions and feelings that may be unacceptable to their parents, friends, or the general public”.<sup>7</sup> The group itself and the messages exchanged were not

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6 <https://groups.yahoo.com/neo/groups/PCVAI/info> (last accessed October 14, 2019).

7 Ibid.

public.<sup>8</sup> It seemed, however, that PCVAI was more or less fizzling out when I conducted my research. According to PCVAI's public message history, which showed how many messages were exchanged in a given month, the group had a total of only 19 entries in 2018, compared to 682 in 2008. Sometime after I had finished my empirical research, PCVAI and other Yahoo groups came to a complete end, with Yahoo announcing in mid-October 2019 that it would be winding down its groups.<sup>9</sup> The ways in which people network online change, with the deletion of previously shared content in the case of Yahoo indicating that these changes can be imposed ones.<sup>10</sup>

In contrast to Yahoo groups, Facebook groups for donor-conceived persons have grown rapidly in recent years. *Worldwide Donor Conceived People Network* for example had been established in 2013 and had 708 members in May 2021.<sup>11</sup> *We are Donor Conceived* had only been established in late 2016 and had already over 2300 members less than five years later.<sup>12</sup> Similar to PCVAI, Facebook groups tend to have certain screening mechanisms in place to ensure that only donor-conceived persons join. Those who wish to join *We are Donor Conceived* are required to confirm that they are donor-conceived, and state where and when they were conceived. They are also asked to describe how they feel about the circumstances of their conception. Telling a story can thus serve as a means to claim membership to the community of the donor-conceived. Since I do not meet these criteria, had no story to tell, and did not want to deceive people, I was not able to join these groups.

Some Facebook groups not only serve as discussion and support spaces but also have an integrated register function that can facilitate matching between members (Crawshaw et al. 2015: 75). For example, a closed group called *DONOR CONCEIVED*

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8 Those who wished to join PCVAI were asked to provide the moderators with some personal information and details about the circumstances of their conception. Crawshaw et al. argue that these introductory texts were “facilitating ‘matching’ between those conceived at the same clinic using a donor with the same donor code” (2015: 77).

9 From the end of October 2019, it was no longer possible to post in the groups, and from mid-December, all content was removed. Until the end of January 2020, requests for data to be downloaded could be made.

10 A similar observation has been made by Kim TallBear (2013), who had joined a genetic genealogy mailing list as part of her research on genetic ancestry testing in 2005 (see section 8.1). TallBear points out that its activity “has declined considerably” (2013: 109) since then. She argues that this is probably linked to “shifts in how people do their online social networking” (2013: 109–110). TallBear then cites genetic genealogist Blaine Bettinger who mentioned to her in an email that “social media platforms such as Twitter, Facebook, and blogs have substantially replaced mailing lists as a means of querying and interacting with other genetic genealogists” (2013: 110).

11 [www.facebook.com/groups/584100634974296/](https://www.facebook.com/groups/584100634974296/) (last accessed May 28, 2021).

12 [www.facebook.com/groups/wearedonorconceived/](https://www.facebook.com/groups/wearedonorconceived/) (last accessed May 28, 2021).

*OFFSPRING, SIBLINGS, PARENTS* – (*sperm, egg, embryo*), established in 2007, encourages those who wish to join to enter their data in a “Donor Offspring Registry” document.<sup>13</sup> This creates an unofficial register that can compensate for the absence of a formal infrastructure or enable members to circumvent official limitations. Although being donor-conceived is not a prerequisite for membership, this group also seems to be anxious to keep ‘outsiders’ away: after trying to join the group in April 2019, when it had more than 6700 members, its moderators seemed to have blocked me. I could no longer find the group when subsequently being logged into my Facebook account. I had mentioned in my request to join that I was doing research on donor conception, and that I was keen to learn more about the way people used online networks to connect with others. A Google search revealed that the group still existed and had over 13,000 members in May 2021. Apart from Facebook, which was mainly used by my interviewees in the UK, and the internal mailing list of Spenderkinder in Germany, hardly any other online networks were mentioned in interviews, with the exception of the website and register Donor Children.<sup>14</sup> However, none of my interviewees mentioned that they actively used this site to network with others or find donor siblings.

The Facebook groups that I was able to find were private and closed, with messages only being visible to members. These groups can be searched and found both within the platform and through search engines. In contrast, there were other groups that I would never have heard of if my interviewees had not mentioned them to me: unlike regular closed groups, secret groups cannot be searched for or seen by non-members. Facebook users can only be added if those who are already in a secret group invite them, and only those who are in the group can see who else has already joined. As in regular closed groups, all posts and comments are visible only to those who are members. I first became aware of the existence of such groups when learning about the DCR’s secret Facebook group. DCR registrants could join by sending their contact information to a specific email address and were then sent an invitation to join the group. According to Elizabeth, most Facebook groups created specifically for and by donor-conceived persons were in fact secret: donor-conceived people would first join one of the regular closed ones

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13 [www.facebook.com/groups/DonorConceived/](http://www.facebook.com/groups/DonorConceived/) (last accessed May 28, 2021).

14 Donor Children was founded in 2013 by an American donor-conceived person ([www.donorchildren.com](http://www.donorchildren.com), last accessed March 17, 2020). In addition to the exchange of information in groups and forums, the site also enables matching between its members. They can add information such as their donor code to their profile and search the site for other users that match their information. Similar to Facebook, members can make friends with other users and exchange messages. When I contacted the creator of the site, I was invited to join and post about my project in a forum. Information about my research was also shared with members through a newsletter that is sent out at irregular intervals. However, none of my interviewees reported that this was how they became aware of my project.

and then be invited to become members of a secret group if someone who was already a member invited them. As people sometimes had to put up with what they perceived to be unsympathetic comments of others when joining ‘mixed groups’ that had donors and parents as members as well, closed and notably secret Facebook groups were described as safe spaces and as communities of “people who got it”.

The way in which not only Facebook but also other platforms and companies handle user data often raises privacy concern. Given this background, it may seem somewhat surprising that they were seen as safe spaces.<sup>15</sup> Similar to the way in which DNA databases were rarely criticised for their handling of data (section 8.3), no one expressed any concerns about the platform’s way of dealing with personal information. The concerns my interviewees had were more about their Facebook friends potentially being able to see their membership in a group and find out about the circumstances of their conception. For this reason, they either preferred secret groups or stayed away from networking on Facebook altogether. While the opportunity to express a critical opinion seemed to attract especially those who were critical of donor conception *per se* to secret and closed groups, this was also something that could deter others. Jessica Robertson, for example, told me that she had joined a Yahoo group a few years ago. However, she mentioned that “the people who were vocal on there were the people who were really quite bitter about it. And who felt that we shouldn’t exist, and that it wasn’t natural, it shouldn’t have happened.” Since she felt that it would not be healthy for her “to wallow in that kind of thing”, she had never become an active member and had soon stopped reading the posts. In contrast, she was more actively involved in the DCR’s Facebook group and had joined the DCN as well.

Due to the closed and secret nature of these groups, it was not possible for me to follow what was happening and being discussed in them. As noted earlier, I was sometimes even blocked when contacting the administrators. The groups I had been able to join did not require an introductory text and seemed to mainly consist of parents who were trying to connect with other families that had used the same donor. A typical post would contain some basic information about the donor and the donor-conceived child: “[name of sperm bank] donor [code and/or pseudonym]. Have a girl born in 2015. Looking for half-siblings.” Since I was not part of the more activist groups myself, it was a particularly strange feeling to learn that without me being aware of it, and without me having the opportunity to comment, people were talking about my work. I knew that members of the DCR’s secret Facebook group had been informed about my research through a post. However, to

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15 It has been argued that “concerns about privacy protection [...] are far from paranoid fantasies” (Loshin 2013: 1), as it was revealed in 2013 that an American intelligence agency had in the past been working with Facebook and other companies “to collect and store data” (ibid.).

my surprise, Elizabeth mentioned at our first meeting that I had been “discussed yesterday” in a different group as well. Someone from Australia, whose name I knew through media reports, but with whom I was not in contact, had “put a big piece on there saying, ‘Amelie is looking for people’”. Even though this person had apparently written favourably about my work, it was still an uneasy feeling not to be able to follow the discussion. It was both fascinating and irritating to hear about the extent to which information about my work had been circulated without me being able to control or witness it.

While people would otherwise make claims for more transparency, they, too, created hidden spaces that are shielded from the outside world – on a platform that usually enables (or requests) users to publicly post information that would otherwise remain private. A strong lobby for openness in donor conception and “the transparency demanded by the Internet generally and social media specifically” (Edwards 2018: 164) have in common that they “both push what was, and could still be, private into the public domain” (ibid.). At the same time, especially the secret nature of invitation-only groups draws a line between those who are involved and those who are ‘merely’ donor-conceived, possibly without those on the ‘outside’ being aware of it. Commenting on the use of secret Facebook groups during student protests in the UK, sociologist Alexander Hensby notes that for the students who are not part of these hidden spaces, “the secret group represented a boundary between themselves and core activists” (2017: 475). The ‘outside’ students he interviewed were in fact aware of the secret group’s existence. Hensby argues that “it is significant how Facebook – depicted as a driver of networked openness and ‘connective action’ by many scholars – came to play such a key role in drawing hierarchical boundaries and maintaining network secrecy” (ibid.). Given the constant insistence on openness and transparency that otherwise permeated my research, I found the closed and sometimes secret nature of these online networks surprising. However, it also seemed to be in line with the merging of authority and authenticity: if those who lack the experience of being donor-conceived are seen as having less authority, then excluding them from discussions can seem appropriate or even necessary. Besides, some experiences – particularly of those who have ‘strong’ opinions – might be seen as being more authentic than others, necessitating the creation of an ‘insider group’ among those who are already on the inside of donor conception.

#### **4.4 Conceiving Spenderkinder: Donor-conceived activism in Germany**

In contrast to Jennifer Bunton, who had joined as many groups as she could find (section 4.3), many of my German interviewees told me that they had ended up very quickly on the website of Spenderkinder, which was usually their most important

source of information. It was through the site and the internal mailing list that they first learnt that DNA testing was a way to find relatives. This was the case for Diana Kraft who enthusiastically told me, “You turn on the Internet or you go online and find this association and you have all the information you need to get started *gathered together*.” It turned out that not everyone I interviewed in Germany was also a member of Spenderkinder. Some were just on the mailing list without officially being part of the association, while others were members, attended the annual meeting and got involved in the board. The level of engagement did not necessarily have to do with how long the person in question had been a member, and some of those who were particularly active had only joined a few months before I interviewed them. Although there were differences in terms of identification with Spenderkinder and in terms of involvement, the association was nevertheless of central importance for my research: on the one hand, because it brings together (virtually) donor-conceived people, and thus was a logical contact point for me in my search for persons I could interview; on the other hand, because the association plays a central role in the transformation of anonymity in gamete donation and constitutes a particularly interesting example of donor-conceived activism.

Journalists that write about members of Spenderkinder seem to be concerned with ‘giving voice’ to the donor-conceived and adhere to “conceptions of voice that invoke claims of authenticity” (Cairns 2009: 328).<sup>16</sup> I do however take a different approach in this section, as I am interested in how Spenderkinder constitutes itself as a powerful voice in the public arena. I will also examine how the association itself deals with anonymity and identifiability, and how their terminology and certain official positions relate to the link between permanence and biology that was frequently evoked by activists in the UK. I will then discuss a conflict between Spenderkinder and another association, which in part also revolves around the appropriate choice of words. In the last part of this section, I will discuss the media presence of Spenderkinder, and of donor-conceived persons in general, focussing on a newspaper article that appeared in 2019.

The situation of those who could simply “turn on the Internet” and find information was not only different from the experience of Elizabeth Chapman, who began her search in the 1990s (section 4.3). Jasmin Hellermann, who was conceived

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16 This seems to be the case for the first portrait of a donor-conceived persons that appeared in the weekly *Die Zeit* (Sußebach 2010). The donor-conceived protagonist is introduced as a member of Spenderkinder, which had been founded the year before the article was published. The author argues that the protagonist “Sonja” (a pseudonym) and her parents “are in the middle of a debate that always revolves around the same question: How far does one go for a child?” (Sußebach 2010, author translation) ‘Giving voice’ to the donor-conceived seems to be both a journalistic and an ethical project for him, as the following excerpt suggests: “Stories like Sonja’s remain untold because the participants fall silent at the moment of conception.” (Ibid., author translation)



in Germany in the 1980s, began her search for her donor and donor siblings in the 2000s, when she had already begun her studies. Having access to PCs and the Internet was already more widespread, especially for her generation, than it had been a decade ago. However, her story indicates that it is not only the availability of a particular technology that determines how it is used. Jasmin had already been told about the circumstances of her conception at the age of ten. Although she was immediately interested in the donor and donor siblings, Jasmin had waited for some time to initiate the search process, as she wanted to control it herself without being dependent on her parents. Her plan had been to first contact the clinic where she had been conceived. Looking back on the start of her search made her laugh, as her approach was quite different from what had become common practice in recent years:

Amelie Baumann: “Did you have repeated conversations with your parents about this over the years [after she had been told that she was donor-conceived]?”

Jasmin Hellermann: “Yes, of course. Well, I didn’t protocol it, but of course right at the beginning the topic probably came up more often. I would guess that later on it sometimes wasn’t talked about for a year or also two years because for me it was clear, ok, I won’t pursue it until later anyway. And even at the beginning of my studies it wasn’t that urgent, it was also more difficult because I didn’t have a reference point [*Anknüpfungspunkt*], so for me it was somehow clear, ok, I have to start in the clinic to generate information, because how else am I supposed to find others who have been conceived the same way. And with the Internet back then it just wasn’t as [laughs] today, you can’t really imagine that anymore, you would google it first, but I didn’t come up with that idea back then. And this term “*Spenderkinder*” was also not yet really established so that you could have googled it.”

Although PCs and the Internet had already been available to her in the mid-2000s, it had not occurred to her to turn to Google in particular, which for many of my interviewees seemed to have become a kind of automatic reaction to questions and concerns of any kind. DNA databases like FTDNA had not existed at that time either. Sometime after starting her studies, Jasmin eventually contacted the clinic where she had been conceived and met the doctor who had treated her mother. He did not give her any information about her donor but told her about DI Kind (“DI child”), the website created in 2006 by another donor-conceived person, when she asked him if others had contacted him before. The physician had made a contribution, albeit unintentionally, to the later founding of the association Spenderkinder, as Jasmin contacted the person behind DI Kind. She told me that in 2009, when the group around DI Kind had grown to about 15 people living in Germany, Switzerland and Austria, they decided to take the next step: “Then we said, ‘And now we are founding an association, so that we can speak a little bit more in public of an as-

sociation opinion [*Vereinsmeinung*], and so that we're not always perceived as being isolated from each other.”

Since Spenderkinder officially argues that anonymous donations have never been legal in Germany, one of their first goals was to *enforce* the current legal situation – instead of *changing* it. In addition, they advocated the creation of a register early on to ensure the permanent storage of donor information. Especially the government consultations they participate in show that Spenderkinder is now considered an authority on anonymity in gamete donation and reproductive technologies. For example, they were invited to a hearing on the German donor register and also when a draft law on the cost absorption for fertility treatment was being discussed. They are now being asked about topics that are not exclusively related to sperm donation and anonymity. When watching online streams of these public hearings, it was striking that their representatives often received many questions compared to other experts present. I would argue that the legal training of one of the persons who was particularly active in the public sphere and often represented Spenderkinder on such occasions helped them to establish themselves in the political arena. This opinion was also shared by others outside the association: despite being critical of their influence, they spoke with respect and admiration about her commitment and legal expertise.

Before the association was founded in 2009, there had already been a mailing list for donor-conceived persons under the name “Spenderkinder”. According to my interviewees, those who join the list are asked to introduce themselves in an introduction email, with information on where they were conceived and how they had learnt about the circumstances of their conception. Similar to Facebook groups, having a story of one’s own functions as an entry ticket. However, these texts do not appear to be uniform in terms of content and length: while Melanie Weber told me that she had kept her text very short, David Winkler had written a long and detailed text which he had sent me before the interview. Melanie had also mentioned that the person she first contacted had told her that she did not have to use her real name. While none of the people I interviewed stated that they used a pseudonym on the list, this possibility seemed to exist.

According to the website, Spenderkinder had over 200 members in February 2021 and a managing committee that is elected annually. The association does however not belong to the group of ‘registered associations’, which, in Germany, have the affix “e.V.”-“*Eingetragener Verein*” attached to their name. I was told by a member of the board that this was only a question of costs, since registration and any changes, for example a new board member, must be paid for. Critics of the association argued that due to the missing registration, it was not possible to verify information that Spenderkinder posts on its website by requesting information from the register of associations (*Vereinsregister*). Such a request can be made by anyone to find out the names of the board of directors, for example. At the time

of my research, the association and its activists in particular did indeed have a rather complex and seemingly contradictory way of handling their own anonymity and identifiability. Some members appeared in public with their full names, for example when appearing as experts at government consultations. Nevertheless, at the time of my research the website itself did not show pictures of members or of the board.<sup>17</sup> Surnames were usually only mentioned in press releases. The first names used in blog posts often seemed to be abbreviations. Those who appeared in public with their names did not seem to be afraid that the circumstances of their conception would become publicly known. Nevertheless, it is noticeable that on the website itself the members were to a certain extent indistinguishable from each other, even though the section “Opinions and Stories” did highlight individual members with stories that focused on how they found out and felt about the anonymous nature of their conception.<sup>18</sup>

In the mid-2000s, Jasmin had not yet had the idea to google “*Spenderkind*”. This points to a particularly interesting aspect of donor-conceived activism in Germany, namely the development and establishment of the term “*Spenderkind*”. When I started working on my dissertation at the end of 2015, it had already become a widespread term and was used in Germany not only for the members of the organisation Spenderkinder but also for all donor-conceived persons.<sup>19</sup> However, my brief enquiry into media representations of reproductive technologies published since the 1970s suggests that the term and the way of referring to donor-conceived persons has undergone some changes. Some of the first articles on sperm donation that were published in the weekly *Die Zeit* in the 1970s use the word “*Kunstkinder*” when referring to children conceived with donor sperm (Löbsack 1972, 1973). The author’s critical stance towards technologically assisted reproduction suggests that the term was chosen to emphasise the unnaturalness and artificiality (*Künstlichkeit*) of children conceived with donated gametes.<sup>20</sup> When the term *Spenderkind* first appeared in *Die Zeit* three decades later (Spiewak 2004), it was not yet used to describe

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17 A banner announcing their social media campaign (introductory chapter) was added to the website when the campaign was launched. It shows the faces of two members, both of whom had already appeared in the media.

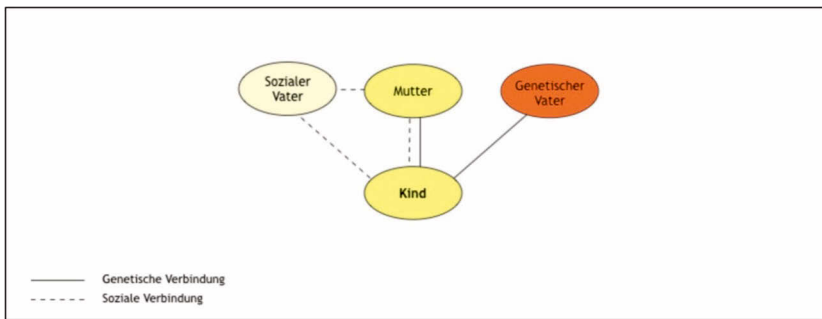
18 [www.spenderkinder.de/ueberuns/meinungenundgeschichten/](http://www.spenderkinder.de/ueberuns/meinungenundgeschichten/) (last accessed April 10, 2020).

19 Often people were irritated when I used the term “*donogen gezeugte Person*” and not the term “*Spenderkind*” when speaking or writing about my work in German, even though I explained that I avoided the term in order to avoid confusion with the association of the same name.

20 According to Theo Löbsack, doctors seem to have no reservations about “wrestling from nature at any price what it has decided to withhold in individual cases, perhaps not without good reason” (1972, author translation). He was firmly against DI, which he described as the “instrumental insertion of sperm from an extramarital third party into the sex organs of women” (1973, author translation).

donor-conceived persons (see also Spiewak 2007; Bahnson and Spiewak 2008). Instead, it was used to describe those who today are often referred to as the “saviour siblings” that are suitable as an organ or cell donor for an ill sibling. They are conceived through IVF or Intracytoplasmic Sperm Injection (ICSI)<sup>21</sup> and PGD.<sup>22</sup> It was not until 2008 that *Spenderkind* appeared as a (or rather *the*) term for donor-conceived persons (Spiewak 2008).

Figure 2: „Samenspende“- das Kind mit seinen genetischen und sozialen Elternteilen (“Sperm donation” – the child with its genetic and social parents)



Source: [www.spenderkinder.de/infos/psychologisches](http://www.spenderkinder.de/infos/psychologisches)

Jasmin, who had been with the association from the beginning, told me that when Spenderkinder was founded, the first members had thought carefully about what they should call themselves. The English term “donor offspring” did not seem to have a perfect translation, and “*Spenderkinder*” was the most accurate one they could find.<sup>23</sup> They had chosen this name because they felt it best expressed the relationship between the donor and the person conceived with his sperm. This person would eventually grow up and no longer be a child in terms of age but would always remain a child in relation to the donor with whose sperm it had been conceived.

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- 21 ICSI is an IVF procedure. It involves the injection of a single sperm cell directly into the egg.
- 22 Only an embryo that has a high genetic compatibility with the sibling that is to be ‘saved’ is implanted. PGD was only allowed for life-threatening diseases in 2011. The creation of “saviour siblings”, which are now commonly referred to as “*Retter-Geschwister*” in German, continues to be illegal.
- 23 Jasmin Hellermann also mentioned that similar terms and groups had emerged in other countries when Spenderkinder was founded; for example, the Dutch organisation Stichting Donorkind was founded in 2007 ([www.donorkind.nl](http://www.donorkind.nl), last accessed May 28, 2020), with “*donorkind*” corresponding to the German “*Spenderkind*”. The term “*donorkind*” is used in academic publications written in Dutch (such as Pennings 2016; Schrijvers et al. 2018), suggesting that the Dutch term might not be as contentious as the German one.

The permanent and special nature of the connection between donor and donor-conceived person is also highlighted on the association's website. Here, among other things, information is provided on the "psychological aspects" of treatment with donor sperm.<sup>24</sup> According to the site, when a family is 'started' with donated sperm, three people are involved, and the term "founding a family in threes/with three people" – "*Familiengründung zu dritt*" is introduced. The "family systemic" (*familiensystemische*) situation and position of donor-conceived persons is then explained in various diagrams (see for example figure 2). Connections are represented by lines between ovals representing the child, parents and the donor. While the connections between a child and his/her mother and the child and his/her "genetic father" are shown with solid lines, the connection between the child and his/her "social father" is represented with a dashed line. The donor is described as having "a guaranteed, inextricable genetic link with the child, without any obligations attached". The position of the "social father", however, is described as "the weakest in the family system" since he "cannot be sure of his relationship with the child [...] because there is no genetic connection" (author translations). These schematic representations fit with the "familiar kinship pattern of bilateral descent, through which the offspring inherits an equal amount of shared substance from both parents" (Franklin 2013: 254). While the work of Weston (1991) questions, in the words of Carsten, "the taken-for-granted link between permanence and biology" (2000b: 695), the permanence of connections is again presented as something rooted in the biological nature of relationships. As Strathern points out, "for Euro-Americans there is no getting around the tie that exists with those persons whose genetic substances combined at the child's conception" (1999a: 22) – regardless of whether a relationship is activated or not. This characteristic of Euro-American kinship is, I suggest, epitomised in the terms that Spenderkinder uses. Strathern argues elsewhere that anonymous donors are involved in the procreation of a child, but not in his/her reproduction, which "bring[s] into existence something that already exists in another form" (1995: 354). 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" (1995: 351). They can thus be said to "disperse kinship". At the same time, the way in which Spenderkinder makes sense of the connection between the donor-conceived person and the donor illustrates that "ideas are always enunciated in an environment of other ideas" (Strathern 1992: 10). Both among German donor-conceived activists and internationally, there seems to be a longing for an older model in which reproduction and procreation are *not* separated. While "there is more to kinship than family life" (Strathern 1995: 351), ideas about dispersed kinship are formed and explored, as is the case for any ideas, "in contexts already occupied by

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24 [www.spenderkinder.de/infos/psychologisches](http://www.spenderkinder.de/infos/psychologisches) (last accessed March 02, 2020).

other thoughts and images” (Strathern 1992: 10), namely by ideas about (nuclear) family life.

Finding the right terminology also seemed to play a role in a conflict that existed between Spenderkinder and another organisation at the time of my research:<sup>25</sup> DI-Netz was founded in 2013, is a registered association, and sees itself as an association of *families* created through sperm donation, rather than merely as an association of *parents* (as it was usually referred to by the donor-conceived persons I interviewed). Together with a group of other couples who had chosen to be open with their children, Claudia Brügge and her husband had founded DI-Netz in 2013. The association has become politically influential over just a few years and got invited to some of the same consultations as the donor-conceived group. DI-Netz also offers seminars for people considering treatment with donor sperm, as well as seminars that deal with the topic of disclosure. On the DI-Netz website it is noticeable that the term “*Spenderkinder*” is only used in relation to the association of the same name, but not in relation to the children within the association or donor-conceived persons in general.<sup>26</sup> Brügge, who was on the board of directors at the time of the interview that took place in 2017, explained that she did not refer to the children of the member families as “*Spenderkinder*”. While she advocated early disclosure and emphasised that she was open to talking about the donor, she did not use the term, as she felt that it was too narrowing. According to a blog post, the association would like the term “*Spenderkinder*” to no longer be used on the website of the German sperm donor register, arguing that many of their member families “do not feel understood when this term is used” (*fühlt sich mit diesem Begriff nicht verstanden*) (DI-Netz 2019, own translation). At the time of writing (May 2021), however, the term was still used on the register’s website,<sup>27</sup> although it is not mentioned in the Sperm Donor Register Act.<sup>28</sup>

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25 The controversy surrounding the term is reflected in the debate surrounding a book entitled *Spenderkinder*, which was published in 2016 (Oelsner and Lehmkuhl 2016). The authors, a psychotherapist and psychologist, interviewed ten persons who are members of Spenderkinder; in the book, the term is however also used for donor-conceived persons in general. In its main part, their stories are condensed into “life sketches” (*Lebensskizzen*). In its cover text the book is described as follows: “They [the authors] present the authentic voices of today’s adult children and explain why knowledge about one’s own origins is so important for the development of identity.” (Author translation) While the book received a very positive review on Spenderkinder’s website (Spenderkinder 2016c), it was met with a lot of criticism elsewhere (see for example Brügge 2017) and was described as unscientific and one-sided.

26 The DI-Netz website sometimes uses the term “children after sperm donation” (*Kinder nach Samenspende*).

27 [www.dimdi.de/dynamic/de/weitere-fachdienste/samenspender-register/](http://www.dimdi.de/dynamic/de/weitere-fachdienste/samenspender-register/) (last accessed May 28, 2021).

28 The Sperm Donor Register Act speaks of “people conceived through heterologous insemination in medically assisted artificial fertilisation” (*Personen, die durch heterologe Verwendung*

The conflict between the two organisations became particularly clear in a conversation with a member of Spenderkinder whom I told that I had attended an event where I had been able to make some interesting contacts with various organisations. My interviewee then commented with a disdainful tone that I probably had met someone from DI-Netz as well. In view of the central claims of DI-Netz, which at first glance appear similar to what Spenderkinder was and is fighting for, this conflict might initially seem surprising. Although the founding members of DI-Netz had the much larger DCN as their model, the German organisation is more explicit in its rejection of anonymity than its British counterpart.<sup>29</sup> DI-Netz advocates for early disclosure and openness in families, which are also central claims of Spenderkinder, and had early on lobbied for the creation of a central register. However, some of Spenderkinder's more activist members were mainly of the opinion that DI-Netz did not recognise, or played down, the challenges that donor conception could pose to a child and to families in general, which are depicted in the "family systemic" diagrams. Other members of Spenderkinder were less critical and interpreted the existence of the association as an indication that parents are now more aware of the importance of openness.

In contrast to families of DI-Netz, members of Spenderkinder are often portrayed in German magazines, newspaper articles, podcasts and documentaries. In media reports about donor-conceived persons, it is in fact mostly members of Spenderkinder who are portrayed.<sup>30</sup> Of the ten persons that I interviewed who were members and/or were on the mailing list, seven have been in the print media, on radio or on TV. To what extent this ratio is representative is unclear. It seems likely that someone who wants to convey a message to the public is also more inclined to talk to a researcher. However, the large number of people whose stories are now circulating online and in print, and of whom I do not all recognise, suggests that the people I met are not the only members who are talking to journalists. Being active in the media does not seem to be a marginal phenomenon.

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*von Samen bei einer ärztlich unterstützten künstlichen Befruchtung gezeugt worden sind*) (SaRegG 2017 §1(2)).

29 DI-Netz is explicitly against anonymous donations and has, for example, issued posters and postcards with short messages that convey the organisation's main principles; the child's right to know being one of them. In contrast, the DCN's position is more ambivalent, although the organisation supported the change in the law that came into force in 2005. The DCN points out on its website that parents who would like to secure access to information for their children might feel forced to go abroad for treatment because of financial or time pressure, and as a result have to accept anonymous donations. The DCN therefore aims to "support parents in making decisions they can feel confident about, with a clear view of the long-term implications for the whole family" (DCN, n.d.).

30 This is the case for all three major articles that appeared in the weekly *Die Zeit* between 2010–2019 and focused on donor-conceived persons (Sußebach 2010, 2019; Becker 2014).

Although David Winkler and Diana Kraft's experiences (section 4.2) were in some ways unlike other stories I had been told, their decision to make their stories public was in itself not unusual. This also appears to be the case on an international level: half of my interviewees have in the meantime already spoken to a journalist at least once. There clearly seems to be a market for their narratives. The question arises as to why stories about donor-conceived persons have become so popular. While I will not go into detail about the content of the articles and documentaries for which donor-conceived persons were interviewed, as such an analysis would go beyond the scope of this book,<sup>31</sup> I briefly want to argue that their growth seems to tie in with a general trend towards representing topics pertaining to reproductive technologies via personalised reportages.

In her analysis of how the public image of sperm donors and reporting on reproductive technologies has developed over time, Kristina Schneider (2010) found that from the 1990s onwards, personalised histories were increasingly published, the protagonists of which were mostly childless women and couples. This trend continued in the 2000s, with the 'fate' of the donor-conceived now also being taken up by the media: the first portrait of a donor-conceived person that appeared in the weekly *Die Zeit*, for example, was published in 2010 (Sußebach 2010),<sup>32</sup> whereas sperm donors continued to be mostly absent in the media (Schneider 2010: 68–69). Commenting on what she describes as "I can't have a baby" stories, which are circulated by British, Canadian and US media, Maureen McNeil argues that narratives depicting the suffering of childless women and couples "have become classic tales of the late twentieth- and early twenty-first-century Western life" (2007: 103). McNeil suggests that apart from "the growth in testimonial cultures" (2007: 105) and "revelation media programmes" (ibid.), "the concerted excavation and generation of difficulties around human reproduction" (2007: 106) has been a crucial factor for the immense proliferation of stories about infertility. I suggest that the ongoing "elaboration of the ways in which reproduction can go wrong" (ibid.) has also contributed to the growing media presence of the donor-conceived. Similar to personal stories about infertility being used as "lead-ins for expositions about developments in reproductive technoscience for popular readerships and audiences"

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31 But see earlier this section for a brief insight into how the donor-conceived are represented, or referred to, in the weekly *Die Zeit*.

32 A donor-conceived adult was first interviewed, together with his parents, in 2000 (Grefe et al. 2000). The introduction of the article contains the names of the interviewed persons (who are also listed as co-authors), and the article does not state that they were pseudonymised. Its content differs significantly from what was published later (see Sußebach 2010, 2019; Becker 2014), as the donor-conceived person, who was told about the circumstances of his conception at the age of seven, emphasises that he has no interest in the donor. The word "Spenderkinder" is not yet used.



(ibid.), stories about donor-conceived persons have become another means of “human-interest framing” (ibid.). Interviews with donor-conceived persons are often part of TV documentaries that deal with reproductive medicine, as was also the case with the documentary Diana had been interviewed for (section 4.2).

McNeil argues that “I can’t have a baby” stories embody “a classic and simple form of salvation narrative” (2007: 103), with those struggling with infertility moving away from suffering and towards change. A similar narrative line characterises the 2019 *Die Zeit* article (Sußebach 2019), in which the protagonist, who had managed to identify her donor with genetic testing, speaks of “healing” (*Heilung*) after having moved from not-knowing to knowing. The multi-page article, which was entitled “*Deep in the Genes*” (*Tief in den Genen*), tells the story of one of the founders of Spenderkinder who is depicted on a large-format, colour photograph.<sup>33</sup> The article’s contents speak to the far-reaching consequences of DNA testing in terms of anonymity, which will be discussed in detail in chapter 8: after years of being registered with a commercial genetic testing site, the protagonist had joined another site in the hope of finding her anonymous donor. She was immediately matched with a close genetic relative whose name she did not recognise. A subsequent Google search led her to an obituary that this person had published. It listed someone from Germany as one of the relatives of the deceased person. The protagonist recognised his name as the name of the doctor who had treated her mother, and who was also one of the pioneers of DI in Germany. He had used his own sperm for the insemination, without telling his patient.<sup>34</sup>

The way the protagonist’s search for her donor is described is also reminiscent of the journey narrative, with the donor-conceived person overcoming numerous obstacles in the process of searching, such as the doctor choosing not to reveal any information about his donors. Several of my British interviewees spoke of their “journey” with donor conception (see for example Jade Foster in section 6.3).<sup>35</sup> Anthropologist Gay Becker describes the metaphor of life as a journey as “a central motif in Western societies” (2000: 31; see also Mattingly 2010: 72). It is an organising metaphor that can help to (re)create a sense of continuity (Becker 1997: 7), as a

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33 The article was published in the “*Dossier*” section of *Die Zeit*, which is characterised by particularly long articles that often focus on the story of a specific person.

34 In addition, the physician had bought a test from yet another testing site, which the protagonist had also joined. Apparently, he had been interested in the personalised health reports that the company offers and had forgotten to log off from the “matching” function. He was therefore matched with the donor-conceived protagonist.

35 None of my German interviewees spoke of their “*Reise*”, which would be the direct translation of “journey”. However, they too used words that conveyed a sense of transformation. Several people spoke of their “*Auseinandersetzung*” with their origins (see for example David Winkler in section 8.4). This term can range in meaning from “dispute” to “analysis” and was mostly used to describe an active and critical n with donor conception.

potential disruption can be reinterpreted as being part of a transformation. Apart from the recourse to a classical narrative form, the story also becomes resilient because, similar to the stories studied by McNeil (2007: 103), questions of context are not reflected upon despite the highly personal nature of the article. The protagonist's need to know is not discussed in relation to the prevailing understanding of kinship, within which such a need makes sense in the first place. Instead, genes are merely presented as "a sought-after narrator" (Sußebach 2019, author translation).

The author also argues that "the case is of exemplary relevance, of public interest [...] because it shows what can happen when progress is beyond the control of society and legislation. When a blind spot opens up in which pioneers – whether nuclear physicists, bacteriologists or reproductive physicians – remain unobserved. And act." (Sußebach 2019, author translation)<sup>36</sup> Fears that reproduction and technology might 'go awry' are analysed by Susan Erikson (2003) in her ethnographic study of prenatal diagnostic technologies in two German hospitals. Both ultrasound and amniocentesis may result in the detection of foetal anomalies, with some women choosing to terminate a pregnancy. Erikson argues that the Nazi era, with its history of eugenic politics and medical abuse, has left its imprint on policies and public discourses where "a history of "society gone wrong" provides an inescapable backdrop to contemporary praxis" (2003: 1988). Post-diagnostic abortion therefore not only raises the question "whether such abortions are "medicine gone awry", but also about whether medicine has gone awry *again*" (ibid., emphasis in original). Given this background, it is not surprising that the actions of a pioneer of DI are interpreted as an example for science escaping societal and legal control. The reference to nuclear physicists as another group of potentially dangerous pioneers evokes images of nuclear explosions, and the mention of bacteriologists immediately suggests the release of invisible, yet deadly particles. Putting reproductive health professionals on an equal footing with them frames the treatments they offer as something that requires stricter control mechanisms. While the article describes a new phenomenon with its focus on DNA testing, this analysis shows that it also ties in with a common pattern of interpretation.

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36 See also Brüggé (2018) for a commentary on the case. Even before the article was published, the person named in the article had reported her discovery on the website of Spenderkinder under a pseudonym (Spenderkinder 2018c). In the commentary that Brüggé subsequently published, she argued that the physician had violated his patient's reproductive autonomy by choosing to procreate with her without her being aware of it (Brüggé 2018).

## 4.5 Recapitulation

Although the decision to talk to journalists and to become publicly active could be motivated in different ways, for those who decided to go public, it was often about advocating a certain ideal of what family should be like. For those who were critical of donor conception per se and not only of the principles of anonymity and secrecy, it was about using their personal story to warn others of the dangers of the practice. Real families, in their eyes, were those whose members were genetically related to each other. They were convinced that anonymous gamete donation had a negative effect on the wellbeing of the donor-conceived and their ability to be intact members of society. I suggest that this kind of harsh criticism is based on the alleged connection between knowledge and “identity formation” that was also evoked by ‘milder’ voices. Others, who were not critical of gamete donation per se and believed in the importance of openness, wanted to promote the normalisation of the practice by putting their stories in a public space. They also wanted to increase their chances of finding donor siblings and the donor. The ideal of the open, honest family was something that was also very prevalent in the interviews with those who had not shared their stories with journalists.

Since most of the donor-conceived did not know anyone else who shared the same ‘fate’, and whom they could tell their stories without being misunderstood, many turned to the Internet to find others who were in the same situation. The safe spaces they found online, where they felt protected from the intrusive comments of uninformed outsiders, were described as places where they could experience and create community, understanding, encouragement and normality. The groups they joined online were mostly closed and often hidden. They create a new ‘outside’ and ‘inside’ by keeping away not only those who are not donor-conceived but also those who are not invited for other reasons. While the people I interviewed in the UK were sometimes members of several groups and usually the most active on Facebook, the association Spenderkinder was the first (and often only) contact point and source of information for the donor-conceived persons I met in Germany. The association began as a website and mailing list and has developed into a powerful but not uncontroversial player in debates about anonymity and reproductive technologies. The more ‘sober’ line of argumentation pursued by Spenderkinder with regard to the right to know, which also seems to have shaped the views of its members, differs from the positions of British activists. Nevertheless, the connection between permanence and biology is again part of the association’s official terminology and public statements. Spenderkinder has a strong media presence, and the narratives of the donor-conceived seem to be popular among journalists on an international level as well. While articles and documentaries sometimes address new technologies, they also seem to tie in with common ways of interpreting medical and reproductive technologies.

## 5. Micropolitics of not-knowing

### Imagining continuities and relations

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The search for “origins” or “roots” was an omnipresent theme in almost all interviews, and the formulaic character of statements such as “I just want to know where I come from” or “You need to know where you come from” was striking. In her research on adoption reunions, Carsten (2004) has made very similar observations. Adoptees were looking for their birth family “in order to know who I am,” “to find out where I came from,” or “to be complete” (2004: 104). Carsten found that some of those who grew up not knowing their birth kin experienced a “sense of incompleteness” (ibid.). She argues that such a “deficit should make us pause” (ibid.), and that “this suggests a notion of personhood where kinship is not simply added to bounded individuality, but one where kin relations are perceived as intrinsic to the self” (2004: 106–107). This kind of relationality is, I suggest, also evident in the narratives of the donor-conceived.

Finding out “where you come from” can become a necessity if what people know about themselves and their kin relations is called into question. This was the case for the vast majority of the people that I interviewed. Most of them could point to a specific moment in time when they were told that they had been conceived with donor sperm, and thus found out that they were not genetically related to the person most of them still referred to as their father. While genetic relatedness is something that cannot be terminated on one’s own accord (you might be able to decide that you do not want any contact with your genitor, but you cannot reject the fact that you share a genetic connection), the people that I interviewed experienced a potentially challenging situation: a connection that is considered indissoluble has dissolved, as it turned out to be non-existent. It is thus “not their biological bodies that are compromised but instead the kinship they know as significant” (Edwards 2018: 171–172, note 13). Their life receives a new temporal dimension, as they look back to a time when they had not yet been told.

Temporality is thus my second point of reference and analysis in this chapter, next to relationality. I am interested in the temporal and relational dimensions of anonymity, kinship knowledge and the way they are problematised by the donor-conceived. This chapter thus constitutes a micro-political exploration of becom-

ing donor-conceived from a relational and temporal point of view, and I follow a similar approach in the next chapter. I do not interpret micropolitics as something that translates political decisions made at a macro-level into the choices of individuals, and thus as a counterpart to ‘large-scale’ politics. Instead, I am interested in investigating what kind of negotiations take place on an everyday level and how anonymity and knowledge about relations become significant and potentially problematic (see Macdonald 2010 for a similar approach to micropolitics).

In this chapter, I will first introduce one of my interviewees in whose narrative the need to know played a central role. Her desire to “complete” herself highlights that while continuity might be an illusion, it is nevertheless firmly embedded in everyday life (Becker 1997: 191). I will then examine another element that marked many accounts, namely the assertion that one had always intuitively felt the truth about one’s origins. A focus on how people narratively work with the “cultural model of continuity” (Becker 1994: 401) as part of their retrospective reasoning allows for a shift in perspective that goes beyond an analysis that would merely reproduce these narratives. Following this, I will explore how continuity and similarity emerged as key modes of relating in the accounts of the donor-conceived, who often told me that they did not fit into their families. In the last part of this chapter I will examine how my interlocutors built imaginary relations with their unknown relatives by searching for similarities in strangers and/or friends, a process I have termed “scanning”. Overall, the empirical examples discussed in this chapter touch on relational aspects of personhood that remain obscured in discussions about the right to know, despite or maybe because of “the very ordinary quality of this relationality” (Carsten 2004: 107). At the same time, they also testify to the central importance of temporality and continuity for the making of persons and kinship relations.

## 5.1 Half a family tree: Lost identities and recreated continuities

Sitting in her living room in an industrial town in Northern England, 23-year-old Lindsay Billington told me that she had “no knowledge or even inkling” before her parents told her shortly after her twenty-first birthday that she was not genetically related to her father. Her anger at them was accompanied by an intense sense of shame, as she was firmly convinced that she should have been able to figure out the truth by herself. A sense of embarrassment and disappointment manifested itself in the tearful voice in which she told most of her story. There were several moments during the interview when I thought that she would burst into tears, which gave me a slightly uneasy feeling, as I was unsure about how to react. It was obvious that some of my questions evoked painful memories for her. This seemed to be reinforced by the fact that the room we were in was the room where her parents had first told her about the circumstances of her conception. However, I was

surprised at how focused Lindsay remained throughout our two-hour conversation, even though some parts of the interview were noticeably upsetting for her. She seemed determined to talk about these painful experiences and had prepared for meeting up with me: on the coffee table in front of us she had put several documents that she thought might be of interest to me and that she allowed me to photograph. This included the response letter from the HFEA that contained non-identifying information about her donor and donor siblings (see section 7.3). Her openness and desire to tell her story had already been indicated in her first email, as she had offered to come to Cambridge (where I was based during my time in the UK) for an interview, even though it was several hours by car from her hometown. She stated that although she did not know much about gamete donation and its legal regulation yet, she would still like to participate in my research, and that she had a lot to say on the subject of anonymity.

Her parents as well as her in-laws, whom she had known for a long time since she had already been dating her husband as a teenager, lived just around the corner of her house in the town where she had grown up. Her life made a thoroughly orderly impression: Lindsay's house was neat and tidy, the interiors were colour-coordinated, she was married and worked in a law firm, thus fulfilling her long-standing wish to work with the law. The town centre of her hometown seemed to be rather dull and abandoned, and I was not surprised to read online that the locals tended to go shopping in a nearby shopping centre. It appeared to be the kind of place you have to grow up in if you want to feel comfortable there in the long run, and Lindsay had indeed grown up there. The continuity and predictability of her life had been shaken when her parents told her one evening about the circumstances of her conception:

Lindsay Billington: "I was completely taken aback. And upset at the time because ... you feel like your whole world comes crashing down because you feel like you're going through life and you know who you are, and you know where you've come from, and you know your family history. And then all of a sudden, you've just got this black hole. You've got half a family tree. Do you know what I mean? Because you don't really know where you've come from. So then I started to sort of lose my identity, I didn't really know who I was as a person because I didn't know where I'd come from."

The use of genealogical models such as the family tree mentioned by Lindsay is a means to establish order in what can otherwise be a set of chaotic relations. Such models have the potential to "significantly shape people's self-positioning and perception" (Pálsson 2002: 351). The tree metaphor in particular, with the tree being turned upside down, has "not only survived but flowered into the present" (Pálsson 2004: 188) after family trees first appeared in medieval imagery, despite "the botan-

ical absurdity of the image of a tree that extends its roots into the sky”(ibid.).<sup>1</sup> The persistent popularity of this metaphor can be seen today in the naming of FamilyTreeDNA (FTDNA), one of the genetic databases used by the donor-conceived.<sup>2</sup> The family tree Lindsay was speaking of consisted of the persons with whom she was genetically related. Since her donor was anonymous, half of her genetic roots were missing, and her own place in the present was less firm. Lindsay had already started seeing a counsellor before the disclosure talk with her parents, as she had always struggled with anxiety. It was the counselling that had made her realise that it might be the right time to try and find her donor. At that time, she had in fact already received non-identifying donor information from the HFEA (see figure 3 in section 7.2 for a replica of the table Lindsay received). Shortly before we met up, she had decided to consciously “look into it” even more in the hope that more knowledge about her genetic origins might give her a sense of completeness: “If maybe I can complete myself and know who I am, where I’ve come from, that might help my anxiety.”

Many of my interlocutors told me about similar experiences and talked about feeling “incomplete”. Not only did they no longer know where they came from, but they also no longer knew where they belonged in the here and now. Such accounts illustrate that roots are important in two ways: they “are not only about linking a person to the past but also about locating them in the present” (Edwards 2000: 230). The feelings of identity loss in particular, which came up repeatedly throughout many interviews, illustrates an argument made by Carsten: “When people find out new information about their kin, [...] that knowledge becomes incorporated into their sense of identity [...]” (2007: 405) If it is information about an anonymous donor, this may result in the kind of “black hole” Lindsay talked about. As Carsten argues in her study of adoptees, “knowledge [...] has the power to create, and also potentially to dislodge, a sense of self” (2007: 415). Carsten also suggests that “[...] the constitutive power of new kinship knowledge might be reinforced when such knowledge has been concealed. And that is because identity for Euro-Americans rests not just with self-knowledge, and hence kinship knowledge, but also with a sense of control over one’s own life.” (2007: 421–422) The accounts of the

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1 As Gísli Pálsson (2004) shows, the tree imagery has undergone significant changes over the centuries. Whereas today family trees are mostly depicted with their roots in the sky, they were initially depicted as regular flowering and growing trees, “which underlined the joyful proliferation of the lineage, drawing its vital energy from the earth and stretching into the divine light in the heavens” (2004: 188). However, this imagery came to be seen as problematic because it did not “project the past in glorious terms” (ibid.). The image of the flowering tree was met with resistance, as it put “the ancestors (and the gods) in the soil and degenerated contemporaries in the heavens” (ibid.).

2 [www.familytreedna.com](http://www.familytreedna.com) (last accessed May 28, 2020).

donor-conceived suggest that similar dynamics are at play in the case of anonymous gamete donation and late disclosure. For those who grow up without the knowledge of the circumstances of their conception, their sense of self can potentially become dislodged under the conditions of anonymity and broken secrecy. At the same time, it seems reasonable to assume that for those who grow up knowing about the circumstances of their conception, and who want to know more, not being able to know their donor might not be as problematic as it is for those who grew up in secrecy. Given the composition of my sample, my insights into how those who grow up knowing make sense of their conception are very limited. My guess is mainly based on the interview I conducted with Jacob Moore, who always knew that he was donor-conceived, and whom I will introduce in more detail in section 7.5.<sup>3</sup> His egg donor, whose “non-identifying” information he had already received from the HFEA, was still anonymous. Although he was interested in finding out more, the thought of never being able to find her did not worry him and had not dislodged his sense of self: “I mentioned to quite a lot [of friends] that I’d like to find out but ultimately, if I never find out, I will never find out. It’s not going to bother me all that much, it’s not going to be something I’m lying on my death bed worrying about.”

For many people, finding out that they were donor-conceived had changed not only how they felt about their past and present, but also how they felt about their future. Lindsay, too, described that she was unsure not only about where she came from, and about her identity, but also about where she would be going in the future:

Lindsay Billington: “I just feel like if I had been told when I was younger, you sort of grow up knowing and it’s just part of your life, but then it’s told at 21, when you’re going through life and you’re getting married, and you think you know where you’re going, you think, ‘I’ll get married, and then in so many years I’ll maybe have children,’ and you sort of plan your life out, and then when that happens, you think ... what are you going to *do*, I don’t know ... it’s just hard to explain.”

Concerns about no longer knowing “where you are going” illustrate that in “kinship time” (Carsten 2000b: 692), the past, present and future are intertwined, which I will explore in more detail at the end of the next chapter (section 6.4). Against this background, the attempt to find the donor constitutes not only an attempt to find out more about one’s past but also an effort to establish “continuities of identity which can link together [...] past, present, and future” (Carsten 2000b: 700), as

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3 Amber Jones, who also always knew she was donor-conceived, was not interested in her donor. Interestingly, the main reason why she did not want to find out anything was because she was afraid that she might learn something that would have a negative effect on how she saw herself. She seemed to be afraid that donor information might dislodge her sense of self (see section 7.3).



Carsten argues in the context of adoptees searching for their birth kin. The donor-conceived's desire to find out where they come from, who they are and where they are going implies that the temporal reasoning of my interviewees was based on the assumption of linearity, as neither conceptions of the future nor of the past are possible without at least "a degree of linear temporal reasoning" (Jansen 2016: 454). This presumed linearity is also a precondition for the possibility of hope (*ibid.*), an orientation towards the future that I will come back to when exploring how official registers in the UK create a space of hope and uncertainty (chapter 7).

In the conversations with those who had experienced receiving information about their donor-conceived origins as a painful rupture, I repeatedly noticed that they had detailed ideas about how their lives could have developed if they had always known where they came from. They believed that they would have fitted better into their families, that they would have gotten along better with their relatives, and that they would never have had a gap in their lives – if their parents had talked about the circumstances of their conception early on, if the donors had been contactable or, as imagined by some, if they were not donor-conceived. I draw on the concept of the "disnarrated" to explore these alternative visions of what life could have been like. The disnarrated, a concept originally coined by American literary scholar Gerald Prince (1992), has been described by him as "all the events that *do not* happen though they could have and are nonetheless referred to (in a negative or hypothetical mode) by the narrative text" (1992: 30, emphasis in original). It is hence different to that which is not mentioned because it is taken for granted (Vindrola-Padros and Johnson 2014: 1604). When analysing a narrative and its disnarrated elements, "the main question [...] is, if the event did not happen, then why is it part of the story" (Vindrola-Padros and Brage 2017: 17). Anthropologists Vindrola-Padros and Brage argue that "the disnarrated makes the reader consider alternative realities" (*ibid.*). It can give insights into reflections, needs and desires (2017: 20).

In Lindsay's account, disnarrated elements seemed to be particularly strong and painful because in retrospect it seemed as if a different course of events had been possible. Unlike other parents who had been told to keep the donation secret, her mother and father had been advised by the clinic where the treatment took place in the early 1990s to tell their daughter early on. They had even received a book from the clinic that was designed to help couples with the process of telling, and which they had given to her shortly after she had been told. She had put the book on the coffee table so that I could have a look at it during the interview. It seemed to be a physical and painful reminder of a direction her life could have taken if her parents had followed the clinic's advice. When asked why they had decided against telling her at an earlier age, her mother had told her that they just missed the right moment. Lindsay concluded that "they found it difficult to say it". She was noticeably upset by her father's confession that he would have taken the information to his grave if events had not "pushed" him into telling the whole

story (see section 6.1). Lindsay's vision of how her life could have developed under different circumstances was linked to an idea of what difference a non-anonymous and contactable donor would have made:<sup>4</sup>

Lindsay Billington: "If I had known when I was a child, and maybe had the opportunity to meet the donor, not have a relationship with him, but just to piece it together as a child, then maybe you grow up being a bit more stable, I don't know, because that has not happened to me, I'm just sort of thinking how I would have liked it to have happened. And how I feel like it would have suited me better, if I had known and had the opportunity to see him and know a bit about him as well, where he's come from and what he's doing and if he's got children, what they're like ... because I feel like in my dad's family, I've never fitted in, really, so I just feel like I'm constantly looking for somewhere to fit in."

Lindsay interpreted knowledge about and contact with the donor as the factors that would have enabled her to develop a sense of stability and possibly escape the feelings of anxiety and nervousness that had plagued her for a long time. She would not have developed the need to "complete" herself if she had known about her origins and met the donor, as her life would have been a coherent and continuous whole. The conditions that not only characterised her alternative vision of her life, but that also made the disnarrated scenarios that others included in their stories "tellable" (Vindrola-Padros and Brage 2017: 18) were the same conditions that are at the very centre of narratives, which "arise out of a desire to have life display coherence, integrity, fullness, and closure" (Becker 1997: 12).

Becker has shown in her work that narratives themselves are "empowering" (1997: 25) and argues that they "represent action and, thus, agency" (*ibid.*). In her ethnographic study of reproductive technologies in the US, Becker interprets "actions" not only as the decision to undergo treatment but also as "*all* the decisions they [women and men making use of IVF and other technologies] take on their own behalf" (2000: 102, emphasis in original). A similar idea has been put forward by Carsten, who argued that "both telling [...] stories and having them listened to is constitutive of the process of rearranging the past to assert one's own creative control over events shaped by others" (2000b: 698). In the case of those who have been conceived with gametes from anonymous sources, talking about what happened and what might have happened constitutes a form of "taking action"

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4 Her wish to meet the donor differed from the demands voiced by others who stated that they "just wanted to know" and expressed no or only little desire to meet up in person (see section 3.5). A wish for contact would not necessarily be fulfilled under current UK or German law. Although those who donated after 2005 or 2018 respectively have agreed to their identifying information being released to those who request it, they are not legally required to meet up with their donor offspring.

(Becker 2000). For the donor-conceived, telling their story, regardless of whether it concerns disnarrated elements or not, can be a means to ‘narratively take action’ against the experience of discontinuity. It restores a certain order in their lives, which is arguably why someone like Lindsay, for whom the interview clearly brought up painful memories, decided to talk to me and remained very focused throughout the interview. However, narratives alone cannot create or restore “generational continuity through biological linkages” (Becker 2000: 213), which is, according to Becker, “at the root of the cultural ideology of continuity” (ibid.). Telling alone will not bring back the other half of a family tree that is missing due to the donor’s anonymity. Nevertheless, talking about the experience of being donor-conceived has still become a powerful resource in the fight for change. The stories of the donor-conceived can also enter a public and political realm, which illustrates Becker’s point that “taking action [...] can also lead to large-scale collective action” (2000: 102). As I have shown in chapter 4, speaking publicly about the experience of being conceived through anonymous donations has become a crucial part of the donor-conceived’s fight against anonymity.

## 5.2 Truth will out: Retrospective reasoning and feeling the truth

The effort “to consider life as a history” (Bourdieu 2000: 300) by understanding and narrating life as “a coherent and finalized whole” (Bourdieu 2000: 299) was part of an element that kept reappearing in many narratives. In contrast to Lindsay, several of the people I interviewed told me that they were not really shocked by the information that they were not genetically related to their father. They mentioned that they had always intuitively felt the truth, which had then eventually come out, even in their early childhood days. Since they had little or nothing in common with their father and other family members, they had always had the impression that they did not really “fit” into their families. As I will argue, the idea that one had somehow been able to feel the truth about one’s origins allowed people to re-establish a sense of continuity. It gave them the narrative means to rework the disruption they had been experiencing, as it could be interpreted as something that they had always been anticipating. The feeling of being different from one’s family was also a central concern in the stories of those who had not experienced a painful “loss of identity”. What I am interested in here is how the idea of intuition can act as a narrative vehicle for the expression of certain ideas about anonymity, secrecy and kinship. In order to explore these dynamics, I will first focus on retrospective reasoning on a more general level and examine the specific understanding of childhood that underlies these representations. Following this, I will give an example of a donor-conceived person who mentioned that he had always felt the truth. I will

conclude by exploring the question of what it can mean for a person to have 'failed' to do so.

When my interlocutors told me that they always felt that something about their origins was 'odd', this was always connected with a look at their past and especially at their childhood. Retrospective reasoning is based on the idea "that knowledge rests in the recesses of one's mind" (Edwards 1999: 75). Of course, "look[ing] to the past into order to explain a current concern is a commonly evoked form of evidence" (ibid.). Retrospective thinking is hence not something that is unique to the accounts of the donor-conceived. Retrospective reasoning is instead central to the sensemaking process (Czarniawska 2004: 23). What makes the accounts of the donor-conceived interesting and special, however, is the fact that for those who can remember a specific moment of being told, the information they have received is constitutive for their identity. Retrospective reasoning can be a means to reorder experience and counteract the potentially "destabilizing effect" (Carsten 2007: 409) that this constitutive kinship information can have.

In her ethnographic analysis of how people that experienced infertility re-ordered their experience and restored order in their lives, Becker describes metaphor as "a cultural resource" (1994: 404) and as "one mediator of disruption that enables individuals to recreate a sense of continuity and to reconnect themselves to the social and cultural order after a disruption" (ibid.). I suggest that retrospective reasoning, which can entail a strong sense of "having known it already", performs a similar function. This kind of reasoning, too, can act as "a conduit for locating new meaning" (1994: 384) and can be way to 'edit' a narrative (Becker 1997: 28). By linking information about the circumstances of one's conception with stories and events from the past, a sense of being lost can be prevented or at least limited. Looking back to what happened does not produce insights that are 'more real' than predictions about the future, since both histories and futures are "imaginative constructions built out of people's perceived realities" (Malkki 2001: 328).

In the case of my interviewees, these constructions were connected to and conditioned by a particular idea about childhood. In accounts that contained a description of having felt the truth as a child, the pure character of a childhood self, which has not yet been corrupted despite the lies and secrets of one's parents, was contrasted with the dishonest behaviour of adults. Moreover, it was common for people (both interviewees and acquaintances) to tell me that "children can feel the truth". Charles Lindholm (2008) argues that the idea that children are innocent and more 'authentic' than adults is an idea that has deep roots in European philosophical and pedagogical thought.<sup>5</sup> In *Culture and Authenticity* (2008), Lindholm argues

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5 Lindholm, whose work has shown that authenticity is a distinctively modern value (2008; see also Fillitz and Saris 2013 for an analysis of modernity's 'obsession' with authenticity),

that these ideas have been profoundly influenced by Jean-Jacques Rousseau, whom he describes as the “‘inventor’ of modern authenticity” (2008: 8). Rousseau was convinced that children “were repositories of humanity’s fundamental innocence” (2008: 9), and thus more authentic than grown-ups, as they are not yet corrupted by external, societal influences.

Retrospective reasoning and a look back at childhood events were central elements in the story of David Winkler. His search for his donor and his very intense preoccupation with donor conception that had resulted in him talking to a journalist (section 4.2) did not appear to be painful for him, and his behaviour towards me seemed to match his positive attitude towards his origins. Not only did he seem to be in a good mood already at the beginning of our encounter, which took place on a weekday afternoon in a busy but not overcrowded café in the city where he lived, but he also seemed to really enjoy the actual interview. His interest not only in my project but also in donor conception in general became clear when he sat down and took several documents out of a bag. One of them turned out to be my study information, which had been distributed through Spenderkinder’s mailing list. It was full of handwritten notes, indicating that he had prepared for the interview. Other papers seemed to be printouts and notes from his general research on everything related to reproductive technologies. His thirst for knowledge seemed inexhaustible, and David explained that he had invested “200 percent energy” in it in recent months.

Before the interview, he had sent me the text with which he had introduced himself to the members of Spenderkinder via their internal mailing list. In the text, which he had written a couple of months before we met up in March 2017, he had described how he had found out that he was donor-conceived. He had also mentioned that even before being told, he had felt that something was wrong with his family. This had made me curious, and I started the interview by picking up on this part of his email:

Amelie Baumann: “You mentioned that you found out a year and a half ago that you were conceived through sperm donation, but that you had a suspicion that something wasn’t entirely right already before that.”

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points out that there are “two overlapping but distinct modes for characterizing an entity as authentic: genealogical or historical (origin) and identity or correspondence (expressive content)” (2013: 363). For example, a piece of furniture made in a particular historical period can be considered truly authentic “if its source can be traced, and if its characteristics mark it as fitting properly into a recognized category” (ibid.). An individual in turn can be described as authentic if it lives “life as a direct and immediate expression of [its] essential being” (ibid.). A person’s conduct is labelled authentic if it is “connected with, and somehow expressive of, the core of the actor’s personality” (Ferrara 1998: 5).

David Winkler: “Well, actually ... I keep thinking about whether I’m over interpreting things, and I keep realising more and more how things fall into place and how they prove to be true. I feel like all my life, I always somehow had the impression that something was missing. With me or in me, but what does missing actually mean, well that I don’t really fit into this family. Because I was always the one who always had completely different interests and dispositions [*Neigungen*] and whatever, and I never really felt that I was one hundred percent part of it. Something was missing from one hundred percent. If I compared that with my circle of friends, there were families with siblings as well, a nuclear family of four, there was this feeling of unity that we didn’t have. But ... I never thought much about it. I’ve just always noticed that it’s different with us, or with me anyway.”

David then told me that he had only become really suspicious many years later when he had observed his son playing. The way he moved around had very much reminded him of his own behaviour as a child, and David remembered that this had not surprised him at all: “Of course, that’s my son, and I see him, and I see my own reflection.” Suddenly it had become clear to him why he and his brother had so little in common, and why he was not his father’s reflection: everything would make sense if he and his father were not genetically related, and if he and his brother, with whom he had never gotten along, were genetic half-brothers. A secret paternity test had confirmed his suspicion, and after he had finally confronted his parents with the results, they had told him, albeit hesitantly, about the circumstances of his conception.<sup>6</sup> They also told him that his brother had been conceived in another clinic. Given the circumstances of the treatment – his research had shown that ‘fresh’, unfrozen donations had been used, mostly from medical students – it seemed highly unlikely that the two brothers had the same donor. By referring to his intuition, which early on had pointed in the direction of truth, he could tell this story as one in which there were no major breaks, even if he only learnt as an adult about the circumstances of his conception.

Usually, stories about not fitting into one’s family were very emotional and marked by tears, anger and frustration. This was not the case for David. He mentioned that his parents had desperately tried to maintain a “constructed normality”. Although David felt this had always been a doomed failure, he stressed that he was not upset or angry about the absence of family harmony in itself “because there are simply reasons for that”. The “reasons” he referred to were the lack of genetic connection between him and his father, and the fact that he and his brother had probably been conceived with sperm from two different donors. While his insistence on the importance of genetic connection for the emergence of strong family

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6 Since secret paternity tests are not legal in Germany, David Winkler had sent a bottle that his father had drunk from to a laboratory in another country.

bonds might suggest that he subscribed to a heteronormative view of kinship, his decision to become a sperm donor for a lesbian couple (see section 4.2) tells a different story. The complexity of his views illustrates that narratives constitute “versions of reality” (Ochs and Capps 1996: 21) that are always “embodiments of one or more points of view rather than objective, omniscient accounts” (ibid.), resulting in narratives often containing seemingly contradictory elements.

Like Lindsay Billington (section 5.1), David had an idea about how things could have been if his parents had chosen to be honest with him and his brother. He was convinced that they would be “a completely easy-going family” (*eine total entspannte Familie*) that would occasionally make jokes about the two brothers coming from “elsewhere”. Others were much more critical of the fact that their parents had not told them earlier. Several of my interviewees firmly believed that their family relationships would have been better if their parents had been open and were convinced that they themselves would have been happier and more confident. They believed that their parents’ secrecy had resulted in them always having self-doubts and felt that they had only been able to trust themselves once they found out that their feeling of not fitting into their family had been justified. They clearly believed that truth had “transformative power” (Gandsman 2009: 454).<sup>7</sup> Although they had been a lot more hurt about not fitting into their families than David had been, they, too, were happy about finally knowing the truth, and usually stressed that secrets in general, and family secrets in particular, were toxic for relationships and personal development.

Looking back in time to specific moments, conversations and family gatherings and re-interpreting them on the basis of the newfound truth about one’s conception was a common practice amongst my interviewees. Even those who had not been suspicious about their origins commented that despite initial feelings of surprise or shock, certain things that had occurred in their life suddenly “made sense”. Truth had ‘shown through’ secrecy in such moments, but they had not been able to fully see the truth until much later. David, too, not only talked about his deep-seated feeling that something was wrong but also mentioned several incidents from his childhood and youth that suddenly “made sense” now that he had accurate information about his origins. He told me that he “collected these memories” that kept coming to his mind from time to time. David mentioned, for example, that his father had once desperately proclaimed, “No, you are not my son, you are not my son” when David had struggled with his homework in mathematics and had asked his father, who was good with numbers, for advice. At first, he did not think this was significant at all, but he mentioned that “in hindsight, something probably

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7 See also the experience of Alexandra Gerstner (section 8.3). Alexandra, who had been struggling with autoimmune diseases for a long time, told me that her health had improved since she had learnt about the circumstances of her conception.

came through, which he perhaps wasn't even aware of". Similar to David, others told me that they could not imagine that it was really possible for parents to permanently ignore the true origin of their child, and that parents would unconsciously reveal something through their actions and words. In David's case, his father's behaviour was turned into an "episode in a story" (Mattingly 2010: 49) which made his statement intelligible, whereas this and other memories were previously not only inexplicable, but also irrelevant.

While 'collecting' memories had a reassuring effect on David and others by confirming and explaining their early intuitive feelings of not fitting in, looking back to the past could also have the opposite effect. This got particularly clear in the case of Lindsay. Not having been able to 'detect' the truth was an extremely painful and vivid memory for Lindsay, who told me with teary eyes about her constant, nagging feeling of intense shame and failure. She repeatedly mentioned that she felt incredibly "stupid", as she was convinced that there had been "so many different signs that pointed to something not being right". With a tearful voice, she then described several situations that she believed should have made her suspicious, and that could have been opportunities for her parents and other relatives to tell her the truth. Since Lindsay believed that she had failed to correctly interpret her parents' behaviour and various events in her life, which was in hindsight full of obvious "signs", she interpreted her story as a story of personal failure.

In contrast, David and others who had spoken about their deep-seated feeling of not belonging to the families they had been raised in managed to edit their narratives in a way that established a sense of closure. In this sense, looking back at what one had already known intuitively as a child is not only a narrative resource that enables people to re-establish continuity, but also a resource for expressing ideas about anonymity and secrecy in kinship. Since the donor is perceived to become visible or perceptible in the child who inherits certain traits from him, both secrecy and anonymity are interpreted as mechanisms that have failed at keeping the donor away. His influence cannot be ignored, and he was described as a form of 'absent presence': he might not be there physically, but he manifests himself in the child through traits that are passed on, resulting in the child not 'fitting in'. The attempt at permanent secrecy appears as a plan doomed to failure since the truth will come out eventually: even though the donor might still be anonymous, the genealogical origins of the child cannot be hidden. However, looking back can also point towards a perceived personal failure if the individual has not seen the "signs". If this is the case, then the error appears to be not only with the parents, who did not tell the child, but also with the child that 'failed' to sense the truth.



### 5.3 Similar relations: Generational flows and curious continuities

Descriptions of feeling the truth were connected with my interlocutors telling me they had never fitted into their family. Since they differed from their parents and other relatives in aspects that they considered constitutive of their personality, they felt they were not really part of the family in which they had grown up. The question of whether the traits that they regarded as special and characteristic of themselves had been passed on to them from the anonymous donor seemed to occupy most of my interviewees. What struck me early in my research was the wide range of characteristics, talents and interests that were mentioned when people commented on what distinguished them from their parents and what had possibly been passed on to them from the donor: among other things, a love for swimming, general sportiness, a talent for languages, creativity, musicality, and educational success, which was mentioned very often. If potential similarities in term of looks were brought up, they were mostly merely mentioned and not talked about in detail. It was noticeable that overall, people very much focused on aspects of their personalities that are coded as positive, which is remarkable since “inheritance is totally amoral, you inherit for good and bad” (Bestard 2008: 25). In the following I will first discuss the significance of similarities for the establishment of relations on a more general level. I will then present and discuss two examples from my ethnographic material, showing that similarities are central to the way people construct imaginary “non-relations” (Konrad 2005a) with their anonymous donor.

The importance of similarities for the creation of relationships has been explored and critically commented upon by Strathern in her reflections on the Scottish Enlightenment (2018). She describes the legacy of the Enlightenment as the “premise that degrees of similarity and difference indicate closeness and distance, that likeness or similarity is the basis of solidarity and common feeling while difference leads to strangeness and estrangement” (2018: 183–184). Strathern argues that this assumption is not “necessarily benign” (2018: 184) and that “the very possibility of formulating similarity and difference as ‘likeness and unlikeness’ perpetuates similarity as a key mode of relating” (ibid.). In order to show that there are other “possible markers of intimate relationships” (2018: 185), Strathern cites the example of naturalist Maria Sibylla Merian who brought back specimen and illustrations from a trip to Surinam in the early eighteenth century. Strathern refers to her illustration of an entire lifecycle of a frog that depicts its transformation from one distinct form to another, thereby showing that “radically different things might metamorphose into one another” (ibid.). Since the different forms of the frog differ markedly from each other, it would not have been possible to infer a relation between its various developmental stages that Merian depicted if one had exclusively focused on similarities. Strathern concludes that Merian can offer “a present-day

comment on the persistence of this particular premise [regarding similarities and relations]" (ibid.).

She points out elsewhere that "Euro-American understandings of the similarities involved in human reproduction are not at all neutral as to the nature of the relationship at issue. A relationship is thought to inhere in a continuity of (personal) identity." (1995: 354) Continuity is thus central to the way kinship is conceptualised in its Euro-American rendition: "The very idea of continuity between generations is contained in the idea of a downward flow of characteristics. The reverse lies in the desire to trace origins, establish roots, claim inheritance." (Ibid.) However, Euro-American kinship evokes not only ideas about continuity but also change (1992: 166) or "spontaneous hybridisation" (1992: 54). Strathern points out that "[w]hile the child claims its origins in its parents' make-up, it itself evinces a unique combination of characteristics, and the combination is regarded as a matter of chance. This lays the basis of its individuality." (1992: 166) Parents do not reproduce themselves completely, but "only reproduce parts of themselves" (1992: 165). A child, like any other reproduction, "repeats the original, but not in quite the same way" (Strathern 1999b: 209). In this sense, identities are understood "as inherited while inheritance leads to individuality" (Lawler 2008: 39).

While similarity is central to how kinship relations are made in a Euro-American realm, ethnographic research has shown that this is not the case worldwide. Studies conducted in Amazonia are of particular importance here, as they have shown that alterity instead of similarity constitutes "the fundamental premise of [Amazonian] kinship" (Carsten 2017: xxii, foreword to Costa 2017; see also Vilaça 2002) and that "Amazonian kinship is constructed from difference" (Costa 2017: 131). In his ethnographic study of kinship amongst the Kanamari people of Western Brazil, Luiz Costa argues that for the Kanamari, the birth of a child "does not create a kinship tie but instead threatens those that already exist" (2017: 99). The parents and other adults need to be protected from this danger through a series of perinatal practices, and the making of kinship ensues gradually through the feeding relation (2017: 22).<sup>8</sup>

It was striking that even those who did not speak of a "loss of identity" were still very much interested in possible similarities and perceived differences. Not being able to know the donor's identity was not a traumatic or hurtful experience for everyone. Although virtually all of my interlocutors mentioned that parents should inform their children about the circumstances of their conception as early as possible, not all of them felt that late disclosure had been harmful for them. They often stressed the fullness and completeness of their busy lives and the strength of their

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8 The practices Costa (2017) refers to and explores in his work are *couvade* rituals. They are performed by fathers before and after the birth of a child, with fathers symbolically taking the place of the mother and mimicking her behaviour.

family relationships, which had not been disturbed by the newly found information about their origins. But even though they did not feel they had to fill a “gap” in their lives, they still wanted to find their donor, and their curiosity was very much fuelled by what set them apart from their parents and other relatives, and by what they might have inherited from the donor. This was the case for Kai Silberschlag from Germany who had been conceived in the former GDR and taught history at a local school. Even though he had not told many people about his origins when I met him in March 2017 and was thus not as used to talking about his experience as others, the conversation with him never came to a standstill. Kai had been interested in learning about the history of his surname, which he said was extremely rare in Germany, when he found out that he was donor-conceived. His last name had been passed on to him by his father, who had already died when Kai was only seven years old. On the day of the baptism of Kai’s youngest child, which took place in late 2009, he had once again asked his mother about his name. She then told him that he had been conceived with donor sperm, and that his search was therefore pointless; after all, he had no genetic connection to his surname. Although this information had come as a surprise, Kai stated that his mother’s spontaneous revelation had not thrown him off track, as his father had been dead for more than two decades by the time of the baptism. Besides, his parents had been divorced at the time of his father’s death, and he had not been an everyday part of Kai’s life already for quite some time. Kai’s initial Internet research on DI in the former GDR had not resulted in a lot of information. Since he had a lot to do professionally and privately at the time, and also did not suffer from not knowing, Kai had quickly dropped his investigations.

It was only after watching a documentary in which two members of Spenderkinder and their search for information were portrayed that Kai decided to re-start his search in 2015: “That made me think again, and I said, this can’t really be it, not as a historian. That was sort of in the back of my mind all the time, I would like to know more about my origins and especially about these special circumstances [of DI] in the GDR.” Shortly afterwards, he contacted the organisation Spenderkinder, whose website he had already discovered during his initial search for information. In the meantime, he had also done a DNA test and, among other things, had visited an archive in the town where he had been conceived in order to search for information about his mother’s doctor. For Kai, curiosity seemed to be a fundamental part of his personality, and his decision to actively search for his donor and conduct historical research was more in line with his curious nature than his previous passivity. Curiosity has been described as one of the most common motivations for trying to find one’s donor and/or donor siblings (see for example Jadva et al. 2010: 528–529; Beeson et al. 2011: 6; Persaud et al. 2017: 19). Hertz and Nelson even make the following claim: “All children are curious about how they came to be born.” (2019: 33) This reflects the general

taken-for-grantedness of the “need to know” and does not take into account the cultural and historical particularity of such a claim. Since “more transparency, more information, and more openness within families are imagined as enhancing and lubricating relationships” (Edwards 2018: 167), curiosity and the attempt “to explore a space that must still be furnished for us” (Nowotny 2008: 3) are hardly neutral. If having knowledge is seen as something that is inherently good, then “curiosity and the desire to explore the unknown” (ibid.) is seen as desirable, or potentially almost mandatory. In turn, a lack or low level of interest in the donor was something that many of my interviewees described as incomprehensible, even though it was generally emphasised that the donor-conceived should be given a choice as to whether they wanted to access information (see section 3.5).

Although Kai did not mention a deep-seated feeling of always having felt the truth, he also emphasised that he was very different from his family. He had always wondered how he “fit into that”, which in turn had made him curious about his donor:

Amelie Baumann: “Do you see for example certain character traits or interests in yourself or maybe in your children that make you think, well that could be from that side, something that you can't see in your mother's family or in your wife?”

Kai Silberschlag: “Does it absolutely have to be about character traits, or could I start by mentioning something else, because there's indeed something else that I've always wondered about, even before I knew about the thing with the origins. I'm the one who has by far the highest degree of education within the family because I've studied at a university. And when I look at my social father's family, I've always asked myself how I fit into that. [...] And it's the same with my mother's family, sure, they all have some sort of job, and ones that, without a doubt, come with responsibilities, but there has never been anybody that studied. And there was never anyone who did Abitur [German university entrance certificate]. And I've always asked myself [laughs] what's the background to that, and it's the same now, was that person [the donor] somehow a student or whatever, where did he come from, this old question whether genes are responsible or whether it's just the family that you grow up in, or is it both. And if it were only the family that was responsible, in that case I would also ask myself, where does it come from, that I went so far regarding that aspect.”

He then mentioned his wide range of interests, his bustling nature as well as his sportiness as differentiating him from his maternal and paternal family.

Having so little in common with his relatives, it seemed inconceivable to him to attribute his academic success to the influence of his family. Others seemed to consider it possible that their interests and talents had developed without any kind of genetic influence. They wondered whether the qualities that distinguished them from their families had actually been passed on to them by their donors, or whether

they had simply emerged from within themselves. My interviewees were interested not only in what they might have in common with their donor but also in potential differences that might characterise their connection to him. These differences, however, concerned characteristics that they actually expected or anticipated to be similarities.

Differences and similarities played a central role in the way Sabrina Frey, who had been conceived in Germany in the 1980s, thought about her donor. At the time of the interview, she was in her mid-30s and on parental leave after the birth of her second child. She had last worked as an engineer and commented in an email she sent to me later on that the interview had been a nice change from her temporary life as a full-time housewife and mother. Unlike Kai, I did not meet her at home, but in a café in the pedestrian zone, while her children were still in a day care centre. Sabrina was only a few years older than me and offered me, after we had entered the café, almost immediately to switch from the formal “*Sie*” to the more informal “*Du*”. She made an extremely relaxed, open first impression on me, and this did not change during the following three hours. Just like Kai, she had known about the circumstances of her conception for several years by the time she had started searching for her donor and donor siblings. Although she had found out at the age of 20, her interest in the donor had only been awakened about a decade later when she had her first child. As her son resembled neither her nor her husband, Sabrina kept wondering if he might look like her donor. She started to look online for information on donor conception and came across Spenderkinder. Through the organisation, she learnt about the possibility of finding her donor and donor siblings via a DNA test, and she soon ordered a test kit. Her search was immediately successful, and Sabrina found three donor-conceived half-sisters through the database. One of them had received the donor’s name and his donor number from the clinic where Sabrina herself had been conceived as well, and this half-sister had also found another half-sibling via the homepage of Spenderkinder who had already met the donor in person.<sup>9</sup> At the time of the interview, Sabrina thus thought she had already identified the donor, as well as four donor siblings.<sup>10</sup>

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9 Sabrina Frey’s donor-conceived half-sister had found a fourth donor sibling who had received the same donor code and included it in her public “search profile” on the homepage of Spenderkinder. The homepage contains search profiles of 54 members of the association (May 2021). These profiles contain their date or approximate time of conception, include assumptions about the donor, state whether the member is registered with FTDNA, and contain a personalised email address in the form of name@spenderkinder.de ([www.spenderkinder.de/verwandtsuche/suchprofile/](http://www.spenderkinder.de/verwandtsuche/suchprofile/), last accessed May 28, 2021). Several donors (nine in May 2021) have search profiles as well ([www.spenderkinder.de/verwandtsuche/suchprofile-spender/](http://www.spenderkinder.de/verwandtsuche/suchprofile-spender/), last accessed May 26, 2021).

10 The story of Sabrina Frey is a particularly complex example of how kinship can be made. It illustrates that knowledge management connotes not only human agency but also the in-

Similar to Kai's account, her story was not marked by feelings of pain and loss, which seemed to be related to her extremely positive attitude towards sperm donation (see section 6.1). However, Sabrina herself mentioned that she would probably have experienced a crisis if she had not been successful in her search for information immediately after her registration with FTDNA. She seemed to be astonished about this herself and suspected that this probably had to do with her needing to have some sort of additional "activity" (*Beschäftigung*) during her parental leave. Her past ideas about what her donor might be like had been shaped by her own educational achievements, for which she had previously had a different explanation:

Amelie Baumann: "Did you have any idea about what he might be like before you found out about him [the donor that one of her donor siblings had met]?"  
 Sabrina Frey: [laughs] "I need to quickly think about what that was like. So, I always somehow thought it might have been a medical student, that's also what my parents were told. Well at least that many medical students would donate there. But I didn't really think about anything else in terms of looks. I only knew that he would have blue eyes because my children now also have blue eyes. And well, I have to somehow carry it in me genetically so that I can pass it on. And apart from that I didn't have any real ideas. So ... the only thing I could think of was that he probably also has a more advanced school education because I am the only one in my family who has an Abitur [German university entrance certificate] and who has studied. Whereas before I knew about the sperm donation, I actually always thought, 'How amazing is this, even in socially weak families, children can actually do that, well, they can get this kind of education.' [...] Yes, and now in the end, after I knew that I was the result of a sperm donation, I did actually think, well it is probably also down to the genes a little bit. I imagined that he is also an intelligent man."

While the picture of the donor that one of her donor-conceived half-sisters had shared with the rest of the donor sibling group did not look anything like Sabrina, what she found out about him seemed to match her life perfectly. Like Sabrina, he seemed to have a talent for both languages and science. In addition, he also seemed to share her passion for travelling. The information about his professional

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involvement of infrastructures (Klotz 2014: 55). At the time of the interview, the five donor siblings already had doubts about the validity of their discoveries. Sabrina had realised that the donor, whose date of birth they knew, would not have been of age at the time of her conception. She doubted that the sperm bank would have allowed underage donors to donate. Shortly after we had met up, it turned out that these doubts had probably not been unfounded. The half-sister who had not yet taken a DNA test eventually registered with FTDNA. However, she was not matched with Sabrina and the others, and Sabrina 'lost' one half-sister. Besides, she suspected that the one who had been matched with her had received false donor information from the clinic. Sabrina's search for the donor therefore continued.

background in particular immediately evoked associations with her own life. He was neither a doctor nor an engineer like Sabrina but worked in an area which she had considered as a possible professional alternative at the beginning of her studies. Sabrina seemed almost overwhelmed by the extent to which their lives matched:

Sabrina Frey: "I saw these parallels to him and said to myself, oh my God, I have so much in common with him, with this man although I don't know him at all, and then he's apparently also talented in natural sciences. In that moment I really thought, I got all of that from him. And it has nothing to do with how my parents raised me. Because before that I really thought that well, my parents raised me in such a way that maybe I'm just interested in learning or in school, and now that I have the information, I do actually assume that I've had it in my genes. So now I do actually think that genetics are very important for it after all."

Although the donor was still a stranger, he suddenly came very close, as he seemed to have a lot, and maybe even too much, in common with her. Her individuality that was based on inheritance seemed to dissolve, and Sabrina had the impression of being almost identical to her donor. Since "the child [...] signals the way variety and diversity are brought into existence" (Strathern 1999b: 209), feeling as if she was a copy of her donor was an uncanny experience for her (see also section 7.5 for a discussion of a similar fear, namely the fear of having too many 'clone-like' donor siblings). Similar to those of my interviewees who felt overwhelmed by the thought of possibly being physically close to a donor sibling or donor without realising it (section 5.4), the knowledge of having a close genetic relationship but no social relationship at all seemed to unsettle Sabrina. Finding out that she was donor-conceived had changed how she explained and classified her own achievements. Her narrative almost seemed to resonate with a sense of wounded pride: what had been the result of her upbringing and her own talents now seemed to be down to the influence of the identified yet distant donor.

Like Sabrina and Kai, many people in both countries stated that they were the first ones in their family to have received a university entrance certificate, and/or that they were the first ones to study. Even those whose parents were academics usually described their specific intellectual abilities and talents as something that distinguished them from their family. As for the educational background of my interlocutors, my sample of donor-conceived persons was indeed very homogeneous. Most people had at least one academic degree or were still studying when I met them. Given the nature of our encounter – a research interview in the context of a doctoral project – it is arguably not surprising that most of the people who contacted me did have an academic education. Since most of my interviewees had either already completed a degree, were still studying or were thinking about doing a PhD, my own experiences in German and Swedish academia, and espe-

cially with postgraduate studies, were often a subject of conversation before and after an interview. Nevertheless, it is not self-evident that education, intelligence and academic talents were the categories people referred to particularly frequently when talking about what set them apart from their families, and when reflecting on what they might have inherited from their donor. Many imagined them to be doctors, partly because their parents had been told that the donors were medical students. I suggest that the way in which they oftentimes imagined the donor as a well-educated, intelligent, multi-talented and successful person can be read as a means to imagine and situate themselves as middle-class. Just as children can be a symbol of their parents' class position (Ortner 1992: 5), anonymous (or, as it was the case for Sabrina, presumably identified) donors can become a symbol of the donor-conceived person's own class status.<sup>11</sup> My research contacts tried to situate themselves as belonging to the middle class by imagining their donors in categories that evoked notions of both class and biology.

#### 5.4 Scanning for similarities: Active not-knowing and unfinished relations

While my interviewees focused less on possible outward similarities when talking about what they might have inherited from the donor, appearances played a larger, but not all-determining role in a process I have termed "scanning". Many people told me that they often caught themselves scrutinising others, searching for similarities and thinking about whether a stranger or someone they already knew might be their donor or a donor sibling. Scanning was generally described as being particularly prevalent in the period following the initial disclosure talk with one's parents. It could take place in public, on trains and buses, or in supermarkets, when people examined other passengers or shoppers and wondered if their donor or a donor sibling was one of them; it could occur when people watched TV and suddenly discovered an actor who had some resemblance to them, or take place in a gymnastics class; some scanned not only strangers but also their friends. My choice of words is inspired by Sabrina Frey. She told me that she and two of her newfound donor siblings had "scanned" each other (*man scannt sich erstmal direkt*) at their first meeting to figure out if they had any similarities. They found that

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11 Sherry B. Ortner (1992) argues that middle-class parents are particularly preoccupied with the fear of losing their class status, which their children might not reproduce. She suggests that "[i]t would be vulgar and reductionistic, and even downright silly, to claim that everything parents feel for their children, and do for and to their children, is only a matter of insuring class reproduction" (1992: 7), but claims that "it would also be silly to deny that, in some very broad sense, this is a large part of what is going on" (*ibid.*).



they were all talented in foreign languages as well as natural sciences and enjoyed travelling. In my analysis of scanning, I will first draw on Konrad's ethnography of ova donation (2005a), and more specifically on her notion of "active not-knowing" (2005a: 170). Afterwards, I will discuss scanning in more detail, using two examples from my research. In doing so, I will show that the process of constructing imaginary relations is not exclusively agency-driven.

Throughout *Nameless Relations*, Konrad shows that donors as well as recipients make "effective action from out of the uncertain knowledge set up by the conditions of anonymity" (2005a: 117), which counteracts tendencies to ascribe them a passive role in reproduction (2005a: 14). She cites the case of a donor called Penny who views her donation as "a form of pseudo-procreation" (2005a: 117), should she remain childless, to illustrate her point. While others were disappointed about not being able to know the outcome of their donation, it is precisely this uncertainty and the possibility of someone else having conceived a child with her donation that matters to Penny (*ibid.*). Konrad suggests that Penny transforms herself into "her own 'bio-engineer' whose productive agency circulates 'through' others as the spatio-temporal effects of transilience" (*ibid.*). Konrad's work thus shows that in the context of anonymous ova donation, not-knowing is not a passive condition that women simply endure. Instead, Konrad argues that "within anonymous sociality, active not-knowing sets up 'unfinished' relations' relations whose unconcealing makes persons 'transilient'" (2005a: 180). These relations cannot be 'finished' because that which is imagined cannot be known. Another example for active not-knowing are ova recipients who frequently wonder about their donors and ask themselves whether they will ever be able get in touch with them (2005a: 170). Similarly, my interlocutors told me that they kept wondering about whether the donor ever thought about his past donations, and his donor-conceived offspring at least from time to time (with many of them believing that this would be the case; see section 6.4). The scanning of others is a particularly interesting case of active not-knowing, as it was usually described as a process from which one could not escape.

While scanning was mostly focused on strangers, Jade Foster from the UK also scanned people she already knew. She had only started her studies a few months before we met up in a coffee shop in the town where she studied. Despite expressing her opinions with great determination, she seemed a bit nervous especially at the beginning of the interview and kept moving back and forth on her chair. Jade had not talked to many people about the circumstances of her conception since her parents told her four years ago that she was donor-conceived. Her younger brother, who had been conceived with sperm from a different donor, had not yet been told by their parents that he and his sister were donor-conceived (see section 6.3 on "sibling trouble"). Like others of my interlocutors, Jade said she was interested in finding out who her donor was "as a person" (section 7.3). For this reason, she had requested information from the central HFEA register. Even if the HFEA letter,

which she had not yet received, would not contain the kind of donor information she had hoped for, especially if it turned out that the donor had not removed his anonymity, it would still give her basic information about the existence of donor siblings. For her, the thought of having donor-conceived half-siblings was both exciting and unsettling, and her hopes regarding the register information seemed to be focused on them and not on the donor:

Amelie Baumann: "Do you hope that it [the HFEA letter] will answer some questions?"

Jade Foster: "Yeah, I really hope that I do have siblings, but I don't want to get my hopes up in case I don't. But I think it would be really exciting, it's like a secret family. And it's exciting that they could be people that I know because of, you know, people conceived at a similar time and a similar area. It could be someone from my school, I could already be friends with them, but it's exciting. And terrifying. [...] I'm worried that it'll be someone that maybe that I do know and don't like, that would be disappointing if it's someone that I know and aren't friends with."

Amelie Baumann: "Have you ever met someone where you thought this could be"

Jade Foster: [interrupting me] "I'm terrible for doing that, every time I see similarities in someone to me in any sort of way, 'Maybe, maybe', even if there's no chance and I know their whole family and I know that they're not donor-conceived. And still part of me will be thinking, 'Maybe they could be, we look similar, or we have similar personalities, similar interest. Maybe there's a chance.' And whenever someone says, 'Oh, Jade, you look like my friend so and so', 'Do I? Which friend? Give me their number!' [laughs] It's tiring [laughs] and frustrating, I'm always looking, I'm looking for similarities in everyone."

The thought of finding donor siblings was an exciting one for Jade, as it would put her in a situation where she could hide something from her parents, who had kept information about her origins from her for 14 years. This time it would be Jade herself who could decide whether information should be passed on or not. Her excitement illustrates that "the power and attraction of the secret lie in the possibility that it may be disclosed" (Beidelman 1993: 41). Not knowing whether she had any half-siblings conceived with sperm from the same donor, Jade found herself in a situation where scanning others and making imaginary connections with strangers, acquaintances and friends was an almost endless undertaking. Although the persons she was looking for might have been near her, they could not be identified by her as donor-conceived. This caused restlessness in her, which was also described by others who had initially been intensely involved with scanning. While scanning illustrates that not-knowing comes with its own imaginative possibilities, which is a point that has also been made by Copeman in his ethnographic study of voluntary blood donation (2009: 10), it also shows that not-knowing comes with its own challenges and frustrations.

Melanie Weber from Germany also described scanning, or “inspecting” as she called it, as exhausting. While scanning for Jade was still an ongoing process or rather constant condition, Melanie reported that she no longer constantly looked for similarities in others when I met her less than a year after her parents had told her that she had been conceived with donor sperm in the 1970s. She stressed that she had very quickly forgiven her parents for their secrecy, knowing that her father would have been stigmatised by his relatives if the truth about his infertility had come to light. Melanie described her handling of the late disclosure and her way of thinking about her anonymous donor as “relatively soft”. Although she was curious about the donor, she said that the thought of never being able to find him did not worry her. Her description of the first weeks after the disclosure talk with her parents contrasted with the overall “soft” undertone of her story, which extended into the actual interview situation: the atmosphere of the interview, which took place in the house of her and her husband in a quiet and strikingly green suburb of a big city, was very relaxed. While we sat on very comfortable sofas in her living room, her daughter, who was not yet a year old, crawled back and forth between us and other parts of the room. While I had initially feared that this might be distracting, it contributed even more to an almost homely atmosphere.

Her relaxed manner and “soft” view differed from what she had experienced in the weeks after the conversation with her parents. She described that at first, she could hardly believe that she was not genetically related to her father, as she was very similar to him in appearance and character traits. For this reason, she had initially thought of doing a paternity test, which she felt was her attempt to “hang on” (*festklammern*) to his paternity. Apart from the fact that she could hardly believe her parents at first, what bothered her in the beginning was her constant urge to look at men who might be her donor, whom she alternately referred to as her “donor”, “genetic father”, “donor father”, or, as it is the case in this passage, simply “father”:

Melanie Weber: “I had difficulties in the first months, I really looked at every man who was around 50, inspected him and always asked myself, ‘Oh my God, you could be my father, or you could be my father!’ So that drove me crazy at first. And then I thought, he could walk around somewhere here. I can actually imagine that the likelihood of him still living in [large town in which she had been conceived and which was close to where she lived] or somewhere around here is relatively high. Yeah, that drove me a little crazy.”

Although she had never felt that her life and her family relationships had been destroyed or damaged after she had found out that she was donor-conceived, she was still drawn into “inspecting” men who might be her donor. Finding out that there had been something she had not known for over three decades seemed to draw her attention to something she still could not know, even though she had been told: she

could not find out whether the donor was near her. For this reason, her scanning seemed to be especially strong at the beginning, as was the case with others. Since the town she lived in was, as Melanie laughingly remarked, “overcrowded with pensioners” of the right age to be her donor, and since there was a big city nearby, the potential number of men she could scan seemed pretty much unmanageable. However, her initial worries had soon been removed by the birth of her daughter, with whom she had been pregnant at that time, and the new family’s bliss.

Since her “soft” approach was distinctly different from the persistent feelings of loss described by others, I found it all the more striking that Melanie was also drawn into “inspecting” for at least a few months. Although more systematic inspecting/scanning with the purpose of finding the donor could be ignited by the (mostly sparse) donor information individuals had received (see for example Nadine Fuchs in section 8.2; she had ‘scanned’ the Internet for pictures of her donor), scanning could also occur in a more diffuse way that seemed to have an almost uncontrollable dynamic from which people could not escape. Similar to the way in which people felt compelled to at least try and find their relatives (see section 8.3 on “having to try” DNA testing), the practice of scanning was not entirely agency-driven. Usually it was something that people did not consciously initiate, although some people at some point consciously tried to stop scanning and analysing their environment. Despite this commonality, I suggest that scanning is different from the more goal-oriented process of searching for one’s donor or donor sibling. While a search was usually conducted with the aim of destroying a “brick wall”, as Sarah Holmes had put it when talking about donor anonymity, scanning was usually characterised by a different relationship to the unknown.<sup>12</sup> Instead of addressing it directly and trying to undo anonymity through targeted search-actions, those who scanned others seemed to be circling around that which they could not know for sure.

The thought of possibly being physically close to donor siblings or the donor and not being able to determine whether there was an actual genetic relationship was a challenging, stressful or at least irritating one for many. When people know that they were conceived with donated gametes but do not know the identity of their anonymous donor and/or donor sibling, they know that they could potentially meet them in a public or private environment without knowing that they are related to them. The fear of unknowingly entering into an incestuous relationship seemed to play a subordinate role and was rarely discussed by the people I interviewed (but see section 7.5 for an exception). Instead, the constant scanning of others seemed to

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12 Sarah Holmes mentioned that not being able to talk about her origins with her parents and not knowing her donor had kept her from “really knowing who I was”, adding that there was “not only [...] a void, it was a brick wall in my quest because I couldn’t go anywhere for that information”.

bother them because although they could speculate about whom they were related to or not, they could not find out whether their assumptions were really accurate. The number of their imaginary relations could become too big. Some tried to solve this problem by consciously deciding not to scan others for similarities anymore, thus trying to limit anonymity's imaginative possibilities.

## 5.5 Recapitulation

When people receive new kinship information, their kinship time and the way they relate to past, present and future relations is disrupted. Often, the people I interviewed had an idea about how their lives would have been if such a disruption had never occurred. I have analysed these scenarios as disnarrated elements that shed light on how people imagine a desirable alternative to the secrecy and late disclosure they had experienced. These alternative visions were mainly characterised by continuity, which is what the donor-conceived had lost. Apart from these alternative scenarios, another recurring element in many narratives was the look back at past events. Reinterpreting memories based on the experience of having felt the truth as a child, despite the secretiveness of one's parents, could help to counteract a feeling of lost continuity. The news about the circumstances of one's conception could be interpreted as something that in itself was not really new and therefore not an actual disruption. At the same time, having 'failed' to see the truth could be extremely painful.

Accounts of always having "felt the truth" were accompanied by a description of what distinguished a person from their family, which illustrates that establishing and identifying similarities is central for the way in which relations are made. As ethnographic studies on Amazonian kinship have shown, similarity is however not always central to the making of relationships. When people talked about how they were different from their family, and about what they might have inherited from their donor, they mentioned particularly frequently that they had a higher degree of education than their parents. On the one hand, I interpret this as an imagination that is inspired by the widespread idea that donors were medical students. On the other hand, it also constitutes an effort of the donor-conceived to position themselves as middle class. While these imaginations seemed to be very positive, another instance of active not-knowing was mostly perceived as very unpleasant. Especially in the beginning, right after being told, many searched for similarities in the people they saw in their everyday life or on TV and tried to figure out whether they had seen their donor siblings or their donor, a process which I have termed "scanning".

## 6. When the cat has been let out of the bag

### Managing kinship trouble

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In his ethnographic study of anonymous sperm donation in China, anthropologist Ayo Wahlberg points out that “[b]oth recipient couples and donors engage in various negotiations of who to confide in” (2018: 177), instead of sticking to “absolute secrecy or confidentiality” (ibid.). Wahlberg argues that it is “the management of who should know what” (2018: 171) that is their biggest concern. Parents want to avoid having to deal with their social environment’s gossip, and donors want to protect “their imagined future family life” (ibid.) from any disruption that could occur if children conceived with their sperm would contact them one day. Referring to anthropologist Sebastian Mohr’s (2015) exploration of how Danish sperm donors make sense of the connections between them and the children conceived with their donations, Wahlberg interprets this as an effort to manage any potential “kinship trouble” (2018: 171), which can “arise[...] when connections to third-party children are negotiated in particular cultural and juridical settings” (ibid.).<sup>1</sup> Clinics are also involved in the process of managing kinship trouble, as they ensure that donors and recipients stay separate. However, Wahlberg points out that “further kinship trouble” (2018: 177) cannot be precluded “should the proverbial cat be let out of the bag” (ibid.).

In the case of my interviewees, the cat had already been let out of the bag. They thus looked back at how their parents had imagined and managed kinship trouble in the past and critically evaluated their decisions regarding disclosure. Some

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1 Mohr argues that donors in Denmark, which allows both anonymous and non-anonymous donations, face kinship trouble, as they are “in a cultural and organizational context that offers different and contrary ways of how to make connections to donor-conceived individuals meaningful” (2015: 470). Sperm banks and Danish laws expect them to conceive of these relations as “contractual relations” (2015: 474), whereas “the dominant kinship narrative” (ibid.) urges donors to interpret them as belonging to the realm of family relationships. Mohr argues that donors “walk unexplored territory, not really knowing how to ascribe meaning to connections that defy existing classifications of kinship” (2015: 481). He suggests that although kinship trouble is commonly perceived as negative, it “might open avenues for new types of sociality not grounded in traditional concepts of being related” (2015: 482).

of them had learnt in conversations with their parents that they had followed the instructions of their doctors, who had advised them to simply forget the whole treatment. This used to be a common practice (Dempsey and Kelly 2017: 205). Others had been told by their parents that they had been indecisive immediately after the treatment and then simply missed the opportunity to tell their children. Since their parents had opted for donor conception in a context where there was a clear “cultural expectation that men uphold the patriarchal status quo through their biological contribution to the creation of a child” (Becker 2000: 134), the danger that the donor posed to the patriarchal family order had to be minimised through secrecy (and anonymity). However, in most cases they had already told others – mostly inside, but sometimes outside the family, even if they did not necessarily intend to tell their children about it. I found that a central question people asked themselves was not only who the donor was, but also who else knew about the circumstances of their conception – and who else within and outside the family should be told about it. At times, they were even more concerned with these questions than with the identity of the donor.

The importance of finding out who else knew and actively managing kinship trouble by telling or not telling others indicates that constitutive knowledge matters in ways that are not fully reflected upon in policies and debates about openness and access to information. The examples discussed in this chapter illustrate that anonymity, secrecy and information have the potential to become problematic in ways that are not accounted for in policy documents and discussions regarding the individual’s right to know. Moreover, the decisions people make when it comes to kinship trouble are often far more complex than the ideal of honesty would suggest. In my analysis, I am again inspired by Konrad, who has analysed “right to know” discussions in a different context (2005b). In her insightful ethnographic account of predictive genetic testing, Konrad argues that the “moral decision-making within and across generations” (2005b: 4) is more complex than genetic “right to know” debates might suggest.<sup>2</sup> “Right to know” arguments are part of the discussions surrounding predictive genetic testing, which can determine one’s personal risk of a specific disease (Chadwick et al. 2014). Proponents of these tests argue that individuals have a right to know and access information about themselves (Sheehan

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2 In their study of the history of direct-to-consumer genetic testing, Stuart Hogarth and Paula Saukko discern two “waves” (2017: 197) of companies. Whereas the first wave that started to emerge in 1996 mainly offered nutrigenetic testing and personalised dietary advice, a second wave of firms that emerged about eleven years later started to sell risk tests for common diseases that can have polygenic origins (2017: 197). Hogarth and Saukko argue that these newer firms “have been able to shift the discursive terrain on which the future of genomics is contested” (2017: 205), as they have managed to establish a view of predictive genetic knowledge as something other than frightening. They “have asserted the principle that individuals have a right to their genome” (ibid.).

2015: 287) and maintain that “knowledge increases autonomy” (Bourdeaut 2016: 53; see also Borry et al. 2010; Prainsack 2014), which in turn is assumed to have a positive impact on important life decisions.

In her analysis of the experiences of families affected by Huntington’s Chorea, an inheritable disease that can be detected in pre-symptomatic persons, Konrad points out that discussions about a genetic right to know are largely based on a framework in which the rights of an autonomous individual are dominant (2005b: 88). She argues that the debates fail to take into account that predictive testing does not just raise questions for the individual that is being tested. Instead, it can have implications for other relatives as well: if one person is found to be a carrier, then any family members to whom they are genetically related are at risk too. This can lead to serious “disclosure dilemmas” (2005b: 4). Konrad gives the example of a woman who tested positively for Huntington’s Chorea but decided not to tell her healthy father, who had already lost her sick mother to the disease. Konrad concludes that “considerations of care and kindness [...] seem more relevant to her than the disassociated norm of straight talk imbibed in the principle of honesty” (2005b: 92), and I found the same to be true for the way my interviewees approached telling others.

I will start off by discussing the preoccupation of my interlocutors with the question “Who knows what?” on a general level. In the second part of this chapter, I will examine how my interviewees themselves made decisions about whom they wanted to tell, and what kind of kinship and friendship trouble they envisaged and experienced in that process. Following from that, I will turn towards the situation of those whose siblings had either not yet been told that their parents had used donated gametes to conceive them, or who had only found out later on. In the fourth and last part, I will examine how my interviewees felt about telling their non-donor-conceived children about their donor-conceived origins. This will show that the effect of constitutive information extends into people’s kinship future.

## 6.1 Who knew what and when: Broken trust and foreign children

Several people mentioned that immediately after being told about the circumstances of their conception, they had asked their parents who else knew about it. To find out that relatives or close friends of their parents had been informed years ago was a very painful experience for many. It could reinforce the feeling that one could have been told way earlier, which in turn reinforced the feeling that one should have been told early on. The more people had already been informed, and theoretically could have talked about it, the more likely a different outcome and an earlier disclosure would have been. But it could be just as painful to learn that one’s parents only told a grandparent, aunt or uncle who then remained silent, especially if peo-



ple had a close relationship with this person. My interlocutors often described that this had impaired their ability to trust their parents in particular. Trust is commonly seen as deriving from kinship (Carsten 2004: 142), and it is mostly accepted that “kinship forms an archetypical sphere of trust” (Zitelmann 2018: 66). In the following pages I will give two examples of people for whom broken trust and the subsequent management of kinship trouble played an important role. I will then investigate why strict secrecy was rejected, especially by those who did not believe that using donated gametes inevitably causes kinship trouble.

For Timothy Parsons, who was in his mid-20s and had been conceived in the UK shortly before the HFEA was founded, it was particularly important to find out who knew, rather than focusing on the identity of his anonymous donor. At the time of the interview, he had known for about ten months that he had been conceived with donated sperm, and he was not completely sure whether he should even try to find his donor. Unlike those who had known for years or decades, and who seemed to be experienced in telling their story, it was a new experience for Timothy to talk about it extensively. He described our meeting as a useful “preparation” should he meet his donor sometime in the future, as such a meeting would be “immeasurably more difficult” if he had not previously talked about it with anyone. The way he jumped from one topic to the next seemed to reflect how much the news about his origins still stirred him up. At several moments during the interview, he seemed to be close to tears, which matched his self-description of being “a very emotional person” and of having been “emotionally torn” when his mother spontaneously told him that he was donor-conceived. Timothy himself pointed out that his life had already been quite “unstable” prior to finding out because he worked freelance. Since work commitments could come up at short notice, he had informed me by email that he could not plan the interview long in advance. After he had already postponed a first meeting, Timothy emailed me one afternoon that he would have time the following day. Fortunately, I had no plans yet, and we agreed to meet up in his favourite café. It was very small but well attended, and I was not sure at first if Timothy would feel comfortable enough with so many people to talk openly. He had already informed me that it was extremely important for him to remain anonymous, which was why I was surprised about the meeting place he suggested. In the café that he often visited, the probability that those present might listen in on our conversation and might even know him seemed to be relatively high, despite it being situated in a big city. While speaking in a low voice at first, Timothy did seem to feel a lot more comfortable later when the room emptied, which was reflected in his voice becoming louder and him getting more emotional. As I found out during the conversation, his anonymity was a concern to him because his father’s family did not know he was donor-conceived, and Timothy wanted to avoid them finding out. While I had feared from his inquiries about my anonymisation practices that he probably would not be very open, my fears turned out to be unfounded.

Timothy mentioned that he had been shocked when his mother spontaneously decided to tell him about his donor-conceived origins as they were driving her car, and he was sure he would have processed the news better if he had been told in a more planned way. He remembered that there had been three things he immediately wanted to know: who else knew that he was donor-conceived, whether his younger brother (who was also donor-conceived, but with sperm from a different donor) already knew, and who his “biological father” was. Whereas his mother could not tell him who the donor was, she did tell him that while his younger brother had not been told yet, her family members, to whom Timothy had always been very close, had known for a long time. Finding out who else knew became the basis for a reassessment of both his life and his family relationships:

Timothy Parsons: “You’re trying to figure out who the hell am I, who can I trust, who can I talk to, who do I need to feel accepted by, and I guess I was finding out who knew because I felt it was such big information, and I then I want to know who knew before I knew because obviously it says a lot about, I kind of felt cheated in a way because I felt like most people knew, but I didn’t know, and then my mom and my dad, I felt like they’d trust me, they would tell me this kind of information before they’d tell anyone else.”

While others were very angry about their parents’ secrecy, Timothy showed understanding for his parents’ decision not to tell, noting that his family had already been “quite broken as it was” due to his parents’ early divorce. He interpreted their decision as an attempt to protect him and his brother from further damage. However, ten months after the first conversation with his mother, it still hurt him that the majority of his maternal relatives had known but had never mentioned it to him or his brother. Finding out who else had been informed had been “a really big thing” for him, although his intention had never been to talk to his relatives about the circumstances of his conception. His trust in his maternal family and in his parents was still shaken, despite his understanding and his decision to forgive them. However, his anger and disappointment did not lead to him severing ties with his family. Instead, he made a conscious decision to practice and cultivate trust by spending more time with his family and tried to see all of his relatives regularly, believing that not getting in touch with them would only make him angrier.

Unlike Timothy, Lindsay Billington knew that relatives on both sides of the family as well as several of her parents’ friends and colleagues had been told before she herself was told by her mother and father shortly after her twenty-first birthday. Lindsay reasoned that her parents’ frequent visits to a clinic in the early 1990s, combined with her mother suddenly getting pregnant after trying unsuccessfully for a long time, had almost forced her parents to tell since “it would have seemed strange if you try for seven years and then you conceive naturally without help”. In fact, her parents eventually decided to talk to Lindsay precisely because people in-

side and outside the family already knew about it. Her paternal grandmother had never agreed with donor conception, and they were afraid she might tell her out of spite. They were also afraid that a man outside their circle of friends might tell her, as one of Lindsay's uncles had warned them that this person had found out. She was noticeably hurt by her father's confession that he would never have told her if it had not been for her grandmother "acting up" and her uncle's colleague finding out. Her own initial feeling of shock gradually changed into anger as she struggled to come to terms with realising that people remained silent even after she had been told:

Lindsay Billington: "I mean I wouldn't be bothered that somebody else knew, I was bothered that all my family knew and didn't tell me for my whole life, and that since I've been told, there has only actually been ... one of my uncles and my brother, one of my brothers [from her father's first marriage, not donor-conceived] who have dared to actually talk to me about it, like no one has mentioned it to me."

Amelie Baumann: "Although they know that you know?"

Lindsay Billington: "Yeah, even though they know [...] it is hard to know that all your family knew and look at you, and they don't say anything because it was such a big secret in the family, and you just think, two of my mom's best friends knew, and then you find out that in fact *all* of her friends that she used to work with knew, and you just think, why did everyone know, but not me?"

In order to find out whether it was known "further in the family than just the grandma's siblings", Lindsay eventually told one of her cousins. As it turned out, she had not been told, and Lindsay swore her cousin to secrecy. Lindsay's trust in her parents had been unsettled, and the sense of betrayal that many people talked about was particularly strong in her case. She described herself as having been "a trusting person" prior to finding out and mentioned that she had "lost trust in other people". Her parents had repeatedly tried to raise the issue over the past two years, but Lindsay had blocked the conversation time and time again, as she did not feel comfortable talking to them about donor conception.

The issue of lost or broken trust that appeared in both Timothy's and Lindsay's account was a common theme in many interviews, with people frequently mentioning that they feared that their parents might have even more secrets. Trust, which my interviewees deemed essential for family relationships, has been described by Niklas Luhmann as a complexity-reducing mechanism (2017). Similar to hope, which is directed at an uncertain future (Mattingly 2010: 15; see also section 7.4 for an exploration of the connection between hope and uncertainty in the context of voluntary registers), trust has a specific relation with what is yet to come. Since "not all futures can become the present and hence become the past" (Luhmann 2017: 15), the future needs to be 'pruned' through trust (*ibid.*). In the case of people who found out that their parents had kept information about their ori-

gins from them for years or decades, while mostly telling others, their ability “to enter a social relationship on the expectation that the other will act according to one’s expectations” (Müller 2013: 42–43) had at the least been temporarily damaged. Since trust is integral to the way they conceptualise kinship, managing broken trust becomes an essential part of becoming donor-conceived. Although the realisation that others had already known could be painful, even those for whom this was the case often emphasised that while their ability to trust had been damaged, it had not resulted in them turning away from their parents. For example, Lindsay mentioned that although the relationship between her and her parents had changed, they were still very important to her: “I do love them to pieces, and they’re my mom and dad and they always will be.” I will return to the donor-conceived’s use of kin terms in the last part of this chapter.

While for most of my interviewees it was painful or at least unpleasant to learn that others had already been informed, complete secrecy on the part of the parents or one parent was also considered undesirable. Those whose parents had not shared the information with anyone else sometimes mentioned that secrecy had damaged relationships in their family and especially their parents’ marriage. They usually interpreted their parents’ refusal to talk about it as a sign of especially their fathers’ insecurity. My research contacts themselves sometimes stressed that they found their parents’ secrecy unnecessary, as the decision to have a child through sperm donation was something they admired. They felt that their parents could and should be open about it. Respect was expressed both for the fact that parents had decided to undergo an elaborate and strenuous treatment and for the fact that fathers had agreed to have and raise a child with whom they were not genetically related. I suggest that the respect people voiced especially for their fathers indicates that they were aware of the “norms around fatherhood that deem genetic connections between child and father important” (Mohr 2015: 471). Since their fathers had been ‘brave’ enough to have children through sperm donation despite these norms, they wanted them to feel pride instead of shame. Some of them mentioned that they were grateful to their parents for having chosen this special and difficult path. They were impressed by their decision to raise, as Melanie Weber put it, “a foreign child” (*ein fremdes Kind*) instead of an ‘own child’. Donor-conceived children can be seen as “foreign” in two ways: firstly, they are not genetically related to the man who raised them, and their roots therefore do not lie within the family their fathers are familiar with. Secondly, the anonymity of the donor means that neither they nor their parents can know where they “really come from” in terms of genetic origins. Since having knowledge “is perceived to be good in itself, alleviating insecurity and diminishing unpredictability” (Edwards 2009a: 140), genetic foreignness set up by the conditions of anonymity was interpreted as something that demands courage from parents and especially from fathers. It was seen as a step into an unknown kinship future. Although my interviewees sometimes described themselves

as the “foreign children” of their father, it does not follow from this that they saw themselves as the children of their donor. When they spoke of the donor’s “own children”, they referred to those who had been conceived *and* raised by him. The genetic connection alone was thus not seen as sufficient for the creation of “own children”, which illustrates that “what an ‘own child’ is and what it means is not given a priori” (Melhuus 2012: 25).

Sabrina Frey from Germany was one of my interviewees who believed that fathers should be respected and admired for their decision to raise a genetically foreign child. She mentioned that her parents had in the past treated the circumstances of her conception as “a gigantic family secret” and told no one that their daughter had been conceived with donated sperm. Sabrina had learnt of the circumstances of her conception when her parents, who were now divorced, had had a fight, and she believed that her mother had told her in order to hurt her father. Her mother had become more open over the years and was interested in Sabrina’s search for the donor and donor siblings, whereas her father had still not told any of his friends or relatives. He did not want to talk about it with her either. Even after more than ten years, he was still not comfortable with the thought that she knew. Sabrina reasoned that he was still afraid that she would turn away from him, despite her repeatedly trying to reassure him that this would not happen. She also guessed that he was afraid of no longer being seen as a man if others found out about his infertility. Sabrina hoped that he would overcome his fears in the future, and she was convinced that he would not encounter negative reactions if he told others, believing that “all fathers who decide to use a sperm donation because of their infertility, they really deserve a lot of respect because they decide to raise a child that’s not their genetic child”. She admired her father’s courage and felt that he was placing an unnecessary burden on himself by trying to keep it a secret “come hell or high water” (*auf Biegen und Brechen*). Sabrina was of the opinion that the decision to have a child with donated gametes was something to be proud of and that he could and should tell others about it: “Maybe he would just make the experience of people telling him, ‘What you did is great’, something like that. Or something like, ‘I would not have had the courage to do that’, maybe he would get a reaction like that.” Overall, she felt happy and proud about being a “*Wunschkind*”, a child that had been wished for. Sabrina was convinced that “there’s nothing better than that”.<sup>3</sup> For this reason, she believed that the use of donated gametes did not have to be concealed: “That’s why I don’t understand why you have to hide it. It’s nothing bad.”

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3 “*Wunschkind*” literally translates as “wish child”. The term is commonly used to refer to a child that his/her parents had wanted and ‘planned for’ but has a more emotional and less technical connotation.

Several people also argued that nothing better could happen to a child than to know it had been wanted this much, instead of being born as a result of an ‘accident’ or because one’s parents felt pressured to have children.<sup>4</sup> However, the question of whether a decision to conceive with donated gametes was something admirable (for which donor-conceived people should be grateful) or not, was highly controversial. In Germany, these debates were particularly evident in the way in which the term “*Wunschkind*” was evaluated and used. While Sabrina and others emphasised that a donor-conceived child was a “*Wunschkind*”, others rejected the term as irrelevant and offensive. For them, the term symbolised that parental desires were respected more than children’s rights. Not everyone was of the opinion that they were particularly wanted. While some emphasised that they felt very loved, others commented that their parents would have preferred to procreate with their own gametes, and that they therefore did not feel wanted at all.

## 6.2 Who should know what: Relations between concealment and revelation

Apart from trying to figure out who else knew, my interlocutors also engaged in the management of kinship and friendship trouble by deciding whom they themselves wanted to tell, and when they should conceal the information. Even Melanie Weber, who was afraid that her parents and especially her father might get stigmatised if others found out, had told her husband and her best friend about the circumstances of her conception. Otherwise, she was very anxious to keep this information secret. Although she admired her parents for their decision to raise children that were not genetically related to her father, Melanie had initially had concerns about joining the mailing list of Spenderkinder. She had been very afraid that other members of Spenderkinder might misuse the information about her conception,<sup>5</sup> and that it might ‘escape’ the safe space of the mailing list and reach the outside world. In general, my interviewees mentioned that they had at least told their close friends that they were donor-conceived. Many felt that it was such an important part of their lives that they did not want to hide this information from people they were close to, and everyone who was in a relationship told me that “of course” they had

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4 A similar line of reasoning has been observed by Heather Paxson (2003) in her ethnographic study of IVF in Greece. Some of the women she met felt that “their commitment to having a child using IVF makes them better mothers when many others around them appear to have a child merely because it is expected of them” (2003: 1858). Paxson argues that “the efforts they make to achieve motherhood are incorporated into a longstanding ideology of maternal suffering or sacrifice” (ibid.).

5 Melanie Weber explained her fears with reference to her work in the police force: “I just had a lot of negative experiences with people, so I always assume the worst.”

told their partner. For some of my interviewees, telling others had been a positive experience: since the people they had confided in had reacted sympathetically, they felt that their own emotional response to finding out had been justified. However, this was not the case for everyone that I met. In the following pages I will first explore why this was usually described as a very painful experience. I will then go into more detail about how Timothy Parsons, whom I introduced in the previous section, felt about telling others, and how not being met with a lot of sympathy lead to him rethinking his friendships. In the last part, I will focus on the decision to withhold information from certain individuals and explain why this can be read as an attempt to manage kinship trouble.

Several of my interviewees mentioned that they had not been met with much understanding, especially from their friends. They had the impression that others could not understand why it even mattered to them that they were donor-conceived. Above all, their friends did not seem to understand why it was painful for them not to know the donor's identity. Repeatedly I was told that others did not understand why someone would be interested in finding him. It was not uncommon for people to become more hesitant about telling if they got reactions that they perceived as unhelpful or unsympathetic. They had expected the people they were close with to understand "what it's like" since they, as their friends or relatives, had personal experience of what it is like to be donor-conceived. For them, "knowing' is achieved through experience" (Edwards 2000: 240). According to Edwards, the idea that knowledge and experience are linked is "central to the way in which people make sense of NRT [new reproductive technologies]" (ibid.). Although the people she talked to during her fieldwork were critical of certain technologies, they assumed that either being infertile themselves or knowing someone who was unable to conceive would change their perception (2000: 240–241): "An understanding of the implications of involuntary childlessness is not gained through discrete items of information [...] but is achieved through experience transferred along axiomatic links between those who are already *close*." (2000: 241, emphasis in original) The disappointment my interlocutors felt when not being met with a lot of sympathy illustrates that they, too, had believed that "feelings travel between people already connected" (ibid.). Their expectations were not always met. It was striking that what I was told by my interviewees does not correspond to some of Spenderkinder's statements: on its website, Spenderkinder emphasises that its members cannot report any negative experiences with regards to telling others.<sup>6</sup> Given the association's emphasis on the importance of telling donor-con-

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6 For example, one blog post (Spenderkinder 2014b) describes the results of an internal survey that Spenderkinder conducted amongst ten members who had been told about their donor-conceived origins before their fourteenth birthday. The blog entry mentions that almost all of them had initially only told very few persons about their origins, and that half of them had

ceived children early on, comments about members never or hardly ever having had any negative experiences are not surprising. They strengthen Spenderkinder's insistence on early disclosure.

Although it was experienced as painful and disappointing when others did not empathise with their feelings of hurt and betrayal, being donor-conceived was also interpreted as something that formed the basis for appropriate opinions and judgements. It was common for people to mention that, as Becca Haste from the UK put it, "people who haven't been in it, they wouldn't know how to react". For this reason, it was sometimes seen as a little surprising that others who were not "in it" had little or no understanding of their own, more critical opinions. Repeatedly my interviewees told me that their own opinions on gamete donation had changed after they had found out that they were donor-conceived. Jade Foster, for example, told me that she used to toy with the idea of donating her own eggs: "I was thinking, 'It would be a nice thing to do, I can help people out.' And then I found out, I started researching, *no*, [laughs] it's not something I want to do *at all*, I don't want to become a part of that system." While her own opinion had changed, her best friend, who was gay, was still in favour of gamete donation and anonymity:

Jade Foster: "When I told her how I was conceived, she was like, 'Oh, I don't want my child finding out, I'll just go to America, I'll get the sperm shipped from America because I don't want my kid finding out at all, and me and my wife, we're their parents, we don't need to find out anything.' Which bugs me because she can see how I felt about it, but it sent her in a completely different direction."

While Jade and her friend were still close, friendships could also change if expectations in terms of sympathy and empathy were not met. The way in which telling others could become the basis for the re-evaluation and reconfiguration of relationships became particularly clear in the case of Timothy Parsons. As already mentioned in the interview passage quoted at the beginning of the last section, "who can I talk to" was a question that had come to his mind right after he had been told. Timothy felt a great need to tell people about the circumstances of his conception "because that's who I am and I can't deny it, that's who I am, and I feel like I need to live who I am". At the same time, however, he had been hurt by the unsympathetic comments made by some of the people whom he had already told. He mentioned that the "classic" comment that he tended to get was "Oh but come on, you've still got a dad". He acknowledged that this was said in order to make him feel better but argued that it was essentially just a sign of others not being able to appreciate

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been (sometimes implicitly) told not to tell others. However, the post also mentions that their experiences with telling others have not been negative: "Nobody encountered negative reactions, the only negative experience that was reported was the feeling of not being understood." (Spenderkinder 2014b, author translation)



what being donor-conceived really meant for him. Telling others was still a big step for Timothy when I met him:

Timothy Parsons: “And then you have a whole choice about who you’re going to tell, and I think that’s one of the biggest things, is who you’re going to tell, because then, [sighs] when I first found out, when I was making that decision [sighs] it felt like a massive trust thing, who I was going to tell, and if I felt like I could have trust in you to tell you, and then how you reacted to that, it turned into a really big thing, because it’s like oh I’ve told you, and then if you show me care or compassion, it’s kind of like, alright, now I can trust you. And then if you just don’t show me care and compassion, it’s like alright now I’ve entrusted in you this information that is to me the most important information that I’ll ever find out, and if you don’t show any compassion after all or call me afterwards to see how I’m doing or any of that, then I just feel like I can’t trust you anymore. No matter how or what our previous relationship was [laughs] which is something that I never thought would happen.”

Since many of his friends’ reactions had not been compassionate, Timothy distanced himself from some of the people with whom he had previously been close. He had been anticipating sympathy and support but had instead come to the painful realisation that his expectations were not always met. Timothy felt that it had become difficult for him to get to know new people since he had been told, as he found it difficult to trust others. However, he felt that the ability or willingness to confide in others was fundamental to building close relationships since “it’s so close to my identity, that for me not telling them, it feels like I’m not keeping them close [...] I’m keeping them at arm’s length”. His remarks tie in with what Weston (1991) has written about coming-out narratives of lesbian women and gay men. She found that the people she spoke to “experienced unspoken truths as things that come between people, barriers that interject “distance” into relationships” (1991: 50). Weston argues that “[i]n coming out, a person acts to create a sense of wholeness by establishing congruence between interior experience and external presentation” (ibid.), which corresponds to Timothy’s desire to tell people and “live who I am”.

Whereas several people described how they had over time become more careful because their friends’ and/or relatives’ reactions had been disappointing, others who had known for a long time mentioned that for them, telling others had over the years ceased to be an emotionally charged event. However, this did not necessarily mean that they wanted everyone to know, and most people chose to reveal information in one situation and decided to conceal it in another. This was the case for Sarah Holmes, who had known for about two decades that she was donor-conceived. She told me that she had initially followed her parents’ example, which had been “modelling secrecy”, and hardly ever talked about the circumstances of her conception. Whereas her parents had not told anyone apart from her maternal

grandparents, Sarah herself had gradually become more open as she had gotten older. She brought this up when I asked her whether she had told her friends that she was donor-conceived:

Sarah Holmes: “Over the years, I’ve become a lot more comfortable with being donor-conceived. And I feel more comfortable talking about it. I think I’ve processed a lot over the years. If I was talking about it when I was in university, when I was 18, it still felt like a big secret, and it felt like I shouldn’t be talking about it. And it felt like I wasn’t sure about what it meant to me, being donor-conceived, so I’d quite often just well up, ‘Oh my god I’m donor-conceived, and I can’t believe I’m telling you this.’ But now it’s just like, ‘Meh, I’m donor-conceived, that’s what it is, it is quite an interesting fact, this is who I am, do you know what that is’, so I’m much more open about it now.”

It was notably finding out more information about her donor, who was still anonymous at the time of the interview, that had contributed to her feeling more at ease with talking about her donor-conceived origins. However, having her real name revealed by journalists or researchers was out of the question for her, as it was still “a massive secret” within her family, and Sarah did not want them to find out “that way”. Although being donor-conceived was nothing she was ashamed of, she still actively managed “who knew what and when” and had only told very few relatives. Like her, some of my interviewees were afraid that telling people both inside and outside the family would have a negative effect on their family relationships, and many worried about the way their father might feel or be treated by other people. While many of them talked about it openly with their friends, they had not told any of their relatives, as their parents did not want them to know. Although my interviewees themselves would have liked their close family members to know, they respected their parents’ decision to remain silent and did not want to hurt them.

Those who talked about it a lot more openly interpreted such decisions as a sign that many of the donor-conceived were still too considerate of their parents’ feelings, and that they suppressed their own needs. However, I would argue that the decision to conceal information can also be read as an attempt to protect close relationships and prevent kinship trouble. When seen from this point of view, such behaviour can be interpreted as an example for decision-making that is more complex than ideals of openness and transparency might suggest. This complexity was evident in my interviewees’ ways of sharing and not-sharing information that were often seemingly contradictory and sometimes surprising. Some were very open with me but mentioned that they had only told very few friends and relatives. Others shared their experiences anonymously in online forums and magazines, but only let very few offline friends in on their secret. One person even wrote an essay about donor conception as part of her studies and mentioned in it that she was donor-conceived, even though she had only told very few of her friends.

Furthermore, the decision not to tell someone so that others will not get hurt also illustrates that information about a person's conception was understood as something that is not only of relevance to the donor-conceived themselves. The way in which my interviewees who chose to search for their genetic origins attempted to protect their parents from getting hurt constitutes another example for these dynamics. They usually told their parents little or nothing about their search for the donor, as they wanted to avoid hurting them. They thus tried to prevent kinship trouble by concealing information. A similar observation has been made by Carsten in her research on adoption reunions (2007). She was occasionally told about adoptees that were worried about upsetting their adoptive parents and who therefore did not want to search for their birth families (2007: 419). According to Carsten, "this suggests that the constitutive effects of acquiring this information is felt to have the potential to impinge on others beyond adoptees themselves and their birth parents" (*ibid.*).

### 6.3 Sibling trouble: Similar relations, uneven knowledge

Brothers and sisters who grow up within the same family and have the same or different donor are generally not referred to as "donor siblings". This term is usually used for persons conceived with gametes from the same donor but raised in different families (Edwards 2013: 286). Siblingship in general has largely been neglected in the anthropology of kin relations. This tendency was arguably reinforced by a focus on reproductive technologies, which have shifted the focus of attention further towards procreation (Lambek 2011). Examining sibling relations counteracts these tendencies, as it "allows for insights into the making and breaking of kinship ties across the life course" (Thelen et al. 2013: 2). I argue that this applies not only to those who are commonly classified as donor siblings. Instead, a close examination of the descriptions of my interlocutors who grew up with siblings in their own families can also yield important insights. I am particularly interested in the experiences of those who had a sibling who was also donor-conceived.<sup>7</sup> For them, the question of who else knew, or did not know, played a particularly central role: especially those who had been told more or less spontaneously had often found out in the absence of their sibling. Some of my interviewees had known about the circumstances of their conception for several years, and their brother or sister had still not been told. In addition, most of them had also learnt that their sibling had been

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7 Only Becca Haste, who had a twin sister, and Tamara Haste had more than one donor-conceived sibling.

conceived with gametes from a different donor.<sup>8</sup> In these cases they had gained new information about the relationship between the siblings themselves, as they knew that they were genetic half-siblings instead of full siblings. Knowing more than one's sibling was described as extremely stressful and unpleasant. I will examine this discomfort using two empirical examples. In doing so I will also explore how my interviewees felt about having a different donor than their sibling, and how official regulations on anonymity can result in complex interfamilial relationships.

The uneven distribution of knowledge between her and her younger brother was extremely uncomfortable for Jade Foster, who had been told at the age of 14 that she and her brother were donor-conceived. Jade, who was 18 years old, believed that her parents had always intended on telling her once she was at an age when she would have "an understanding of genetics and of conception". However, she did not think that her parents had made the right choice: "It makes me annoyed that it was kept from me, it feels like it was a secret that they had that power to tell me when they wanted." Her brother, who was five years younger than her, had not yet been told. Jade had learnt from their parents that her brother had been conceived with sperm from another cryobank because at the time of their second treatment, there was no more sperm available from Jade's donor. Although their parents had intended to use the same one, she thought that this might actually be beneficial for them. If it turned out that her brother was not interested in finding out more, then "his own journey and his feelings" would not be affected if she was ever to find her donor. Jade did stress, however, that she would feel very differently about her brother having a different donor if he had been conceived after 2005: "If they'd have waited a couple more years to have my brother, he would have access to all of his information, and I wouldn't. And *that* would really get to me. I wouldn't be able to handle that, if he could get it and I couldn't." If her brother had been conceived just a few years later, he would have been able to request identifying donor information

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8 When telling me that their sibling had been conceived with a different donor, my interviewees referred to the results of DNA tests, what their parents had told them (e.g. treatment in another clinic), or a lack of similarities between themselves and their sibling. In total, four of my interviewees had grown up as only children; three had non-donor-conceived half-siblings with whom they were related either through their mother or father who had children from a different or previous relationship; two persons each had a brother who had been conceived with sperm from a different donor, and one (Timothy Parsons) or more (Jade Foster) non-donor-conceived half-siblings; one person had a younger non-donor-conceived brother who had been conceived with sperm from their father, who had successfully undergone fertility treatment after my interviewee was born; four had siblings who had been conceived with gametes from the same donor, two of whom were sisters (Becca and Tamara Haste); ten of my interviewees told me that their only sibling had been conceived with sperm from a different donor. Those who had a sibling that had been conceived with the same donor had all found out that they were donor-conceived either at the same time as their sibling, or just before them.

from the HFEA. Their respective possibilities of obtaining information about their donors would have been unequal. This illustrates that different legal regulations concerning anonymity can lead to complex relationships within a family and have the potential to cause “sibling trouble”.

Ever since Jade had been told about the circumstances of her conception, she felt like she was complicit in her parents’ secretive behaviour. She was deeply uncomfortable with that and with her brother not knowing. Jade believed that him being told would make them closer, as they would then share the knowledge about the circumstances of their conception. Sharing has been described as a key mechanism for the forging of sibling relations (Thelen et al. 2013; Pauli 2013), whether it be shared parentage or shared experience. If one of two siblings does not know of the circumstances of their conception, the two are not able to forge siblingship based on the facts of donor conception. They may be known to each other as siblings, but not yet as siblings who are both donor-conceived. Their commonality in terms of the circumstances of their conception can only become effective and activated if both siblings know about it. Although Jade was in a position where she could choose to tell her brother, she had chosen not to do so. She felt that telling was their parents’ responsibility, which was typical for those of my interviewees who had been told before their sibling found out.<sup>9</sup>

How much having an uninformed sibling could put a strain on people became particularly clear in the case of Timothy Parsons, whose mother had spontaneously told him about his origins without his younger brother being present. Their father, from whom his mother had long been divorced, had been out of the country at the time; Timothy told him a few weeks later that he had been told. As mentioned earlier, he wanted to know immediately whether his brother already knew. It turned out that their mother had not yet told him that he and Timothy were donor-conceived. She was of the opinion that her younger son should not be told immediately, as he was still in his final year of university. She feared that finding out the truth would unsettle him too much. In the following months, Timothy experienced what he described as an almost unbearable “limbo period”:

Timothy Parsons: “I had to wait six months to tell my brother. The first month was probably the hardest, but then the next six months, I decided to go away January, February, March, I went out of country for a bit, which was kind of nice, but then I came back and it all hit me like a ton of bricks because it was kind of like, I’ve

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9 Only two of my interviewees had told their siblings themselves. In both cases, the parents had originally planned to tell their children at the same time. One of them was Diana Kraft. After Diana’s mother had told her, Diana spontaneously told her brother about it over the phone. Since both knew that their mother was planning on telling them something important, he had not been shocked. Nadine Fuchs had told her brother about it without their parents being present, presumably because he had hardly any contact with them.

just been ignoring this, which is great to ignore but then I really struggled when I came back to kind of accept what it was that I was going through. And the fact that I couldn't speak to my brother about it was really, really, really, really hard, it's excruciating because I couldn't concentrate on anything. At work, I couldn't concentrate on anything, in my personal life, I couldn't concentrate on anything, I was just in this limbo period. I'd say that period between November and June, finding out and telling my brother, honestly, when I look back on the story, it would be the 25 years up until I found out, then the six-month period where I couldn't speak to anybody, and then the day I could actually tell my brother and move on from there because I had to. So, since I told my brother in June, I've been trying to just rebuild my life essentially."

The use of the limbo metaphor which took up a central place in his account has been explored by Becker in her monograph *Disrupted Lives* (1997), in which she explores "the process by which people attempt to create continuity after an unexpected disruption to life" (1997: 4). She points out that for those who experience a disruption such as infertility, their "culturally derived sense of being propelled through time" (1997: 120) has stopped. Becker suggests that the limbo metaphor helps them "to begin the slow and painful process of re-establishing a sense of future and a sense of order. By understanding this period of disorder and disaffection as temporary, they were able to better endure their sense of disruption." (Ibid.) For Timothy, the limbo began by him receiving information that was constitutive not only for himself but also for his brother. When Timothy eventually managed to "orchestrate a way of telling him in the best possible circumstances", which was in sharp contrast to the completely unplanned way in which he himself had found out, the "limbo" came to an end. Although his mother took over the part of actually telling his brother, he had ensured that he would be close by, and his brother called him soon after he had been told.

Interestingly, Timothy pointed out that he felt that they were "in it together in a way", although his younger brother dealt with the news completely differently. Since he had never been particularly close to their father and, according to Timothy, was not at all an emotional person, Timothy believed that he was still "denying things a little bit" and had not "really truly accepted it for what it is yet". To Timothy's relief, his brother had not been angry with him when he learnt that Timothy had already known for several months. They now had the same knowledge about their origins, and sibling equivalence had been restored, at least to some extent: like Jade and her younger brother, Timothy and his sibling had been conceived with sperm from two different donors. Since his mother had miscarried after having been inseminated with semen from the same donor the second time, his parents had, as Timothy put it, "changed sperm" for his brother. While Timothy had been conceived before the establishment of the HFEA, his brother had

been conceived just after 1991. This meant that his brother, unlike him, would be able to obtain information from the central register, which Timothy described as a “strange” thought. A certain inequality between the two brothers remained. Nevertheless, Timothy felt that he could now “move on a bit”. After finding out that he was donor-conceived, he had gotten back together with his ex-girlfriend, which he interpreted as his attempt to go back to “a time when I didn’t know”. Making sure that his brother knew gave him “the strength to actually leave that relationship behind”. The need to “move on” was also addressed by others whose siblings did not yet know of their origins. Many had the feeling that they could not really process the news and, for example, could not start their search for their donor as long as their sibling did not know (see for example David Winkler in section 8.4).

These examples suggest that having a sibling who had not been told brought an element of unevenness into a relationship that is generally considered to be characterised by equality, at least in Euro-American kinship thinking (see also section 7.5 on donor siblings). Kinship trouble is caused not only by what the donor-conceived themselves do not know but also by them knowing that others do not know where they come from, and how they are related to them. However, the “ideal of sibling equivalence” (Konrad 2005b: 133) may not be fully restored even once everyone is informed.<sup>10</sup> Different laws on anonymity can lead to different ‘starting points’ in terms of the possibility of gaining knowledge.<sup>11</sup> The examples discussed in this section thus illustrate that anonymity and its transformation, notably in legal terms, not only affect individuals but also have the potential to impinge on intra-familial relations.

While having donors that donated under different regulatory frameworks was imagined or described as challenging, having been conceived with sperm from two different donors was usually interpreted as something that would actually prevent sibling trouble. People felt that difficulties might arise if one person was more interested in the donor than the other, and several of my interviewees did actually tell me that they were more interested in finding their donor than their sibling. None of those who reported of such interfamilial differences had been conceived

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10 This ideal has been explored by Konrad (2005b) in the context of predictive genetic testing. She found that those who had not yet undergone testing after a parent had tested positively for Huntington’s Chorea were oftentimes worried about how the results would affect their relationship with their brother or sister if their sibling had different results. Konrad suggests that “the sharing of uncertainty and the joint propensity to misfortune between siblings” (2005b: 111) may even “comprise[...] the primary kinship link, the strongest tie” (ibid.).

11 This may in fact not only be the case with siblings conceived under different legal frameworks: for example, Jade Foster and her brother were both conceived after 1991 with sperm from two different donors. Theoretically, one of the two donors could make himself identifiable while the other remains anonymous. In this case, only one of the siblings would be able to obtain identifying information from the HFEA.

with the same donor as their brother or sister. While recipients might think of having several children with sperm from the same donor as “a strategy of damage limitation that minimizes exposure to the unknown” (Newman 2019: 714), my interviewees tended to think about their ‘divided’ origins differently. They saw it as a situation that had the potential to protect an uninterested sibling from being ‘exposed’ to that which they attempted to make known.

In contrast, the decision to have several children from the same donor can constitute recipients’ attempt to avoid kinship trouble and protect their children from not being perceived as real siblings. Especially for lesbian couples who run the risk of not being recognised as real families, choosing the same donor can be a legitimising strategy and a means “to construct and demonstrate a sibling relationship” (Nordqvist 2012: 652), with siblingship being defined as a (full) genetic relationship. Such a view was also partly present in my material; for example, some of my interviewees mentioned that they were not very close to their sibling and were very different from them. They attributed this to the fact that they had been conceived with sperm from two donors, thus interpreting full genetic relatedness as a prerequisite for close sibling relations (see for example David Winkler in section 5.2). Having been conceived with sperm from the same donor could in turn be experienced as something that could create sibling unity, as I will explore in more detail in section 7.5 when introducing Tamara and Becca Haste, two donor-conceived sisters from the UK. For them, it was the fact that they had been conceived with sperm from just one donor that had prevented sibling trouble. Tamara pointed out that finding out that they had been conceived with sperm from different donors would have been “upsetting”, as it might have resulted in only one of them finding their donor which, she believed, would have been “really bad” and “dividing”.

#### **6.4 The offspring’s children: Managing intergenerational relations**

As Edwards has pointed out, “reproduction is always about more than conception” (2000: 30). A child’s birth “reproduces not only a new human being but also significant social relationships” (ibid.). While the donor-conceived may not be born as parents, it was striking that even those who did not yet have their own families thought about what the circumstances of their own conception would mean for their future children and their children’s future grandparents. Sometimes it was the potential for “significant social relationships” that was significant. This section thus shows that complex intergenerational relations arise in the context of anonymous gamete donation. The degree of closeness and importance of these relationships, which my interlocutors determined in varying ways, had an influence on how concrete decisions were made on the question of whether one’s own children should be told. Although there was a strong tendency to tell them, opinions



and practices differed. I will start off by examining what shaped the practices of telling and the stories people formulated for their children. I will then explore why telling could also be seen as problematic and discuss how this relates to the way people conceptualised their child's kinship network. In the last pages, I will give a concrete example of intergenerational kinship trouble caused by anonymity, and also explain why relationships with donors were, at least by some, expected to be unproblematic.

The way people told or planned to tell their children about the circumstances of their own conception was very much shaped by what they thought about disclosure and donor conception in general. It was emphasised in particular not only that children should be told about their origins as early as possible but also that donor-conceived adults should tell their children as early as possible that they, as their parents, were donor-conceived. My interviewees often emphasised that they wanted it to be as "normal" and "natural" as possible for their children, instead of turning it into a burdensome and potentially dangerous family secret. When I asked them what they would advise people who were thinking about having a child with donor gametes, these points were almost always part of their replies. In addition to the donor's identifiability, early disclosure and general openness were the criteria mentioned when it came to how donor conception could be an ethical practice.

In some cases, it was striking how similar the stories that my interviewees told their own children were to those presented in 'disclosure books' for recipient parents today. Klotz found that these books, which are oftentimes written and published by concerned groups such as the DCN, "were key to how the canonical idea of (passive or active) early disclosure was facilitated through the groups of parents (and children) involved with DI" (2014: 208).<sup>12</sup> The English and German books she analysed, which parents used to tell their children about their origins, had very similar storylines: "There are one or two parents who would really like to have a child; children are normally conceived by egg and sperm; there is a difficulty with this because of reason X; but then the parents – or a doctor – have an idea; the parents get help; "you" are born." (Ibid.) The books were structured along "three central themes: love, biological reproduction, and assistance" (2014: 209).

The story that Sarah Holmes, who had joined the DCN long before she started her own family, had told her eldest son had a very similar storyline and message.

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12 Klotz found that at the time of her research, "the concept of an early *active* disclosure by talking to toddlers about gamete donation" (2014: 207, emphasis in original) was more dominant in the British than in the German discourse. Those who chose a more passive approach would "start telling once their children start asking their first questions about reproduction" (2014: 202).

Sarah was in her mid-30s and had known about the circumstances of her conception for over two decades. Through her longstanding and active membership in the DCN, she had met and talked to many families who propagated and practiced early disclosure. Sarah described how the organisation's pro-openness stance had given her "another model of how things could be". This "model" differed from the behaviour of her parents, who had kept the treatment with donor sperm secret. For years after Sarah's mother had told her about it during an argument when Sarah was 13, they did not want to talk about it with her. She herself had only begun to deal with it differently and openly when she had moved out of their family home and started her studies (see also section 6.2). At that time, she had also joined the DCN, which she had discovered online. Meanwhile, Sarah had become a mother herself. After commenting on the importance of early disclosure, she mentioned that her son already knew that his mother had been conceived with donor sperm:

Sarah Holmes: "I've told my son from the age of about three or four and simply said, 'You need eggs and seed to make a baby, the eggs come from the mommy, and the seed come from the daddy, so we used mommy's egg and daddy's seed to make you. But when nanny and grampy wanted a child, they used nanny's eggs and granddad's seed didn't work, so they went to the doctor's and they used a kind man [...] they borrowed his seed and used it with nanny's egg, and it made mommy.' So, although he doesn't know about genes, and he doesn't know that he's not genetically related to his granddad yet, he knows that a kind man made mommy, so I've always been very open with him. And eventually that will all fall into place as he gets older. It won't be a big secret or a revelation for him. It will just be pieces of information being added over time as he gets older."

Whereas Sarah did not mention that she herself had used a DCN book to tell her son, Jessica Robertson from the UK had used one of the association's books to tell her daughter about her origins. Besides, she had also bought another book to tell her about her own reproductive plans. Jessica tried to get pregnant with donor sperm at the time of our encounter. She had been divorced from her daughter's father for several years and by her mid-30s had decided not to wait any longer for a partner to have a second child, as she feared she might "run out of time". Jessica had told her daughter about her own origins with a disclosure book for heterosexual couples, and she had spoken with her about her plans to conceive with donor sperm with a book for single mothers. Jessica was the first donor-conceived person I interviewed, and at the beginning of my research in the UK, I did not meet anyone who did not plan on telling their child. Everyone seemed absolutely sure that the children of the donor-conceived should also be informed. Only in the course of time did I meet people who still hesitated or who pointed out potential problems. However, it was striking that even those who had not yet told their children usually mentioned that they would have preferred to be immediately open with them.

I suggest that the importance my interviewees often attached to telling their own children, and the way some of them had already told them, underlines how much emphasis was placed on “see-through kinship” (Edwards 2018). The donor-conceived did not want to repeat the mistakes of their mother and father but were determined to be good parents who lived up to their parental responsibility of being open with their children. But while they wanted to be “good parents”, they also wanted to be “good daughters/sons”. Thoughts about whether or how to tell one’s own children did also reflect concerns about their children’s kinship network, which was their own network as well. Although the ideals of openness and honesty were central, the concerns that my interlocutors expressed also show that this ideal was not all-determining in practice, and that other considerations did matter as well.

The extent to which telling one’s children could be a topic that could bother people became particularly clear to me in the interview with 18-year-old Jade Foster, whom I met towards the end of my stay in the UK, and who, unlike Sarah and Jessica, did not have any children. Like others of my younger interviewees who had no intention of having a family in the near future, she did not dismiss the issue of telling her future children as irrelevant to her own life, especially since she knew that she definitely wanted to be a mother at some point. Jade was very critical of anonymous gamete donation, believing that “every child should have the right to know”. She felt that the changes in the law had made sperm and egg donation “more ethical”, but pointed out that “many people don’t ever find out” since parents could still choose not to tell their children. Jade was particularly critical of the commercial nature of gamete donation and of “the industry as a whole”, as she believed that clinics and sperm banks focused on “buying and selling” rather than caring for the welfare of the child (see also section 6.2). The way she thought about her own reproductive future as a bisexual woman was influenced by her experience of being donor-conceived and having an anonymous donor: “I’m bisexual, so I could end up with a woman, and I could end up having to look at reproductive technologies to have a child, and I think I’d have to think very carefully if I wanted to go down that route.” While others were sure that they would either talk about their own origins with their children as early as possible, or at the latest when the issue arose, Jade was not yet sure what to do:

Amelie Baumann: “If you had children, do you think you would want to tell them that you are donor-conceived?”

Jade Foster: “I don’t know. I’ve thought about that a lot because the donor is their grandparent, which is close enough that it is still a big part. And I would feel like if I didn’t tell them, I’d just be doing what my parents did. And hiding something. But I wouldn’t want to ruin their relationship with my dad. Or to make it seem like I was meddling with it. But then I was thinking maybe after he dies, I’d tell them,

but I wouldn't want to then ruin his memory. I really don't know whether I'd tell them. I thought a lot about it, and I haven't reached a conclusion."

Her reflections on the subject were determined by her concerns about different kinds of relationships: firstly, she thought about the relationship between her donor and her children. She conceptualised this connection as one between grandparent and grandchildren, which she deemed as "close enough" for it to still be important. Secondly, Jade was also worried about how telling would affect the relationship between her children and her father. It follows from this that she was also concerned about her own role as mother of her children and as daughter of her parents: Jade wanted to be not only a responsible mother but also a caring daughter. She felt that she would have a responsibility to tell, as the information would concern her children's origins. At the same time, she was afraid that telling would potentially be damaging for the relationship between her children and her parents. Especially her concern about not wanting to "meddle" with the relationship between her children and her father was shared by others who were still hesitant about telling their children. Whereas my interviewees usually emphasised, notably in relation to donor-conceived children, that openness and honesty would strengthen family relationships, I found that people hesitated to tell their own children because they did not want to jeopardise their child's relationship with their parents. They also wanted to protect their parents and especially their father from any hurtful comments their children might make, such as "You are not my grandfather".

Apart from her concerns about the relationship between her children and her father, Jade's considerations were also determined by the way she thought of the connection between her children and her donor and the importance she attached to this link. Like others, she conceptualised it as a relationship between grandchildren and grandparent. She envisaged a connection that tends to get overlooked in discussions about donor conception and in academic studies: the link between the donor and the donor-conceived offspring's children.<sup>13</sup> In contrast, Carsten observed that several of the adoptees she interviewed had not told their children that they had been able to locate their birth parents and meet up with them: "As far as these children were concerned, they just had two sets of grandparents." (2007: 419) Carsten interprets their decision not to tell as an attempt "to accommodate or limit the "constitutive force" of new information" (ibid.). In contrast, several of my interlocutors thought of their donor as a grandparent to their own children. Since they felt that this was a potentially meaningful relative, sharing information with their sons and daughters became a non-trivial matter.

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13 A notable exception is *Relative Strangers*, a sociological study by Petra Nordqvist and Carol Smart (2014b). Part of their work is an exploration of how grandparents negotiate kinship when their children conceive with donated gametes. See also another publication from Nordqvist and Smart (2014a), as well as Beeson et al. (2013).

Donor anonymity was seen as harmful not only because it kept the donor-conceived from knowing who they were but also because it meant that the children of the donor-conceived could not know all of their roots. Tamara Haste from the UK, who had just finished her studies and had no children yet, saw this as one of the overlooked consequences of anonymous sperm donation. She was no longer in contact with the man she had previously believed to be her father. While she hoped that the man she would have children with would “know his heritage, and that’s all fine there”, this was not the case with her. As a result, she feared that her children “won’t know a quarter of their heritage, it will completely blank to them”. In general, policies and regulations on information sharing and openness prioritise the connection between the donor-conceived and the donors (Gilman and Nordqvist 2018; Raes et al. 2013). The relationship between donors as “grandparents” and the children of donor-conceived persons is not one that is currently highlighted in German or British laws, and “donor-conceived grandchildren” have no rights to access information about their “donor grandparents”.<sup>14</sup>

The significance people ascribed to telling their children and the difficulties that many anticipated illustrate that the closeness of kinship relations is conceptualised in a twofold way: on the one hand, people take into account “the strength or dilution of shared substance” (Edwards 2000: 220) when determining how closely people are related; hence, the parent-child relationship is conceptualised as being closer than the grandparent-child relationship. It is fitting that my interlocutors usually mentioned that they hoped and thought that their children would not be affected by the donor’s anonymity as much as they were, since they had an unknown grandfather, but knew their father. On the other hand, “the quality and quantity of social interaction” (ibid.) can be an influential factor as well. Since they either wanted their parents to be involved in their children’s lives, or because they were already very involved, this relationship was thought of as being close and important as well. They oftentimes thought about their own relationship with their donor and their father in a similar way, describing themselves as being close to the donor in terms of shared DNA and close to their father in terms of time spent together. While the donor had provided them with their genetic make-up, their father had raised them and had also had a formative influence on them. The way Sarah, who had told her own son early on, formulated her thoughts on the subject appeared in a similar form in many interviews. She argued that she had “three different people who make up me, and I’ve got my mom and my dad, but I can’t just ignore the fact

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14 This was criticised by Spenderkinder in the debates about the German sperm donor register. In their commentary on the draft bill, Spenderkinder (2017b) argued that the second generation of offspring might have a legitimate interest in accessing information, especially if the donor-conceived do not exercise their right themselves, or if information had not been passed on to their children.

that I have 50 percent of somebody else's genes". She emphasised that her father was "completely my dad" and stressed that he was "very much a part of who I am, even though we're not genetically related".

Reassuring remarks such as "my dad is still my dad" kept reappearing in many interviews. Only very occasionally did people speak of their "social father" (*sozialer Vater*); if the term was used, then only very rarely, and never continuously throughout an interview. Even those who were disappointed by their parents and spoke of a breach of trust oftentimes emphasised that they were still referring to their father as "father". Timothy Parsons for example, when telling me how he had first talked with his father after being told by his mother that he was donor-conceived, said, "I'll call him my father because he is, it will not make a change, he's always my father." He and others thus denied that a genetic connection made a difference. Commenting on the kin terms used by her interlocutors, who would refuse to refer to a sibling who had another father as "step sibling", Edwards argues that "[i]t is in the denial of difference, however, that difference lies" (2000: 232). The refusal to qualify a connection "suggest[s] a resistance to the privileging of biological connection while reaffirming biological connection" (*ibid.*). Edwards suggests that "in order to emphasize shared substance [...] an alternative [...] is needed" (*ibid.*). If an alternative is evoked, then a connection can be "embraced in kin terms, whether substance is shared or not" (*ibid.*).

The alternative that the donor-conceived frequently evoked was the time they had spent with their fathers, and the extent to which they had had a positive impact on their lives. While the majority of people did not use the term "social father" (*sozialer Vater*), some did occasionally use the term "genetic father" (*genetischer Vater*) when talking about their donor. While the term "father" can be interpreted as an instance of them "attributing humanity to what has been called 'mere' cells" (Hertz et al. 2013: 62), I suggest that "genetic" was used to highlight that this was a qualified connection that did not match the relationship they had with those who had raised them. In contrast, the terms "donor" and "genetic parent/father" were not used, and in some cases explicitly rejected, by those who were critical of donor conception per se. According to them, those with whose gametes a child was conceived were his/her parents (section 4.1). This, too, suggests that kin terms "do more than fix and locate people in relation to each other, they also connote special types of relationship and are thought to create particular kinds of ambience" (Edwards 2000: 232).

While telling children about their "genetic grandparents" was imagined to be a difficult task especially by those who were not yet parents, children's reactions to being told were rarely commented on, possibly because most of my interlocutors who were already parents had very young children who arguably could not show much of a reaction. Those whose children were a little older sometimes mentioned that their children had simply taken note of the information and emphasised that

it had not changed anything in the relationship between their children and their father. They saw this as an indication or proof that donor-conceived children could accept the circumstances of their conception as something completely normal if they were told about it at an early age. When people described more emotional reactions, they usually interpreted them seen as a sign that children could intuitively recognise the truth. This view is consistent with the way in which children are seen as purer and more authentic than adults, which has been an influential view in European pedagogy (see also section 5.2). An emotional response was described by Jennifer Bunton. Jennifer was very critical of donor conception per se (section 3.4), believing that a donor-conceived child “is not going to have half of their family”. She mentioned that her daughter had cried when she had told her that she was donor-conceived. Her daughter said, “So you don’t know who your real dad is.” Jennifer concluded that “children say things quite as they are”.

The desire and need to be a responsible parent, which motivated many people to be open with their own children, was also expressed in my interlocutors’ wish to know their full medical history so that they would know what they, as parents, would pass on to their children. Similar to Klotz, I found that not knowing their complete medical history was usually “mentioned by informants as one genre to explore their general sense of deprivation of knowledge and injustice” (2016: 51) instead of being “interrogated in medical detail” (*ibid.*). If a lack of medical history was a pressing concern for someone, it was mostly because they worried about their children, and not primarily because they were concerned about their own health. This was the case for Kai Silberschlag, who was a father of three and worked as a teacher. Aside from his curiosity, which was primarily focused on those characteristics that distinguished him from his family (section 5.3), his desire to learn more about his donor was also related to his desire to be a responsible father. He raised the issue when I asked him what he thought the duties of parents, the state and clinics were in terms of disclosure and the wellbeing of the donor-conceived. Kai pointed out that whereas he knew the medical history of his mother’s family, he knew nothing about what had been passed on to him from his donor, and what he might therefore have passed on to his own children:

Kai Silberschlag: “I look at my mother’s family, and I know there’s a problem with dementia. My great-grandmother took the tram in her nightgown. And it was exactly the same with my grandmother the last few years. I’d like to know if there’s anything like that. Not just because I’m worried for myself, but because I have three children. A few years ago, I had a student, she was in sixth grade, eleven years old, she had to go to cancer screening all the time, not because she had it, but because it’s very common in that family. It has so far not been in my family. But what about the donor’s family? I simply have three children, and I have a responsibility towards them, and I would like to be able to live up to that responsibility,

it would be better if I knew something. When I did my community service [*Zivildienst*] I worked with this man, he turned blind when he was 30, there was nothing you could do about it back then, but it was already in the family. How should I know if there is something like that? And I think that that's of course where the state could force the clinics to maybe really reveal more information because after all, there's really nothing that we know."

While he had earlier stated that a fertility clinic could only ever be a "service provider" that was not responsible for children learning of the circumstances of their conception, Kai did not believe that clinics were free of any kind of responsibility. Since they had the information that would enable the donor-conceived to fulfil their parental responsibility, he considered it justified to force them by law to release relevant information. The desire to have access to complete medical records was frequently mentioned by the adoptees interviewed by Carsten (2000b: 696–697). They, too, were interested not only in what the medical history of their birth parents meant for them but also in what this information could mean for their own children. Carsten concludes that

"Knowledge of the medical history of forebears is desired not just as a means to acquire a complete personal biography, but as something that might be transmitted down the generations. It encapsulates a history of kinship, but its significance is for the future. The difficulty is, of course, that this sense of the future is not only connected to the present, and to the future-in-the-present, but it can also not be detached from the past." (Carsten 2000b: 697)

The problem people had with 'passing on the unknown' to the next generation, regardless of whether or not their children had already been born (or conceived), is an example for how "past, past, present, and future chronologies of kinship" (Carsten 2007: 419) are intertwined. When people find out that they were conceived with donated gametes, it is not only their view of the past and present of their kin relations that changes; instead, the way they view and engage with the future is also affected. New information about their origins is thus information about past, present and future kinship.

This intertwining of chronologies is also evident in the way people would start and/or restart their search. My research suggests that the chronology of a search might be dependent on the life history of the person that is searching, which is again similar to Carsten's argument about "kinship chronologies" (2007). The adoptees Carsten interviewed had often interrupted their search for their birth parents over and over again. The decision to continue searching for them was usually linked to changes in their own family life (2007: 418). While most of my interviewees were immediately interested in finding out more about their donor, there were also several people who had only started searching years later. They often explained a



new or renewed interest in the donor with reference to something important that had changed or happened in their life. Moving out of the family home and starting one's own family (see also the experience of Sabrina Frey, as described in section 5.3) were usually the events that were described as such turning points. Sarah, who had learnt of the circumstances of her conception at the age of 13, explained that "it's been significant bits in my life that made me readdress who I am and my identity", such as the beginning of her studies, her wedding, and the birth of her first child. These events had coincided with further steps in her search, such as the purchase of a DNA test, without Sarah necessarily being aware of this connection at the time. Many of my interviewees believed and/or hoped that donors would make a similar experience. While some believed that donors would not be interested in them and argued that they had only donated for the money, others reasoned that donors would become interested in their donor offspring when they had their own children.<sup>15</sup> While the intertwining of kinship chronologies could mean that anonymity was perceived as problematic because it prevented people from being responsible parents, it also forestalled the expectation of kinship trouble with regards to the donor.

## 6.5 Recapitulation

While many of the donor-conceived persons I interviewed did not learn about the circumstances of their conception until adulthood, in most cases their parents had already told relatives or friends. Thus, others within or outside the family had already been in possession of information that my interviewees considered to be of central importance for their own lives. This was described as a painful breach of trust. At the same time, those whose parents had not told anyone worried about their parents' adherence to secrecy. Especially those who did not oppose donor conception often regretted that their parents were not open about their treatment. They argued that men who raised a "foreign child" should be proud of their willingness to do so and interpreted the unknown origins of a child as something that required a lot of courage from parents. They admired their parents and especially their fathers, as they had not been deterred by the prospect of experiencing kinship trouble.

The donor-conceived themselves were usually very careful not to cause any such trouble and thought carefully about whom to tell, and whom not to tell. The ideal

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15 A study conducted on the experiences of five German sperm donors suggests that the way in which donors interpret their donation might indeed change over time, and that "sperm donation is connected with wishes, ideas and experiences in the field of reproduction" (Baumeister-Frenzel et al. 2010: 108, author translation).

of absolute and unconditional openness was less important than considerations of care when people made that decision. A concrete case of intra-family trouble existed for those whose siblings did not yet know that their parents had conceived their children with donated gametes. They had information that was constitutive for their siblings but that they did not want to share with them on their own. Those for whom this was the case described these situations as extremely difficult and challenging. They wanted their parents to take over the telling and ensure an even distribution of knowledge. If siblings have different donors, the sibling relationship may stay uneven once everybody has been told, as one sibling might be able to find out more than the other. Nevertheless, it was usually described as advantageous to have a different donor. My interviewees hoped that this would ensure that a sibling with less interest in finding out more would not be affected by their brother's or sister's search for information. Another case of actual or anticipated kinship trouble was the sharing of information with their own children and the negative effect the donor's anonymity was expected to have on them. While there was a strong tendency to tell, people were not always sure what to do: on the one hand, the donor-conceived did not want to interfere with their children's relationship with their grandparents. On the other hand, they did not want to withhold information about their origins and their "genetic grandparent" or "donor grandparent". They were guided in their decisions not only by the ideal of openness and honesty but also by concerns about relationships, and they wanted to be responsible parents as well as good daughters and sons.



## 7. Connections you might (not) make

### Mandatory and voluntary registers

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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.<sup>1</sup> 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 rela-

tions 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).<sup>2</sup> 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.<sup>3</sup>

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).<sup>4</sup> 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.<sup>5</sup> 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).<sup>6</sup> 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.*).<sup>7</sup> 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.<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup> 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.<sup>11</sup> Standardisation was implemented only in response to the Ministry of Health’s 2001 consultation on the release of donor information (Blyth 2015).<sup>12</sup>

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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).<sup>13</sup> 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,

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.<sup>14</sup> 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”.<sup>15</sup> 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 Ayesha 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.<sup>16</sup> 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 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.<sup>17</sup> 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.<sup>18</sup>

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, "scan-

ning” 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.<sup>19</sup>

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.<sup>20</sup>

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 disabling 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).<sup>21</sup> According to HFEA meeting papers, 193 registrants had joined the DSL up until the end of 2018 (HFEA 2019a).<sup>22</sup> The first sibling match had been made in 2015; with ten more matches having been facilitated since then (ibid.).<sup>23</sup> 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.<sup>24</sup> *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.<sup>25</sup> 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.<sup>26</sup> 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.<sup>27</sup>

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.<sup>28</sup> 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.<sup>29</sup> 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”.<sup>30</sup> 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.<sup>31</sup> 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.<sup>32</sup> 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.<sup>33</sup> 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).<sup>34</sup> 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 turned 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.<sup>35</sup> 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](http://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.<sup>36</sup> 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).<sup>37</sup> 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,<sup>38</sup> 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,<sup>39</sup> 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](http://www.fiom.nl) (last accessed May 28, 2020).
- 39 [www.ancestry.com](http://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.<sup>40</sup> 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.<sup>41</sup> However, STR tests are not as accurate if they are used to prove a sibling relationship,<sup>42</sup> 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).<sup>43</sup> 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.<sup>44</sup>

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/](http://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.



## 8. Infrastructuring DNA

### Commercial genetic testing

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Apart from mandatory and voluntary, formal and informal registers that are specifically designed for the donor-conceived and donors, there is another way of obtaining information about unknown relatives. Commercial genetic testing websites brought about significant changes for my field and some of my interlocutors during the time of my research, especially after I had already conducted the majority of my interviews. These sites differ in many ways from the registers already presented, and the tests that they sell are different from the type of genetic tests used by the DCR. DNA tests offered by companies such as 23andMe are sold directly to the consumer and have become a way to circumvent clinical and official regulations on donor anonymity.<sup>1</sup> In contrast to the central HFEA register, this possibility is available to all donor-conceived persons, regardless of when they were conceived, or where their donor had donated. Using DNA tests to identify donors or donor-conceived half-siblings is clearly not the main aim of neither those providing the services, nor of the main user community. Instead, genetic databases are mostly joined by people interested in genetic ancestry research (Klotz 2016: 46), or health reports (which are currently not permitted in Germany).<sup>2</sup> The appropriation of commercial genetic testing through the donor-conceived is thus an example of how infrastructures can be used in a way that differs from the intention of their designers (Akrich 1992).

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1 [www.23andme.com](http://www.23andme.com) (last accessed May 28, 2020).

2 In my analysis, I concentrate on companies that offer autosomal (pertaining to chromosomes that are not sex chromosomes) DNA testing for genetic genealogy and have a matching database. Such tests are currently offered by Ancestry, FTDNA, 23andMe and MyHeritage. Besides, Living DNA offers ancestry analysis consisting of Y-DNA and mtDNA haplogroup reports, but does not currently have its own database for matching ([www.livingdna.com](http://www.livingdna.com), last accessed May 28, 2020). However, test results can be uploaded to GEDmatch if users want to search for genetic matches. A plethora of other tests are available as well. For example, Christofides and O'Doherty found 86 companies that offered direct-to-consumer genetic testing in Canada, with 29 of them offering health tests (2016: 108).

The use of commercial genetic testing to search for one's donor and donor siblings is a subversive way of using technology, as it can lead to "authoritative regimes of managing genetic knowledge" (Klotz 2016: 55) being bypassed. While the collection, storage and release of information on donors and treatments was previously controlled by medical professionals and/or state authorities, such systems and institutions are challenged by the emergence of new technologies and the way in which people appropriate them. DNA databases significantly change what can be known by whom and when, reconfigure the conditions of anonymity in gamete donation, and expand the ways in which information can be exchanged, shared and linked. Donor-conceived persons may learn about the circumstances of their conception through their registration with a database, instead of being told by their parents. They do not even have to be registered themselves, as their children might use these tests and get connected with their parent's genetic relatives (as shown in two of the case studies explored by Crawshaw (2017)). A particularly important feature of these increasingly popular databases is that they can enable the donor-conceived to identify their donors even if the donors themselves are not registered.

In view of these possibilities, it is increasingly argued that the anonymity of donors is a thing of the past: "the spread of genomic testing is likely to make anonymous gamete donation and parental non-disclosure highly problematic" (Harper et al. 2016: 1138; see also Brügge 2018).<sup>3</sup> Online commentaries have already started to play on words and use DNA as an abbreviation for "Donors not Anonymous" (Kramer 2016). However, my remarks on this subject, based on conceptual considerations and ethnographic insights, represent an attempt to break down the absoluteness of these statements. I suggest that a broad statement such as the title of Harper et al.'s article "The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business" (2016) fails to take into account that anonymity is always partial and relational. A donor listed as anonymous by a sperm bank is anonymous only in relation to certain persons: while he remains unknown to the recipient parents, he is known to the person who registers him. To speak of 'complete' anonymity that has a clear beginning and an end is therefore misleading. Furthermore, my research has shown that the way DNA tests are used in the search for donor siblings and donors can be very complex. It is not an infrastructure that 'eliminates' anonymity, but a complex process of *infrastructuring* that makes things knowable and new connections possible.

Both my empirical material and my approach to the topic reflect the timing of my research: with two exceptions, I had conducted all interviews with donor-conceived persons before June 2017. That year, however, a change seemed to be taking place. Since December 2011, the German organisation Spenderkinder has

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3 Harper et al. focus on SNP-based testing (2016: 1137), which will be explored in the next section (8.1).

encouraged donor-conceived persons to register with FTDNA, thereby creating an unofficial register (Klotz 2014: 268).<sup>4</sup> They recorded more and more half-sibling-matches especially in the second half of 2017. My impression that much was in motion in terms of DNA testing was also shared by an interlocutor from the UK, who was in touch with donor-conceived persons nationally and internationally via various Facebook groups: when I visited Elizabeth Chapman for the second time in summer 2018, she mentioned that from what she could witness online, “DNA testing has really blossomed”.

A look at the statistics seems to support her and my impression that genetic testing was gaining in importance. In recent years, genetic databases have grown rapidly and have more and more members: for example, 23andMe’s database had over two million profiles in 2017, compared to 800,000 in 2015 (Herper 2017). According to a popular blog run by a genetic genealogist, it had more than twelve million customers in May 2021, and Ancestry alone had a database with more than 20 million profiles (DNA Geek 2021). Nowadays, the apparent triumph of DNA testing seems to be an unstoppable process. This contrasts with what I was told when I conducted interviews in 2016 and during the first six months of 2017, which seemed to be a time when searching and waiting for matches instead of finding them was the most common experience of people purchasing a DNA test. Out of my interviewees who were interested in their donor and donor siblings, only four had already made a connection via a testing site when I met them, but five found at least one donor sibling or their donor after I had already interviewed them. Eight had registered but still not found a match that I knew of at the time of writing (May 2021). Additionally, five had not yet purchased a test, but had thought about it or already decided that they would do so in the future. The increase in the number of matches indicates that my research took place at a time when the conditions of anonymity in gamete donation were reconfigured through the way the donor-conceived use genetic testing.

This technology will be discussed in detail in this chapter. I will first explain what distinguishes this type of DNA testing on a technical level from the testing technology examined in section 7.6. I will also explore how these databases define kinship and ethnicity in a certain way, and why the test results are still uncertain. In

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4 Another example for how the donor-conceived use these databases is the “Donor Conceived” FTDNA group ([www.familytreedna.com/groups/donor-conceived/about](http://www.familytreedna.com/groups/donor-conceived/about), last accessed May 27, 2020), created in 2011 by Lindsay Manzoian-Greenawalt, an American donor-conceived activist who ran the blog *Confessions of a Cryokid* ([www.cryokid-confessions.blogspot.com/](http://www.cryokid-confessions.blogspot.com/), last accessed March 17, 2020). While the FTDNA group itself does not control the matching process, it does list the clinics where its members (126 as of May 2020) were conceived and can thus “encourage other donor-conceived people still undecided about whether to take the test, and [...] highlight their need to the wider community for finding their genetic relatives” (Crawshaw et al. 2015: 75).



the next section, I will examine the complex processes of infrastructuring, through which some donor-conceived persons tried to combine results of their online and offline search in order to obtain information about their donor even if he was not registered. Afterwards, I will address the fact that even those who were not willing to take such measures still felt that they had to at least try to find their donor and donor siblings with a DNA test. In the last section, I will discuss how the waiting for a genetic “match” has evolved with the increased yet slowed down growth rates of DNA databases.

## 8.1 Relationship ranges, ethnicity estimates: Measuring kinship and ancestry

In genealogy blogs and forums that facilitate exchanges between genetic genealogists, the tests used by companies like FTDNA are often described as superior to STR tests. They are said to measure the amount of shared DNA and be more than just a statistical ‘guess’. In the following pages, I will take a brief look at what makes the tests offered by commercial websites different. I will show why the connections that can result from these tests are not the result of a straightforward measurement process, and that the interpretation of these results often requires additional information and research. Nevertheless, this section also highlights that the results are always based on kinship categories defined by the respective database. Finally, another important feature of these databases will be addressed: while my interlocutors may have attached little importance to what another platform called MyHeritage calls “ethnicity estimates”, the popularity of such estimates seems to be partly responsible for the rise of genetic testing. For this reason, the measuring of “deep ancestry” will be discussed briefly.

While tests used for the DCR register and forensics examine STRs, FTDNA’s popular test “Family Finder” and the genetic ancestry tests offered by Ancestry, 23andMe and MyHeritage examine Single Nucleotide Polymorphisms (SNPs; pronounced “snips” in laboratory and genetic genealogy jargon).<sup>5</sup> SNPs are variations in the order of nucleotides that occur when a specific nucleotide is different from what the majority of the population would have. When most individuals of a population might have the nucleotide “A” at a specific location, one percent might have

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5 I followed the advice of my interviewees and used genetic genealogy blogs and websites to better understand DNA testing, and I found the website of the International Society for Genetic Genealogy, which is a volunteer-run organisation, particularly informative ([www.isogg.org](http://www.isogg.org), last accessed May 31, 2021). Those of my interviewees who were particularly involved in the “infrastructuring” of DNA also recommended genetic genealogist Kitty Cooper’s blog to me (<https://blog.kittycooper.com>, last accessed May 31, 2021).

a “G”. SNPs mutate less frequently than STRs, which results in specific sequences being passed on unchanged across generations.<sup>6</sup> If two persons have a number of consecutive SNPs in common, they are said to share a segment of DNA. Whereas one will share larger segments of DNA with close relatives, the amount of shared DNA will decrease if the “most common recent ancestor”, from whom two persons have inherited a SNP, is more distant. The more distant this ancestor is, the more distant the genetic relationship between them will be. The number of shared centiMorgans (cM) indicates how much DNA two persons share, with a high cM value indicating a larger amount of shared DNA and thus a closer relationship.<sup>7</sup> Genetic databases not only detect genetic connections between close relatives, but also more distant genetic links, and the majority of my interviewees had only found more distant relatives, with whom they only shared a small amount of cM. Their most common recent ancestor, from whom they and their “genetic match” had descended, had mostly lived several generations or centuries ago. Such matches or distant genetic relatives are also referred to as “genetic cousins”, which are differentiated by two main categories: degree and removal. The “degree” of a cousin relationship indicates how far back in the family tree the most common recent ancestor is located, whereas a “removed” cousin relationship indicates that two relatives are from different generations.<sup>8</sup> Remarks about “third” or “fourth” cousins that were “once” or “twice removed” were scattered through many interviews when people talked about their test results, as most of them had not yet found any donor siblings or the donor.

One might share the same amount of cM with various relatives.<sup>9</sup> However, algorithms are not able to distinguish between different types of relatives who might

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6 Commercial sites test between approximately 630,000 and 700,000 SNPs. These specific locations on the genome are then compared to the results of others who are already on a database.

7 For practical purposes, cM values are oftentimes talked and written about as if they measured length, and I do the same here. However, cM is in fact a measurement of probability. FTDNA’s Learning Center defines cM values as “measurements of how likely the segment is to recombine as it passes from parent to child. Segments with higher cM values have a greater probability of recombining in any one generation. Therefore, when you share DNA segments with larger cM values with a match, your common ancestors are likely to come from generations that are more recent.” (FTDNA, n.d.)

8 Whereas one shares one set of grandparents with a first cousin, second cousins will have a set of great-grandparents in common. When a cousin relationship is “removed”, it means that one cousin has a closer relationship with the most recent common ancestor in terms of generational distance; removed cousins are thus separated by at least one generation. A “first cousin once removed” relationship exists between a person and their mother’s first cousin, as well as between a person and the children of their first cousin.

9 For example, one shares on average 25 % of one’s DNA not only with a half-sibling but also with a grandparent, an aunt or uncle, and a niece or nephew.

share a similar amount of cM with the person taking the test. Besides, they are not able to detect every genetic cousin. About ten percent of all third cousins will not share enough DNA for the relationship to be detected by an algorithm.<sup>10</sup> For these reasons, additional information is usually needed to determine the exact nature of a match, to make sure that a supposed match is not actually a false positive one (Abel 2018), or to find additional branches of one's family tree that have not shown up in a test. Any additional research needs to be conducted by the person taking the test, and is not done by the testing company, although some of them offer a collection of digitised historical records that can be used for further research.<sup>11</sup> The lack of certainty concerning the interpretation of results is also reflected in the way in which they are presented. Registrants will usually be presented with a possible "relationship range" that indicates the possible relationships between two persons. Various blogs and other online resources can then be accessed in order to interpret test results.<sup>12</sup> While tests might not determine the exact nature of a relationship, they are nevertheless prescriptive with regard to the type of relationship that is conceivable in genealogical terms. For example, FTDNA might state a relationship range as "Half Siblings, Grandparent/Grandchild, Uncle/Nephew". The registrant might then choose "Half Sibling" as the actual "Linked Relationship" but would not be able to enter "Parent" in this column. The kin terms used by such sites and the way in which they order relationships are consistent with Euro-American kinship thinking, where "kinship is whatever the biogenetic relationship is" (Strathern 1995:

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10 Third cousins have a great-great-grandparent, who is four generations 'away' from them, as their most recent common ancestor.

11 Ancestry and MyHeritage offer a large collection of digitised historical records. However, access to these documents is not included in the DNA test and must be purchased separately. In addition, Ancestry has been offering the ThruLines™ tool since 2019. It shows how a person on the database may be related to their genetic matches, and is based on information from family trees. Ancestry points out on its homepage that the tool is only reliable if the family trees contain accurate information: "Since ThruLines™ are based on the family trees of you and other members of Ancestry, they're as accurate as the trees they're based on. Mistakes in family trees can cause inaccurate ThruLines™. Because they're based on trees, ThruLines™ don't prove your specific connection to a DNA match." (AncestryDNA, n.d.)

12 The Shared cM Project, initiated in 2015 by popular genealogy blogger Blaine Bettinger, is an interesting example of such a tool. Bettinger describes it as "a collaborative citizen scientist project" (2016: 38) to which everyone who has undergone genealogical DNA testing can contribute by submitting information about the number of shared cM with known relationships. On the basis of the submitted data, a minimum and maximum of cM for a given relationship is calculated, as well as an average. The results are displayed in a "Relationship Chart", the fourth version of which was launched in March 2020 (<https://thegeneticgenealogist.com/wp-content/uploads/2020/03/Shared-cM-Project-Relationship-Chart.png>, last accessed May 07, 2020).

348). While these tests are available worldwide, they do employ an understanding of kinship that is not universal.

STR testing is not entirely absent from the commercial database offering, although none of the people that I talked to mentioned having purchased this type of test for themselves.<sup>13</sup> STR tests are mostly used to give information on “deep ancestry” instead of more recent relatives. They are used to establish a person’s haplogroup, which, in a genetic genealogy handbook, is defined as a “[g]roup of individuals who share several genetic mutations as well as a common (usually ancient) ancestor” (Bettinger 2019: 280). Haplogroups are commonly understood as a means to obtain information about “a person’s descent from “founding populations” that inhabited regions and continents of the earth thousands of years ago” (TallBear 2013: 41). In addition to SNP testing, which pertains to chromosomes that are not a sex chromosome, males also have the option of having their Y-chromosome tested, which is passed on only from father to son (or from sperm donor to male offspring). While SNP-based testing can mostly be purchased for less than US\$100, Y-DNA testing is more expensive, although prices for this type of test are decreasing as well.<sup>14</sup> As the paternal ancestry line corresponds to the inheritance of surnames in many cultures, such testing can potentially reveal the donor’s surname.<sup>15</sup> Another testing option is mtDNA testing, which tends to be of little significance for those searching for their anonymous sperm donor, as it examines a part of the

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13 Nadine Fuchs, whose brother had been conceived with sperm from the same donor, had paid for her sibling to have an additional Y-DNA test.

14 FTDNA’s basic Y-DNA test tests 37 STRs and was available for US\$169 in September 2019. The company’s “Big Y-700” test, advertised as giving information on an “expert level,” examines 700 STRs as well as 100,000 SNPs and was available for US\$649 at that time. In January 2020, the basic test could be purchased for US\$119, and the ‘expert’ version was available for US\$449.

15 The “surname projects” that those who have tested with a specific company can establish within a database “utilize[...] the logic of crowdsourcing” (Stevens 2015: 396), as they rely on registrants to provide their test results in order to establish whether people with the same surname are genetically similar.

DNA that is passed on from a mother to her children (or from egg donor to donor offspring).<sup>16</sup>

Even when customers do not purchase a “deep ancestry” test, they can still access maps that provide them with a geographic breakdown of where their ancestors came from when viewing their test results online. This information is referred to as “ethnicity estimate” by MyHeritage, which only started to offer its genetic testing service in 2016 but seemed to quickly gain popularity amongst my interviewees. MyHeritage prides itself with offering 42 ethnicities. Their “ethnic groups” are split into six categories (Africa, America, Asia, Europe, Middle East, Oceania). Ethnicity estimates are contingent not only on the membership of a testing site but also “on the contents of their reference population database, as well as how they categorize and label their results” (Abel 2018: 4). As a result, “the estimates provided by different companies can vary wildly” (Abel 2018: 3). While MyHeritage lists “Nigerian” as an ethnic group, FTDNA does not (*ibid.*). These estimates were not the main reason why my interviewees, who were interested in closer relatives, bought these tests, although a few people had mentioned that they had hoped to find out more about the donor’s ethnicity. When people talked about their results, they referred almost exclusively to the list of their genetic matches, and only rarely to their ethnicity estimates. However, it is striking that the ethnicity aspect is clearly emphasised in the way tests are advertised. Apart from the possibility of finding unknown relatives, advertising focuses on the potential of these tests to enable people to find out where they and their ancestors “really come from”. MyHeritage, for example, promises its users on its webpage that their “simple DNA test can reveal your unique ethnic background, and match you with newfound relatives”.<sup>17</sup> Various databases have sponsored videos on YouTube in which content creators discuss their test results with their audience and reveal where they “originally/really come from”.<sup>18</sup> The extent to which the desire to find out more about one’s ethnicity and “deep ancestry”

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16 mtDNA testing looks at the mitochondrial DNA passed on from a mother/egg donor to both female and male children/offspring. In September 2019, mtDNA testing was available at FTDNA for US\$89 for a basic version or US\$199 for the “mtFullSequence”. In January 2020, it was only the extended version that could be purchased for US\$159. Nobody that I had spoken to had purchased or even just mentioned this kind of testing, which arguably reflects the fact that, apart from one exception, my interviewees were all sperm-donor-conceived. A few of them did in fact have a keen interest in their maternal ancestry as well. They felt that this was fuelled by their maternal line being the only ‘branch’ of their family tree they could find out about (see for example Tamara Haste in section 8.2). However, testing mtDNA to find out even more about the known side of one’s tree was not something anybody had considered.

17 [www.myheritage.com](http://www.myheritage.com) (last accessed March 08, 2020).

18 See Lily Pebbles (2018) for an Ancestry-sponsored video in English, and Jessi Cooper (2018) for a MyHeritage-sponsored video in German.

is behind the increase in sales figures is a question that calls for further research on genetic testing.<sup>19</sup>

Kim TallBear's work (2013) on genetic ancestry testing in the US offers an insightful critique of this type of DNA analysis. In her monograph *Native American DNA* (2013), she argues that the genetic markers used in ancestry tests "have not been simply uncovered in human genomes; they have been conceived in ways shaped by key historical events and influential narratives" (2013: 5). According to TallBear, "[t]he concept of Native American DNA is [...] constituted of relations between molecules, happenings, instruments, and minds" (2013: 32; see also Bardill 2014) instead of being something that is 'out there' to be discovered and classified. While ancestry tests, which are supposed to detect "Native American DNA" through a cheek swab, deploy the logic of lineal descent, TallBear has shown that this is "a biological concept that is not always compatible with "traditional kinship" concepts or with contemporary ways of determining tribal membership" (2013: 155). Companies and tests have evolved considerably since TallBear started studying the market in 2003 (2013: 69). However, her work seems even more relevant today, with MyHeritage presenting "Native American" as one of the database's 42 ethnic groups.

Commenting on what she perceives as an "overwhelming America-centric bias" in research on genetic testing, anthropologist Katharine Tyler suggests that studying the use of genetic ancestry testing in the UK could provide a "specific ethnographic insight into the ways in which these tests are mobilised and their results interpreted in the context of postcolonial Britain" (2018: 1). She proposes a research agenda that specifically focuses on Britain, "[t]aking on board the specific histories of empire, slavery, race, nation, racism, nationalism and multiculturalism that have formed and continue to shape the UK and its ethnically diverse citizenry" (ibid.). I suggest that focusing on German genealogists and their use of genetic ancestry testing could add yet another perspective on how ideas about ethnic and other identities are conceptualised. Occasionally my German interlocutors told me that they were sometimes accused of being attached to a Nazi-like racial ideology due to their interest in their origins, which they always firmly rejected. In view of the strengthening of nationalist movements in Germany, I would nevertheless suggest that further research on genetic ancestry testing should look at how ideas about national identities and belonging are discussed by those interested in DNA tests and "deep ancestry".

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19 What I was told in Germany points in this direction: for example, one of my interviewees found a donor sibling after the interview. Her donor-conceived half-brother had not known that he was conceived with donor sperm. He had received a test kit from MyHeritage as a gift from his wife, who was interested in the company's ethnicity estimates.

## 8.2 Digital DNA: Working out relationships and infrastructuring information

Via genetic testing, participation in a digital world and genetic material gets merged (Ruckenstein 2017: 1026). Most importantly, genetic databases offer not only DNA tests whose results can be viewed online and exported to other sites but also ways of communicating online with other users. As I will argue, this can pose new challenges for the donor-conceived, although (or because) it might bring them in touch with donor siblings. I will also show how some of my interlocutors attempted and sometimes managed to combine information from a variety of sources to make the best use of their test results and ‘work out’ genetic relationships. This illustrates that DNA testing does not end anonymity, but that it opens up new ways of linking information. It is this process, which I call infrastructuring, that calls into question whether a distinction between identifying and non-identifying information can be made with certainty. I suggest that a distinction is challenged by new ways of connecting, circulating and networking information. The boundaries between what can be used to identify donors and what keeps them anonymous get blurred.

The tests offered by FTDNA, Ancestry, 23andMe and MyHeritage are increasing rapidly in terms of scope and accuracy and implement developments in genetic testing faster than voluntary registers. Additionally, prices continue to fall: FTDNA’s test “Family Finder” was sold for US\$300 when it was first launched in 2010 (Stevens 2015: 394) and was available for US\$79 in May 2021. Besides, testing companies frequently hold sales not only at official holidays but also on occasions such as “DNA Day”,<sup>20</sup> during which the tests can be bought at a reduced price. It should be noted that even though they have become cheaper, not all of my interlocutors were able to afford this sum. However, the prices were something that made people postpone a purchase rather than give up the thought of it altogether.<sup>21</sup>

After buying a test kit online, sending in a saliva sample for analysis to the company’s laboratory, and receiving a notification email about the results, customers

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20 DNA Day is celebrated on April 25. It commemorates the discovery of the double helix structure of DNA in 1953 and the completion of the Human Genome Project 50 years later. In the US, it was an official holiday in 2003 only and merely supposed to be a one-time celebration. However, the National Human Genome Research Institute continued to organise a yearly DNA Day, and other groups have since started celebrating it as well.

21 Jacob Moore, for example, was still attending university when I interviewed him. Although he had “definitely considered” purchasing a test, as he was keen to find his half-siblings and learn more about his ancestry, he had not yet been able to do so: “I mean the problem with those things is they’re all not very expensive but a little bit costly, and as a penniless student I can’t really afford that at the moment.” He was planning on doing at least one DNA test once he had the money for it.

can log into their accounts, view their own data online, and see how they are related to other persons on the database. In the case of FTDNA (figure 4), this data is presented in the form of a table that lists other registrants and the specific relationships that are possible based on the amount of shared cM.<sup>22</sup> Registrants can then enter the “linked relationship” in a specific field. If matching is not enabled, a person’s data will not be matched with that of other users. Those who decide to participate in the DNA matching feature have to consent to information such as their email-address and profile picture being made available to genetic matches. The matching features of other companies are optional as well, and registrants can usually decide to opt in and out of DNA matching at any time after the registration process. Customers can connect with other users via messaging functions, or even access the email-address of a genetic match in the case of FTDNA’s matching service, discuss their findings, exchange messages and family trees. The opportunity to get in touch with others gives them the chance to discuss test results and work out how a match came about.

Figure 4: Screenshot of FTDNA results

Name	Match Date	Relationship Range	Shared Centimorgans	Longest Block	X-Match	Linked Relationship	Ancestral Surnames
[Profile Picture]	08/31/2016	Full Siblings, Half Siblings, Grandparent/Grandchild, Aunt/ Uncle, Niece/ Nephew	2,010	173	X-Match	Sister	
[Profile Picture]	08/31/2016	Half Siblings, Grandparent/Grandchild, Aunt/ Uncle, Niece/ Nephew	1,783	175	X-Match	Sister	
[Profile Picture]	08/31/2016	Half Siblings, Grandparent/Grandchild, Aunt/ Uncle, Niece/ Nephew	1,511	146	X-Match	Sister	
[Profile Picture]	01/16/2017	5th Cousin - Remote Cousin	67	8	X-Match	[Add]	
[Profile Picture]	08/31/2016	4th Cousin - Remote Cousin	67	11		[Add]	
[Profile Picture]	08/31/2016	4th Cousin - Remote Cousin	64	11	X-Match	[Add]	

Source: Sabrina Frey

Apart from purchasing a specific company’s own tests, users also have the option to export ‘raw’ genetic data and upload it to other sites (Ruckenstein 2017: 1026), although not every company offers the same import and export options. Raw data files contain thousands of lines that consist of the information for all of the

22 The original list contained both names and profile pictures.



SNPs that were tested. Without any analysis tools, raw data documents appear to be nothing more than endless strings of letters and numbers. There are several online platforms that can serve as analysis tools but do not offer their own DNA test. It was notably the genealogy website GEDmatch that seemed to be popular with those who made particular intensive inquiries to find their relatives.<sup>23</sup> The site is free of charge but does offer several “premium tools” that can be purchased by users. The possibility of exporting and importing raw data demonstrates that in the context of online DNA databases, genes are presented “as digital big data to be browsed, uploaded and shared” (Hogarth and Saukko 2017: 202). Uploading results to other sites and registering with several companies in the hope to maximise one’s chances of finding a donor sibling or the donor was a phenomenon that I first encountered in the UK. Several of my British research contacts had already registered with multiple sites by the time I met them. In contrast, Nadine Fuchs was the only one of my German interviewees who had already registered with more than one company when I did my research. She had also started to use GEDmatch in her search for her donor.

The possibility of directly contacting other people on the database constitutes a significant difference between commercial genetic testing and registers such as the central HFEA register, the DSL, or the DNA database managed by the DCR. Whereas these formal registers act as intermediaries in the case of a match and usually offer psychosocial support for those with newfound relatives, commercial genetic testing sites do so far not offer a comparable service. Instead, people get directly in touch with each other without the mediation of a third party. While commercial databases can be seen as empowering donor-conceived people, as they are not dependant on an intervening third party to establish contact, there are also more critical and sceptical voices lamenting the lack of support (see for example Crawshaw 2017).<sup>24</sup>

My interviewees themselves pointed out that genetic testing might potentially bring the donor-conceived into challenging situations, particularly as they might get matched with donor siblings who do not know yet that they were conceived with donated gametes. Elizabeth Chapman, for example, told me about the experience of one of her donor-conceived friends who had been matched with a donor-conceived half-sister. She had not yet known about the circumstances of her conception and had soon after broken off contact with Elizabeth’s friend. Elizabeth

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23 [www.gedmatch.com](http://www.gedmatch.com) (last accessed March 08, 2020).

24 The question of support and responsibilities is addressed by Crawshaw in a commentary on donor conception and commercial genetic databases (2017). She argues that given their growing popularity, it is increasingly necessary to raise questions “about their ethical responsibilities to provide additional information about where their customers can turn in the event of uncovering the probable presence of donor conception” (2017: 4).

commented, “It’s a lot to take in, isn’t it? And to find out that way, when you’re interested in genealogy, and to suddenly find out you’ve got a half-sibling.” However, she pointed out that it had also been a difficult situation for her friend since “that puts a lot of onus on donor-conceived people [...] to be careful how they frame things when they talk to people”. Some of the concerns discussed in chapter 6 become relevant here at a different level. The question of who knows what at what point in time and who can, should or may tell others, and how things need to be ‘framed’ needs to be re-addressed. Those who already know that they are donor-conceived have information that is constitutive for their genetic match. However, they must find a way to convey it without causing any kinship trouble.<sup>25</sup>

Whereas the central HFEA register and the DSL each have a minimum age for accessing information or joining the database, minors can usually take a DNA test if their parents give their consent. This makes it possible for parents to register even small children (as exemplified by the case described in the concluding chapter).<sup>26</sup> And whereas registers such as the DSL and the central HFEA database only match the donor-conceived with their donor siblings, or with their donor, commercial databases establish links between distant “genetic cousins” as well. A match was only considered useful by my interviewees if the cousin they had been matched with was of a relatively low degree, and not too far removed. Elizabeth had shown me various testing sites and the accounts as well as matches that she, her husband and one of her donor-conceived friends, whose accounts she managed, had on them. She argued that whereas a third cousin could be a good enough match to find a donor, more distant cousins were usually not sufficient. Elizabeth summarised it as follows:

Elizabeth Chapman: “You just find your cousins, and then you have to try and work out relationships. You do need to find close matches though. It’s no good finding a sixth cousin, you do need a first or second or third cousin. But some have worked it out from third cousins. It’s marvellous, it’s revolutionist, it’s fantastic.”

‘Working out relationships’ required putting in effort and having matches that were ‘close enough’. However, Elizabeth knew of donor-conceived people for whom finding more distant cousins had worked:

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25 In a blog post on the subject, Spenderkinder (2019b) advises the donor-conceived to be cautious when they have a match and not to ask immediately in which clinic the other person was conceived. Instead, the author suggests to first ask why the other person has taken a test, and argues that it is “patronising” (*bevormundend*) to advise them to talk to their parents first “because if you register with a DNA database, you are an adult and can decide for yourself what you want to know” (2019b, author translation).

26 FTDNA does not allow persons younger than 13 to take a test, while other databases do not have a minimum age. However, they also require a parent or legal guardian to give their consent if the person to be tested is under 18.

Elizabeth Chapman: “If you can see their family tree, you can work it out, you go down a few generations, and you find out if they’ve had someone who trained to be a doctor or went to a university, you can tell, ‘Oh yes they went to such and a university in [a town], oh, was he there in the 1970s, yes, he was there in the 1970s, when [her friend] was born’, and you think, ‘Ah’. And that’ll give you a good idea. And it has worked. People have found their father that way.”

It is not only genetic material and digital participation that gets merged when people are working with DNA tests, but also other forms of knowledge people might have, such as information on the profile past donors are likely to have had (“student in town X where treatment took place”). Moreover, genetic testing does not replace other methods of searching. Many of my interlocutors used various other online and offline resources. They visited physical archives, libraries and the clinics where they had been conceived to search for information. This was especially the case among donor-conceived persons in Germany, as there were no official or voluntary registers that they could use. Most of them did not access these resources with the explicit intention of linking the results of their offline search with the results of their DNA test. However, infrastructuring practices that interweave information from different resources could become a powerful, albeit work-intensive, means of searching for those who did not have close matches.

The story of Nadine Fuchs, who was conceived in Germany in the late 1970s, is a particularly striking example of the infrastructuring of information. While others spent time in archives and libraries out of an interest in historical contexts and were driven by curiosity, pain and the desire to overcome it seemed to drive her search. Compared to what other people told me, her experience is unique in terms of the time and other resources she invested in her search. Nevertheless, I will summarise it in the following paragraphs, as the complexity and creativity of infrastructuring can be shown particularly clearly by the rather ‘extreme’ nature of her story. Although no one else invested as much time and work as she did, her experience of unsuccessfully contacting doctors was something that was shared by many of my German research contacts.

A central theme in Nadine’s story was the feeling of not fitting into her family and being completely different from her parents. Like many of my interlocutors (section 5.3), she mentioned that she was the first in her family to attend high school (*Gymnasium*). Instead of being proud of her, her parents had shown little support and understanding, and constantly asked questions such as “Do you think you are better than us?” Since she had always felt like a stranger in her own family, she had not been shocked at all when she learnt that she had been conceived with donated sperm. Her constant feeling of not fitting into her family had not deceived her. However, she had soon felt another kind of ‘dissonance’, which prompted her to search for her donor immediately. Nadine mentioned that when she had looked

in a mirror, her face had no longer “fitted”. She had felt as if she was looking at “an alien being” (*ein fremdes Wesen*). She had immediately felt a strong urge to find her donor, “so that this gap can be closed. So that someone would be there.”

Nadine was very critical of donor conception per se and argued that couples who thought about using donor sperm should take into account that a man might “suffer terribly from the fact that he does not have the same relationship with the children, that he cannot love them as much as his wife”. Her own father had never really been a “present” parent, with other male figures such as her grandfather or even a neighbour being more involved in her and her brother’s lives. For her, adoption was the preferable ‘solution’ for involuntary childlessness, as it resulted in ‘even’ relationships with neither the mother nor the father being genetically related to the child, and with both parents having “the same access [*Zugang*] to the child”. Others voiced similar opinions, although not all were critical of gamete donation.<sup>27</sup> Statements according to which adoption creates a balanced “access” to the child reflect a belief in the idea that “each parent must somehow occupy a position with respect to the child that can be understood as similar or the same in some crucial aspect” (Melhuus 2012: 43), with DNA not being the only way of ensuring an equal or even connection.<sup>28</sup>

Since the doctor who had performed the insemination in the 1970s had already died, Nadine had contacted the physician who had taken over his gynaecological practice. However, he claimed that all documents that might contain information about the treatment and her donor had already been destroyed. Other donor-conceived persons that I interviewed in Germany talked about similar experiences. Most of them had contacted their mothers’ doctors or the clinics where the inseminations had taken place. In some cases, the clinics and physicians maintained that access to information could not be granted for legal reasons. They did not necessarily state that the documents had been destroyed. Some of the people I interviewed had been met with little understanding when they contacted clinics and sperm banks. For example, one person had been told by a doctor that her parents

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27 In contrast to Nadine Fuchs, Sabrina Frey repeatedly mentioned that she considered donor conception to be a perfectly acceptable practice. She believed that fathers in particular should be proud instead of ashamed of having chosen this path to parenthood (section 6.1). She nevertheless made a very similar argument regarding the ‘evenness’ of genetic connection. Sabrina mentioned that she would have chosen adoption over donor conception if she or her husband had been infertile, as she thought it was “fair that then both are not the genetic parents. So that nobody gets excluded.”

28 The importance of having a child that equally belongs to both parents was also highlighted by the couples in Melhuus’s (2012) study on involuntary childless couples in Norway. Some of them decided for adoption and against donor conception because they did not want to “risk skewing the parent-child relationship in favour of one or the other, and thereby also, in their understandings, undermining the conjugal relation” (2012: 43).

who had raised her were much more important than her donor. Unsurprisingly, he did not give her any information about him. Many were upset by such reactions and stated that they did not believe that the doctors who claimed that they had no treatment records left were telling the truth. Interestingly, a few people told me that they could in fact understand when doctors refused to give out information (see also section 3.5). Diana Kraft from Germany, for example, who had been told by a doctor that even if he still had documents, he would not give her information about her donor, told me that she could understand him: after all, he had promised past donors that they would remain anonymous. Diana believed that if doctors had given their donors this kind of promise, “then they have every right to keep that promise, even if it is at the expense of the children”.

However, an inquiry could also be successful. In the case of another person, who had been conceived in the late 1980s, the doctor, after initial hesitation, eventually arranged contact between the donor and my interlocutor. He had also initially claimed that all documents had been destroyed and had only become more cooperative after she had told him that, if necessary, she would sue him for information. These experiences illustrate that, in the absence of a central register and clear regulations, doctors in Germany exert or try to exert more control over information than their British colleagues. At the same time, however, this can also create new opportunities for action for donor-conceived persons, as it can lead to doctors having to appear in court. This was what happened in the case of another one of my German interviewees who did successfully sue a doctor for information about her donor.

While Nadine’s research into the late doctor’s professional and family environment had been unsuccessful, the two DNA databases she had already joined seemed more promising, even though she had no close matches at the time of the interview. Nadine had not only her own genetic data to work with but also the test results of her brother and a maternal aunt, who had also agreed to be tested. Her aunt’s data allowed her to ‘filter out’ her maternal matches from her match list and focus on her paternal matches. Her brother’s registration had revealed that they had the same donor, which her parents had not known. This finding was especially helpful for Nadine, as it meant that she could use his genetic data to better assess the actual significance of her own matches:

Nadine Fuchs: “So it’s not always the case that someone with whom you share an incredible number of genes is necessarily very helpful. Sometimes it’s the other way around. Because the good thing is that I have my brother, and we are full siblings, and sometimes it’s a very high match with him, and I see that it’s a very low match with me. Simply because we are different, because the genes are differently distributed and scattered.”

Although all of her distant cousin matches lived far away in the US, Nadine mentioned that “real friendships” had developed in the meantime. The newly formed group of cousins exchanged not only genealogical information but also messages such as birthday wishes. Many of her matches had put their family trees online, which they constantly updated and expanded with new information. By carefully searching and comparing these trees, Nadine had been able to identify the person who linked the different trees, making him the most common recent ancestor of her and her cousins. The genealogical research of her cousins had revealed that this person had been born in eighteenth-century Germany. Nadine concluded that another descendant of this person must have been her donor. However, since her ancestor had died long ago and probably had thousands of descendants, she knew that it would be impossible to recreate his complete family tree, locate all his descendants and find her donor. Apart from the sheer number of people she would have to check, her search was further complicated by the fact that the existing data was probably incomplete. Although the genetic genealogy blogs she used to read up on DNA testing and the Facebook groups she had joined to exchange information with others were helpful, they did not lead to a breakthrough.

In the meantime, Nadine had also discovered a doctor through an intensive Google search, whom she believed could be her donor. After she had been ‘scanning’ images of doctors online for a long time, she had come across a physician who had not only studied medicine in the city where she had been conceived but who also looked like an older version of her brother. This doctor had denied ever having been a sperm donor when Nadine contacted him. Nevertheless, she had started to research his family history intensively, without him being aware of her search. Her goal was to find a connection between his family tree and the trees of her genetic cousins. To achieve this, she had already spent many hours in archives, some of which were located in other parts of the state she lived in, trying to trace and build his family tree. Although she had already invested an enormous amount of time and effort, she did not limit her search to him: “I also follow up on others, so I try somehow not to be guided by my feelings, but I also try to really think *out of the box* [she said this in English] [...] I try everything.” Since she did not know who her donor was, she felt compelled to follow up several leads at the same time. Her attempt to trace the family tree of her brother’s lookalike in particular, without the doctor being aware of her efforts, illustrates that she did engage in a detective-like search, a practice that has also been described as “technological sleuthing” (Nelson and Hertz 2017: 153).

Sometime after the interview, she bought another test, which was not yet available in Germany at that time and which she had therefore ordered through a friend living abroad. At this point her search seemed to be at a dead end, and Nadine mentioned in an email that, for the first time, she had decided to stop searching. This test was her last attempt to find out something. However, this time Nadine was

lucky to get a very close match immediately. She recognised the last name of this genetic cousin, as she had come across it during her previous investigations. She had already 'built' this part of the family tree some time ago based on an intuitive feeling that made her return to this particular family again and again. For this reason, she knew immediately where exactly in her family tree this new match was located. Nadine concluded that one of her match's three maternal uncles had to be her donor. Nadine knew, "thanks to the Internet and Google", that the wife of one of these men had studied in the city where she was conceived and assumed that her husband would probably be her donor. Through an inquiry at a registration office (*Einwohnermeldeamt*), she managed to get his address.<sup>29</sup> Nadine sent him a letter, to which she attached a photograph of herself. He contacted her by email a week later and said that he had not expected anything like this. It turned out that her donor was in fact not a former medical student. Instead, he had met the doctor who had performed the insemination of Nadine's mother through his wife, who had once been his patient. In the meantime, Nadine and her donor had also met in person. Although no close relationship had developed, she wrote me that she was happy and relieved to have found him: "I have found my peace." Up to now she had not had any contact with his children, who were her genetic half-siblings, but not donor-conceived. Her donor did not seem to want them to know about his past donations, and Nadine did not want to initiate contact against his will.

Before returning to the infrastructuring of DNA, I will briefly discuss how donor-conceived persons reacted when their donor, as was the case with Nadine, did not meet their expectations. While they did not necessarily imagine their donor as a likeable person, many seemed to hope and expect that they would meet a man they could respect and admire. In particular, many seemed to imagine their donor as an intelligent, ambitious and professionally successful man (see also section 5.3). Based on what I have heard from, or read about those who have identified their donors, I would say that in many cases their expectations were not met. Nevertheless, even in these cases the donor-conceived usually commented that they had "found their peace". I suggest that similar to the way people talk about having always felt the truth (section 5.2), "finding peace" recreates a sense of continuity and

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29 By making a request to a resident register (*Melderegister*) managed by a registration office, private individuals can obtain limited information about other residents. These requests are fee-based. Extended information, which includes the date of birth and marital status, is only provided if a "legitimate interest" (*berechtigtes Interesse*) can be demonstrated. Such circumstances include, for example, a dunning procedure. It is possible to apply for a two-year ban on one's own data so that it cannot be released. In Germany, I was told about a person who had located her donor by making a request for his address after she had found out his name. After she had contacted him, he had his data blocked, and another person was later unable to request his information. Out of respect for the donor's decision, the person who had already received his data had decided not to give it to her.

coherence. Something that could have become a painful experience – that is, not finding the kind of donor one had hoped for – is narratively reworked into something that does not bother them too much.

Not all of my interlocutors were willing or able to put this much time and effort into continuing their search on the basis of more distant genetic matches. Some did not want their search for the donor to get out of hand, while others did not seem to be aware of the possibilities a distant cousin could create. Still others mentioned that they would like to put more effort into their search, but had not yet found the necessary time to do so due to professional or private obligations. Tamara Haste, for example, had been matched with a fourth cousin with whom she was in email contact and who had given her information about his ancestry. Like others who had made contact with genetic cousins, Tamara had done so in the hope of ultimately identifying her donor. Since she loved history and “anything to do with the past”, Tamara had already started to do ‘conventional’, non-genetic ancestry research on her maternal ancestors after she found out she was donor-conceived. She explained that this was “the side that I can find out about” and commented that tracing her maternal ancestry back over several centuries had been “quite satisfying”. The family tree she had been given by her distant cousin did not match any of that information, and Tamara therefore suspected that he might link her to her unknown paternal family, and not to her known maternal one. However, due to her full-time job, she did not have the opportunity to invest a lot of time in the search. Finding the most common recent ancestor of her and her match seemed impossible, at least for now, which frustrated her. She had not yet succeeded in becoming involved in campaigning for the rights of the donor-conceived either, although this was something that was close to her heart as well: “It’s something that is difficult to make a priority when you’ve got other stuff going on, but at the same time it’s something you think about literally every day.”

Elizabeth, whose thoughts on ‘working out relationships’ I have commented on at the beginning of this section, had made searching for genetic relatives a priority. When I met her for the first time, she not only showed me FTDNA as well as GEDmatch on her laptop but also talked at lengths about how the emergence of the Internet, PCs and emails in the mid- to late-1990s had helped to establish an international community of donor-conceived people and other activists (section 4.1). She concluded that without these technological developments, neither connecting with others nor finding one’s relatives would be possible and proclaimed that the Internet had “revolutionised things” for the donor-conceived. Nevertheless, she also pointed out that despite new possibilities such as online groups and genetic testing, finding one’s donor was still dependant on fortunate coincidences. The revolutionist potential of genetic testing could only be unfolded if a ‘close enough’ match was made, which depended on who else joined the database:



Elizabeth Chapman: “Without the technology, hardly anything would be possible. [...] I mean this FamilyTreeDNA ... [shuts down her laptop] it’s wonderful, really. You don’t even have to leave home. You can find your father now without leaving home, you don’t even have to go and pay for it because you use your credit card online. And the stuff comes, it’s delivered to your door, the hardest bit is going to the post office to send it back. And then everything is done, and you can actually find him. It’s amazing really. But you do need the luck. So not everybody’s going to be lucky. Which is a shame.”

Even with DNA testing, there was still no guarantee that one would be successful, as there was an element of chance and good luck involved as well. Elizabeth framed genetic testing as something that was accompanied by a high degree of unpredictability, which was again emphasised by the comparison she drew later on between genetic testing and gambling: “There are lots of opportunities, but you do have to put your money into it, take a leap of faith, it’s a bit like playing roulette, you’ve got to be in it to win it, so you’ve got to take your chances.” While genetic testing gives the donor-conceived the chance to “put themselves out there”, the outcome of their search, similar to a round of roulette, cannot be predicted. While they might ‘win’ and find their donor, they have to try it first. In the following section, I will explore the feeling of “having to try” in more detail.

### 8.3 Having to try: Anonymity and inevitable choices

Similar to the intense scanning of others that people were drawn into (section 5.4), genetic testing emerged as something that many of my donor-conceived interlocutors felt they had to do: they felt that they had to at least try and find their donor and their donor siblings, and DNA testing was seen as the easiest way of finding someone. Genetic testing could be experienced as a way of *doing* at least *something* to find genetic relatives and “put yourself out there”, which was also the main reason why people decided to join voluntary registers. While searching for genetic connections can be “comforting in terms of providing a sense of previously lost agency brought about by past experiences of an absence of kinship knowledge” (Klotz 2016: 51), DNA testing and scanning both emerged as practices that were not entirely agency-controlled. My interviewees generally felt compelled to make use of the commercial testing opportunities that were available to them, and often bought a test as soon they found out about genetic ancestry testing. Jessica Robertson, who had joined the DCR as soon as she was told about its existence (section 7.6), commented that she had ordered several DNA tests as soon as she had found out about them: “It was like, ok, they exist, I’m doing it.” Not buying a test and not giving it a try was not an option for the vast majority of people that I interviewed. Their approach

to genetic testing bears interesting parallels to what anthropological research on reproductive technologies and especially IVF has shown. In the following section, I will focus on the work of two authors who explore why, especially for many women, not trying IVF is not an option (Franklin 1997), and why ending treatment can be difficult (Throsby 2004). I will use an example from my material to show that DNA testing, similar to IVF, could draw people in, and discuss how it was still possible for them to end their active search. Finally, I will address the criticism of those who argue that genetic testing is a threat to privacy, which was a concern voiced by only a few of the people that I talked to.

Sarah Franklin's study *Embodied Progress* (1997) was one of the first detailed accounts of the lived experiences of IVF.<sup>30</sup> "Having to try" was a central motif in all of the interviews Franklin conducted with women who were in the midst of treatment (1997: 102).<sup>31</sup> At the time of her research in the late 1980s, the average UK success rate for IVF was 8.6 percent (1997: 82). Franklin shows that while pursuing IVF can be seen as giving infertile women the possibility to pursue motherhood, it is also experienced as an inevitability: "If the procedure is seen as the only way to realise this desire, then there is no decision, no 'choice'; the answer is a foregone conclusion." (1997: 171) The women she interviewed felt compelled to leave nothing untried and wanted to have "the certainty of knowing they did everything possible to succeed" (1997: 173). However, "this is precisely the certainty that IVF takes away" (*ibid.*), and despite low success rates, women felt compelled to try *and keep trying*, as IVF offered them the hope of having a child. Deciding to stop treatment and "to abandon hope for success may have become much more difficult after 'living for the dream' from cycle to cycle, often over several years" (1997: 12).

In her study of what happens when treatment fails, Karen Throsby found that those who underwent IVF would frequently mention "[t]he need to have tried every possible means" (2004: 164) before ending treatment. However, "what actually constitutes 'doing everything' is frustratingly indeterminable" (*ibid.*).<sup>32</sup> Even though

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30 The chapter entitled "'Having to try' and 'Having to choose': how IVF 'makes sense'" (Franklin 1997: 168–197) inspired the title of this section.

31 Franklin and Roberts (2006) have shown that a similar dynamic shapes the way people approach PGD. While having a child born free of a specific genetic disease might have motivated patients to start treatment, experiencing failure in the form of not being able to conceive is not entirely and permanently negative because "a child is not the only potentially positive outcome of PGD" (2006: 192). Instead, "satisfaction and a sense of shared achievement" (*ibid.*) can also derive "from having given PGD your best try, from those aspects of the technique that have succeeded (such as producing good embryos), or from being "free" to move on to something else" (*ibid.*).

32 Asserting that one has tried everything has several aspects to it: it refers to having tried everything that is not excessive and risky. It also indicates that patients accept that they are, at least to some degree, responsible for the outcome of a cycle and enables those who end

Throsby's research in the UK took place about a decade after Franklin's study, the failure rate for IVF was still high, with about 80 percent of all cycles not resulting in a live birth (2004: 7). Throsby found that "while there are well-trodden paths *into* IVE, the routes *out* of treatment are more obscure" (2004: 162, emphases in original). She argues that ending treatment can be a long process that might be imposed upon patients "as a result of financial limitations, health problems, age, or their partner's refusal to participate" (2004: 15). Once treatment has been stopped, women have "the task of creating, or at least imagining, a future different from the one on which their engagement with IVF was predicated" (2004: 185). While some found resolution around their inability to conceive, Throsby found that "the inability to imagine a positive future without children remained an apparently intractable barrier" (2004: 184) for others.

In my field, too, it sometimes happened that the desire and the need to find the anonymous donor was so great that people would keep on trying and trying. This was especially the case with Nadine Fuchs, whose time and work-intensive search for her donor I have described in the previous section. Searching for the donor, which was not only limited to buying DNA tests, seemed to have taken over her life, similar to the way in which IVF can become "a way of life" (Franklin 1997: 101). Interestingly, those who invested a lot of time in their search often emphasised that having a match was also a matter of luck, and not just down to hard work, with Elizabeth Chapman (section 8.2) stating that DNA testing was "a bit like playing roulette". Here too, a similarity with the way in which women make sense of IVF can be observed: "It is like a kind of gamble or roulette. Hence, on the one hand, IVF is sought out as an enabling technology, yet on the other hand it is perceived as subject to a kind of random element no amount of assistance can mitigate." (Franklin 1997: 177)

Unlike Nadine, who wanted to leave no stone unturned, most of my interlocutors approached their search and their use of genetic testing differently. But even those who told me that they were not desperate to know and who emphasised that they were not willing to take extreme measures mentioned they had taken a DNA test, which was oftentimes described as an "easy thing to do". Although they would sometimes point out that they would be fine without knowing, not buying a test was not an option for them. Especially my German interlocutors, who had no mandatory or voluntary registers that they could access, oftentimes told me that they ordered a test kit from FTDNA as soon as they had found out about the database via Spenderkinder's website and internal mailing list. As they mostly did not receive any information from the physicians and clinics they had contacted, they felt that this was their only chance to get information.

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treatment to demonstrate that they overcame obstacles and did not give up (Throsby 2004: 165–167).

The way in which trying could have its very own dynamic that would draw people in got particularly clear in the way in which Alexandra Gerstner described her experience with genetic testing. She was conceived in Germany in the mid-1970s, making her one of my oldest interviewees. When I interviewed her, Alexandra knew for about a year that she was donor-conceived. Already in her first email she had mentioned that she was still struggling with the consequences of this information. As she told me during the interview, her talents and character had never fitted in with her parents and their family business. Knowing that she was not able to follow in her father's footsteps had torn her apart in the past. She also mentioned that she looked very different from her parents and bore little resemblance to her sister, and she suspected that her sister had been conceived with the sperm from a different donor. Alexandra stated that she was relieved to know the truth about her origins and happy to finally be freed from the pressure of having to fit in. Her newfound freedom seemed to help with her autoimmune diseases, as her health started to improve after she found out that she was donor-conceived. Nevertheless, she was in tears during most of the interview, which clearly brought back painful memories. After I stopped recording, we talked for another two hours, and Alexandra seemed to be more at ease. I told her a bit more about my time in the UK, from where I had just returned, and Alexandra went on to mostly tell me about her friends' and relatives' experiences with infertility.

Somewhat to my surprise, her donor was not the person she was most interested in. Alexandra suspected that he had simply been "a happy student" (*ein fröhlicher Student*) who probably donated without really thinking about it. However, she was very curious about the women in the donor's family, whom she could only find by locating the donor first. Alexandra had already contacted and even visited the clinic where she had been conceived, but her visit had not yielded any concrete results. In the meantime, she had also done a DNA test. She described the process of ordering the test kit and sending it back to FTDNA's lab as something that had occurred almost automatically, with her executing the different steps as if she was controlled remotely:

Alexandra Gerstner: "I'm very sceptical about disclosing information, and I'm very careful, and sending my genetic material to America would have been unthinkable before that, and I knew it [that she was donor-conceived] and heard about this Family Tree [she meant FTDNA] and did it immediately as if I was somehow a different person because I thought, 'Damn it, somehow you have no possibilities at all, you're simply doing this now', I don't know if it was the right thing to do. I stood there, I don't know, I somehow stood there at the post office and dropped off this parcel [with the test kit]. I don't know if I really understand what I was doing, but I didn't get any information. And I think that's unlikely, too."

Although taking the test had given her the opportunity to get active, receiving the results seemed to reinforce her feeling of being in a dead-end situation, as they did not reveal any useful information. However, Alexandra mentioned that she was not willing to “drag it around” (*rumschleppen*) her entire life and was therefore thinking about having a symbolic funeral for her anonymous donor. Similar to those who identify a new phase in their post-IVF life, which “contains the IVF and its failure within a discrete time period” (Throsby 2004: 181), Alexandra was hoping to leave her anonymous donor behind. She added that she would like her two sons to be at the funeral with her “because it’s kind of about them too”. Alexandra had mentioned earlier that she felt it was a pity that the anonymity of the donor deprived her sons of the opportunity to identify with their genetic grandfather: “Because you only really become a human through this identification, and I think it’s a pity that my children don’t have that opportunity.” She had decided not to continue the search for her donor actively, but instead to trust that she would get the information she was supposed to receive: “Because that [an active search] doesn’t get me any further and that doesn’t make me healthier, or help the children [her sons] either, I think if I am allowed to find out something, then I will find it out.” She thus evoked a future that, despite not being predictable, was organised in a specific way: even without an active search, she would find out what she was meant to find out. This approach enabled her to keep any fears about never being able to know at bay. Her belief bears similarities to the concept of fate that was frequently evoked by Throsby’s interviewees (2004: 168). According to Throsby, asserting that there is “an unknowable, but directed, greater purpose offers a framework within which to accept the ending of treatment without writing off that treatment as futile” (2004: 170). The assertion of fate could justify both the choice to continue treatment and to end it (2004: 168–171).

For Alexandra, asserting that she would receive the information she was “allowed” to receive enabled her to remain moderately hopeful while not searching actively, and despite telling herself that she was probably not going to get any results. Alexandra did not explicitly refer to genetic testing when talking about her ‘fate’. Commercial genetic testing, however, allows the donor-conceived to remain moderately, and reasonably, hopeful. As long as the donor-conceived do not delete their accounts, which none of my interlocutors had done, it is still possible that one day they will find a donor sibling or their donor. This allows them to simply wait until they get a match. While a one-time registration is sufficient for FTDNA and other databases, a new cycle must be started if one round of IVF does not lead to pregnancy and then birth. Since each cycle has to be paid for, and especially if the number of insurance or health authority funded cycles is limited, continuing to try and conceive via IVF might no longer be a financially feasible option at some

point.<sup>33</sup> I will elaborate on this difference and what it meant for those who had not found any relatives yet in more detail in the next section (8.4).

Whereas Alexandra usually had reservations about the disclosure of personal data, these reservations had been temporarily suspended when she found out that there was something she could do to try and find her donor. In fact, my interviewees rarely expressed concerns about the sharing of genetic information, even though I was told in Germany that some members of Spenderkinder were not comfortable sending their saliva samples to the US where the FTDNA lab is located. In the UK, Jessica Robertson suspected that more and more people would find out that they were donor-conceived, as genetic testing was getting more popular. She laughingly commented, “Maybe that’s a little bit dodgy, companies with all of our DNA”, with her laugh indicating that she was not really concerned about her genetic data being misused. This seemed to be different with Jade Foster from the UK, who had not yet bought a test kit:

Amelie Baumann: “Have you ever thought about submitting your DNA to a genetic testing site?”

Jade Foster: “I thought about it, but part of me feels weird about a corporation having access to my genetic material. You know, what are their ulterior motives, which I know is a little bit conspiracy-theorist, but the fact that this is you, that is the essence of you, and you’re handing it over to a big anonymous corporation, and they’ve got *all* of the information about you. And they can do what they want, and that scares me a bit.”

While rejecting DNA testing might be interpreted as a sign that genes are not considered important, an acknowledgement of the authority of genes did figure into her decision (see Gandsman 2009: 450 for a similar argument). She considered genetic data to be information that was not merely about her, but also constitutive of her. It should be noted that despite her belief in the importance of genetic data, Jade, as was the case for the majority of my interviewees, did not hold on to a geneticist idea of kinship. She remained close to her older sister from her father’s first marriage, whom she had previously believed to be her genetic half-sister, and her sister’s children whom she loved (“they are my world”).

Whereas concerns about the sharing of genetic data were rarely expressed by my interviewees, genetic testing is viewed more critically elsewhere. Concerns

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33 Interestingly, Throsby found that a “continued possibility of conception was a recurring theme in the interviews” (2004: 173). Even after the end of treatment, “the possibility technically remains” (2004: 174), although stories about others suddenly conceiving without any medical intervention “were generally approached with scepticism and annoyance” (ibid.). Instead of actively trying to get pregnant, it mostly meant that couples were simply not using any form of contraception (ibid.).

about the privacy of genetic information are rooted in debates about the Human Genome Project, a research project aimed at determining the complete sequence of the human genome that was initiated in 1990, and the emergence of population biobanks. These developments triggered concerns about genetic information potentially becoming a means for stigmatisation and discrimination, which in turn lead to the creation of “genetic privacy” (Knoppers 2010: 416) laws.<sup>34</sup> However, a 2016 review of how companies offering health and ancestry testing comply with guidelines formulated by governments and professional bodies found that “there have been only modest developments toward improvements in transparency about privacy risks, the fate of data, and secondary use of data over the past decade” (Laestadius et al. 2016: 518). The authors note, for example, that one-third of all companies did not require consent to use genetic data for research, which they interpret not only as a violation of official recommendations but also as “a continued blurring of the lines between consumers and research subjects” (ibid.). A study that looked at how companies offering testing in Canada communicate privacy information found that the information they included on their websites tended to address “aspects of privacy related to the web interface, rather than privacy implications of genetic testing, disclosing health information, and third parties gaining access to an individual’s genetic information” (Christofides and O’Doherty 2016: 117). Companies have also been criticised for formulating their contracts in a way that does not give costumers sufficient control over their data. A lot of companies have variation clauses that allow them to significantly alter their terms and privacy policies. They might, for example, decide to share and sell genetic information despite initially having stated that they will not do so (Phillips 2017: 284).<sup>35</sup> For these reasons, it has been argued that in order to protect genetic privacy in countries where this is not yet the case, testing should be regulated by

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34 At the same time, genetic health testing in particular is also interpreted as increasing the individual’s privacy and as having the potential to “democratize health care by enabling individuals to make choices that maximize their own health” (Green and Farahany 2014: 287). Offering a more critical perspective as part of her analysis of genetic testing in the UK, Teresa Finlay argues that it “capitalizes on neoliberal policies that emphasize individual consumerism” (2017: 227). Responsibility for managing and monitoring health is increasingly devolved to individuals (ibid.). At the same time, the welfare state is being reduced, which leads “to wide disparities in the level and quality of care people receive” (Sakellariou and Rotarou 2017: 199(2)).

35 Privacy concerns have also been voiced concerning third party analysis offered by GEDmatch and other sites. A review of companies offering this kind of analysis found that they did not share or sell genetic data (Badalato et al. 2017). However, they tended to have “vague, non-specific privacy policies, some risk of breach of privacy, and a lack of discussion of the risks associated with privacy breach” (Badalato et al. 2017: 1192).

state authorities and not by the companies themselves (Christofides and O’Doherty 2016: 120).

While the use of DNA tests can be a way to circumvent regulations, the companies providing these tests operate in a space that has so far largely evaded regulation. Considering the importance that my interviewees attached to managing who else knew about the circumstances of their conception (section 6.1), I found it surprising that genetic testing and the sharing of genetic data rarely elicited critical comments. The impression of having to try seemed to be so strong that concerns about privacy were pushed aside or did not even arise in the first place.

#### 8.4 Waiting for DNA: More matches, more hope, more frustration?

While those who try IVF hope not only for conception but also for a parent-child relationship, my interviewees would oftentimes stress that for them, it was primarily about having the knowledge, and not about developing a relationship with the donor (see also section 3.5 on the “right to make a choice”). They were usually hoping for a closer connection with any donor siblings they might find. With DNA testing, a donor-conceived person might find not only a donor sibling but also the donor long after registration, without having to register and pay twice. This enables the donor-conceived to maintain a sense of hope without actively searching for a genetic relative. Those who have tried their luck with genetic testing can put an end to their active search because they have tried, similar to those who have experienced the failure of IVF, “everything that is reasonably, rather than literally, possible” (Throsby 2004: 165). Given the growth of DNA databases, hopes and expectations appear to be changing. For this reason, I will first discuss this growth and describe how there were more and more matches after I had conducted most of my interviews, which was particularly noticeable in Germany. Against this background, the question arises how people deal with the fact that they are still waiting for matches. Following on from the previous section, I will again draw on the work of Franklin (1997) and Throsby (2004) on IVF to discuss the specifics of waiting in my field. Finally, I will address the question of the extent to which the growth of DNA databases has the potential to change what it means to wait for DNA.

As there are more and more reports about more and more matches, those who do not have any matches yet seem to have every reason to stay hopeful. My impression that DNA testing started growing in popularity in 2017 is supported by the literature. Erlich et al. state that 15 million people had taken a test as of April 2018, “with about 7 million kits sold in 2017 alone” (2018: 690).<sup>36</sup> They argue that

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36 As mentioned in the introduction of this chapter, Ancestry alone had about 20 million profiles on its database in May 2021.



“a genetic database needs to cover only 2 % of the target population to provide a third-cousin match to nearly any person” (ibid.).<sup>37</sup> Their prognosis projects an interesting scenario: even if not everyone had registered themselves, everyone would potentially become identifiable – at least for those registrants who choose to do more investigations on the basis of third-cousin matches. The rise of genetic testing seemed to be particularly noticeable in Germany, where Spenderkinder has been using FTDNA since late 2011. FTDNA was the first commercial database whose tests were available in Germany. I was told that prior to that, the association had thought long and hard about whether they should create their own register. However, the experiences of American and Australian donor-conceived activists who had in the past tried to set up a designated donor-conceived database, using the same testing system as the DCR (section 7.6), had eventually persuaded them to decide against that option. Given the uncertain nature of the test results yielded from STR tests, their international contacts decided to not continue with their project and recommended Spenderkinder to use FTDNA instead.

The first match between donor siblings was announced on the website in August 2013 (Spenderkinder 2013). Whereas the organisation had announced eight “half-sibling matches” (*Halbgeschwistertreffer*) by the time I started interviewing members in February 2017 (Spenderkinder 2016a), this number quickly started to rise afterwards. In 2017 alone, nine matches had been made, one more than in the first five years combined (Spenderkinder 2018b).<sup>38</sup> A large proportion of the members have discovered that they are related to someone else in the association. This was also interpreted as a sign that doctors probably used to work with a small number of donors who donated over a longer period, resulting in a relatively small number of large donor sibling groups. Meanwhile, new matches are no longer announced on the website. A person in charge of the organisation's homepage confirmed my guess that their growth and frequency had made it impossible to keep writing accompanying blog posts.

Besides, registering with several sites seems to have become a common practice, especially since test kits other than the one sold by FTDNA have become easily

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37 According to Erlich et al., a database with three million Americans of European descent would be sufficient for this to happen in the US (2018: 690). They also argue that in view of “the exponential growth of consumer genomics [...] such a database scale is foreseeable for some third-party websites [such as GEDmatch] in the near future” (ibid.).

38 When the twentieth match was announced in July 2018, the accompanying blog post announced that Spenderkinder would from now on count half-sibling groups instead of single matches (Spenderkinder 2018d). According to the blog post, the association had 18 sibling groups with up to seven members; just three months later, one of these groups had grown even further and had nine members in total (Spenderkinder 2018a). This again constitutes a growth compared to the biggest group at the time of my research, which consisted of five donor siblings.

available in Germany.<sup>39</sup> Ancestry, for example, had only become available in November 2018 (Weichert 2018: 4). In the past, those who wanted to buy additional tests from other companies had to order them through friends or acquaintances living abroad. The goal behind registering with several databases is to achieve the broadest possible distribution of one's DNA, thus increasing the chance of a match.<sup>40</sup> The increasing number of matches indicates that this strategy is indeed working for some members.

In 2019, reports started to emerge that the growth of DNA banks has actually slowed down, and, despite the impressive number of matches, is not as strong as predicted. For example, if Ancestry's growth had continued to be as steep as it had previously been, the database would have had over 20 million users in June 2019 instead of 'only' 15 million, at least according to a popular genealogy blog (DNA Geek 2019).<sup>41</sup> Reports on the subject cite market saturation and growing privacy concerns as possible reasons for this decline in growth (Farr 2019). However, these reports have not been reflected in media reports about the donor-conceived and genetic matching or in the discussions I had been able to follow online. The view that the growth of DNA databases will 'end' anonymity still seems to prevail.

Given the increasing number of 'success stories', one can easily get the impression that having a match has become merely a matter of time. This was in fact the guess of Jennifer Bunton, whom I interviewed prior to the 'blossoming' of DNA testing. By the time she did her first DNA test, she had known about the circumstances of her conception for about two decades. However, she had only found out by chance about the way in which genetic testing could be used to find relatives through an article she had seen on Facebook. Jennifer had immediately decided to order a test, "just because I realised that there are things that I can do to try and find my biological father and to see if I've got any siblings out there". She explained that she had always wanted to know (see also section 4.3). However, she had not known what to do prior to reading the article, which was about adoption and genetic testing. Jennifer had since then registered with the DCR and bought tests from Ancestry, 23andMe and FTDNA, which she commented with "I think I have covered all bases." Despite only having had results that she described as "useless,"

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39 The blog posts that announced new matches usually described how and where a match had been made. These posts indicate that members were increasingly registering with multiple sites instead of only using FTDNA. I also learnt that some of my interviewees registered with at least one more database after I had already interviewed them.

40 This approach is also reflected in the expansion of Spenderkinder's website, which now contains information on how different tests can be combined ([www.spenderkinder.de/verwandtensuche/verwandtensuche-mit-hilfe-von-dna-datenbanken-und-weitererwerkzeuge/](http://www.spenderkinder.de/verwandtensuche/verwandtensuche-mit-hilfe-von-dna-datenbanken-und-weitererwerkzeuge/), last accessed April 07, 2020). This guide was not yet available when I first started interviewing people in Germany in 2017.

41 In the meantime, Ancestry's database has reached (and surpassed) this number of profiles.

Jennifer seemed optimistic about her chances of having a close match in the future, commenting that “Ancestry just had a massive sale on” and, according to Jennifer, sold 250,000 tests in one weekend. She therefore believed that “it’s just a waiting game. And just riding it out and seeing what comes back.” Since she was certain that more and more people would undergo testing, Jennifer managed to remain hopeful as she waited for a match.

In their introduction to the edited volume *Ethnographies of Waiting* (Janeja and Bandak 2018), Andreas Bandak and Manpreet K. Janeja argue that “waiting as a phenomenon is an unstable object” (2018: 16). It may elicit a variety of reactions and “release diverse affects ranging from hope, enthusiasm and urgency to apathy, paralysis and lethargy” (ibid.). While waiting for more DNA and more matches did not seem to be stressful for Jennifer, the waiting involved in an IVF treatment can be extremely difficult for patients. Paradoxically, IVF and other technologies are commonly conceptualised as a means to put an end to the wait for a child and to the “tentative future, a future ‘on hold’” (Franklin 1997: 135) created by the condition of infertility. In the UK, couples that meet the criteria for NHS-funded IVF treatment often have to wait years for their turn which can be “a further incentive to turn to the private sector, or to self-fund treatment in an NHS context” (Throsby 2004: 80). However, the waiting does not stop once a cycle has started. It is not until two weeks after the embryo transfer that a blood test is performed to determine whether pregnancy has occurred (Franklin 1997: 109). Each test needs to be approached with a “‘balance’ of hope and preparedness for failure” (Franklin 1997: 154). Throsby found that in the accounts of the waiting period prior to the blood test, “positive thinking and relaxation played an important role, drawing on the long tradition of assuming that women can influence the outcome of pregnancy by the force of their imagination or mood” (2004: 145). Women in particular often felt a great sense of responsibility following embryo transfer, with many of them taking the time before the pregnancy test off work in an attempt to manage stress (2004: 144). Franklin notes that for the women she interviewed, “a sense of having ones life taken over by the waiting, the worry, the activity and the stress was consistent” (1997: 115).

None of my research contacts spoke in detail about the time between sending back the test kit and receiving the results, which in the case of FTDNA takes four to six weeks. Only David Winkler from Germany briefly described how he had waited impatiently for his results to arrive. At the time of the interview (March 2017), there had only been a small number of half-sibling matches in Germany. Similar to the majority of my interviewees, David had ordered a test soon after he had found out about genetic testing and the way it could be repurposed by the donor-conceived:

David Winkler: “I ordered this set from the US, which arrived, I waited until it finally arrived, did the test immediately and sent it away again, [laughs] and then

waited again until the results were there. And then I got an email that the test was now processed and saved in the database, now the analysis is done, and then a few days later I got the analysis, [the message] that the results have now arrived. And again, I opened the website with heart palpitations and saw, as it is the case with the vast majority [of donor-conceived people], of course I had no direct close relatives [*Nahverwandtschaft*] and hundreds of female cousins, male cousins, fourth, fifth degree [laughs]. And with that the topic was over for me, and then I noticed in that moment how important it was or is for me to find half-siblings, because I told myself a hundred times in a sensible way that the probability to find someone there is low, but I'll register, and that's that. And when I saw the negative result, it pulled the rug from under my feet because I thought, this is the easiest and most convenient way to get to relatives, close relatives, that's over for now. But at the same time, I think it's good that something like that exists. It has been established for completely different purposes, but it's simply now [laughs] used by the association Spenderkinder for this purpose [...] And I think it's great that there is such a thing, and I can only hope that all donor children [*Spenderkinder*] who somehow realise that there is such a thing also register."

Although David had tried to lower his expectations by acknowledging that the test might not have any useful results, he was nevertheless disappointed when the results came back and revealed that so far, no donor siblings were registered. It was this feeling of disappointment that made him realise how much he wanted to find his unknown relatives. Interestingly, David did not seem to consider his "convenient" registration with FTDNA to be part of his actual search. He wanted his parents to finally tell his brother about the circumstances of his conception because he felt that otherwise he would not be able to start his actual search. David told me that once his brother was informed, his "engagement" (*Auseinandersetzung*) with donor conception would enter a new "phase" because "then it's about the search for the father and about the search for half-siblings". David saw his media activities as a means to reach out to donor-conceived persons and motivate them to register with FTDNA (section 4.2). While the women in Throsby's study felt a strong sense of responsibility for successful implantation during the waiting period of an IVF treatment (2004: 144–145), David wanted to do his part to increase the chance for a match, both for him and others, even though (or rather because) his initial results had been 'useless'. He wanted to make sure that other donor-conceived persons also found out about genetic testing. For David, the time between his own registration, his first results and a possible match was not a "waiting game" (Jennifer Bunton) during which he could not do anything, but a time in which he had to remain active himself.

Those who had a weaker desire to know their donor and donor siblings, did not really expect to ever have a match, or had already found someone tended to choose

a more passive approach. For them, it was more a matter of having to wait and see. For example, Diana Kraft from Germany was of the opinion that she had exhausted all possibilities. She had not received any information from the doctor that had treated her mother, and her registration with FTDNA had not resulted in close matches. Diana was particularly interested in getting to know her donor siblings. Through her contact with other members of Spenderkinder, she had seen that the joy they felt when they got a match and made contact with a donor sibling was usually enormous. As mentioned earlier, I had interviewed very few people who already had a genetic match at the time of the interview (but see for example Sabrina Frey in section 5.3). However, the joy mentioned by Diana was also described to me in the interviews with those who had already found a donor sibling. Diana reasoned that “it’s nice to meet someone else who has partly similar roots”. Although she was very curious about her anonymous donor and what he had passed on to her, she emphasised that she did not want to turn the search for her donor into her “purpose in life” (*Lebensaufgabe*) because she was at peace with herself. Diana felt that there was nothing left for her to do and concluded she could “no longer actively search, you’ll just have to see [*man muss halt schauen*]”. She felt that she had done everything she could reasonably do. Waiting for the donor and donor siblings was not something that took over her life.

Similar to Alexandra Gerstner who was confident that she would find out whatever she was “allowed” to find out (section 8.3), Diana did not explicitly refer to genetic testing when talking about the end of her active search. Elizabeth Chapman, for her part, explicitly referred to DNA testing when talking about waiting for her donor siblings. Since Elizabeth herself was in her early 60s, she did not think her chances of finding someone were very high:

Elizabeth Chapman: “I’m always hoping that I’ll find a half-sibling. I mean that’s why I’m there [on FTDNA], waiting, but I don’t think they’re going to turn up now. [...] My father probably started donating 20 years before that [her birth]. I would have half-siblings who are in their 80s, and I don’t think there’s going to be many people in their 80s who are going to be on a computer on FamilyTreeDNA, so I don’t think I’m going to be lucky.”

Elizabeth knew that it was theoretically possible to get a match at any time and had commented earlier that despite not having had any luck yet, she could “get a match fairly soon”. However, she did not want to put too much hope into her FTDNA account. Due to the presumably high age of her donor siblings, she did not think a match was very likely. In contrast, Sabrina Frey from Germany, who was in her mid-30s and had found several donor-conceived half-sisters right after registering with FTDNA (section 5.3), was optimistic about finding even more donor siblings. As there was a large age difference between her and her donor-conceived half-sisters, she assumed that they probably had a ‘long-term’ donor and

rather many donor siblings. While this was a rather unpleasant thought for others (section 7.5), Sabrina felt that this might increase her chances of having and finding donor siblings: “I just hope that they will find out at some point and start searching and then find us. I hope that some of them will get in touch with us. Maybe also some brothers [laughs], it’s only sisters at the moment.” Sabrina was aware that several factors had to come together for a new match to happen. Her donor siblings had to know about the circumstances of their conception, decide to start searching, and look in the right place. However, she seemed rather optimistic about this happening in the near future.

I conducted the majority of my interviews prior to the ‘blossoming’ of genetic testing, which Jennifer had predicted as early as 2016, and which seemed to be indicated in Sabrina’s experience of immediately finding several donor siblings. Given the growth of DNA databases, with reports about its recent slowdown not yet being discussed by the donor-conceived, one can easily get the impression that it is only a matter of time until someone gets a match. In contrast, IVF still has a high propensity for failure. In the UK, the overall live birth rate was at 22 percent “per embryo transferred” in 2017 (HFEA 2019c). Although this represents an increase from the early days of IVF, a cycle is still more likely to fail than to result in a pregnancy and birth. In the case of genetic testing, there seems to be almost the presumption that having a match is more likely than not having one. While official registers and regulations seem to evoke fears of never being able to know, I would argue that genetic testing may fuel hopes that one will know at some point. ‘Never’ is in this case replaced by ‘not yet’. However, I did start to wonder whether “useless results”, as Jennifer had put it, would also cause feelings of frustration, especially since people were likely to be confronted with other people’s ‘success stories’ rather frequently. If genetic testing seemingly works for most people, how does continued ‘failure’ feel for those who are still waiting for matches? Are they still hopeful and encouraged by the matches they have witnessed, or are they increasingly frustrated by their own personal ‘not yet’? If the donor-conceived seem to have more and more reasons to stay hopeful, how do they feel if they still have to wait for DNA?

This crossed my mind especially after I had spoken to Elizabeth for the second time. Elizabeth herself had found her donor after our first encounter, having registered with another database. She had linked the matches she had had on there with the information she had already managed to find through researching on- and offline. Through combining information from different sources, she had been able to identify her donor who was not registered himself, and who had already died. Despite DNA testing having “blossomed”, as she put it, she still had not succeeded in helping one of her donor-conceived friends whose accounts she managed. Elizabeth had previously told me that she was “desperate for her to have a close match”. Her friend’s experience was different not only from her own success but also from what she witnessed online in Facebook groups: people who had just

taken a test, discovered that they had an immediate close match, and thus learnt that they were donor-conceived, were now joining these groups every week. While more and more people seemed to get a match right after registering with a DNA database, her friend was still waiting to get a match despite having been registered for several years. This seemed to frustrate and confuse Elizabeth, and she could not understand why her friend's match list was simply not growing. Due to the timing of my research, which took place mostly before genetic testing seemed to 'take off' and then slow down again in terms of growth rate, my thoughts on these new hopes and frustrations are rather tentative. More ethnographic research is needed to better understand these developments.

## 8.5 Recapitulation

Commercial DNA tests, originally designed for ancestry research and as personalised health tests, are increasingly being used by the donor-conceived to find donor siblings and donors. By creating new ways of linking information that further blur the boundary between identifying and non-identifying information, genetic databases have changed how and when information can be accessed, and by whom. Often the type of testing they use is considered superior to the technology employed in voluntary registers and forensics, as it is said to measure the amount of shared DNA. Since algorithms do not distinguish between different connections that have the same amount of shared genetic material, those who take the test must carry out the exact determination themselves. However, DNA databases operate with a certain kinship terminology and use specific "relationship ranges" that determine how a particular relationship is to be defined. They are therefore still prescriptive and work with an understanding of kinship that is not universal. If there are no close matches, the donor-conceived might decide to engage in a more intensive infrastructuring of information and DNA, trying to connect the results they have from various databases with results of their offline and online searches.

While not everyone was willing or able to invest additional work, for the vast majority it was not an option to not even try a test. Many ordered one as soon as they heard of DNA testing and the way the databases could be used by the donor-conceived. Especially in Germany, where people had no access to mandatory or voluntary registers, and usually got little to no information from clinics, it was immediately clear to many that they had to order a test. For the donor-conceived, DNA testing has become a "hope technology", a term Franklin (1997) coined in her early study of IVF. While IVF is a technology the involuntary childless have to try because it gives them the chance to have a child, the hope it creates also makes it more difficult to end treatment. However, DNA testing and IVF differ with regards to the amount of ongoing involvement they demand from those who use these

technologies. With a DNA database, there is always the possibility that a search will be 'successful' without the donor-conceived having to start a new 'testing cycle' once they end their active search. When IVF fails, a new round of treatment has to be started, which at some point in time will force some patients to stop trying. While IVF still has relatively low success rates, the probability of a genetic match seemed to have increased dramatically during my research. Genetic databases have significantly more members than just a few years ago. More and more people seem to find their donor siblings and donors, which raises the question of how those who are still waiting for a match are dealing with this situation. The question of new or future sources of disappointment also arises in view of the slowed growth of DNA databases. Although their membership numbers have increased enormously since I began my research, they have not grown as much as was expected. However, this development has not yet been discussed by the donor-conceived, and is not mentioned in the reports on DNA testing and donor conception.





## 9. Conclusion

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In this book, I have examined the transformation of anonymity in gamete donation, focusing on how those who were conceived with gametes from anonymised sources in the UK and Germany are involved in this process. Whereas in the past anonymity was either mandated by law or accepted as a standard part of clinical treatments involving donated gametes, this has changed within just a few decades; and while those conceived with donated gametes were primarily seen as the successful outcome of a medical procedure, they now constitute themselves as powerful authorities and make claims about what ought to happen in the world of donor conception. I argue that it is only through employing certain social, political and public practices, using and repurposing technologies and infrastructures, (re)framing their stories in specific ways, and making new relations that “being donor-conceived” becomes constitutive of the self, and not through parents deciding to reproduce via donor conception.

By interviewing 24 people who were conceived with anonymously donated gametes in a clinical setting in the UK or Germany, I have explored how anonymity is transformed at the intersection of these different factors. Many years or even decades have passed between the conception of my interviewees with anonymously donated gametes and my ethnographic research, and I suggest that this temporal distance opens up a special perspective on anonymity. Temporality is a central aspect of anonymity in gamete donation: when donors are guaranteed anonymity, they are promised that they will remain anonymous either forever, or at least until a certain point in time.<sup>1</sup> Information that is “identifying” is only to be released – if at all – by an authority that manages its storage and release. However, my research shows that the possibility of being able to keep such a promise is called into question by the blurring of the boundaries between identifying and non-identifying information.

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1 In the case of the German donor register, which allows parents to request identifying information immediately after the birth of their child, this period can be more limited than in other jurisdictions. However, here too, the promise of anonymity is upheld at least during treatment and pregnancy.

In the introduction, I described the social media campaign with which the German association Spenderkinder, an advocacy and interest group for and of donor-conceived persons, tries to reach out to former sperm donors. According to the accompanying press release, the association had decided to launch the campaign because its members have so far not received any information from cryobanks and clinics (Spenderkinder 2020b). I suggest that the campaign can be interpreted in several different ways. In particular, it is not only a story of a search for relatives, although, as I will argue shortly, it can indeed be read this way. The different ways in which the campaign can be read speak to different aspects of *becoming donor-conceived*, all of which have been explored in this book. I will present a summary of these different dimensions in this final chapter, using some of the campaign's hashtags as headings for the different sections.<sup>2</sup> Moreover, I will discuss the extent to which official and clinical authorities are responding to these changes. In the final sections, I will take up an argument that Carsten made in her exploration of constitutive kinship knowledge (2007). She argued that “although kinship knowledge is constitutive of the self, kinds of knowledge and what people do with them are infinitely variable” (2007: 423). I suggest that this statement applies not only to donor-conceived siblingship but also to the practices and politics of donor-conceived persons in general.

***#righttoknowyourorigins #unknownfather***

The campaign of Spenderkinder can be read as a fight for the rights of the donor-conceived.<sup>3</sup> Anonymity was criticised by the majority of the people that I spoke to because it makes it impossible for the donor-conceived to exercise their “right to know”. Since knowledge about genetic origin is seen as something that is essential for “identity formation”, an argument that has also been taken up and perpetuated by psychosocial studies on donor conception, this assertion has become an unquestionable fact for many people. In chapter 3, I have attempted to break up the taken-for-grantedness of the “right to know” argument by examining its history, the discussions in which it is embedded, and the specific argumentations that have been particularly powerful.

Regulations are important in my research in two ways: on the one hand, they are a space in which anonymity can be established, for example by laws that prescribe permanent or limited anonymity. On the other hand, I have also shown that

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2 For the hashtags that I have translated from German, I include the original word or phrase in a footnote. The hashtags that precede the individual sections are taken from several different Instagram posts; not all of them show a member of the association. Spenderkinder's Instagram account was only created shortly before the launch of the campaign.

3 #rechtaufkenntnisderabstammung (#righttoknowyourorigins).

national laws and international human rights treaties are used to enforce the right to know of the donor-conceived. Treaties such as the CRC and the ECHR have become powerful narrative resources that opponents of anonymity use to raise their arguments to a higher legal as well as moral level, which is seemingly detached from personal sensitivities. These human rights documents have become an important means of arguing for the temporal limitation of donor anonymity. This is particularly noticeable in the UK where Article 8 of the ECHR, which provides for a right to respect for “private and family life”, was invoked in support of the donor-conceived claimants in the 2002 EWHC ruling. The verdict contributed to the change in UK law that came into effect in 2005, which meant that those conceived after 1 April 2005 are able to obtain “identifying” donor information from the age of 18. In relation to Germany, I have shown that the right to know one’s descent was something that was relevant to the enforcement of maintenance claims at the beginning of the twentieth century, not to the protection of personal identity.

While recent verdicts tend to foreground a strong or even causal link between information and “identity formation”, the centrality of choice is another cornerstone of the “right to know” debates. Anonymity is rejected as a violation of the right to make a choice because it deprives the individual of the opportunity to make a choice about whether or not to access information. While demands for de-anonymisation are an expression of an idealisation of transparency, they are also an expression of an idealisation of choice. Since openness and transparency are seen as very valuable for the donor-conceived and their families, parents are not seen as having the right to choose secrecy and/or anonymity. Those who believe that the state has a duty to enforce disclosure argue that not knowing how they were conceived makes it impossible for the donor-conceived to exercise their right to make a choice. Besides, those who are in favour of including information about the donor and/or the use of donated gametes in official documents such as birth certificates argue that the rights of the donor-conceived should be aligned with those of adoptees, who can usually obtain information about their birth family through such records. Referring to the “lessons learnt from adoption” has become a particularly powerful argument of those opposing anonymity, which I have interpreted as an example of people drawing on what they already know about kinship to make sense of reproductive technologies (Edwards 1998: 156; 1999: 67).

While some donor-conceived persons chose to go public with their stories because they thought of donor conception as a violation of their right to live with their “real”, genetic parents, the ideal of the “open family” was evoked far more frequently. A few of my interviewees even took on an ambassadorial role and wanted to contribute to the normalisation of donor conception by telling their stories in a public realm. Stories also play an important role in online spaces. Only those who can tell a personal story and are willing to share it can connect with others online, with groups usually asking new members to describe how they found out about the

circumstances of their conception. Facebook groups and mailing lists do serve as a way to get information, but they have been described to me primarily as safe spaces where one can meet others with the same ‘fate’, without fear of hurtful comments from uninformed outsiders. Being an outsider myself, I was not able to join these groups, which tend to be closed and, I was told, mostly secret. I therefore do not know to what extent members make themselves identifiable to others.

One group that has both a closed online presence in the form of a mailing list and a public website is the German association Spenderkinder. It was founded in 2009 and has become a key player in the field of reproductive medicine and donor anonymity in Germany. Spenderkinder dominates media coverage of donor conception in Germany, with members having a flexible approach to their own identifiability. While they were mostly unidentifiable on the website, some chose not to use pseudonyms when appearing in public. I argue that the terms they use and propagate, such as “*Spenderkind*” (“donor child”) and “*Familiengründung zu dritt*” (“founding a family in threes/with three people”), reflect an adherence to the idea that biological ties embody permanence, regardless of whether or not a relationship is activated. While my interviewees often argued that they only wanted to know the donor’s identity, Spenderkinder, as part of their social media campaign, calls on donors to assume responsibility for their children *as fathers*, thus adhering to the idea that genetic substances are the essence of family relations. The use of the hashtag “#unknownfather” is thus another example of the way people make sense of reproductive technologies, and of the “dispersed kinship” (Strathern 1995) that these technologies create: the meaning of new technologies and new “procreative actors” (ibid.) is always negotiated in the context of what people already know about kinship.

### **#whoareyou #whoamI #wheredIcomefrom**

While the social media campaign of Spenderkinder can be read as a fight for rights, I suggest that their Instagram, Twitter and Facebook posts can also be read in a different way: they illuminate the temporal, relational and micro-political dimensions of kinship knowledge.<sup>4</sup> The campaign is not only about finding information about the donors; the members of the association are also interested in finding out something about themselves. This is reflected in an Instagram post that was published in March 2020. The questions of the person that is pictured in the post are as follows: “Who are you? What qualities did I get from you?” (Author translation) Especially the desire to find out more about one’s origins was omnipresent in the

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4 #werbistdu (#whoareyou); #werbinich (#whoamI); #wokommeichher (#wheredIcomefrom).

vast majority of interviews I conducted. Whereas “right to know” discourses, verdicts and laws take an individual that is marked by uniqueness and boundedness as their starting point, the frequently voiced need “to be complete” and “to know where you come from” points towards a relational notion of personhood.

The desire to (re)build a sense of continuity and completeness was also evident in my interviewees’ attempt to tell their stories as continuous wholes, with many of them claiming to have “felt the truth” before finding out about their donor-conceived origins. “Failure” could be disastrous for those who have not “managed” to “feel the truth”. If there is a duty to practice “see-through kinship” (Edwards 2018), then there is also a duty to see through “kinship lies”. I have shown that the desire to (re)construct continuity was also evident in the way people constructed imaginary relations with their anonymous donors, whom they expected to be similar to themselves. While not knowing who the donor is was usually described as unfair and painful, it was noticeable that many had very positive ideas about their unknown donors, often imagining their donor as an intelligent and well-educated person. The active character of not-knowing was also evident in the fact that people felt compelled to “scan” others they encountered in private and public spaces, asking themselves if they were related to them. While “scanning” was not necessarily agency-driven, I suggest that both imagining similarities as well as searching for them are processes that point to “the sheer inventiveness of anonymity” (Konrad 2005a: 242).

### ***#secret #family #parents #truth***

Non-knowledge is problematised not only in a legal context but also in everyday life.<sup>5</sup> Moreover, it is not only anonymity that is problematised by the donor-conceived but also micro-political aspects of knowing and not-knowing, as anonymity often appears together with other forms of non-knowledge, such as secrecy. When I speak of micro-political dimensions and negotiations, I am not referring to the opposite of large-scale politics. Rather, I am referring to the tendency of my interviewees to think very carefully about how knowledge is (to be) distributed. Such micro-political considerations are less prominent in Spenderkinder’s campaign, probably because their complexity makes it rather difficult to translate them into short, witty captions and tweets.

For many of my interviewees, a central question was not only who the anonymous donor was, but also who else knew, and/or should be told, about the circumstances of their conception. Sometimes they even seemed more concerned with these questions than with the identity of the donor. Efforts to find out and control “who knows what” are linked to intricate constellations of knowledge and power.

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5 *#Geheimnis (#secret); #Familie (#family); #Eltern (#parents); #Wahrheit (#truth).*

Knowing who else knew means not only knowing who else knew about the circumstances of their conception, but also knowing who else knew that they had not known, as well knowing whom they can tell that they know. Besides, finding out about the circumstances of their conception could also mean finding out that a sibling was a genetic half-sibling, or that their parent was not the genetic grandparent of their (future) child. While kinship knowledge is ‘culturally coupled’ with identity (Strathern 1999b: 68), my research thus shows that it always has a relational component to it.

It was striking that the often invoked “right to know” seemed to play a subordinate role when people thought about whether or not they should tell others about their origins. They were more concerned with how telling others would affect their friendship and kinship network. Protecting relationships is arguably also a concern for many parents. Those who opt for donor conception may choose an anonymous donor and not tell their child, attempting to avoid what I have referred to as “kinship trouble” (Mohr 2015; Wahlberg 2018). The donor-conceived not only looked back at how their parents had managed kinship trouble but also intervened in the process themselves: by telling or not telling friends and relatives; ensuring that their sibling would be told; telling their own children in a “normal and natural way”; or by waiting to tell their children. Although my interviewees repeatedly stressed the importance of honesty, transparency and openness, “considerations of care and kindness” (Konrad 2005b: 92) were usually more important to them when it came to managing kinship trouble.

*#searchforpersons #searchmission #showyourself*

The campaign of Spenderkinder can also be read as a story about searching for connections and persons, and the association itself frames the significance of its social media posts this way, using hashtags such as #personensuche (“search for persons”) and #suchaktion (“search mission”).<sup>6</sup> In this book I have investigated the different avenues that are used and created by the donor-conceived in their search for information. I have examined both formal registers and informal means of obtaining information, not only discussing their technical and formal procedures, but

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6 The hashtag “#showyourself” is also the slogan of the campaign. According to a Twitter post from Spenderkinder, the campaign’s slogan was inspired by a song of the same title (“*Zeige Dich*”) from the German soundtrack of the Disney movie *Frozen 2*, as a lot of donor-conceived persons feel that their feelings about searching for genetic relatives are reflected in the song. One refrain of the song reads as follows: “Show yourself, I can’t wait / Show yourself, I want to see you / I have so many questions, I’ve been looking for it for so long / Show yourself, I want to understand you” (own translation).

also focusing on the hopes, expectations and uncertainties that arise in different contexts.

Interviewing donor-conceived adults from the UK, where the way in which donor information is managed, stored and released is marked by a high degree of formal control, allowed me to explore the impact of these formal types of infrastructures on the donor-conceived. Those of my British interviewees who were conceived before the establishment of the HFEA, which is the authority that oversees fertility treatments, regulates embryo research and manages the central donor register, could join a voluntary, government-funded register that has its own DNA database. Those conceived after 1991, but before 2005 could apply for what the HFEA classifies as “non-identifying” donor information, which is stored in the central register, and join a voluntary sibling register. Their donors can choose to “remove” their anonymity. The different regulations and registers in the UK create a situation where the donor-conceived can remain hopeful, knowing that one day they might find their donor and their donor siblings. However, they can never be sure that they will actually make these connections. In Germany, the uncertainty that the donor-conceived experience is related to the fact that there are no official registers at all, at least not for those conceived before July 2018. Until then, how and where information was stored was largely decided by medical professionals who were not controlled by an authority like the HFEA. For this reason, the donor-conceived in Germany cannot be sure whether they will receive information from doctors and clinics. At the same time, this uncertainty also opens up possibilities for action, and some of the donor-conceived decide to sue doctors in order to obtain information.

In recent years, donor-conceived persons have increasingly started to register with commercial DNA databases in both countries. These databases have grown enormously during my research, although their growth now seems to have slowed down. The tests sold online by commercial testing companies are mostly bought by people interested in genealogy and personalised health reports. Users are “matched” with other members; algorithms can determine a “relationship range”, but not the exact nature of a “match”. Although commercial tests are available worldwide, their “relationship ranges” operate with a kinship terminology that is not universal, but distinctively Euro-American. I have shown that some of the donor-conceived invest a lot of time and effort to make the best use of their results and do not stop their search even if they do not have “close matches”. They communicate online with other users; exchange information and family trees; combine this information with what they have found in their additional offline and online research; and often purchase multiple tests to increase their chances of finding a “close match”. My research thus shows that DNA databases do not replace other means of obtaining information but are oftentimes combined with other online and offline resources in a complex process that I have termed “infrastructuring”. It is not necessarily the case that crucial information is provided by formal registers



or doctors when people “infrastructure” DNA. Instead, distant “genetic cousins” are likely to become important players in the field of anonymity by providing the donor-conceived with the additional information needed to identify a donor. Infrastructuring involves a certain level of commitment to making connections: DNA databases enable *and* require the donor-conceived to become active and “put themselves out there”, as some of my interviewees put it, whereas formal registers are more about applying for information. In this sense, Spenderkinder’s campaign slogan “Show yourself” can also be read as an invitation to the donor-conceived to become active and “put themselves out there”.

Especially for those who had not received any information from formal registers, clinics or doctors, not taking a DNA test was not an option. A lot of people ordered one as soon as they learnt about genetic testing. While searching for the donor and donor siblings could give people the comforting feeling that at least they can do *something*, taking a DNA test was not entirely agency-driven. Most people took a test not because they thought they would definitely have a “match”, but because they felt they *had to try* to find their genetic relatives. This was also the case for those who said that they were not desperate to know. Some of those who were not immediately successful decided to stop their active search and decided to just “wait and see”, hoping and trusting that they would have a “match” sometime in the future. Others tried to increase their chances of finding a match by reaching out to the public, which is what Spenderkinder is trying to do with its social media posts. The campaign is not only intended to motivate former donors to take a DNA test. Rather, it also follows the following logic: the more people register, the more likely it is that the donor-conceived will get a match that is ‘close enough’.

### ***#searchedandfound***

In view of the growth of DNA databases, researchers have already announced “the end of anonymity” (Harper et al. 2016).<sup>7</sup> However, based on the assumption that anonymity is always partial and relational, I argue that these developments illustrate instead that it has become difficult, if not impossible, to distinguish between potentially “identifying” information and “non-identifying” information. At the same time, this distinction has probably never been as clear-cut as regulations on the release of information suggest. The decisive factor is not the amount of available information, but how pieces of information that were previously unconnected can now be linked. The developments discussed in this book have weakened the control that physicians, official authorities and parents have traditionally had over information. Donors may become identifiable, even if they are not registered with a database; they may decide to register in the hope of getting matched with

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7 *#gesuchtundgefunden* (*#searchedandfound*).

their offspring, who may take a test because they are interested in “ethnicity estimates” without knowing that they are donor-conceived; donor siblings may come into contact with each other, even if there is no formal sibling register available to them; donor-conceived persons may learn of the circumstances of their conception through their registration, even if their parents want to keep the use of donated gametes secret; and the children of a donor may learn that their father was a sperm donor if they decide to take a DNA test and are “matched” with his donor-conceived offspring.

At the time of my research, not everyone who decided to search for genetic connections ended up being “matched” with a sibling or the donor. The hashtag #gesuchundgefunden (“searched and found”) did not yet apply to everyone. However, more and more people seem to actually be ‘successful’: according to a blog entry published in January 2021, the organisation Spenderkinder knows of 265 donor-conceived persons who have taken a test, and 184 have already found a half-sibling and/or their donor – almost 70 percent (Spenderkinder 2021).<sup>8</sup> It seems to be only a matter of time until someone has a match. At the same time, the question arises of what happens to those who still have not found anyone: are they encouraged by the ‘success stories’ of others, or are they increasingly frustrated because they still have no luck? I cannot give a definitive answer to this, although I would guess that the meaning of “having to try” might be changing. Most of the people I interviewed felt that they had to try DNA testing because it was, as one person put it, “an easy thing to do”, and not necessarily because they expected to have close matches. I would guess that by now, more people feel compelled to try because they expect to find someone.

### **#DNAmatters**

It is perhaps somewhat ironic that while *matching* recipients and donors according to physiognomic characteristics was, and still is, a way to keep the donation a secret (Bergmann 2014), *genetic matching* via DNA databases has turned into something that troubles both anonymity and secrecy. The question is whether, and if so how, sperm banks and/or legislators will respond to these changes. What will happen to donation programmes if donors can no longer be guaranteed that they will remain anonymous forever, or at least for a certain period of time? Will clinics and countries change their policies and laws? In the UK, the HFEA seems to be at least aware of these developments, even if regulations on anonymity and the release of identifying and non-identifying information have not yet been changed. Emma Wheeler,

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8 This represents a growth compared to the previous year: in January 2020, the association knew of 193 donor-conceived persons who had taken a test, and 124 had found a half-sibling and/or their donor – almost 65 % (Spenderkinder 2020a).

the HFEA's Donor Information Manager, whom I interviewed in September 2016, had already noted then that "there will be the potential for a lot more things to be discovered accidentally or inadvertently through these testing sites". She also told me that a few months ago, she had had a conversation with someone whose daughter had only found out about the circumstances of her conception through a DNA test. On the HFEA website, the *Donor-conceived people and their parents*-page, which tells potential applicants how to apply for information, contains the following note:

"Home DNA testing and matching websites have implications for donor-conceived people. Using one of the home DNA tests these sites offer plus opting in (or not 'opting out') of their 'matching services', could mean that your donor, or donor-conceived genetic siblings become identifiable to you and vice versa. It's also possible that a donor-conceived person might be identified by inference, if they have a close genetic relative using home DNA testing and matching services. Even if the donor-conceived person has not used such a service themselves, the information from the matching service may be able to be combined with other publicly available information about the relevant person, and their donor conceived status and/or their identity could be possible to infer." (HFEA, n.d.)

This note was not yet part of the Authority's online presence when I began my empirical research in 2016. In section 7.1, I have pointed out that the HFEA's application forms and website texts tend to present register information as emotionally challenging and potentially even distressing. In comparison, the text on DNA testing, which does not contain any links with further information or advice, seems rather descriptive. There is only vague mention of "implications" for the donor-conceived.<sup>9</sup> A meeting paper from September 2018 (HFEA 2018a) discusses commercial genetic testing in more detail. The author notes that "[d]onor-conceived people or their families are free to identify their donors (or vice versa) by accessing DNA testing and matching websites" (ibid.) and points out that the HFEA "has no regulatory powers in relation to this" (ibid.). The author suggests raising awareness about the use of DNA testing and its implications and starting "a dialogue with the

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9 At the time of writing my thesis (April 2020), there was no comparable note on the information page for donors. However, a similar text could already be found in the Code of Practice (HFEA 2019b). While the Code states that fertility centres are not required to proactively contact past donors, it does point out that clinics should inform the donors they currently register about DNA testing: "The centre should inform and make clear to donors that at any time, outside of the managed system of information provision [...] direct to consumer DNA testing and matching services potentially enable anyone born as a result of their donation (or a close genetic relative) to identify the donor." (HFEA 2019b: 126) In May 2021, the information page for current and future donors contained a short note saying that children can "find out your identity before they reach 18 using home DNA testing and matching services that are available online" (HFEA n.d.).

larger UK-based DNA testing websites" (ibid.) with the aim of asking them to include information about these implications on their websites.

An American sperm bank is taking a different approach. In February 2019, on-line news sites reported that a woman who had conceived her daughter with sperm from NW Cryobank, which is located in Washington State, got into legal trouble because of genetic testing. She had given DNA tests to her 5-year-old daughter, her father and close friends for Christmas. Her daughter had immediately gotten a close match. Believing that it could be the donor's mother, she had decided to reach out to her. In one article, the woman is quoted as follows: "I wrote her and said, 'Hi, I think your son may be my daughter's donor. I don't want to invade your privacy, but we're open to contact with you or your son' [...] I thought it was a cool thing." (Mroz 2019) Shortly afterwards, she was contacted by NW Cryobank. She was threatened with a US\$20,000 fine "for 'flagrantly' violating the agreement she'd signed by seeking the identity of the donor and contacting his family" (ibid.). She was also told that she would not receive any more sperm from the donor with whom she had conceived her daughter should she decide to have a second child. While the bank is not trying to prevent parents or donor-conceived persons from taking a DNA test, it is trying to prevent them from turning commercial databases into search tools:

"Leora Westbrook, general manager and vice president of NW Cryobank, said in an email that the bank does not prohibit clients or their offspring from taking a DNA test. But "we seek to prevent the use of that information to identify a donor who has made a donation in reliance upon anonymity." Once the child is no longer a minor, Ms. Westbrook added, he or she may not only take the DNA test but may also contact the bank to determine if the donor is open to being contacted." (Mroz 2019)

Belgian bioethicist Guido Pennings (2019a, 2019b), on the other hand, proposes to 'solve' the situation differently. He argues that while a recipient's wish to have an anonymous donor and a donor's desire to remain anonymous are "no longer enforceable" (2019a: 788), their wishes "should still be respected in good faith" (ibid.). Pennings argues that "if more evidence comes in that shows that the findings of these tests are causing turmoil in people's lives and are socially and psychologically disruptive, it makes sense to forbid them to offer this service" (2019b). However, Pennings does not question that it is possible to distinguish between identifying and non-identifying information. Instead, he argues that "[t]he difference between identifiers and non-identifiers is only clear in isolation" (2019a: 787) and points out that "a combination of non-identifiers may well lead to identification" (ibid.).

Meanwhile, an American sperm bank is trying to enforce a "no testing" rule on its customers (Donor Sibling Registry 2019). A Danish cryobank only mentions on its website that "there is always a risk that donors, clients and children can trace

or be traced via DNA analysis which can compromise the privacy” (Cryos, n.d.). A uniform approach to DNA testing does not seem to be in sight. Given that reproductive technologies and anonymity have always been regulated differently in different countries, this is arguably not surprising. The fact that it has generally become more difficult to distinguish between potentially identifying and non-identifying information, and that DNA testing is not necessarily required to identify an anonymous donor, is mostly not considered or discussed by cryobanks, policy makers, regulators and fertility experts.

However, if a supposedly non-identifying donor profile is unique or comprehensive enough, it may only take the skilful use of a search engine to identify the person behind the profile.<sup>10</sup> The authors of the Nuffield Report pointed out as early as 2013 that “easy access to personal information through the internet may increasingly challenge the distinction between identifying and non-identifying information” (2013: 24). They concluded that the role of the HFEA may need to change: “The current role of the HFEA as the gatekeeper of identifiable information about donors may thus gradually be forced to evolve in recognition of the extent to which such information may be obtainable in other ways.” (Ibid.) It remains to be seen whether, and if so how, the institutions managing donor information will adapt to these developments, although the above-mentioned statements from the HFEA indicate that at least the British authorities are thinking about implementing some changes. At the same time, it is questionable whether the attempt to enter into a “dialogue” with DNA testing companies will be successful. As the HFEA itself points out, the Authority cannot force them to publish ‘warnings’ on their sites. Moreover, even a ban in one country would not stop people from taking a test. They would still be able to obtain tests that are prohibited or not easily available in their home country, for example through friends living abroad.

### **#halsiblings**

Since the campaign of Spenderkinder was designed to reach anonymous donors, donor siblings – who, unlike regular half-siblings, do not have a parent in common – were rarely mentioned in the organisation’s social media posts at the start of the campaign (this has changed in the meantime).<sup>11</sup> In section 7.5, I have outlined how donor sibling relationships are established in the UK through the voluntary

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10 Commenting on the use of detailed donor profiles, Pennings notes that the large amount of detailed information “provided in an extended donor profile in most commercial sperm and egg banks holds at least the possibility of tracing a donor” (2019a: 787). He suggests that in order to protect the donor’s anonymity, cryobanks should provide “as little information as possible on the donor” (ibid.).

11 #halbgeschwister (#halsiblings).

register DSL. The DSL can delay siblingship, either because people have to wait until they are old enough to join the register, or because they know (through data from the central HFEA database) that their donor siblings are not yet eligible to join. Unlike DNA databases, the donor's "own children" cannot join the DSL. However, most of the people I talked to were more interested in siblings who are also donor-conceived. Donor siblings are not only genetically related, but they also "partake in each other's conception" (Edwards 2013: 291). The donor-conceived oftentimes wanted to reach out to their donor siblings precisely because they did not know anyone else who was donor-conceived.

While it could be argued that donor siblings exist whether they are found or not, knowledge of the existence of donor siblings does not necessarily have to be activated. While people cannot 'unknow' the knowledge about their genetic connections, it is up to the individual whether or not they want to find their donor siblings and form a close relationship with them. Moreover, knowledge of genetic connections, even if already activated, may become less important for donor-conceived persons at a later stage (Edwards 2015: 117–118). Whether these connections develop into close relationships that are not exclusively "latent and removed from everyday life" (Klotz 2016: 50) cannot be conclusively answered in this book due to my research design and the timing of my project. I conducted one-time interviews followed by email and telephone contact, and those of my interviewees who had already found donor siblings at the time of the interview had mostly had a "match" only a short time before meeting me. A longer-term study involving ongoing contact with donor sibling groups, would be needed to see whether activated relationships develop into active relationships.

These unprecedented connections point to an "imperative to connect" (Edwards 2009b; Knecht 2009), which can be described as "an emergent cultural pattern where making connections becomes a moral good in itself" (Klotz 2014: 288).<sup>12</sup>

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12 This "tendency to connect for connection's sake" (Klotz 2014: 267) has been explored by Edwards in her analysis of the growing popularity of ancestry research in the north of England (2009b). She found that "[g]enealogical research is emotional work" (2009b: 10), with the "excitement of discovery" (ibid.) being part of the narratives of all genealogists. The joy of making new discoveries was particularly evident in a conversation I had with Elizabeth Chapman. I knew that she was a genealogy-enthusiast who had started doing genealogical research long before she had learnt of the circumstances of her conception. Nevertheless, I thought she was talking about a close relative when she told me, noticeably excited and thrilled, that she had managed to identify the father of one of her cousins who had been an illegitimate child. Elizabeth had managed to identify her cousin's father through her research on Ancestry, which consists not only of a genetic database but also of a collection of digitised documents. By combining both resources, she had succeeded in identifying the right person. Elizabeth enthusiastically declared, "DNA works!". After a couple of minutes, I realised that Elizabeth was talking about a distant genetic cousin who had lived in the eighteenth century.

This imperative is linked to kinship in the searches of the donor-conceived, and a new form of siblingship emerges. Donor siblingship is both voluntary and involuntary and was often seen by my interviewees as an opportunity to draw indirect conclusions about the donor. To say that it is some kind of “phantom kinship” (*Phantomverwandschaft*; Bernard 2014: 156) because the donor is neither known nor present, and to argue that these sibling relations are bereft of meaning because those conceived with sperm from the same donor do not grow up together (Wehling 2015: 113–114), is, I suggest, misleading. Not only do these statements disregard the imaginative possibilities of anonymity by portraying the anonymous donor as a kind of ‘phantom’ or ‘ghost’; they also ignore that kinship can be made in a wide variety of ways, without one way of making connections displacing another way of ‘doing kinship’. That is not to say that there are no donor-conceived people who think donor siblingship is ‘pointless’. This was the case with Amber Jones from the UK. Not only did she have no interest in her donor (section 7.3), whom she did not want to see “as a person”, but she also had no interest in her donor siblings. She explained to me why she could not understand why others would be interested in people conceived with gametes from the same donor, and why she did not think she could ever see them as actual siblings: “You’ve had completely different upbringings by completely different people, are you ever going to be like brother and sister when you’ve not shared a parent?”

### ***#donorconceived***

What people do with kinship knowledge will vary, and not everyone will decide to search for donor siblings. Amber chose not to do anything with the knowledge that she probably had genetic half-siblings. Besides, several of the people I interviewed told me that they had a sibling who was not interested in finding out anything about their donor or donor-conceived half-siblings. However, the majority of the people I interviewed were not only interested in their donor siblings, but also in their donor. Although I spoke to two people who were not interested in either their donor or their donor siblings, I would hesitate to make general assumptions about people who are not interested in their genetic connections and/or for whom it is rather meaningless that they are donor-conceived. Commenting on the fact that she only spoke to adoptees who had chosen to search for their birth parents, Carsten points out that there is a “methodological difficulty involved in trying to study people who are defined by something they don’t do” (2007: 415). Although “interest in the donor/donor siblings” was not a selection criterion for me, it is arguably not surprising that most people who contacted me were among those who wanted to know more about their donor and/or believed there was a need to talk about anonymity and donor conception. It may be that other people do not feel the need to talk about donor conception and search for the donor because they do

not attach importance to the circumstances of their conception. Some people may fear that new information about their genetic origins and connections will unsettle them and choose not to search for the donor or their donor siblings for that very reason. For one reason or another, donor-conceived persons may choose not to activate their donor relations. As I pointed out in section 7.2, it is not possible to know how many people are interested in their donor and/or donor siblings: first, it is not known how many donor-conceived persons even know about the circumstances of their conception; second, estimates of how many people were conceived with donor gametes can never be accurate because there are massive gaps in the official statistics. In the UK, information about donations and treatments has only been collected centrally since 1991, and the central German register that stores information has only existed since 2018.

Similar to donor siblings, one could argue that donor-conceived persons exist anyway – whether or not they know that they are donor-conceived, and whether or not they attach any importance to the circumstances of their conception. However, I argue that knowledge about the use of donated gametes has to be activated in a certain way for “being donor-conceived” to become a meaningful and powerful identification. In this sense, persons *become donor-conceived* through acting on their kinship knowledge: by (re)framing their stories as a matter of rights; employing the rhetoric of human rights; presenting their stories on a public and political stage; joining forces with others; making imaginary or actual connections with donors and donor siblings; (re)constructing continuous narratives; managing kinship trouble by telling or not telling others; requesting information from formal registers; and infrastructuring DNA. Not all of these factors need to occur simultaneously, and for some people certain elements may not be compatible: for example, some may choose not to find out about their donor because they want to manage kinship trouble.

While there are variations in what people do with kinship knowledge, these variations are masked by the use of a hashtag such as “#donorconceived”, which Spenderkinder uses in its social media campaign. On social media platforms, hashtags serve a dual purpose: “They locate texts within a specific conversation, allowing for their quick retrieval, while also marking texts as being “about” a specific topic.” (Bonilla and Rosa 2015: 5) Hashtags have “the effect of blurring boundaries and levelling out that which is unique and incommensurable” (Bernard 2019: 76–77). While discovering that an unknown procreator was involved in your conception means discovering information that is constitutive of the self, not every donor-conceived person will do the same with this knowledge. However, a hashtag such as “#donorconceived” obscures these differences by marking a specific post and its content as applying to every donor-conceived person. As I have already argued, in a study like mine, a researcher is more likely to capture the perspective of those for whom “being donor-conceived” has become an important identification. While this



might be seen as a limitation in a study aiming for statistical representativeness, it is precisely this identification that has interested me. The activation of kinship knowledge and the emphasis on “being donor-conceived” as a constitutive part of one’s self are among the causes and effects of the transformation of anonymity in gamete donation.

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## List of abbreviations

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*Table: List of abbreviations, part I*

AID/A.I.D.	Artificial Insemination by Donor
BASW	British Association of Social Workers
BGH	Bundesgerichtshof
BVerfG	Bundesverfassungsgericht
CRC	Convention on the Rights of the Child
DCN	Donor Conception Network
DCR	Donor Conceived Register
DI	Donor Insemination
DNA	Deoxyribonucleic Acid
DSL	Donor Sibling Link
DSR	Donor Sibling Registry
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
ETD	European Union Tissue Directive
EWHC	England and Wales High Court
FTDNA	FamilyTreeDNA
GDR	German Democratic Republic
HFE Act	Human Fertilisation and Embryology Act
HFEA	Human Fertilisation and Embryology Authority
HRA	Human Rights Act
ICSI	Intracytoplasmic Sperm Injection
IVF	In-Vitro Fertilisation
NGDT	National Gamete Donation Trust

*Table: List of abbreviations, part II*

NHS	National Health Service
OTR	Opening the Register
PC	Personal Computer
PCVAI	People Conceived Via Artificial Insemination
PET	Progress Educational Trust
PGD	Preimplantation Genetic Diagnosis
PR	Public Relations
PROGAR	Project Group on Assisted Reproduction
SNP	Single Nucleotide Polymorphism
STR	Short Tandem Repeat
TSBC	The Sperm Bank of California
TV	Television
UK	United Kingdom
UKDL	UK Donor Link
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
US	United States

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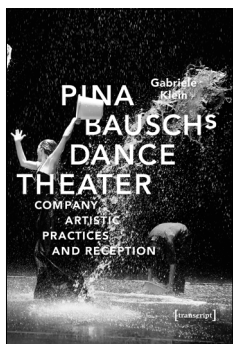
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# Cultural Studies



Gabriele Klein

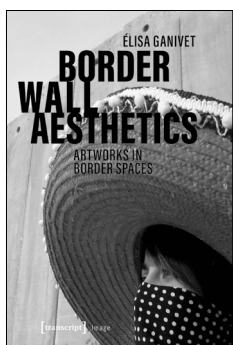
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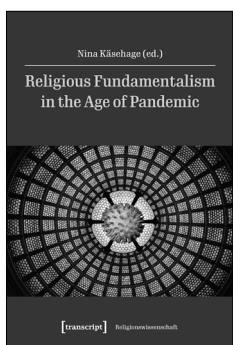
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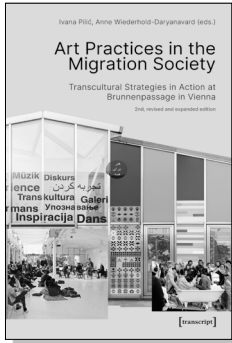
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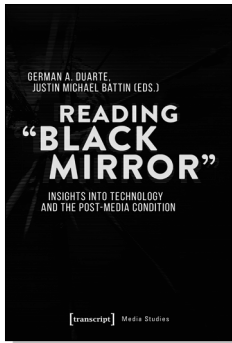


# Cultural Studies



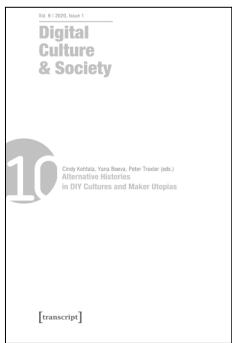
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