

## Update of a Systematic Review - Donor Conceived People's Views and Experiences of their Genetic Origins: A Critical Analysis of the Research Evidence (Blyth et al, 2012)

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**ROYAL COLLEGE OF SURGEONS IN IRELAND**



Update of a Systematic Review -  
*Donor Conceived People's Views and Experiences of their Genetic Origins:  
A Critical Analysis of the Research Evidence*

(Blyth et al, 2012)

by

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A dissertation submitted in partial fulfilment of the requirement for the  
MSc in Healthcare Ethics and Law

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### Candidate Thesis Declaration

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a higher degree, MSc in Healthcare Ethics and Law, is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

Signed Rita Dolan

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Date 22 July 2018

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*Rita O'Leary*

2018

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## **List of Acronyms**

AHR	Assisted Human Reproduction
ART	Assisted Reproductive Technologies
DI	Donor Insemination
DC	Donor-Conceived

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## Abstract

This paper considers the topic of donor-conceived people and their perceptions and experiences of their genetic origins. An update was performed on a previously published systematic review entitled '*Donor-conceived people's views and experiences of their genetic origins: A critical analysis of the research evidence*', Journal of Law and Medicine (Blyth et al., 2012). The methodology and findings of the original review are outlined here along with details of how this was adapted for the update six years on from the original review, during which time AHR (Assisted Human Reproduction) has developed and evolved as techniques continue to be refined. The aim of this undertaking was to identify newer research since the original systematic review was published and review it in light of the recommendations in the original paper, to see if those recommendations were still relevant and applicable. The original review identified 19 articles which published data from 13 discrete studies that met the inclusion criteria. The current paper identified nine studies that met the updated inclusion criteria and also considers other relevant studies containing information which help to illuminate the topic under consideration. Conclusion: The update found that while there is still a dearth of research on donor-conceived people, especially longitudinal studies, research that incorporates newer forms of AHR is starting to come on-stream, with donor-conceived individuals retaining their status as a population of considerable interest to researchers, especially if greater access can be gained to them in the future, for the purposes of further study.



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Finally, I would like to thank my family for all of their help and encouragement.

## **DEDICATION**

This work is dedicated to my parents Christopher Dolan (RIP) and Anastasia Tuck  
- with love, gratitude and appreciation.

## Chapter 1: Introduction

For this dissertation, on the topic of donor-conceived people and their experiences of their genetic origins, an update was performed on a previously published systematic review entitled '*Donor-conceived people's views and experiences of their genetic origins: A critical analysis of the research evidence*', which appeared in the Journal of Law and Medicine (Blyth et al., 2012). The methodology and findings of the original review are outlined here along with details of how this was adapted to take account of the passage of time (and consequent evolution of the topic along with the continuing development of AHR) in order to maximise the likelihood of identifying relevant newer research that could be reviewed with the aim of formulating a robust conclusion and possible recommendations for future policies and procedures in the area.

Donor-conceived people are those individuals whose conception was not achieved via straightforward sexual reproduction involving one male and one female (or more specifically, just two sets of genetic material – one from each parent. An article entitled 'Clinical biochemistry of assisted conception' (Srivastava and Kay, 2009) offered the following definition: "Assisted reproduction is the collective name for treatments designed to lead to conception by means other than sexual intercourse. These include intrauterine insemination, in vitro fertilization, intracytoplasmic sperm injection and gamete donation." Obviously, assisted reproduction by itself does not necessarily involve donation of genetic material – if only that of the male and female who will raise any resultant child(ren) is utilised, their offspring are not donor-conceived and thus do not form part of the population of interest here. In such cases, the parents who would otherwise have conceived via nature's methods are simply receiving a helping hand from modern science in their endeavours. Rather, it is those individuals who came into existence via the introduction of donor genetic material such as sperm, eggs, gametes or oocytes from an individual who may not subsequently be made known to the resultant child and who will not be responsible for their upbringing that are the focus of this dissertation.

## **1.1 Why Donor-Conceived People Are a Population of Interest**

In order to demonstrate why donor-conceived people are a group worthy of study (from a social sciences and public health perspective, as opposed to a medical one) previously conducted research evidence concerning individuals who are *adopted* is key – adoptees share some strong similarities with donor-conceived people. In families with one or more adopted children, a genetic link between the parent and the adopted child(ren) is substituted with an artificial, 'constructed' relationship, as with families where one or more children is donor-conceived. There was a time when adoption was the solution to infertility, and 'supply' of available babies for adoption was boosted by a general societal disapproval of single parents and children conceived out of wedlock. Such disapproval was reflected in the dearth of social assistance for people who found themselves in the situation of an unplanned pregnancy out of wedlock. It is well-documented that where the key facts and circumstances of an adoption were kept hidden, many adoptees will inevitably experience significant obstacles later in life when attempting to identify and make contact with natural parents or other genetic relatives, and often suffer psychological distress as a result of the secrecy involved and the subsequent difficulties they will likely encounter when searching for relatives, particularly if a considerable amount of time has lapsed.

An interesting study published in the Journal of Adoption and Fostering (Riley, 2013), which combined adoptees and DC individuals as participants, attempted to analyse the reported experience of a group of 25 'late discoverers' as the authors termed them, using an ethical perspective developed by a separate author. Some of the participants were the subject of closed adoptions as children and some were conceived via DI and raised by heterosexual couples. The study documented particular ethical concerns with regard to the lateness of disclosure. The risk of psychological distress is also high where genetic relationships within the family are obfuscated, such as in the case of individuals who discover that an older 'sister' or 'aunt' was in fact their natural mother, but this fact was kept hidden due to religious/societal mores at a particular point in time and general disapproval of extra-marital sexual relations. Testimony from individuals who have had material

facts about their origins kept from them demonstrates that some believe the blame for any suffering they experience as a direct result of such secrecy (and lies) can be placed firmly at the feet of those individuals and institutions which facilitated secrecy and non-disclosure around the facts of their adoption.

For one American author of a book on the topic, secrecy and disclosure are the defining issues for adoption in his home nation. (Carp, 1998). This statement holds true for many adoption regimes internationally, and Ireland is no exception. In the case of donor conception, challenges to the prevailing view that it should retain a shroud of secrecy emerged in the 1980s (as noted by the original authors of the systematic review which is the focus of this dissertation), based on the evidence of adults who had been adopted in circumstances which made it difficult for them to trace their genetic relatives. It is a fact of nature that there have always been children who have been raised by a non-genetic parent, with their true descent kept a secret – consider cases outside of the adoption process, such as where there has been a secret affair or extra-marital relationship. However, the existence of facilities such as the clinics which now facilitate AHR have shone a spotlight on the opportunities - and difficulties - that these continually developing techniques present, for example around the question of how the right to privacy and family life (as outlined in articles 8 and 12 of the European Convention on Human Rights) of clients of AHR clinics should be appropriately balanced against the right to the truth, and the right to know their true identity and genetic heritage, which donor-conceived individuals have a strong claim on. The existing evidence regarding adoptees who have had material facts about their origins concealed from them and the resultant negative effect that such deceit by others has had on such individuals, helps to demonstrate why research looking at donor-conceived people (such as the current paper) is justified and has a contribution to make in terms of building up a body of knowledge about this population.

Indeed, the argument that donor-conceived people who cannot access desired information about their donor(s) are the victims of unfair treatment *independent*

of any suffering that empirical evidence is able to demonstrate has been made (Ravitsky, 2014) - the logic here being that the loss of the ability to choose what meaning they assign to the genetic components of their identity means they are being deprived of a key aspect of their autonomy. Opponents of donor anonymity argue that the rights of donors and recipients are favoured over those of donor-conceived people. So what is it that donor-conceived individuals want to know? A 2013 paper which collated studies of DC individuals in an attempt to answer this question (participants in cited studies and other data sources were specifically *sperm* donor-conceived) elucidated at least seven different objectives underlying the desire to know one's donor: "to avoid medical risks and consanguineous relationships; to connect with one's roots; to complete one's life (hi-)story; to understand where one's traits come from; to discover or assess one's defining characteristics and capabilities; to rectify a wrong-doing, and to map out one's ancestral history." (Ravelingien et al., 2013).

Another reason why donor-conceived people are a segment of the population worth of study is that the development of assisted human reproduction is, quite simply, one of the key medical breakthroughs of the last century. In terms of its potential ability to impact the general population and resolve a medical issue (infertility) that must have previously seemed intractable, it ranks alongside other seminal breakthroughs such as vaccination and the development of antibiotics. Since the birth of the world's first 'test tube baby' Louise Brown in 1978 in the UK, this technology has evolved and grown beyond what even the most enthusiastic early adopters could have foreseen.

This attempt to 'quantify the burden' is not to suggest that all donor-conceived individuals will automatically suffer psychological distress on discovery of their origins, but rather that, in a rapidly growing and ever-evolving arena of science and technology, the initial (and explicable) focus on the wants, needs and desires of prospective parents and the ambitions of creative scientists, medics and technologists should shift to the resultant children and their wants, needs and desires as they grow up and come of age. This is where research like the present undertaking comes in. It focuses on the children born via AHR and shines a

spotlight on their lived experience. As a result of such research, any issues identified by studying early generations of children conceived via AHR can be foregrounded and analysed, with a view to mitigating any negative factors via appropriate health and social policy. Such exponential growth in this area of science/technology and medicine needs to be controlled and managed; the question of how the 'lived experience' of these people could inform future policies and procedures is a valid one. If growing numbers of children are 'generated' in this way then they may come to form an appreciable segment of the future population of adults and if this form of reproduction involves potential risks for these children's mental (or indeed physical) wellbeing, then there may be a wider public health question to be addressed, with such risks being identified and managed as far as possible. This research, and other endeavours like it, (at a still - when speaking of generations - early stage of its development) is envisaged as a relevant early intervention to, as it were, 'take the temperature' of this particular social issue. An interim review may yield results which measure the efficacy of early policy and legislation. And by highlighting any emerging problems or issues of concern not foreseen by enthusiastic early adopters, this dissertation may be of assistance in giving policymakers, legislators and other stakeholders robust evidence and meaningful information to help them make decisions on how AHR should be regulated and its continuing growth managed into the future, in order that children conceived via this method experience an optimal family situation growing up, *and* the best life chances, in so far as these can be engineered.

Children conceived via AHR grow up in a particular family 'type' – it could be conjectured that it is not only the children who are conceived via artificial methods here, but also, in a sense, the wider family – it is undoubtedly a novel and more composite set-up to the traditional married couple with 2.4 children (who belong genetically to their parents.) Are such families emotionally safe and psychologically healthy environments in which to grow up? Just because prospective parents can afford to access such treatment, and will be able to support the resultant children materially, does it follow that they should automatically be facilitated in pursuing this avenue to satisfy their desire for children? Is it ethical for clinics to continue to contribute to the numbers of such families and for wider policies to promote AHR if statistically significant evidence emerges that family formation via this method

may ultimately prove to be a sub-optimal environment for many children? It is a potentially emotive topic, so a considered, reasoned approach to the issue such as that offered by an objective review update will ideally serve as a useful contribution to ongoing debate in this area.

And what of the clinicians who facilitate the process of AHR? Obviously their first duty is to their patient, and the recipients of donated reproductive material *are* their patients. These patients have a need (a deeply-rooted human need) to reproduce and create a family and the clinician has the raw materials and technological know-how to meet that need, generally for a fee. Even though the process could be (and has been) characterised as a business transaction it may be safely presumed that the doctors involved will be fully qualified professionals who care about doing their job well and achieving an optimum outcome for their patient, just like any competent obstetrician. After all, in a reputable operation the clinicians will be registered medical practitioners, who sign up to a code of conduct, commit to ongoing professional development and are answerable to an employer as well as their patients. (They will also be accountable to a Medical Council-type entity or other relevant overseer in their jurisdiction.) Does their ethical obligation to patients properly extend to the resultant children who have yet to be created? Obviously the ultimate end purpose of all attempts at assisted human reproduction is a successful pregnancy. But at the time of the clinicians' initial dealings with their patients, the much wanted babies are not yet in existence, and their coming into being is by no means guaranteed in a process that - despite rapid development - is still fraught with uncertainty and unforeseen outcomes. From an ethical perspective, is it actually possible for doctors in this situation to extend beneficence and due consideration about the future mental (and physical) wellbeing of individuals who have not even been conceived yet? Doctors have a duty to not intentionally cause harm – however, how would the knowledge that a certain percentage of future children born via AHR *will* have psychologically challenging experiences in relation to the discovery of their origins influence future clinical practice in this area? These difficult questions help to illustrate why the drafting of appropriate legislation - which balances the rights and responsibilities of all parties involved – is such a complex undertaking.



The other party in this triad of donor/clinician/patient is the donor themselves. In an arresting paper published in the journal 'Bioethics', Botterell (2016) cites a theory by Rivka Weinberg arguing that if individuals engage in activities that put their gametes in the way of joining with that of others and subsequently growing into persons, they assume the costs and consequences of that activity. She calls this the Hazmat Theory of parental responsibility. Clearly this rigid interpretation of what constitutes responsible sexual behaviour is absolutely at variance with the agreed general procedure for the donors in the AHR triad, who, unless their participation is an informal arrangement with close friends who wish them to be involved in the life of any children born, will generally not participate in the upbringing of the resultant offspring. (This would not be feasible anyway, in cases where a large number of offspring have resulted from one donor.)

It should be noted that the scope and length of this paper will not facilitate any in-depth consideration of *all* of the potential issues surrounding donor-conceived individuals, such as the existence of evidence suggesting a higher rate of genetic defects among babies conceived via AHR, and even some studies suggesting that such children may be more prone to behavioural difficulties. This is undoubtedly a growing area and serious consideration of any such questions would certainly merit a standalone academic paper (these matters have already begun to receive scholarly attention.) Some of the other ethical questions surrounding this form of reproduction will be touched on however, such as the potential commodification of children (AHR clinics are essentially businesses after all, and even if a clinic is a not-for-profit, would still have to break even to survive.) How does the knowledge that the conception process preceding their existence could – taking the most reductive viewpoint possible – be characterised as a business transaction, impact on the individuals involved? Does this knowledge create insecurities around whether, in the end, their parents got the 'perfect' child they desired – created and delivered according to specification? And how does the discovery that some or all of their genetic material was contributed by a donor feed into any feelings of alienation or general discomfort/unhappiness they may have experienced (but were unable to account for at the time) growing up?

## **1.2 Findings of the Original Review**

The original review concluded that based on the research uncovered, donor-conceived people generally had an interest in information about their genetic and biographical heritage and also noted that many of them had been frustrated in their attempts to uncover such information. One of the questions that this update seeks to address is whether an improving picture is evident in this regard since the original review was published. Are donor-conceived people who wish to learn more about their origins getting access to the information they want? The original authors also noted the lack of available research at the time pertaining to individuals conceived through newer forms of assisted human reproduction than straight-forward sperm donation or to those conceived under newer arrangements promoting openness and early parental disclosure. However, they recommended that conjecture on the views of donor-conceived people should not be used as a basis for relevant policy formation going forward, even though at the time of their review there was a dearth of longitudinal studies, for example. Rather, they suggested that research from related child, family and adult welfare fields and the ethical principals underpinning such work would be relevant, along with 'grey literature' (i.e. drawn from studies reported in publications other than academic journals – to be discussed later in the current paper) which would likely also be instructive and provide some useful insight until such time as more robust data were available.

Another salient point made in the conclusion of the original review is that the one group of people in what they termed the 'donor-recipient-offspring triad' whose choices - from their very conception on - are constrained by the choices made by their parent(s) and the donors used, were the donor-conceived individuals themselves. The authors pointed out that that the use of anonymous donors (and an allied policy of secrecy) necessarily limits future choices for the resultant offspring – this could amount to a kind of unintentional paternalism on behalf of the clinicians/donors/social parents. Along with the medical professionals working in this area, it is generally assumed that responsible, caring parents will also always act in the best interests of children. What if robust research evidence continues to compound the theory that a statistically significant percentage of

donor-conceived children will experience mental suffering later in life as a result of the discovery of the circumstances surrounding their conception? From an ethical point of view, inflicting suffering knowingly on sentient beings in the pursuit of the means of others is potentially indefensible. Again, for any legislation or policy there is a balancing act to be struck, with regard to the rights of parents who utilise AHR and the rights of donor-conceived children.

The original review also found clear evidence to suggest that many (though certainly not all) donor-conceived people experience considerable psychological distress in discovering the truth about their conception later, rather than earlier in life. It also found that secrecy is not always maintained, even if parents never disclose the truth and that the reactions of donor-conceived people to the truth about their origins are not predictable. It is not difficult to see how secrecy might fail to be maintained in the long run – apart from the risk of accidental disclosure via a blood test (indicating the DC person could not be genetically related to a parent), the discovery of documentation, or indiscreet remarks/inadvertent revelations from family members in the know, disclosure may become necessary in the case of a serious illness in the family. Meanwhile, as with adoptees, donor-conceived people often report feeling in some way different from the family members they have been raised with, or having a distant relationship with what is often termed the 'social parent(s)' i.e. the one who raises them. As with adoptees, they may very likely notice a lack of similarity in physical appearance or personality traits in the parent(s) they are not genetically related to, or to any siblings, who may not be genetically connected either.

Additionally, the original review acknowledged its own, inevitable, limitations (such as the lack of a critical theoretical discussion of the reviewed studies' findings.) It also acknowledged - but did not attempt to catalogue - the existence of a considerable body of the aforementioned 'grey literature' addressing this topic. Another key finding from the original review of relevant studies was that a 'one size fits all' approach to the planning and delivery of services was not likely to address the needs and interests of all parties to such transactions – because even though relatively small numbers of donor-conceived people had been studied,

there was demonstrable variation within the broad themes address in the original SR.

The original SR concluded with a number of recommendations for minimum criteria when performing AHR using donor genetic material. The recommendations were aimed at maximising future choices and opportunities for all donor-conceived people to learn about their genetic and biographical origins should they choose to do so, and can be broadly summarised as follows: use of identifiable donors only, confidential records accessible to donor-conceived people enabling links to be made to half-siblings, enactment of policies facilitating contact between half-siblings by mutual consent (with appropriate mediation and support services), the informing of donors about the outcome of their donations, with encouragement to tell their families about their participation, plus the encouragement of parents to begin to tell donor-conceived children about their conception from an early age. The original authors described these recommendations as being 'relatively uncontroversial' (noting that some were already in force in certain jurisdictions) but also acknowledged that there were more potentially contentious measures that could be utilised, such as annotating birth registration records - interestingly, this was a measure advocated by some participants in the studies reviewed, which conveys an idea of the depth of feeling involved, for many donor-conceived people.

### **1.3 Why an Update of the Original SR Was Undertaken**

The reasons why donor-conceived people are a population of interest have been outlined above but the decision to update this systematic review was also made because, although a worthy undertaking, SRs by their very nature are a snapshot in time, only enjoying true currency for a period. Technology and research methods move on, more research studies come on-stream, and any recommendations arising from an original SR may need to be modified to reflect a changing picture, especially in the case of clinical practice or guidelines.

Additionally, because original SRs are time-consuming to undertake, an update of a previous review might be a more efficient route to identifying new evidence and

obtaining an understanding of the current picture with regard to research in a particular area. This is especially true in the area of assisted human reproduction, a relatively novel area for study even though, as the authors of the original SR point out in their introduction, human sperm donation has been practiced since at least the early 1800s. (Also noted by the original authors was the fact that the further development of AHR in the latter part of the 20<sup>th</sup> century, away from its basic origins, was conducted in an atmosphere that initially promoted secrecy and anonymity.) It should be noted that notwithstanding their limitations, SRs perform a useful function to glean a broad understanding of research evidence in a particular area: "A systematic review is a convenient synthesis of evidence for the busy healthcare practitioner." (Garritty et al., 2010) Meanwhile, in terms of any 'hierarchy of evidence' a systematic review would be right at the top of the scale.

One of the aims of this dissertation is to establish whether the picture has changed significantly in the six years since the original SR was published, and whether meaningful conclusions could be drawn from a review of newer research studies – conclusions that might help to inform future clinical guidelines, social policy or even law in this ever-evolving area. As previously noted, the original authors observed a consistent thread running through the studies they cited of interest amongst donor-conceived individuals in their genetic and biographical heritage. They concluded that there was sufficient evidence to come down on the side of openness and transparency in what they termed 'collaborative reproduction', so that any wish expressed for background information surrounding their conception and any donor involvement can be granted. One of the other aims of this update is to ascertain if the recommendations around openness and transparency are still sound and if newer evidence bears them out.

#### **1.4 Justification for Updating Review and Methods**

In conducting this update, published advice for such an undertaking was consulted, in order to glean an awareness of best practice guidelines. A 2016 paper in the BMJ offered a useful checklist on when and how to update systematic reviews. (Garner et al., 2016) It built on the extensive experience of Cochrane, which found that it was not possible or feasible to continually update all reviews

all the time, and proposed a set of steps to assess the SR against and decide if it should be updated. The BMJ paper recommended assessing the currency of an SR against a number of criteria such as whether the published review still addresses a current question? Has it had good access or use? (a check of the metrics will ascertain this.) Another question to ask of the original publication is whether the review used valid methods and was well conducted?

On interrogating the original SR with these questions in mind for this dissertation, it was concluded that an update would be a worthwhile undertaking, especially given the constantly evolving nature of this area of science and medicine. The question of how donor-conceived individuals fare over the life course should be of ongoing interest to clinicians practising in the area, to prospective parents who are considering going down the route of AHR and to legislators and public policy-makers in all jurisdictions where AHR is practised. So the original review still addresses a current question and has been cited in 60 other articles. It was also believed that such an update was likely to produce an informative picture of the current situation in English-speaking regions, at least. Additionally, any comments or criticism of the original review can be taken on board. (It has already been noted that the original authors acknowledged the inevitable limitations of their review.)

As for whether the original authors chose appropriate methods to answer the research question, it is the current author's opinion that in conducting the original SR, every reasonable effort was made to ensure a good sweep of available information sources (the four databases chosen) with date parameters over a twenty-one year period to identify studies that would enable the original authors to draw meaningful conclusions. Although the current author does not have any plans at this time to conduct original research on the topic in the future, this update may help to inform other researchers about developments since the original review and what is currently out there in terms of empirical evidence on this topic. Such information may assist researchers in identifying areas for further studies or in the formulation of a relevant research question. As outlined later on

in this paper, one of the limitations of the current undertaking is sole authorship (as opposed to the small team that worked on the original SR), but it may supply other researchers with a usable current snapshot of this area along with pointers for specific research questions, whilst also giving a good general idea of what resources might be required to perform further research.

All studies included in the original review by Blyth et al were scrutinised in advance of this update. In order to identify newer relevant literature, searches were run in three of the four same electronic databases as the original review, namely CINAHL, EMBASE and MEDLINE. Search terms employed in the original review were as follows: "gamete donation, sperm donation, semen donation, donor insemination, oocyte donation, egg donation, embryo donation, disclosure, donor anonymity, secrecy, donor offspring, donor-conceived children, donor-conceived adults, donor-conceived people", and these were replicated for this update.

The original review limited itself to English language, peer-reviewed publications from empirical studies with donor-conceived children and adults regarding their experiences and perceptions of donor conception (and the update replicated these limits.) 19 articles, with data drawn from 13 discrete studies which met the inclusion criteria were reviewed by the original authors. As mentioned, searches of these databases for the original SR covered the period 1990-2011, and searches for this update covered a succeeding period, January 2013 – March 2018, in an attempt to make the searching process more manageable as it was felt that the gap between review periods was not long enough to exclude any relevant longitudinal studies, which would be of particular interest as the original authors noted these were generally lacking at the time of their review. And although the latter is a shorter time period, technological developments in this area have evolved quickly and come into use even as legislation internationally struggles to keep up (and varies between jurisdictions.) The authors of the original review felt it was significant that no studies meeting their criteria were published prior to 2000; in their view, this reflected "the relative novelty of research in this field" (at the time.) They also noted that more than half of the reports from such studies

had been published since 2008; for this reason it was likely there would be some exponential growth in research since the original update and thus it was likely that there would be more relevant data to consider, offering further justification for an update.

## **Chapter Two: Results**

The initial search string yielded 6047 articles. After de-duping, 864 articles were screened for relevance. The majority of these articles were excluded judging on title and abstract content. The remaining 33 articles were considered for inclusion either because they referenced studies directly relevant to the research or because they collated relevant information on the population of interest such as direct quotes from donor-conceived people that provided insight into their experiences of their genetic origins (see section following table 1.0). Studies on families of various types where there was at least one donor-conceived child were identified in the searching process but unless they had the perspectives of the DC person as a key focus, they were excluded. Nine publications were included in table 1.0 as they were about research directly relevant to the research question. Three other studies on the population of interest are outlined outside of table 1.0 as the participants were drawn solely from DC individuals on voluntary registers who had connected with these registers as a way to identify genetic relatives, which is potentially a further narrowing of an already narrow population of interest. However, all three studies were relevant for the insight they provided into the lived experience of donor conceived individuals and are outlined in more detail later in this dissertation.

Studies that focused solely on the views and experiences of 'social parents' and *their* perceptions of their children's emotional health and wellbeing were excluded; although some featured interviews where children were present when their social parents were being questioned, or were observed in interactions with parents as part of the study, the *children's* views and perceptions of being donor-conceived were not the main focus. One interesting study from 2014 compared health and quality of life outcomes for a group of ART children v. non-ART children with input from the children themselves (Halliday et al., 2014) but because the main focus



was quantitative – measures relating to physical health, rate of hospital admissions, BMI, educational achievement etc. rather than qualitative - personal views and experiences, the study was excluded from consideration for this paper.

TABLE 1.0 – *Update of Systematic Review (Blyth et al., 2012) of peer-reviewed research into the views and experiences of donor-conceived people*

Authors	Focus of Study	Type of Research	How Recruited	Country of Origin of Participants	Numbers; Gender; Ethnicity	Age Range	Type of Donor Conception; Family of Origin Type	Anonymous or Known Donors used	Age Range at Disclosure
(Blake et al., 2014)	Donor Conception and social family relationships from the DC child's Perspective	4 <sup>th</sup> & 5 <sup>th</sup> phases of a longitudinal study, (when the children were 7 & 10 yrs old respectively) incl. semi-structured interviews	DI egg donation families were originally recruited from nine fertility clinics in the UK. The natural conception families were selected through maternity ward records on the basis of stratification to maximise comparability with the assisted reproduction samples	UK	110 children from 110 families – 55 boys (50%) and 55 girls (50%)	The child participants were aged 7 (phase 4) and 10 (phase 5)	31 donor insemination, 28 egg donation and 51 natural conception families headed by heterosexual couples who were either married or cohabiting	All anonymous donors with the exception of seven egg donation children who were conceived using a known donor	Children in DI & ED families in which parents had disclosed their use of donated gametes to the child were given an additional set of questions focusing on the donor conception. At age 10, parents in 10 (29%) donor insemination & 14 (47%) egg donation families had disclosed this information

Authors	Focus of Study	Type of Research	How Recruited	Country of Origin of Participants	Numbers; Gender; Ethnicity	Age Range	Type of Donor Conception; Family of Origin Type	Anon-ymous or Known Donors used	Age Range at Disclosure
(Carone et al., 2018)	Relationships between recipient families, surrogates and egg donors, fathers' decisions over disclosure and children's views on their surrogacy origins	Qualitative (semi-structured interviews)	Via multiple strategies	Italy	80 fathers & 31 children	The children were aged between 6 & 12 years	All families had used a surrogate & donor egg, plus the sperm of one of the social fathers (all fathers identified as gay)	Known	Before the child was aged 4 years, almost all families (n = 34, 85%) had started to disclose their use of a surrogate, with 16 families (n = 16, 40%) also disclosing their use of a donated egg, and only 4 (10%) disclosing which father's sperm used.
(Goldberg and Allen, 2013)	How DC young people who were raised by lesbian parents make meaning out of and construct their relationships with known donors.	Qualitative – semi-structured telephone interviews	Primarily via listserv mailing list announcements	U.S.	11 young adults selected from a larger sample because they had known donors. (8 participants identified as female, 2 as male, and 1 as 'gender queer'	Aged 19-29 years (M = 22.87, Mdn = 21)	10 participants were born to lesbian couples and 1 study participant was born to a single lesbian mother who intentionally co-parented the child with her former girlfriend.	All known donors (sperm)	In 9 cases, participants "always knew" they were DC and they knew who their donors were, one participant discovered his DC status and his donor's identity aged 5 and one participant knew in childhood but did not know the donor's identity until she was 20.

Authors	Focus of Study	Type of Research	How Recruited	Country of Origin of Participants	Numbers; Gender; Ethnicity	Age Range	Type of Donor Conception; Family of Origin Type	Anon-ymous or Known Donors used	Age Range at Disclosure
(Golombok et al., 2013)	Parenting and children's adjustment in families of children born via AHR	1 <sup>st</sup> phase of a Longitudinal, mixed methods incl. standardised interviews	The egg donation and DI families were obtained through 9 UK fertility clinics. The natural conception families were selected through maternity ward records on the basis of stratification to maximize comparability with the AHR samples	UK	96 (30 surrogacy families, 31 egg donation families, 35 DI families, & 53 natural conception families.	The children in the study were aged 3 at first phase	Sperm donation and egg donation; Fertility clinic recruits were all from heterosexual families	Not specified	Almost all AHR parents had begun the process before the child reached 4 yrs old
(Golombok et al., 2017)	Parent-adolescent relationships in families formed through reproductive donation	Longitudinal study (6 <sup>th</sup> phase) – Standardised interviews, questionnaires, and observational assessments	See above (Golombok 2013)		87 formed through AHR (32 DI, 27 egg donation, 28 surrogacy) and 54 natural conception families	Adolescents studied at age 14 (6 <sup>th</sup> phase of a longitudinal study)	As specified previously		

Authors	Focus of Study	Type of Research	How Recruited	Country of Origin of Participants	Numbers; Gender; Ethnicity	Age Range	Type of Donor Conception; Family of Origin Type	Anon-ymous or Known Donors used	Age Range at Disclosure
(Hammarberg et al., 2015)	To investigate the age at which young adults recalled learning about being donor-conceived & the association with subjective well-being and parental relationship	Qualitative (Structured interviews)	Via clients of ART clinics who gave birth in Victoria between 1982 & 1992	Australia	547 participants out of 594 recruited (92%)	Young adults between the ages of 23 & 33	10.6% (n = 58) were conceived with donor gametes	10.6% (n = 58) conceived using donor gametes, with the rest conceived via ART alone, family of origin type not available	77% had been informed about their ART-conception before the age of 12, 18% when they were between 12 and 17 years, and 5% when they were 18 years or older
(Ilioi et al., 2017),	The question of whether children should be told of their biological origins, and at what stage of their development this information should be disclosed (6 <sup>th</sup> phase of a longitudinal study examining the quality of family relationships)	Longitudinal study (6 <sup>th</sup> phase), mixed methods incl. standardised interviews. (Systematic information on whether and when parents had told children about their biological origins was obtained at earlier phases of the study.)	See above (Golombok 2013)	UK	87 families created through reproductive donation and 54 natural conception families (Majority white ethnicity e.g. 47 of the 54 natural conception families had a mother with white ethnicity)	The children participating in the longitudinal study were aged 14 years	32 families with a child born via DI, 27 families with a child born through egg donation and 28 families with a child born through surrogacy plus a comparison group of 54 families with a naturally conceived child, representing 92% of families seen when the children were aged 10 years. Of the surrogacy families, 10 mothers were genetically related to their children	Not specified	Within the disclosing families (56), 21 (37%) sets of parents had disclosed by age 3, 25 (45%) had disclosed between ages 4 and 6, and 10 (18%) had disclosed between ages 7 and 14.

Authors	Focus of Study	Type of Research	How Recruited	Country of Origin of Participants	Numbers; Gender; Ethnicity	Age Range	Type of Donor Conception; Family of Origin Type	Anon-ymous or Known Donors used	Age Range at Disclosure
(Van Parys et al., 2016)	Family communication about the donor conception in families headed by lesbian couples.	Qualitative, using interviews - (mixed methods used to analyse data)	Via the Dept. of Reproductive Medicine of the Ghent University Hospital	Belgium	13 (6 lesbian parents and 7 of their children 6 boys, 1 girl). Ethnicity : All parents and children who participated were white	The DC children who participated were aged between 7 and 10 years old.)	All offspring were raised in families headed by lesbian couples	Anon-ymous	The children had been told but as all were < 11 years old, had varying degrees of understanding
(Zadeh et al., 2017)	To investigate the relationship between young children's views of their donor & their maternal attachment in solo mother families	2 <sup>nd</sup> phase of a longitudinal, multi-method, multi-informant study of solo mother families incorporating interviews plus qualitative & quantitative analysis	Clients of a large UK fertility clinic	UK	19 (mean = 10.3, SD = 1.82), (10 male, 9 female); ethnicity not recorded	7-13 yrs	DI only; all families headed by solo mothers	Most ( $n = 14$ , 74%) conceived using anonymous donor; remainder ( $n = 5$ , 26%) conceived using an identifiable donor	All participants knew about their DC status & the majority ( $n = 16$ , 85%) were informed before age 3; remainder told at ages 4 ( $n = 1$ , 5%), 8 ( $n = 1$ , 5%) and 12 ( $n = 1$ , 5%)

Table 1.0 highlights nine studies of participants recruited from a variety of sources (other than voluntary registers for donor-conceived people to identify genetic relatives – this is dealt with separately below.) The nine studies identified reflect the use of both qualitative and quantitative methods when researching this population, with some combining both. The use of mixed methods is also apparent, such as an online survey/questionnaire or interviews along with another measure such as an observational measure.

As mentioned earlier, when summarising the findings of the original review, the authors noted the lack of published research concerning families formed via newer forms of AHR than straightforward sperm donation. While no studies involving

embryo donation were identified, the table above shows that studies involving participants conceived via egg and gamete donation as well as sperm are represented. Most studies recorded the gender of participants, family type and type of donor-conceived child e.g. sperm/egg/gamete or if surrogates were involved. Of the studies outlined in table 1.0, five recruited participants from the UK, and the four others recruited from, separately, the US, Australia, Italy and Belgium. All of the following studies focused exclusively on the offspring of gay/lesbian-headed families: (Carone et al., 2017), (Goldberg and Allen, 2013), (Zadeh et al., 2017) and (Van Parys et al., 2016). Four publications from the same longitudinal study (Blake 2014, Golombok 2013, Ilioi 2017 and Golombok 2017) are included in table 1.0. For the other longitudinal study cited above (Zadeh 2017), it is inferred via the presence of common authors that participants may have been drawn from the same pool.

Interviews were generally semi-structured and offered free text options for participants to expand on their answers. The main longitudinal study referenced here reports some interesting results on the relationship between type of AHR (sperm/egg/gamete donation) and family relationships from the 6<sup>th</sup> phase of the study, where the researchers found that mothers in surrogacy families showed “less negative parenting and reported greater acceptance of their adolescent children” plus “fewer problems in family relationships as a whole compared with gamete donation mothers.” The authors also found less positive relationships between mothers and adolescents in egg donation families than in DI families - as rated by both mothers and adolescents. (This phase of the study found no differences between family types for the DC adolescents themselves in terms of adjustment problems, psychological well-being, and self-esteem.) The longitudinal study utilised a comparison group comprising natural conception families.

One recent study outlined in table 1.0 (Carone et al., 2018) investigated the web of relationships between gay fathers, the surrogates who had carried their child and the resultant children. Most families studied reported a harmonious relationship with the surrogate and a distant relationship with the donor, while about 61.3% of the children in the study expressed limited interest in their conception to the researchers and the rest had positive feelings about it except for

one child who was unsure how they felt. The researchers noted that findings had to be interpreted with caution due to factors such as the higher than average income of the fathers, but for the researchers their study represented an attempt to give voice to the under-represented category of children of gay fathers conceived via surrogacy using donated reproductive material.

A number of the studies outlined in table 1.0 focused on the quality of relationships between DC people and their social families, and the effect that age at disclosure might have on such relationships; this is obviously a relevant area for study as DI children grow up. The British phased longitudinal study (two phases of which are described in table 1.0) had some interesting conclusions at different phases. The researchers found that at age seven, children conceived via surrogacy showed higher levels of adjustment problems than children conceived by gamete donation – to the authors, this suggested that the absence of a gestational connection between parents and their child may actually be more problematic for children than the absence of a genetic relationship, as the absence of a genetic connection to either parent was not associated with adjustment difficulties. However, it is encouraging to note that across the phases of the study, a strong association with being donor-conceived and having adjustment or psychological problems was not found, even taking into account any limitations of the study. Different phases of the study researched children at different ages and from the first phase it was noted that almost all AHR parents had begun the process of disclosure in early childhood. Disclosure has been described as a gradual, ongoing process elsewhere – and this makes sense in light of the fact that while very young children will not fully understand the nature or implications of such information, it should happen via an ongoing process and it should be started early so that as they develop cognitively they will come to absorb and understand the full meaning.

### **Chapter Three: Discussion**

On this update of the previous systematic review, it can be stated that the views and experiences of donor-conceived people is still an under-researched area. The original authors noted both the dearth of longitudinal studies plus the lack of

published research concerning families formed via newer forms of AHR than straightforward sperm donation. Certainly the fact that table 1.0 features just two discrete longitudinal studies demonstrates that there is scope for further research of this type, given increased access to the population of interest. AHR may need to be 'bedded in' a little more into society generally and from the current review it would certainly seem that research into this area has not yet hit its peak. It will be interesting to see how it evolves in the future, both in terms of actual techniques and allied policies.

From this review, the current author draws the conclusion that this is an area of considerable interest to researchers – there is no shortage of publications in academic journals considering the issue from an ethical and legal standpoint, with many papers presenting arguments and positions on the issue (rather than the results of actual research studies involving DC people). As mentioned, if the population of interest continues to expand and can be accessed by researchers, the questions of the views and experiences of donor-conceived people on their origins, their relationships with their social parents, their views and feelings on their donor and the overall effect being donor-conceived has on their lives plus what supports people in their situation might need over the life course are certainly ones that should be investigated by researchers in the future. For example, are there more specific recommendations that might be made by clinics to their clients, beyond a general encouragement of open disclosure? Robust longitudinal studies that track the reported experiences of children and their social parents over the course of childhood and into adolescence would likely be a rich source of usable data here. Data from such studies might provide useful insight into how optimal conditions can be created for children conceived via AHR. Is there an optimal age or ages for disclosure and are there specific scenarios where open disclosure might not be the best course of action? How is gradual, age-appropriate disclosure best achieved? What are the main issues that arise in families where there are children conceived via AHR? Data from longitudinal studies may also provide more insight into issues ranging from the challenging behaviours that children conceived via AHR might exhibit (particularly in relation to the discovery of their genetic origins), to what kinds of people make the best 'social parents' - and could be used to make clinical decisions as ethically as



possible. Relevant insights from such studies could be supplied to prospective social parents to aid them in their decision-making about the process.

As things stand currently, drawing broad conclusions and making generalisations about the experience of DC people and what their needs might be is unwise when there is still not a huge amount of research to consult, the sample sizes of available studies are generally small and the focus is often on particular family types. As stated earlier, a key finding from the original review was that a 'one size fits all' approach to planning and delivery of services in this area (which would necessarily entail the making of sweeping generalisations) was not likely to address the needs of all interested parties as there was a demonstrable variation within the themes addressed in the original review and such a finding is still valid for this update. Certainly having more relevant published data would highlight what the most important ethical and legal issues are for this population.

One issue that has been recorded by researchers when investigating young donor-conceived children, their views on the nature of their conception and their donor(s), is that as well as having a limited understanding of the concept the younger they are, as discussed previously, difficulties in drawing meaningful conclusions are compounded by another reason. This reason is that, from a child development point of view, their interest and curiosity about their donor is much more likely to surface during the identity-forming adolescent years, when their self-concept and their attempts to develop an identity independent of their parents may come to be challenged by the knowledge they are donor-conceived. So while attempts to measure the subjective wellbeing of young donor-conceived children are a worthy undertaking - and are valid quests from a research point-of-view, results from studies with older children i.e. adolescents and young adults might have more relevance when attempting to measure the overall effect that being donor-conceived has on an individual's life.

A 2013 paper identified during the search process and published by a National Advisor to the voluntary DNA-based register 'UK DonorLink' collated the experiences of dealing with donor-conceived people (all born before 1991) who had registered with the service in the hope of identifying and connecting with

genetic relatives. It contained some revealing insights into the emotional states of DC people after the discovery of their origins and the realisation that they were artificially conceived plus some useful information on what appropriate support services might look like. The study itself was excluded from this review process as it was administered by the National Advisor to the service, so only featured users of the register (a self-selecting population, as the study itself points out) and would introduce bias. Presumably anyone who registers with such a service favours openness and transparency and some users may have largely negative views on donor anonymity depending on their particular experience of disclosure and searching (plus such participants are too narrow a grouping to draw more widely-applicable conclusions).

The study reported that donor-conceived people “can report feelings of betrayal, anger, relief, shame, identity confusion and genealogical bewilderment. Some feel disturbed by the thought of being “conceived in a Petri dish,” “mass produced” or akin to “animal husbandry.” ” (Crawshaw et al., 2013). However, not all of the registrants viewed donor-conception negatively and this fact was thrown into relief during contact with (unrelated) peers as facilitated by the service. One questionnaire respondent “took being donor conceived as a positive thing, knowing how much my parents wanted me, and most other people were very unsure of themselves and blamed their parents for making them incomplete.” The author noted this variation in general outlook was a challenge for the delivery of peer support (which was found to be a helpful intervention generally.)

Other areas suggested in the realm of support were of a more practical nature, and have possible future application, such as having someone suitably qualified available to explain the statistical nature of DNA results to donor-conceived people looking to discover if they were genetically connected to others on the register. Such a resource would simplify the process for someone who is not from a scientific background. Meanwhile, the opinions of users of the service (both donors and donor-conceived people) were sought on the question of how such services and allied supports should be funded and the most common suggestion across all groups was that such supports should be government funded. Some DC respondents adopted a moral position as to why services should be free of charge

for them, namely that they did not have a choice about the manner of their conception but had to suffer the consequences and any disadvantages because of the decisions of bodies and institutions that, in their view, should have acted more responsibly. For one respondent in this respect “(the) government decided, completely inappropriately, that it would allow anonymous donors and it is up to the government to put right this mistake. It is not the responsibility of the donor-conceived to pay for this.” Another felt that the government’s failure to regulate the fertility industry made it culpable: “... they [government] allowed an unregulated industry to make decisions about people's [lives] and ... there are adults who can have no chance of knowing who one of their parents is. They should fund any service that attempts to compensate for this”. Some of the obstacles and frustrations experienced by donor conceived individuals as outlined by Crawshaw, even when it came down to something as basic as lengthy wait times for processing and results of DNA tests, may be an indicator that having a smooth discovery experience and getting access to the information they want can still be difficult (certainly from a UK perspective). This was a challenge noted by the original authors, as outlined earlier.

Reported comments – positive and negative - on the views and experiences of donor-conceived people, such as the ones reproduced here are certainly illuminating. However subjective, they do provide information on and insight into areas such as feelings about their donor(s), the motivations behind any searches for genetic relatives, issues around their construct of self and personal identity, relationships with their social families and their views about the institutions and structures facilitating AHR plus what appropriate social supports post-disclosure might look like.

Finally, a systematic review was also identified during the searching process (Ilioi and Golombok, 2015), which reviewed peer-reviewed papers on the question of psychological adjustment in adolescents conceived by assisted reproduction techniques: For the authors, the studies identified indicate that children conceived via AHR can have positive parent-adolescent relationships and are well adjusted, with some slight variability found, depending on the type of ART. The authors did comment that the generalizability of their findings may be limited by a mostly low

level of disclosure to adolescents in some publications and the small sample sizes of relevant studies (along with the large age range that encompassed adolescence.) Other limitations included the fact that many publications focused on singleton births with a lack of research on: egg donation, surrogacy and embryo donation, the disclosure processes, adolescents born into non-traditional families and adolescents born using different types of donor (anonymous, identity-release or known.)

For donor-conceived individuals who have difficulty processing and accepting the mysterious aspects of their identity, it seems there may be long-term impact for some. The consequences of both secrecy and late disclosure merit investigation in relation to such individuals. Indeed the Irish Commission on Assisted Human Reproduction (2005) noted that the growing use of the new technologies had “major social, ethical and legal implications” and that relevant guidelines by the Irish Medical Council alone were not a sufficient form of regulation – this was one of its key findings. The Commission was set up to investigate and report on possible approaches to the future regulation of all aspects of AHR and the social, ethical and legal factors to be taken into account in determining public policy. It also recommended that longitudinal studies of children born as a result of AHR be carried out and referenced the policies that other jurisdictions had adopted in relation to AHR (such as the establishment of central registries.)

Another paper (Frith et al., 2018) not included in the review because the data was drawn from the same study as the above (adults registered with UK DonorLink) and for other reasons related to the study design, is nevertheless still of interest because of its comparatively large sample size of 65 adults conceived via AHR (all via anonymous sperm donation) but without any openly gay female parents - obviously lesbian couples are a cohort who would ordinarily feature strongly in such research. The study sought to examine the role that secrecy played in the family life of the participants (again, all DC adults born before 1991 who were looking to identify and connect with genetic relatives) and what events triggered disclosure of the facts of their conception where there were narratives of how participants found out. It concluded that secrecy and uncertainty around who in the family knew the truth were key in providing insights into the relationships

created by donor conception.

A further paper excluded from table 1.0 as it also drew its findings from the same study involving individuals registered with UK DonorLink (Van Den Akker et al., 2015) reported on the expectations & experiences of DC adults and donors searching for genetic relatives via the register, and also had some interesting findings. Again the 91 participants consisted of 65 DC adults (50 female and 14 male plus one who did not specify gender) along with 26 donors who completed an online questionnaire used to obtain qualitative and quantitative responses in an attempt to draw conclusions about the experiences of these individuals, which they reported as largely positive for both DC individuals and donors (with some concerns.) One particularly interesting finding was that of a lowered collective identity for DC people compared with donors and samples in the wider general population. For the authors, this provides empirical support for arguments that a sense of 'belongingness' (being critical to identity generally) has implications for understanding the development of identity in DC individuals. They authors also recommended that research, policy and practice should focus on preparation of prospective parents who are utilising donor reproductive material for meeting the needs of their child(ren) to seek information about their genetic identity and the resultant potentially altered sense of self and of family.

A 2013 study involving registrants of the US-based 'Donor Sibling Registry' attempted to position the relevance of age, awareness, and family form in how DC people viewed their donor (Hertz et al., 2013) and found that donor offspring view the donor as a whole, real person, who they can have a relationship with, and learn about themselves in the process (rather than viewing the donor as merely genetic material.) They also desired that the donor should know about them and not remain "an anonymous genetic contributor." The study also found that family form (whether heterosexual two-parent families or lesbian two-parent families) affects donor terminology i.e. the words used to describe the donor. The issue of the language used to describe donors is one that is referenced in other papers identified during the study including a 2018 publication (Provoost et al., 2018) excluded from the current review because of its focus (a study of the words used

by recipients and their families to refer to the donor, on the basis of previous evidence that this was something considered carefully by such families.) The findings show that the diverse words used have at least four different interlinked functions: "(1) to position the donor in relation to the nuclear family; (2) to safeguard the role of the social parent; (3) to clarify family structure; and (4) to present a positive picture of the donor." The study reported that both parents and children consciously reflect on the most appropriate language to use to refer to the donor. It noted that although parents tried to avoid using the terms 'father' and 'daddy' the children themselves use these words, so in their view, healthcare personnel and policymakers needed to give careful consideration to their use of terminology to describe the donor.

Another study using recruits from a voluntary registry - the US Donor Sibling Registry (Persaud et al., 2017) focused on adolescents conceived via sperm donation and examined their experiences of contacting and meeting 'same-donor offspring' raised in other families. It was a qualitative study involving semi-structured interviews with 16 females and 7 males. A total of 25 participants whose parents had consented to being interviewed were invited to participate. Of these, 23 agreed to be interviewed (92%) and 2 declined. Twenty-two (96%) participants were identified as white and one (4 %) as 'other, unspecified'. Two sets of siblings who were raised in the same family participated in the study 12–19 years (mean = 14 years.) Twenty-two participants (96%) were identified as white and one (4%) as 'Other, unspecified'. 'Fourteen participants were from single mother families, ten of these identified as heterosexual, two as bisexual and two did not specify their sexual orientation. Nine participants were from families headed by mothers in same-sex couples, most of the mothers identified as lesbian and one identified as bisexual. All were conceived via anonymous shared donors. Four (18%) participants reported having 'always known', about their conception, nine (39%) 'could not recall' when they were told, nine (39%) found out before the age of seven and one (4%) found out after the age of 10.

One arresting finding from this study was that some participants did not realise there may be other DC children conceived from the same donor, much less that

they could potentially make contact with such half-siblings. The authors believe this provided an opportunity for families who may not have considered connecting with donor relations to be informed of what such relationships can be like. The authors also noted that increasing numbers of families who share the same donor would likely seek contact with each other in the future, so empirical studies would be important sources of data to inform policy-makers and professionals of the potential outcomes of making these connections.

A further study that also recruited from the above-mentioned Donor Sibling Registry (Slutsky et al., 2016) looked at the processes by which donor-conceived children from lesbian couple and single mother-headed families incorporate donor conception into their subjective sense of identity. This was a qualitative, cross-sectional study, consisting of a semi-structured interview and questionnaire involving 19 adolescents aged 12 to 19 years (mean  $14.18 \pm 2.20$  standard deviation). All were conceived via anonymous sperm donation and came from families headed by single mothers and lesbian couples. In relation to the knowledge that they were donor-conceived, two (10.5%) had “always known,” 9 (47.4%) could not recall when this information was disclosed, and eight (42.1%) reported they had been told at or before the age of seven. For the authors, the results of this study of the influence of parent-child relationships on thoughts and feelings about donor conception during adolescence suggest that the valence of the relationship influences adolescents’ appraisal of their donor conception within the context of their developing sense of identity.

#### **Chapter Four: ‘Grey Literature’ on the Views and Experiences of Donor-Conceived People**

There is undoubtedly a compelling human interest angle here and the appearance of articles on this topic in newspapers and magazines outside of the medical or scientific sphere helps to illustrate this and illuminate the reasons why. As mentioned earlier, the original authors acknowledged the existence of such ‘grey literature’ and its possible relevance in formulating policies and procedures where there is a dearth of other research evidence, such as longitudinal studies. To this end, for the current piece of work, some general internet searches using the

Google search engine were conducted, utilising some of the original search terms in order to find recently published articles in non-academic publications such as newspapers and general interest magazines with a varied readership. Any attempt to quantify such material would realistically be beyond the remit of this paper, but some of the resulting publications are cited here, containing varying views on the topic, in an attempt to communicate a flavour of the different perspectives that donor-conceived individuals have expressed outside of academic research studies.

An article published in UK national newspaper 'The Guardian' in 2011 chronicled the effect that secrecy and non-disclosure around the topic of DC individuals could have: "Donor-conception: 'I'd got to the bottom of a secret.'" (Hilpern, 2011). One DC adult interviewed for the piece (who was the child of an initially anonymous donor with many other offspring) offered the following comment on growing up with a distant, emotionally remote social father: "Any big secret sits in the middle of a family like a landmine – you have to watch what you say because any bit of conversation might lead to that secret. That is certainly the way we lived." Meanwhile, one of the experts interviewed for the same piece contributed the following chilling case: "In 2001, there was a case of a nine-year-old donor-conceived child who was found to have a potentially fatal condition known as Opitz syndrome. His genetic father had carried this inherited single gene disorder. This sperm donor had fathered 43 babies from a London clinic, each with a 50-50 chance of inheriting this rare disease." The idea that insufficiently careful utilisation of AHR could have been responsible for even a small increase in the incidence of rare diseases in the general population (and possibly perpetuating the increase in future generations is indeed troubling.)

And in the same piece another DC adult chronicled a painful and difficult search for her biological father, via discovering the clinic her parents had used in the 1950s, and using a book about the facility to identify the type of donors at that time, which turned out to be university lecturers from academic departments associated with the clinic. She used this information to narrow down possible candidates to a shortlist of 12 men, and after several dead ends, made contact



with the sons of one of the donors (the donor had since died.) However the family initially did not want to know and it took more than one attempt to get them to agree to a DNA test, which confirmed the genetic link. "They didn't understand my plight, but when the older brother turned 70, I felt time was running out and I wrote again, saying it would put my mind at rest just to be able to eliminate their father from my list. They agreed and, just after my 50th birthday, a letter arrived from the lab confirming that we were half-siblings. I'm a different person because of it. I've read my father's autobiography ... and discovered huge similarities. I'm happier and calmer for knowing about him and ultimately who I am." Again, the lengths that some donor-conceived people will go to in order to discover the truth are startling and help to illustrate just how their DC status can impact their lives.

A 2017 article in the Irish Times newspaper drew together the stories of some of the British-raised people who had been donor-conceived (O'Friel, 2018). Among the individuals profiled was social scientist Joanna Rose, who was told by her mother at the age of eight, that her 'father' was not in fact genetically related to her – as he was infertile, her mother had had two children using different sperm donors. Rose's sense of loss and anger around this revelation, along with the obstacles she encountered when trying to identify her real father, led to her bringing a case to the UK High Court, a case which resulted in a ban on donor anonymity in that jurisdiction in 2005 – representing a very significant legal development in this area. The article also profiled two other donor-conceived individuals, both of whom had negative experiences around the revelation of their true origins, and who both came to believe that third-party reproduction is a form of child trafficking, supported by a billion-dollar industry. A damning summary of the process was offered by one of the other interviewees for the piece: In her view, the circumstances of her birth "made many people happy: the sperm donor, the agency who made it possible and the recipient." But it did not make her – the resultant child - happy.

Conversely, in a 2018 article in the British Sunday Times Magazine (Sarnier, 2018), a young British man, Jordan Waller, who had been conceived using donated

sperm (and who had been raised by his genetic mother along with her lesbian partner and a third woman his mother was subsequently in a relationship with) discussed his personal experience of being a donor-conceived adult in a piece which helps to illustrate how some individuals conceived in this way may come to terms with their situation. He described growing up in an environment where his lesbian parents had to be secretive about their real family set-up and could not be 'out' in the workplace etc., and where he experienced heavy bullying at school as a result of coming from what was viewed by others as a non-traditional family set-up. However, as he came of age and gay couples became more of an accepted part of society he found that the attitudes of those around him softened and he became an object of interest and curiosity rather than ridicule. He came to the conclusion that while life as a donor-conceived child could be hard at times, his situation ultimately made for 'a more dynamic, interesting life', where he had successfully channelled his feelings of being an outsider into a burgeoning acting career and had even applied to become a donor himself.

Stories like this help to illustrate that the long-term outlook is not necessarily a bleak one, and can very much depend on the level of resilience of the donor-conceived individual themselves, and on the attitude they choose to adopt in their particular circumstances. It might also be noted that the reported experience of any patient or research participant is always necessarily subjective, and this applies in the case of reported symptoms or physical suffering (e.g. in a clinical trial) as much as any reported psychological or mental suffering. (The original SR sought to elucidate meaningful conclusions from research conducted previously into the 'views and experiences' of donor-conceived people.) The idea that an individual who was themselves donor-conceived would in turn consider donating their own reproductive material is an intriguing one and may be worthy of further study – after all, it could possibly be read as an overall endorsement of the practice, if the potential donor appears to be a generally well-adjusted individual and does not view the practice pathologically. Certainly it could be a key question for further research involving donor-conceived adults.

## Chapter 5: General Reservations about use of AHR

However, it must be acknowledged that there are segments of any given population for whom artificial means of reproduction are always morally questionable and indeed objectionable. Religious belief systems such as Catholicism obviously deserves a mention in this regard, but this is a psychologically challenging area for others too, not just the population of donor-conceived individuals who believe they have suffered because of the nature of their conception. A 2016 article in the Journal of Reproductive & Infant Psychology entitled 'The acceptability of assisted reproductive technology among French lay people' (Muñoz Sastre et al., 2016) noted that most studies of attitudes towards AHR had been conducted in the US and thus attempted to quantify the range of personal positions of ordinary French people regarding this topic. 351 participants were presented with a set of pre-composed 'stories' of AHR, all outlining 1) the reason for the use of the technology in the first place 2) the origin of the sperm, 3) the origin of the egg, 4) the number of children in the family and 5) the person to whom the embryo is transferred, in order to assess the extent to which the use of AHR would in each case, be acceptable. Five qualitatively different positions were identified in the results of the research. The study concluded that while no participants considered the use of ART as wholly unacceptable in itself, conversely, only 15% of all participants in the study considered use of ART as 'mainly acceptable' – inferring that most would deem that its use only *becomes* agreeable under certain specified conditions and with certain rules and limitations in place.

It seems that many people will instinctively place AHR in second place to natural conception. As mentioned previously, techniques have evolved quickly and in an environment where, for example, the sex of a child can be 'chosen', reproductive material can be screened for certain genetic disorders, post-menopausal women can bear a child and parentage can be achieved posthumously using preserved reproductive material, people's previous shared understanding of nature's endless cycle of birth and death as it has played out through most of human history has been increasingly challenged. Even in secular populations there is an instinct that such a deliberate manipulation of mother nature's processes is not to be

undertaken lightly.

Meanwhile, another recent study sought to elucidate attitudes towards AHR in a Muslim society (Iran), where such technology has actually been endorsed by the religious authorities: 'Assisted reproductive technologies and the Iranian community attitude towards infertility' (Ahmadi and Bamdad, 2017). The questionnaire based study, conducted in 2012, found that respondents did not support all types of assisted reproduction, with traditional IVF (using the husband's sperm and wife's egg) the most widely accepted form of AHR. (If no donor material is used, this form of IVF most closely resembles natural conception, obviously.) Newer forms such as surrogacy and donated reproductive material were less palatable to the participants of this study, indicating that general attitudes were not completely in step with an official policy which permitted all form of AHR.

A 2015 paper in the journal 'New Genetics and Society' presented a somewhat dystopian view of sperm banks after the authors' qualitative review of randomly selected donor profiles claimed to show how sperm banks "de-commodify sperm, personify donations, facilitate the romanticization of the donor-recipient bond, and add an emotional context to the economic transaction." Furthermore, "the donors extended profiles constitute a simulacrum of a living male partner and fulfil recipients' fantasies.... (creating) a powerful re-enchantment mechanism (to counter the anonymous and disenchanting character of actual transactions.)" (Bokek-Cohen and Gonen, 2015).

The question of the ethics surrounding AHR generally – for example the increasing commodification of human reproduction - cannot be considered without mention of the uncomfortable reality that those who can afford to access AHR are, in many cases, purchasing the services of those who are in an inferior economic position, for example in some parts of the world where surrogacy or egg donation is widely practised. Of course there can be purely altruistic reasons for wishing to assist a couple in this way (and studies of donors bear this out.) After all, if there is little

that is more natural in this world than the desire for a child, there must be many people who would empathise greatly with such a wish. But would empathy (plus basic expenses, as are usually provided for where surrogacy is legally permissible) *really* always be enough to persuade a woman to go through the very often physically and psychologically challenging state of pregnancy, (where they do not have the usual reward of a child of their own) for purely altruistic reasons, if it were not for a member of their own family? It may not be possible to answer questions like these in a wholly satisfactory manner – after all, a research study would have to be formulated in a very specific way to elucidate informative and meaningful answers to these types of questions whilst at the same time avoiding bias. However, they do merit consideration.

## **Chapter Six: Societal Changes and the Evolution of AHR**

Donor-conceived individuals have a strong claim on the truth, and the recommendations of the original authors reflect this view. However, the value of the opposing view should also be considered in the interests of balance. When these new reproductive techniques began to be utilised, there were legitimate reasons for the initial culture of secrecy – ranging from a natural desire for privacy from infertile couples around such a personal and intimate topic, to fear of general societal disapproval and shame around the idea of non-genetic fathers raising another man's child (early in the development of this technology, the assistive genetic material would have originated from a male donor.) Another reason why anonymity was such a strong feature of early AHR may have been to ensure a viable supply of donors. Donors of reproductive material do not exist in a vacuum, they are real people with real lives, families and roles in society. So the desire for privacy may not have been wholly attributable to the *recipients* of donor reproductive material. Conversely, anonymity was usually a standard condition at clinics offering AHR, so some donors may not have given it a great deal of thought. (Certainly this is an argument invoked by anyone seeking a retrospective change in law.) Policies facilitating secrecy would have been particularly suited to heterosexual couples (who, research shows, are still less likely to disclose use of donor reproductive material), because with a traditional family-set up there is not

the same pressure to explain the facts of life as they relate to such a family the way there would be with, say, a single parent or gay couple.

Several studies have sought to quantify the effect of bans on anonymity in various jurisdictions, such as an Australian study published in 2016: 'Does the removal of anonymity reduce sperm donors in Australia?' (Adams et al., 2016). This study surveyed AHR clinics over a twelve-year period (2000-2012), during which time a ban on donor anonymity was enforced in all Australian states except Victoria (which had introduced such a ban back in 1998.) The authors observed an overall increase in donor numbers over the period observed, which they could not attribute to any specific change in either policy or practice. For this reason they concluded that the removal of donor anonymity had not been detrimental to the supply of sperm donors in this jurisdiction. Results such as this help to give credence to the view that any early stigma is gradually being eroded over time. This may be in some part attributable to other societal changes such as the acceptance and increased visibility of non-heterosexual couplings and families formed via non-traditional methods.

For example, 2018 marks twenty-five years of the decriminalisation of homosexuality in Ireland. The current generation of gay men and women do not, in the main, have to conform anymore to traditional norms (i.e. conventional marriage to an opposite-sex partner) in order to have the experience of raising a family. The passing of the marriage equality referendum in Ireland in 2015 enshrined this new acceptance in law. Consequently, family formation amongst same sex-couples who, for the most part, enjoy an increasing acceptance and visibility that was simply not available to gay people in previous generations, will continue to require the input of donors in the future and altruism is an identified motivation for many donors. So this segment of the general population in many parts of the world, along with heterosexual couples looking to overcome infertility, or indeed single people who wish to become parents will help to ensure there is a market for donors going forward.

In addition to the role of AHR in overcoming infertility and helping gay people in family formation, it may also hold an appeal for some users due to what a 2016

study termed its ability to “notionally expand... women's opportunity set beyond former constraints” regarding who fathers their offspring. ‘What women want in their sperm donor: A study of more than 1000 women's sperm donor selections’ by Whyte et al. (2016) explored female preferences for particular male characteristics when selecting a sperm donor. The female recipients were found to favour younger donors, along with those who had a higher formal education, amongst the available options. For the authors, their study bears out traditional female mate preferences for fathers with resources and the potential to provide for offspring even where the father in such cases will not be involved in the actual upbringing of any child(ren.) The authors of the study also point out that the development of AHR means that access to pre-screened donors with favourable characteristics frees the women from the trouble and investment of time involved in pursuing and securing such a mate by themselves, when his reproductive essence is available to them at their nearest clinic, for a fee. For the authors, the traditional limiting factors of proximity, social class, culture and race are taken out of the equation when AHR is utilised, making it an attractive option and indeed a ‘game-changer’ for some women.

Another interesting and potentially positive offshoot of the growth of AHR is its ability to highlight other general aspects of reproductive health in populations. Because the male and female reproductive material harvested for use in AHR is routinely screened before use (in a way that would not ordinarily happen with natural conception) this screening can be utilised to build up a body of knowledge over time regarding the quality of such reproductive material and the effect that factors from age at donation and socio-economic status to methods of storage and use might have on its quality. A recent study covering ten years of donation at a US sperm bank from 2003-2013, which analysed the semen parameters of 9425 specimens from 489 donors before and after cryopreservation, was able to report a decline in semen quality among young adult men in a particular geographical area (Boston) who were attending college or had completed a college education during the period of the study. (Centola et al., 2016) The authors concluded that such findings were grounds for further research as the decline they observed could not be attributed to demographic or lifestyle factors, which were stable or improved during the time period covered. This ability to study human

reproductive material and the products of AHR to determine the factors that influence its quality may serve as another justification for proponents of AHR, despite reservations (whether from donor-conceived individuals themselves, or other stakeholders such as legislators or the public.)

However, even the prospective parents who decide to utilise AHR in their desire for children are not a homogenous group in terms of their attitudes towards the process. A study by the British Fertility Society (Stuart-Smith et al., 2011) attempted to quantify this by interviewing a group of women going through the egg donation procedure in Britain, some of whom were childless and others who already had at least one genetically-related child. The latter group expressed more reservations and anxiety about proceeding with such treatment and this created what the paper termed 'a state of dilemma', but the possibility of such treatment led to a pressure to proceed for them, whereas for the childless women, the overall feelings were of anticipation and excitement at the possibility of finally having a baby, with few reservations expressed by that group about the methods they were using to achieve their personal goal.

A 2015 newspaper article by Olivia Gordon in the British national newspaper 'The Telegraph', outlined some of the other, more general concerns donor-conceived individuals themselves have expressed, for example their fears around unknowingly entering into an intimate or sexual relationship with someone who is a close genetic relation of theirs. Given that different clients are likely to use a clinic that is within geographic proximity it is not entirely outside the bounds of possibility that a donor-conceived person might meet and form a relationship with someone whose parents utilised the same AHR facility and the same donor. The likelihood of this happening is probably not greatly higher than if there was no such thing as AHR but such fears cannot be entirely unfounded and the question has received scholarly attention - the following articles are offered as examples: 'The optimal number of offspring per gamete donor' (Sydsjö et al., 2015) or 'Anonymous sperm donation does not increase the risk for unions between relatives nor the incidence of autosomal recessive diseases due to consanguinity' (Serre et al., 2014). The question of human sexual attraction has received



attention from the scientific community who have concluded that people are often unconsciously attracted to partners who are in some way similar to them, or to a person who reminds them in some way of a parent. It is for these reasons that in the UK a donor is limited to assisting in the creation of up to ten families but not all legal jurisdictions have such a limit so a donor could potentially have hundreds of offspring who would be half-siblings. And any non-compliance by clinics (whether deliberate or accidental) when it comes to the amount of times a donor's product is utilised would likely only come to light after the fact.

The same 2017 Telegraph article also contained a contribution from a parent of two donor-conceived children which recommended that prospective parents think carefully before going through the process of AHR and which also endorsed transparency and openness as a general policy. Olivia Montuschi of the UK's Donor Conception Network, which represents families with DC children believes that the key to making third-party reproduction work "is parents acknowledging the implications of what they're doing. Some children wonder: 'Who is the real parent?' It's understandable. What's important is that parents understand these feelings and don't push them under the carpet." Montuschi also believes prospective parents should go through licensed clinics, rather than utilise an informal arrangement, and the article notes that such licensed clinics may be able to provide information such as a donor's ethnic group, physical characteristics, medical history and if they have other offspring.

Of course if a particular AHR service (such as sex-selection for reasons other than serious sex-linked heritable disorders) is not permitted by law in one jurisdiction, those who have the financial wherewithal can circumvent this by travelling to an area where the desired service *is* available, so a country's legislation, however robust, will not completely eradicate any illegal and unethical practices. The - for some - questionable ethics of donor conception are further thrown into relief by a quote attributed to another donor-conceived adult interviewed for the same piece, who called for a more critical approach to the issue: "A lot of people don't want to think about it very deeply - they'd prefer to think that nice, smiling babies come

out of this and it makes everything OK.” It is noteworthy that calls for legal reform in this area have been led by donor-conceived people.

In terms of law reform, (and as discussed earlier), donor anonymity has already been banned in some jurisdictions. However, one recently published paper suggested that anonymity would become a thing of the past independent of any legislation, as it would prove impossible to maintain in light of the ongoing development and refining of genetic testing (Harper et al., 2016). In light of this, the authors took the view that “parents using donor conception need to be fully informed that their children's DNA will identify that they are not the biological parents and they should be encouraged to disclose the use of donor gametes to their children.” A 2016 article in the journal ‘Human Reproduction’ agreed: “the argument that not telling is a ‘risky strategy’ for parents of donor-conceived children is one that... has traction” (Zadeh, 2016). However good their intentions in keeping the nature of a child’s conception secret, social parents have to weigh the risks of their desire to maintain a stable family set-up and protect their child from information that may be distressing against the possibility that the child will eventually find out for themselves and the possible consequences for family unity and interpersonal relationships.

Another ongoing development not considered in any detail by the original authors is the creation of various interest groups over the past number of years such as ‘Donor Offspring Europe’ and ‘Anonymous Us’. These groups seek to promote the rights of donor-conceived people (and have those rights reflected in legislation.) The current author has not chosen to research these in any detail, because of the risk of introducing bias – some of the groups were initiated by individuals who have had negative experiences around the disclosure of their status as donor-conceived people and who do not view the practice in a positive light. For example, some take the view that their inability to access medical history puts them at an overall disadvantage in life and amounts to a form of discrimination. For others, use of anonymous donors in the pursuit of their desire for children is a selfish act by social parents. On a less controversial note, and as discussed earlier,

there are voluntary registers in existence now (and this source provided the participants for some of the studies cited in the original and current reviews), which aim to give donor-conceived people the opportunity to search for genetic relatives. (Indeed Ireland's Children and Family Relationships Act 2015 provided for the establishment of a National Donor-Conceived Person Register.)

The ban on donor anonymity enacted in UK legislation in 2005 means that people who were donor-conceived in that jurisdiction, on reaching the age of majority in 2023 will have the right to access information relating to their donor(s), should they be aware of their status and should they desire to know this information. (Some DC individuals conceived under the UK regime will be able to access this information earlier, if their donor has registered that they are agreeable to this.) The experiences of these individuals and the outcomes of any searches they choose to undertake will provide a very interesting snapshot of the effect of this legislative change and is likely to provide fruitful material for academics and researchers.

## **Chapter Seven: Conclusion & Limitations**

In 2005, the aforementioned Commission on Assisted Human Reproduction published a report which contained recommendations for this area, and many of these echo what the original SR authors recommended, such as facilitating information for the donor-conceived individual about the donor(s) involved in their conception and limiting the amount of children born using the reproductive material of a single donor. Earlier this year, an Irish fertility expert (Prof Mary Wingfield, who was a member of the Commission, representing the Institute of Obstetricians & Gynaecologists at the Royal College of Physicians of Ireland) discussed the proposed legislation at a meeting of the Irish government's Joint Committee on Health and noted that except for the proposals on parenthood in surrogacy, the draft bill proposed by the Irish government accorded with the recommendations of the Commission. Prof Wingfield criticised the plans in relation to permitting surrogacy in Ireland, describing them as too restrictive, and allied with the plans to prevent doctors from assisting patients in accessing more suitable surrogacy services abroad would create an ethical dilemma for clinicians who wished to act in the best interest of their patients. She also expressed

support for the view that a donor-conceived person had the right to know his or her biological parent - but not in the way outlined in the draft bill. Her position and that of the Institute of Obstetricians and Gynaecologists was that it was "irresponsible, dangerous, and an invasion of privacy" that a donor-conceived person seeking a birth certificate would be told he or she was donor-conceived without requesting that information, as proposed in the draft bill. The submission of another expert present at the same meeting of the Oireachtas Joint Committee on Health (John Waterstone, President of the Irish Fertility Society was referenced in the same article. He emphasised the need to bring together the people who are formulating the legislation with people like him, Prof Wingfield and other professionals who are at the coalface, "to make sensible laws that are good for everybody."

Meanwhile, the recommendations of the original systematic review were sound, being evidence-based, and after conducting an update for the purposes of this dissertation, the current author is inclined to agree with them. An AHR regime which facilitates openness and transparency would indeed appear to be an optimal 'modus operandi.' Although some donor-conceived individuals may (depending on their circumstances) prefer not to go down the route of looking for information about their donor(s), the fact that relevant information on genetic, medical and biographical heritage is available means that those donor-conceived individuals who *do* wish to know more about their parentage can be facilitated and this, in addition to being useful from a health perspective, may help to bring a level of closure to what, for some of them, will inevitably be a challenging aspect of their identity. Measures suggested by the original authors in the interest of maximising choice for DC individuals were outlined earlier: (use of identifiable donors only, confidential records accessible to donor-conceived people enabling links to be made to half-siblings, enactment of policies facilitating contact between half-siblings by mutual consent (with appropriate mediation and support services), the informing of donors about the outcome of their donations, with encouragement to tell their families about their participation, plus the encouragement of parents to begin to tell donor-conceived children about their conception from an early age.) All remain valid on completing the current update.

As mentioned in the introduction, another key finding from the original review was that a 'one size fits all' approach to planning and delivery of services in this area was not likely to address the needs of all interested parties as there was a demonstrable variation within the themes addressed in the original review. So a considered, nuanced approach from legislators and public policy-makers would seem to be ideal. This technology is fulfilling a previously unmet need and put simply, assisted human reproduction is here to stay.

The current (sole) author also acknowledges the inevitable limitations of this update, both in terms of the studies reviewed for the paper and the resources available to the author. Sample sizes for studies were often small, perhaps reflecting the sensitive nature of the issue and the fact that many parents have not disclosed the nature of conception to their children. Clearly the successful targeting of the population of interest is an ongoing challenge. On a related note, a number of studies recruited participants from voluntary registers facilitating contact between genetic relatives – such participants are more likely to favour transparency and open disclosure, and this means a potential selection bias with any valid reasons for discretion or partial disclosure possibly being obfuscated. Meanwhile, the original paper had four authors, with two assigned to the task of scrutinising search results to identify relevant studies, so there is less capacity available for the current author in comparison plus a stronger likelihood of human error as a sole author, such as inadvertently missing or discarding material which is actually relevant to the research question (particularly in light of the growth of potentially relevant material available for scrutiny since the original review.) The current author is also limited by the set instructions with regard to the composition of the paper as a dissertation. Meanwhile, one of the suggestions for updates of SRs (proposed by the previously referenced BMJ paper (Garner et al., 2016)) is that relevant new methods should be considered, but the current author is not a professional and thus would not have the requisite experience to critique research methods with confidence. Another suggestion proposed by the same BMJ paper is that the authoring or commissioning team would need to routinely survey the relevant area of research for new studies that are potentially relevant to the review, but this is less feasible with a pre-set deadline. However, on a more positive note, the current author is not aware of any particular biases with regard

to treatment of the topic generally, having no conflict of interest - or direct personal or professional experience of the process, beyond a general interest in the concept of how individuals fare when raised by a social parent or parents they are not genetically connected to.

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