

2022 ESHRE Working Group on reproductive donation

Good practice recommendations for information provision for those involved in reproductive donation.

European Society of Human Reproduction and Embryology

REVIEW REPORT



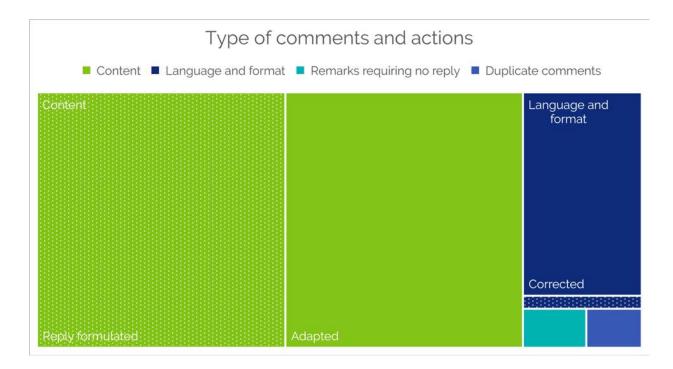
The draft of the paper "Good practice recommendations for information provision for those involved in reproductive donation" was published for public review for 4 weeks, between 15 May and 15 June 2021.

This report summarizes all reviewers, their comments and the reply of the working group and is published on the ESHRE website as supporting documentation to the paper.

During the stakeholder review, a total of 499 comments (including 7 duplicates) were received from 19 reviewers. Reviewers included professionals and representatives of donor-conceived offspring organisations.

The comments were focussed on the content of the guideline (401 comments), language and style (83 comments), or were remarks that did not require a reply (8 comments). All comments to the language and format were checked and corrected where relevant.

The comments to the content of the paper (n=401) were assessed by the working group and where relevant, adaptations were made in the paper (n=196; 48.8%). Adaptations included revisions and/or clarifications of the text, and amendments to the recommendations. For a number of comments, the working group considered them outside the scope of the paper or not appropriate/relevant (n=205; 51.1%)



Experts that participated in the stakeholder review

The list of representatives of professional organization, and of individual experts that provided comments to the guideline are summarized below.

Representatives of professional organisations

| Organisation | Country | Representative |
|--|-----------------|-------------------------------------|
| British fertility society | UK | Bryan Woodward |
| FertiForum (Sub-Society of Reproductive Medicine, Switzerland) | Switzerland | Verena Ehrbar |
| Progress Educational Trust (PET) | UK | Sarah Norcross |
| Interest group of gamete and embryo donation (Spanish Fertility Society) | Spain | Jose Antonio Castilla |
| Human Fertilisation and Embryology Authority (HFEA) | UK | / |
| Verein Spenderkinder | Germany | / |
| Stichting Donorkind | The Netherlands | / |
| Cryos International sperm and egg bank | Denmark | / |
| Donor Conception Network, UK | UK | Nina Barnsley & Yael Ilan-Clarke |
| British Infertility Counselling Association (BICA) | UK | Angela Pericleous- Smith |

Individual experts

| Reviewer | Country |
|--|---------------------|
| Susan Golombok | UK |
| Marilyn Crawshaw | UK |
| Tim Bracewell-Milnes | UK |
| Arianna D'Angelo | UK |
| Juliana Pedro | Portugal |
| Anne Schrijvers, Marja Visser, Monique Mochtar | The Netherlands |
| Hana Konečná | Czech Republic |
| Astrid Indekeu | Belgium/Netherlands |

Reviewer comments and replies

| Reviewer | Page | Line | Comment | Action / Reply |
|------------------|-------------------------|------|---|---|
| Astrid Indekeu | GENE Disclo | | Throughout the document an inconsistency in recommendation is felt regarding the topic of disclosure. Substantiation of the evidence is unclear in this section: "there is a general lack of evidence regarding the benefits of disclosure": what about L760-761/ L 771? What about the absence of harm of disclosure (how far long term evidence is needed before being included)? What about the increased risk of harm of non-disclosure due to more and more possibilities of discovery? p 21L768: why caution? It is always seen as an ongoing age-appropriate process. It is unclear when the evidence is 'enough' (and again see paper Freeman, limitations of evidence). This should be reworked. It is also an incorrect repetition of ASRM guidelines stating "Disclosure to donor-conceived persons of the use of donor gametes or embryos in their conception is strongly encouraged, while ultimately the choice of recipient parents.' Off course the parent's choice depends also on cultural elements, developmental health of the child. | We have defined disclosure in the glossary, and have checked consistency of the messages regarding disclosure throughout the text. We refrained from making a clear recommendation for or against disclosure or the appropriate age for disclosure. |
| Marilyn Crawshaw | GENE Gaps literat | in | There were some surprising texts missing. Some of Indekeu's; ones from the VARTA experience (Dempsey, Hammerberg) Nordqvist et al), Hudson et al. There's been quite a few published since July 2019 so not sure if you'll do an update I also note you've included quite a number from pre 2014 although I thought you said you were not doing so – it even includes one from 1998! There was nothing about what those seeking info and contact themselves wanted in terms of services, e.g the VARTA papers and those from UKDL on this | We have looked at the literature between 2014 and 2020, but also included older and newer key papers identified by the experts. The literature was last updated in August 2020 (which was corrected in the methodology) |
| Sarah Norcross | GENE | RAL | We may have missed it, but this document does not seem to address the fact that donor - conceived child may have a full sibling who does not want to know or is ambivalent about their donor and how this scenario should be navigated. | We have considered that DC offspring should be mindful on the impact of their search for genetic relatives with regards to their social parents. We added "siblings" in this sentence as well. |
| Sarah Norcross | GENE | RAL | Again, we may have missed it, but we did not notice any recommendations as to what should be done if either a donor discovers he has /is a carrier of a genetic condition post donation perhaps because he has an affected child, or if a child is born as a result of the donation has a rare genetic condition. This could be a de novo mutation not picked up in screening. Recommendations should be made about the information flow as clearly it may have serious implications for all the parties. We have heard of this happening in the UK. | We have added a recommendation that the donor should be encouraged to share relevant medical information with the MAR centre/gamete bank |

| Jose Antonio Castilla | GENERAL | The document focusses on aspects which are mostly dealt with by European or national laws. We believe that a document addressed to Those using and participating in reproductive donation should also include warnings about unlawful practices relating to reproductive donation without | Although the working group considers that recommendations can only be formulated for donation within the clinic, we agree that the |
|------------------------------------|--|---|--|
| | | scientific evidence. That is to say, this document should function in order to provide reproductive health education. For this reason, we consider that issues such as the search for semen donors on the internet or at-home insemination after acquiring semen from a donor catalogue on the internet (Amazon-style) should be clearly discouraged in these guidelines. | information should also be available to parties involved in donation outside the system, and that they should be encouraged to attend a clinic. This information was included in the introduction |
| Petra Nordqvist and Leah Gilman | GENERAL | 1. Although mentioned briefly in places, the document is very focussed on donor conception with an unknown donor in a clinic. The clinic focus makes sense given the audience but there could be more acknowledgment throughout of the possibilities for known donation in clinics, as well as known donation in a non-clinic setting (a growing practice), and how to support this kind of donor conception for both donors and recipients. | Although the working group considers that recommendations can only be formulated for donation within the clinic, we agree that the information should also be available to parties involved in donation outside the system, and that they should be encouraged to attend a clinic. This information was included in the introduction |
| Petra Nordqvist and Leah Gilman | GENERAL | 4. Contact with donor siblings is discussed at length in relation to donor conceived peoples' potential interest in their genetic half siblings but such interests are not considered with reference to donors' own children. Due consideration should be given to the possibility that donors' children may also have such interests but often current regulations do not enable them to seek contact with donor-conceived genetic half siblings. | We included that donors should be considering potential future impact of the donation on their close family, which includes their own children. |
| Petra Nordqvist and Leah Gilman | GENERAL | 5. It would be useful to make more acknowledgement of the growing numbers of people conceiving and donating outside of clinics, particularly since we have found that men who donate in clinics can and do also choose to donate outside of clinics. In this context, it would also be helpful to acknowledge that these are not new practices, but there is a rich history of known non-clinic donation amongst lesbian couples and gay men (an absence that refers back to point 2 above). | The recommendations are prepared for donation within a MAR centre. In donation outside the clinic, there is no professional caretaker involved who could provide information or has the professional responsibility to do so. Still, the considerations in the paper would still apply. We have clarified the relevance of the paper for donation outside the clinic in the introduction |
| Marilyn Crawshaw | GENERAL Processes for updating donor information | There is nothing about the importance of processes through which donors can update their information over time; they are often lacking, including here in the UK | We have added the recommendation that donors should be informed on how they can update their information. |
| Marilyn Crawshaw | GENERAL Research limitations | You've pulled together a good range of work (tho see below for gaps) but I wonder if there should be a para near the start on limitations as well as that on gaps – which is at the end. The evidence base certainly has its limitations (study sizes; range of methodologies; recruitment challenges etc) and we do well to always be reminded of that. In many places, the style of referring to study findings is such that they appear to be facts and that's at worst dangerous and at best misleading Research is also always playing catch-up and the DTC DNA developments in particular are having a major impact but there is scarcely any research. | We have added some more information on the limitations of the available studies. |

| Nina Barnsley & Yael Ilan-Clarke | GENERAL | It can be particularly challenging for parents who might have tried to make specific choices about a particular donor or legal structure to protect their child from huge numbers of half siblings and have integrated that into the narrative that they share, only then to discover that the donor has bypassed those regulations. | We agree with this comment, and have added a recommendation that donors should be informed about the relevance and reasoning behind donor quota, hoping they would not bypass them. |
|--|---|--|--|
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | GENERAL | I didn't see anywhere – the importance on discussing with recipients at what stage they as parents can get information about donor siblings and exploring the implications of this | We have a recommendation reading that recipients should be informed if and at what age at which their children can access identifiable information the identity of the donor. They should also be provided information about how any medically relevant updates could occur as well as details on numbers of donor-siblings. |
| Stichting Donorkind | GENERAL | Human rights especially The convention on the rights of the child: This seems to be completely missing for donor conceived people. It is only mentioned very shortly while it is a very important topic for donor conceived people and should therefore be explained and mentioned thoroughly. | We have added the reference to the UN convention |
| Astrid Indekeu | GENERAL Title- general framing | Using and participating": Donor-conceived people (DCP) do not participate but are involved. Now the title only refers to donors and recipients. This is also an overall comment: while I understand that for reasons of clarity the different stakeholders are discussed separately, I miss an overarching frame-work and that is the one (a few times mentioned) of family-building by donor conception, in which these three parties are involved. Referring to reproductive donation means referring to a one-off, medical act. While referring to family-building makes clear from the start that this is about families with long-term consequences (whether being formed in an anonymous or identifiable system). Cfr S Golombok's book "Modern families" where she summarizes her research on Again also -while stating the goal is to focus on psychological and ethical aspects several reference/wording are made to technical, medical elements (cfr intro it is a safe method, cfr P17 1604: 'even though chances are higher for success', this is not about higher chances, recipients do not just want 'any family', they wanted their own genetic family) Recommendations p 23: advantages/disadvantages eg success rates: I do not agree with this recommendations. This is a medical approach (success of a treatment) but this is about making a transition/ going through a process from genetic to social parenthood (see ESHRE CC Jan. 2021). | We have adapted the title accordingly |
| Marilyn Crawshaw | GENERAL Transfer of later genetic information | There is nothing about the importance of processes for the transfer of genetic information that later comes to light to the recipient(s), offspring, or donors. And the need to get consent for this at the outset Often tricky issues | We have added a recommendation reading "Donors should be encouraged to update their information in the MAR centre/gamete bank should relevant medical history appear in the donor or their family." |
| Marilyn Crawshaw | GENERAL | This is a comprehensive document and I commend the work that has gone into it. I know how time-consuming and complex that this can be! Please bear that in mind as I offer my comments as these identify gaps or suggestions about how some aspects might be presented differently. All my suggestions are, I believe, evidence-based though I've not always had time to check sources. | Thank you for this comment |

| Astrid Indekeu | GENERAL | I am pleased to finally see some good practice recommendations from ESHRE regarding psychological and ethical aspects of donor conception. As ASRM regularly send out recommendations/guidelines for practice. A lot of work has been already invested in this document. First I will discuss my main concerns about the document, below are very specific comments to the text. | Thank you |
|--|--|---|---|
| Nina Barnsley & Yael Ilan-Clarke | GENERAL | Congratulations on putting this together. It's a fantastic overview of the field and will be an incredibly valuable resource. | Thank you |
| Arianna D'Angelo | GENERAL | This is a very useful paper, well done to the authors. | Thank you |
| Tim Bracewell- Milnes | GENERAL | I commend the authors for putting together a very comprehensive, interesting and much needed document that I believe will be of great use to fertility clinics worldwide, particularly of course in Europe. | Thank you |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | GENERAL | Thorough document. Well done. | Thank you |
| Marilyn Crawshaw | GENERAL Psychologic al and social | In some places, it refers to 'psychological' when I suggest it should be described as 'psychological and social' as both are important to take into account. In other places it refers to psychosocial. Maybe more consistency? | We have adapted the terminology and used "psychosocial" throughout |
| Arianna D'Angelo | GENERAL Recommen dations | The format used in this paper differs a lot to the previously ESHRE released papers. Is there a reason why the recommendations are not graded? Also there seems to be many recommendations after each section, it feels more like a summary of the section. Some recommendations are also repeated more than once. | The format is appropriate for a good practice recommendation paper |
| Nina Barnsley & Yael Ilan-Clarke | GENERAL Family narrative | In countries where everything is anonymous and there is no regulator, all activities and assumptions rely on trust, this can also be a problem for disclosure where parents may be given wrong information. Families might construct the narrative for their child, based on incorrect information and assumptions (e.g. nationality of donor, or embryo donation where two embryos were implanted under the assumption they were full genetic siblings but may not be). | We understand the comment of the reviewer, but people should not be getting the wrong information, either due to error or intentionally. Therefore, further information on this was not included. We recommend support and guidance in disclosing, which should cover aspects like the one suggested by the reviewer. |
| Astrid Indekeu | GENERAL | As a reader I am a bit confused by the composition of the group of authors, of which the majority has a medical background and document having a psychological/ethical focus based on psychological literature. Why were the SIG psychology & Counseling and Ethics not more involved? Seen the importance of the interpretation of the data. | The working group included representation of the SIG Psychology and Counselling (Mariana Martins), the SIG Ethics and Law (Lucy Frith), so we consider this comment not valid, |
| Marilyn Crawshaw | GENERAL Biographica I donor information | Regarding Donor Information, it was disappointing that you paid this relatively scant attention. I can understand the attention given to whether or not the donor's identity is released but I would strongly urge you to also include something about the responsibility to collect non-identifying biographical information and make that available to raising parents and in due course to the offspring. There is also interesting research into the gendered nature of recruitment and hence the way this can creep into donor information | We have discussed this comment within the working group, but we consider additional information on non-identifying biographical information outside the scope of the current paper |

| Astrid Indekeu | GENERAL Choice of papers? /evidence | It is not always clear why certain papers are mentioned explicitly and others not? E.g. P 9 Bay is mentioned with 38 euro, what about Thyssen saying it is around 80 euro? Thijssen A, Dhont N, Vandormael E, Cox A, Klerkx E, Creemers E, Ombelet W. Artificial insemination with donor sperm (AID): heterogeneity in sperm banking facilities in a single country (Belgium) FVV in ObGyn, 2014, 6 (2): 57-67- Recommendations: See P18 (Recommendations): (dis)Advantages of anonymous, identifiable and known donation should be discussed: this is based on what evidence of (dis)advantage? And asked at what moment in time at recipients (as people can change their view on it)? There are several situations like this in the document (section on contact/searching DCP seen the space given to this topic this might give the impression that all ot of research is done, while we are still at the beginning in this area). Especially in an area where research is limited, it can cause readers bias. I suggest making the limitations more explicit e.g. we lack follow-up research, so research results report mainly on one moment in time, while DC is about long-term processes. | We have listed the most relevant studies, but do not consider this a comprehensive overview. The document aims to guide practice, rather than performing a comprehensive literature review. |
|--------------------------|--|--|---|
| Marilyn Crawshaw | GENERAL Contact | With the growing international trade in gametes and growth in international travel for treatment, we've yet to see much trickling through about the challenges of contact with genetic relatives in other countries, including where language and/or culture are not shared there is also emerging evidence about burn out among donors and among siblings | This item was discussed in the working group, but there is little information on the implications of international trade, and how to approach this in donor conception. The challenges of contact with genetic relatives in other country may be included in discussion of international use of gametes. However, it was agreed not to add specific information on this topic in the paper. |
| Astrid Indekeu | GENERAL Context of the paper | (P7 l228). Now the recommendations seem to be developed mainly because the increase of direct-to-consumer-genetic-testing (DTCGT), while other changes occurred as well. It is a missed opportunity to frame the timing of the recommendation not broader (increase in DC, more visible, more discussed, societal/medical emphasis on genetics, children's rights/voices of DCP, impact of internet,) | The scope of the paper is on donor conception and the implications of direct-to-consumergenetic-testing. Therefore all other aspects of donor conception were not covered, or only reported in the context of the paper. |
| Astrid Indekeu | GENERAL Counseling | Given the importance to counselling in these recommendations and the complexity of the themes that need to be discussed it feels strange that there are no ESHRE recommendation/guidelines on psycho-social counselling: who should counsel, what kind of skills would be required etc. Cfr HFEA recommending a BICA trained counsellor for accredited clinics, are we talking about screening, implication, or preparation counselling? Different skills are needed for recipient/donor counselling and supporting contact, who should do this? Emphasizing counselling without more structure/phramework around counselling will limit the impact. | The aim of the paper is to provide guidance on information provision. The availability of counselling is relevant to that end, but not the specific details of counselling. Any initiative towards an ESHRE guideline for counselling should be started from the SIG Psychology and Counselling |
| Tim Bracewell- Milnes | GENERAL Different countries | I think my only general comment regarding the guideline, is the importance of knowing the country of origin when the authors talk about research findings, so clinicians using the guideline can more quickly draw conclusions for their own country and clinic. Within Europe, there are significant cultural differences between countries, so it would be important to know which country the different findings are coming from, without readers having to look up the refences individually. This is especially relevant if the studies were outside of Europe. I understand this is a difficult task to achieve, particularly in the manuscript. A table with the country of origin of the different studies could be one way of doing this. | We have added the country of the research in most studies, and have added to the limitations that most of the evidence pertains to the Western context. We still considered that mentioning the country or study limitations for each study would forego the goal of presenting the data to support the recommendations |

| Stichting Donorkind | GENERAL donor conceived persons | The empowerment and possibilities for empowerment of donor conceived people in the paper is problematized. Furthermore every possible 'problem' real or imagined is taken as a subject for counselling. This is building a discourse of DCP's who have no agency and parents who have every opportunity to imagine 'threats' for the child to justify taking their human rights away. Human rights such as knowing one's family and genetic identity. | The paper intends to be balanced in protecting the donor, the recipient and the offspring. We do not recommend against empowerment, on the contrary, we recommend counselling and extended information provision which can only contribute towards empowerment of DCP. |
|------------------------|--|---|--|
| Marilyn Crawshaw | GENERAL Donor numbers | When reference is made to donor limits (offspring, families) I suggest it makes clear that these limits only apply to the country where the treatment took place and that the donor gametes may also be used in other jurisdictions meaning that actual numbers can be quite a lot higher | We have clarified in the paper and the recommendations that there is a lack of international limits, and the consequences thereof |
| Marilyn Crawshaw | GENERAL Donor's 'own' children | In almost everywhere, you omit to make clear that donors may also have non-DC offspring. For example if you refer to 'same donor offspring' it excludes them whereas if you say 'donor-related siblings' it includes them. This is especially important when you're talking about DTC DNA testing. Maybe have a glossary somewhere or something at the start to clarify what you mean by which terms? | We have considered the donor's own children as part of his/her family/genetic relatives. As there is no link between professionals in MAR centres and donor's own children, nor any professional responsibility, we considered it appropriate to address them specifically. We do include at several occasions that the donor should be conscious about the impact on his/her children/family. |
| Astrid Indekeu | GENERAL Evidence collection | Mainly quantitative studies are included, + only a medical oriented database (pubmed) is used, causing to miss valuable studies that help understand underlying process that could explain differences in results. (see eg. Nordqvist P. (2012). Origins and originators: lesbian couples negotiating parental identities and sperm donor conception. Cult Health Sex; 14:297-311. doi: 10.1080/13691058.2011.639392. // Nordqvist P. (2010).Out of sight, out of mind: Family resemblances in lesbian donor conception. Sociology; 44:1128-1144// Already 2 years past (lit search ended June 2019) – is an update possible? | The design of study was discussed upfront and followed accordingly. Even if the literature search was focussed on PubMed only, experts were able to add key papers including qualitative studies. |
| Astrid Indekeu | GENERAL Framework | First of all, it is clearly mentioned (p7-L234-240) that the focus would be psychological and ethical aspects rather than on technical, medical aspects. Yet the framing of the recommendations are still done in a very medical model. Literature is searched for "empirical evidence". Yet in the situation of psychological and ethical questions, empirical evidence is very often not the only, neither always the good measurement (cfr Freeman T. Gamete donation, information sharing and the best interest of the child: an overview of the psychosocial evidence. Monash Bioethics Review DOI: 10.1007/s40592-015-0018-y regarding how to use/misuse empirical evidence and the difference between 'what is' and 'what should be'). Purely empirical evidence will not deliver the wanted material to substantiate the recommendations. Interpretation of the results and integrating contextual elements and underlying processes are needed. Also with more interpretation of the results, the clinical relevance becomes more clear for the reader and the document will be able to contribute more to the practice. I feel this is a missed opportunity for the document. e.g section on 'choice of donor'- P18-19: it is a sum research with different results: What is the main message/ clinical relevance (there is no recommendation here)? E.g. possibilities of and feelings regarding choice can also change over time. | We have read this comment and considered it when more clearly writing the scope of the paper. We do acknowledge that in this broad succinct overview, there may be additional specificities which are only touched upon. Recommendations for the section on choice of a donor where considered |

| Verena Ehrbar | GENERAL Length | I acknowledge the amount of information that needs to be transmitted to the readers and everything that was stated in the guidelines is important, however as reader, it is very long and I wonder if a shorter version would make it more readable and easier to digest? | We fully agree that the paper is very long related to the many aspects covered. It is aimed to ensure the key messages are clearly extractable, leaving the majority of the information as background for the interested reader |
|------------------------------------|-------------------|--|---|
| Jose Antonio Castilla | GENERAL | It would be better to be more concise. We recommend shortening the document | We agree that the document is very extensive, and still reviewers made several comments for additions. For clarity, table I-III were included as a quick overview of all recommendations |
| Petra Nordqvist and Leah Gilman | GENERAL | Congratulations on the draft of the above text. We have read it and think it is a very important intervention into assisted reproductive practices, and it contains a huge number of key insight and recommendations. It spans an impressive number of studies and covers a vast number of dimensions that are important to consider in the context of donor conception, and everyone touched by donation. We think this is a very impressive and significant achievement, and we think the project that you are undertaking with this draft is hugely important. We are very grateful for the opportunity to review said draft. In doing so we draw on qualitative sociological research into donor conception families in the UK, spanning the last 15 years, where we have studies both the point of view of recipient parents, both heterosexual and lesbian, and grandparents (Nordqvist), as well as donors (Nordqvist and Gilman). We are currently coming to the end of a large scale ESRC funded qualitative project exploring the ways in which being an egg or sperm donor in the UK impacts on donors' own everyday life and relationships (PI, Nordqvist, for more information see https://www.socialsciences.manchester.ac.uk/morgan-centre/research/research-themes/kinship-and-relatedness/being-an-egg-or-sperm-donor/). As part of this study, we have reviewed current UK law and policy (Gilman and Nordqvist, 2018), as well as conducted almost 90 qualitive interviews with donors (52), donors' kin such as partners, parents and siblings (23, five of which were also themselves donors) and also fertility counsellors/donor coordinators (18). In reviewing this draft, we refer to our qualitative research which will be presented in our forthcoming book 'Donors: Curious connections in donor conception' (Emerald Publishing). In doing so, we are aware that this knowledge is not yet in the public domain, but nevertheless feel that the insights from it adds in important ways to your draft. If you have any questions about our findings, do please feel free to contact either of | Thank you for this information, we acknowledge that future published research may require a need to update the current information. |

| Petra Nordqvist and Leah Gilman | GENERAL | 2. The report tends to be heteronormative in places (e.g. section on 'transitioning to DC', images in fig 2 as well as the discussion on grief in the recipient section), as though the starting point for the report is heterosexual couples, rather than other users of reproductive donation. Although references are made to lesbian and gay family making and solo mothers in some sections of the report, other sections appear to assume that recipients are heterosexual couples | The figures were pictorial, but have been adapted. In the recommendations, we have used the term "recipients" or "intended parents" to ensure we did not have a bias towards heterosexual couples. In the evidence sections, data are reported according to the population included in the studies, and this could not be adapted, still we have double-checked any possible bias towards heterosexual couples, |
|------------------------------------|---------|--|--|
| Petra Nordqvist and Leah Gilman | GENERAL | 3. It would be helpful to acknowledge that families/partners of donors and recipients might feel themselves to have a stake in donor conception and to suggest best practice would be to discuss these with donors and recipients and also to allow donors' partners/children, parents, siblings and others who may feel themselves to be implicated to access support services (e.g. counselling) too as well as make various forms of support tailored to them (e.g. via websites). | We included that donors should be considering potential future impact of the donation on their close family. However, we decided not to go into detail on counselling or support services for family and friends, based on the absence of evidence on relevance, or feasibility. We did include counselling for the family in known donation |
| Petra Nordqvist and Leah Gilman | GENERAL | 6. The discussion of the ethics and considerations around payment does not consider the perspectives of donor conceived people. I.e. how will/do donor conceived people feel about the ethics of paying, or otherwise compensating donors? | The research focussed on the motivations for donors, and was presented as such. The impact of the motivation on the offspring are not discussed here, and to our knowledge have not well studied. Still, we have, based on another comment, included a study mentioning that sperm donors considered the effect on the offspring in their opinion towards payment. |
| Petra Nordqvist and Leah Gilman | GENERAL | 7. Overall, we have noticed that the draft, largely speaking, draws on quantitative studies into reproductive donation. In contrast, it would appear that important qualitative research, published in the assigned period, is largely ignored (including our own, but also other sociological and anthropological studies). That means that important insight is not yet included in this report (for details see below). We encourage the authors to consult evidence from qualitative studies also. | The methodology section states that the evidence was collected from PUBMED and from the input of the experts. We included studies retrieved from the literature search and the experts and selected them based on relevance to the topic and availability if the full text. We did not use any inclusion criteria on whether the studies were quantitative or qualitative. As a result, relevant qualitative studies have been in the paper, and hence we consider this comment invalid. |

| HFEA | GENERAL | As the UK regulator of fertility clinics, we ensure that fertility clinics and research centres comply with the law, and the rules and standards we set to ensure high quality care and research. By law, the HFEA is required to hold a Register (database) of fertility treatments and outcomes since 1991. Donor-conceived people and their parents can apply to us for information held about their donor and genetic siblings on the Register. We also have a dedicated support service for donor-conceived people who are considering, or are actively getting in touch with, their donor or donor-conceived siblings. Donors who donated after 1 August 1991 are able to request information about the number, sex and year of birth of any children conceived from their donation. Our web page for donor-conceived people, their parents and donors who are thinking of applying to us for information can be found here. While direct-to-consumer DNA testing and matching services are not within the regulatory remit of the HFEA, we recognise the growing popularity and wide-ranging impact of these services, including the implications for donors, donor-conceived people and their families. We recognise that this changes the context in which the HFEA offers managed information provision to donors, donor-conceived people and recipients of donated gametes. Our Board (the 'Authority) discussed this in September 2019. This paper outlines some of the work we have done to address the increasing use of direct-to-consumer DNA testing and matching services, including making changes to our Code of Practice and meeting with a number of commercial genetic testing and matching companies to encourage them to include more prominent information on their websites about the possibility of uncovering unexpected relatedness information in relation to donor conception, and to signpost to available support. Please note that some of the good practice recommendations refer to areas outside of our regulated irect-to-consumer DNA testing and matching services. Some of the | Thank you for this comment and this information. We have clarified in the introduction that the recommendations are directed at professionals and policy makers, as we agree that some recommendations may be relevant for regulators, such as HFEA, while others may not. |
|--------------|---------|---|--|
| | | support services, than to the centres we regulate. | |
| Hana Konečná | GENERAL | We welcome the decision to address this issue, which we consider to be very serious. In our view, however, the proposed recommendations create far more problems than they solve. | We read this comment with interest, but this comment does not help us to identify or solve the issue, and expect this is addressed in other comments from the reviewer |

| Hana Konečná | GENERAL | The draft supposes that these children will need lifelong psychological support. ESHRE thematic courses (for example Leuven, February 2020) have shown that this is an extremely complex situation which leads to a life in uncertainty, including legal uncertainty. The complexity of the situation is multiplied by the fact that gamete donors and recipients tend to be from different parts of the world. It is certainly not in the child's best interest to be in the care of psychologists throughout her/his live and to search for parental persons and half-siblings around the world, including language barriers. In this case, children, unlike the participating adults (donors and recipients), do not have the opportunity to make a decision about their future. We consider the 'identifiable donor' system to be particularly problematical. Instead of the formation of the child's identify, this actually disrupts it. If a child will have access to all potential parental persons, she/he must have this possibility naturally from birth. We have another fundamental objection to the assumption that we will gradually move to a commercial system, ladder strategy' (lines 293 – 303). This contradicts the current European legal rules and hides a fundamental danger of trafficking in children, women and body parts. Children are born under different problematic circumstances; the state then makes an effort to sort out their situation. In this scenario, however, the state is at the center of the source of the problem. If the state interferes, through laws and technologies, it must assume responsibility. In the case of a covid pandemic, ESHRE very responsibly considered even the smallest health risks for all involved and did not recommend many procedures. Psychological and ethical risks are no less significant than health risks. The preamble in the Convention of Human Rights and Biomedicine is categorical that the "misuse of biology and medicine can lead to acts endangering human dignity" and that "progress in biology and medicine should be us | We consider the reviewer has a strong opinion towards best practice with regards to anonymity. In the paper, we have been careful not to express such clear personal opinion, as the paper is intended to be applicable to different local and legal contexts, to which professionals, donors, recipients and children may have no impact. We mainly focus on provision of information as a fundamental issue. We do suggest counselling is available, but only where it is needed for the child, recipient, donor. Again, we do not recommend to move towards a commercial system. The ladder system suggests to adapt the compensation to the type of donation, and for instance the risks for the donor. We present these recommendations as recommendations for good practice, and we acknowledge that they may, or may not, be acceptable to be endorsed in different countries. Finally, we have corrected in the recommendations on counselling for offspring that these are relevant for offspring requesting counselling/support. We do not recommend lifelong counselling. |
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| Verein Spenderkinder | GENERAL | Regarding "anonymous donation": "Anonymous donation: Donation in which the donor will not know who receives the gametes/embryos, and the receiving women/couples will not know who the gametes/embryos came from." - What about the DCP? Will they know their genetic parent(s)? Regarding direct-to-consumer testing it should be clarified, that DCPs have a right to know their genetical parents under the UN Convention on the Rights of the Child and that it is also practically unrealistic to maintain anonymity in light of direct-to-consumer DNA testing. Recommendation: A sentence should be added regarding the donor conceived people: Promises of anonymity do not concern the resulting human being. According to the UN Convention on the Rights of the Child everybody has the right to know their genetical parents. Regarding direct-to-consumer-DNA-testing it is unrealistic as well to maintain anonymity between genetic relatives. | Article 7 of the UNCRC says that all children and young people have the right to a name and nationality, which they should be granted at birth. It also says that they have a right to – as far as possible – know and be cared for by their parents. Whether the parent is the genetic parent or the social parent is not specified. Although we have mentioned the UNCRC, we have not copied the suggested sentence in the text |

| Verein Spenderkinder | GENERAL Making genetic parents linguistically visible as human beings | Intended parents should be clearly told that the "donor" is a person whom their child will probably want to meet sooner or later (e.g. Beeson, D. R., Jennings, P. K., & Kramer, W. (2011). Offspring searching for their sperm donors: How family type shapes the process. Human Reproduction (Oxford, England), 26(9), 2415–2424. https://doi.org/10.1093/humrep/der202; Hertz, R., Nelson, M. K., & Kramer, W. (2013). Donor conceived offspring conceive of the donor: The relevance of age, awareness, and family form. Social Science & Medicine, 86, 52–65. https://doi.org/10.1016/j.socscimed.2013.03.001; Scheib, J. E., Riordan, M., & Rubin, S. (2005). Adolescents with open-identity sperm donors: Reports from 12-17 year olds. Human Reproduction (Oxford, England), 20(1), 239–252. https://doi.org/10.1093/humrep/deh581). In order for the social parents to fully accept the child, it is important that they can also accept the genetic parent as such. The way the parents talk about the genetic parent transmits to the child the needs of its parents. The child feels, for example, whether it is allowed to express interest in this person at all or not. | The paper discusses disclosure and the impact of direct-to-consumer genetic testing, but we decided not to be directive towards whether parents need to disclose donor-conception to the child. We have included a recommendation that parents should be informed on this. Furthermore, we advise disclosing. |
|-------------------------|--|--|---|
| | | Recommendation: make clear that social parents should speak about the genetic father/mother as a person and in an open way in front of their children which does not inhibit DCP from expressing any eventual interest in their genetic parent(s). | |
| Verein Spenderkinder | GENERAL Need for independen t counselors | A major issue in counselling DCP is the lack of cooperation from reproductive physicians with DCP and the ongoing disregard for the right to know the genetic parents. Counselors should operate independently from reproductive medicine and not liaise with reproductive physicians. They should be well-educated and able to provide basic legal advice to DCP when there are problems with doctors and clinics who do not want to provide information even though they are required to do so. | Whether or not clinics are required to provide information is a legal matter, and something the current paper cannot really elaborate on. The need for professional and independent counselling is recommended in the paper |
| Stichting Donorkind | GENERAL Neutrality | The paper has a lack of neutrality. It presents growing possibilities to take human rights from donor conceived people as neutral trends but growing possibilities for donor conceived people to regain their family- and medical information as threats. Information about what intended parents or donors supposedly want or need is not always backed by scientific evidence while what donor conceived people want or need is topic of scientific scrutiny. Recommendations are almost all directed to donors and intended parents and are not considering the needs of the unborn child. | We respect the point of view of all parties, and have considered the protection and perspective of donors, recipients and offspring equally. We have tried to do so in a neutral way, without being directive towards protecting only one party involved. |
| Marilyn Crawshaw | GENERAL Precis of child devt studies | I found the way that these studies were reported to be confusing. I have just myself been going through them for a paper and they are more complex than you describe, I suggest. They also mainly stop in adolescence (cos unethical to keep going with offspring that are not aware of their origins) and that needs saying as it's a significant life stage. They are important because there are so few research groups doing this work but I seem to recall the work of the Golombok team being rated low-medium quality by the Council of Europe? I anyway wonder if Susan G could review what's been said as it's mainly from her team. There are also so many places where these studies are reported: I wonder if this could be reviewed? | We have invited all experts with several papers on the topic to participate in the review, and Dr Golombok did review the paper and made suggestions, We have described the studies in an attempt to gather information for professionals in the field, and consider more details and theoretical considerations more appropriate for in depth overviews. |

| Verein Spenderkinder | GENERAL Overall remarks | The "Good practice Recommendations for information provision for those using and participating in reproductive donation" are intended to bundle relevant and appropriate information for intended parents, genetic parents and donor conceived people on this type of family formation. We appreciate that the ESHRE report reflects research on donor conceived people (DCP), and makes some key points clear, including that: • many DCP want contact with their genetic parents; • many DCP believe genetic parents should take responsibility for their actions; • genetic parents should be informed that DCP might want to make contact (Hertz et al., 2013). Furthermore, we have the following remarks about the text in general: | We have read these comments with interest and we think they are largely in line with what we have described. The point that "many DCP believe genetic parents should take responsibility for their actions" is not in line with the professionals view on the matter, especially as donors donated years ago, often anonymous, and where not aware, nor informed, that they would ever be contacted by offspring. We respect the point of view of all parties, and hope we have done so in our paper. |
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| Verein Spenderkinder | GENERAL Overall perspective | The first sentence of the introduction is written from a perspective which is clearly in favor of gamete delivery and does not take the perspectives of DCP into account. If that is the intention of the ESHRE, this is a huge and central problem. From a DCP perspective, gamete "donation" is not altruistic, even if the word "donation" suggests that. The genetic parents give their gametes and agree to possibly never have contact with their genetic child(ren). The plan is that they have no interest in the resulting child. The resulting human beings may perceive this as hurtful. Recommendation: We strongly urge ESHRE to include the perspectives of DCP in the introduction, so that gamete transfer is not presented in a one-sided, uniquely positive way. This means concretely to use the word "transfer" instead of "donation", "genetic parents" instead of "donor", and "fertilization" instead of "treatment". Where DCP are specifically referenced, it is recommended to use the word "people" instead of "offspring". "Offspring" places DCP in the framework of being other people's children, as well as the "product" of something (commodification). There are some other terms in the document which are inappropriate or poorly used. These are pointed out in the following section ('specific comments'). | We respect the point of view of all parties. Donation is a well established word, and not emotive from the perspective of the professionals. We do acknowledge that the paper is prepared mainly for professionals. In writing it, we have considered the protection and perspective of donors, recipients and offspring equally. |
| Arianna D'Angelo | GENERAL Screening | In light of the pandemic I would mention the need to inform recipient of the unknown effect of C-19 or any future viruses on gametes and long term effects on children and ask them to sign a disclaimer that they accept these unknown risks. | This is a relevant point for ART in general, but outside the scope of the current paper |
| Marilyn Crawshaw | GENERAL Who provides counselling; who pays | There is no reference to who might provide the 'counselling' and what skills, experience or qualifications are needed, including at the different life stages (again a very thorny issue!) and who regulates the standards. And, really importantly, there is nothing in here about payment – who has any responsibility to provide it, or not? | The paper focusses on information provision and considers counselling as part of this. The further details on counselling and the issue of who has to pay for the counselling is outside the scope of a recommendations paper. |
| Juliana Pedro | GENERAL | Psychological counselling for donors and recipients should be standardized and "mandatory", not only in the decision making period, but also after pregnancy and through child growing. These guidelines are very detailed and claims attentions to the need of prepare people to the end of anonymity and all the implications that might result from that. Congratulations for the amazing work done! | We clearly recommend counselling for the different parties at different timepoints. Suggesting mandatory counselling is outside the options of a good practice paper. |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | GENERAL | It would be good to include more recommendations/guidance/information for the donors children | We have incorporated some information on the donors children and further social circle although the main focus is still on the donor, recipients and offspring |

| Tim Bracewell- Milnes | 3-5 | | Should a mention be made that some people buy these tests to confirm they are genetically related to their parents? Therefore if its use continues to increase it could make the chance of inadvertently finding out the nature of their conception far more likely. | We have inserted a sentence explaining the different consequences and uses for direct-to-consumer genetic testing, including to test whether people are genetically related to their parents |
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| Nina Barnsley & Yael Ilan-Clarke | | Intro | Introduction seems to be slightly out of keeping with the whole document. See specific comments below. The opening statement in particular seems strange. | We have adapted the opening statement and added more information in the introduction regarding the scope of the paper |
| Petra Nordqvist and Leah Gilman | | 6 | Line 6 – opening line is conjecture. Consider removing. | Sentence was adapted |
| Astrid Indekeu | 1 | 6-7 | Altruistic: more often the motivation to donate is a mix of different motivations: see Review Van den Broeck in reference. This wording does not give a correct image of donation. | The sentence is only an introduction and the issues is discussed in more detail later in the paper. Still, we have removed altruistic |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P1 | 6 | The authors write "having the family they desire", but heterosexual couples desire family building with their own gametes. We feel "having a family is one of the most" would be better. | Sentence was adapted |
| Marilyn Crawshaw | 1 | 7 | Here's the first example where it's based on heterosexual couples – using 'involuntary childlessness' would be more encompassing | We have rephrased the sentence based on another comment and consider this comment addressed. |
| Marilyn Crawshaw | 1 | | You miss out surrogacy with the use of a donor – this is a rapidly growing area so I think you need to refer to it now and again (I think I only found two other references) | Surrogacy is covered in so far a donor is involved, but other additional considerations specific to surrogacy were considered outside the scope of the current paper. We have added a sentence explaining this in the paper |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P1 | 7 | Lesbian couples and single women do not have "fertility issues". Also, donor conception is not always "successful". We feel a better sentence would be: Donor-assisted conception is an option for heterosexual couples who cannot conceive because of untreatable male sterility, lesbian couples and single women who want to achieve parenthood | This sentence was slightly adapted and included in the introduction |
| Marilyn Crawshaw | 1 | 7 | Strange to use 'altruistic' at this stage: as you later demonstrate, not all donations are motivated by altruism so I'd favour you leaving it out here. I know policy documents like to think altruism is strong! | We have removed the word 'altruistic' from the introduction. More details are available later in the paper |
| HFEA | 1 | 7 | 'For those with fertility issues donor-assisted conception is a successful and safe method to achieve parenthood.' This sentence could also refer to same sex couples and single parents who may not have fertility issues but who may still wish to use donor assisted conception to have a family. | We have rephrased the sentence based on another comment and consider this comment addressed. |
| Astrid Indekeu | | 7-8 | For those with fertility issues": the largest group (lesbian/singles) do not have a fertility issue but a lack of a male partner. It is a too limited way to start the guideline | We have rephrased the sentence based on another comment and consider this comment addressed. |
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| Stichting Donorkind | | 7 | As a donor conceived, I do not see this as an altruistic action. As a donor you are creating a life with half of your genes and that always comes with consequences. If the word altruistic is used, to me it sounds like one could donate gametes endlessly to do good deed and as advertisement for gamete donation. While I think people should make well thought-out decisions for themselves and the unborn child. As parents but also as a donor. | We have removed the word 'altruistic" from the introduction. More details are available later in the paper |
|--|-------|--------------|---|--|
| Nina Barnsley & Yael Ilan-Clarke | 1 | 7 | "most impactful and altruistic action" – this is an unestablished and peculiar statement and would be challenged by many DCPs amongst others. | We have removed the word 'altruistic" from the introduction. More details are available later in the paper |
| Stichting Donorkind | | 8 | For donor conceived people it involves considerable risks so it is not that safe. | We have rephrased the sentence based on another comment and consider this comment addressed. |
| Nina Barnsley & Yael Ilan-Clarke | 1 | 8 | "donor-assisted conception is a successful and safe" – perhaps should be 'can be' a success, and not sure what 'safe' means in this context. | We have rephrased the sentence based on another comment and consider this comment addressed. |
| Nina Barnsley & Yael Ilan-Clarke | 1 | 9-11 | It would be helpful to clarify the significance of embryo donation vs double donation, i.e. full siblings in another family, possibly (probably?) being raised by the genetic parents. With double donation, we are talking about two unconnected donors. | We have clarified the difference between embryo donation and double donation in the glossary and in the text, |
| Verein Spenderkinder | 1 | 9 | It is cynical to call an intentionally created embryo "surplus" just because the intended parents' desire for a child has already been sufficiently fulfilled or changed. How might it feel for the resulting human beings to know that they have been created from "surplus" embryos? What contact might they have later with their biological full siblings, who were desired by the biological parents and were allowed to grow up with them? | We have discussed this comment within the working group. We recognize that the terminology is contested, but it is standard in the field. We have clarified this in a footnote. |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | intro | Line 9-11 | Egg sharing debate on ethics needs to be included somewhere | We have included egg sharing as a type of donation and all recommendations for donors are relevant for egg sharers as well. We acknowledge that with egg sharing there are additional aspects to be considered, but addressing these in detail is outside the scope of the current paper. This is explained in the introduction. |

| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | | | Possibly describes Embryo donation as either: Embryo donation – couple created embryos and have surplus embryos Double Donation/Embryo Donation 2 – created from donated sperm and oocytes – better known as double donation If embryos are ever created by clinics in anticipation of need then groups could be sub-divided further as follows: Embryo Donation 1 – couple/individual created embryos and have surplus embryos (donation arranged at Embryo stage Embryo Donation 2 – clinic creates embryos and they are ready and waiting in the freezer for recipient/intended parent (here the donation is arranged at embryo stage) Embryo Donation 3 / Double Donation – or more accurately known as Double Donation - two donors are found specifically to donate to that intended parent, and their donations are used to create embryos specifically for that intended parent (here the donation is arranged at the gamete stage involving sperm and eggs) | We have assessed this comment, and although we agree on the 3 scenarios presented, we have used embryo donation and double donation in the text, and clarified that we would differentiate with regards to whether there would be full siblings in another family. For the second scenario explained, there could be full genetic siblings, or not, depending on how the clinic proceeds, so it could be considered as double donation (when the gametes are paired only for 1 recipient) or embryo donation when embryos are created and used for different recipients |
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| Verein Spenderkinder | 1 | 10 | "from couples who have completed their family building via ART" - The idea of "family-building" is a very technical one. You can build a house, but not a human relationship. Such a relationship can grow, but you cannot force/control it. Additionally, there is the implied assumption that you are only a family if you have children. The term "family" can have many meanings and is deeply personal. It should not only be seen in the context of adult and children (https://www.ncfr.org/ncfr-report/past-issues/summer-2014/what-family). Recommendation: Change the phrase "Embryos can be donated by a couple (often "surplus" embryos from couples who have completed their family building via ART)" to "Embryos can be given away by a couple (often these are embryos that are still existing when a couple decides that they do not want to continue using ART)" | We have removed the word 'building' as it was not essential in the sentence. Still, family building is a common terminology |
| Stichting Donorkind | | 11 | Why is double donation a more correct term? | We have clarified the difference between embryo donation and double donation in the glossary |
| Nina Barnsley & Yael Ilan-Clarke | 1 | 12 | Unclear why there is a mention of gamete-sharing specifically, without other kinds of donation | In the introduction, we have introduced all types of donation further included in the paper. As oocyte sharing is discussed, it was added as well to the introduction |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P1 | 13 | Figure 1. Two women – a lesbian couple - can also be recipients. | The figure is a pictorial overview, but a lesbian couple was added for completion |

| Petra Nordqvist and Leah Gilman | | 13 | Line 13 – title of figure is misleading as excludes others who may feel themselves to be involved in or implicated by donor-assisted conception. We found the label 'social circle' confusing as the pictures omit all references to the social relationships around each of the parties represented. Sociological research into both recipient parent families (Nordqvist and Smart, 2014) and also donors ((Nordqvist and Gilman, Forthcoming) show clearly that parents, donors and children are not free-standing individuals (as this picture would imply) but embedded in important relationships, and these relationships both shape and are shaped by the donor conception. Also, the image of recipient is very traditionally gendered in the imagery (women in skirts). That being the case, I think it also needs to show clearly a lesbian couple, which it currently doesn't, going on the internal logic of the pictures. | We have clarified the circle and added the lesbian couple to be inclusive. The figure provides a pictorial overview of the parties involved in reproductive donation, and focusses on those included in the paper. |
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| Jose Antonio Castilla | Fig 1 | | It's hard to believe that a society like ESHRE has left female couples out of the recipients section in figure 1. A scientific society on reproduction should be inclusive regarding the people who can receive ART treatments. We hope you can correct this unforgivable omission. | The figure was pictorial, showing examples, but has now been adapted to be complete. |
| HFEA | Figu re 1 | | The diagram could make clearer what is meant by 'social circle'- perhaps by providing some examples e.g. 'donor's partner,' 'donor's child,' 'recipients' parents,' or broad categories, eg. 'partners,' 'friends,' 'family' etc. It could also refer to the fact that these may be past, present or future- as, for example, a sperm or egg donor's genetic child not yet born at the time of donation will be a genetic half-sibling of any donor offspring born as a result of their parent's donation. | We have clarified the social circle in the picture |
| Stichting Donorkind | | 13 | About figure 13: where are the doctors and clinics in this figure? They are the most powerful party in the whole process. | The paper provides recommendations for clinics on how to provide information to all parties involved in reproductive donation. As such, we have left the doctors out of the figure and focussed on the parties |
| Nina Barnsley & Yael Ilan-Clarke | 2 | 17 | It might be worth including the wider family of the donor and the recipient | The figure is a pictorial overview, with the social circle representing family and friends of each party. This was clarified in the title of the figure |
| Petra Nordqvist and Leah Gilman | | 18 | Line 18 You could add here 'both inside a clinical environment, and in non-clinical donation' | The recommendations are prepared for donation within a MAR centre. In donation outside the clinic, there is no professional caretaker involved who could provide information or has the professional responsibility to do so. Still, the considerations in the paper would still apply. We have clarified the relevance of the paper for donation outside the clinic in the introduction. |
| HFEA | Audi enc e | (and line 19- 22) | It may be useful to make clearer who the intended audiences are for these good practice recommendations e.g. whether they are aimed at fertility clinic staff, regulators of fertility treatment, fertility counsellors, relevant professional bodies etc and whether the recommendations are applicable generally to all countries. | We have added a sentence to the introduction clarifying the target audience. It was already mentioned that the recommendations should be applied in line with national guidance and |
| Madbar O. | | | According to the form of the control | legislation |
| Marilyn Crawshaw Petra Nordqvist and Leah Gilman | 2 | 21 21 | An early example of where you should say 'psychological and social' Line 21 add in parent or parents (not just parents) | This was adapted We have used "(the intended parent[s])" |

| Marilyn Crawshaw | 2 | | Section on Trends – maybe specify that it's only the countries that were included in the IFFS survey? There are more than 71 countries in the world! | We agree with this comment, but decided not to add this much detail to the paper. The reader can check the original report |
|--------------------------|----|--------------------------|--|--|
| HFEA | 2 | 23- 34 | It may be better to refer to 'direct-to-consumer genetic testing and matching services' or similar- to ensure it is clear that it is not the testing itself, but the 'matching' service (which are usually opt-in) which can have an implication for those involved in donor-assisted conception | We have adapted the sentence as suggested |
| Marilyn Crawshaw | 24 | 23 | The vast majority? A bit like the use of 'excellent' | We have corrected "vast majority" to "majority" to be more objective |
| Astrid Indekeu | 2 | 29- 54 | It is mentioned that numbers of OD is increasing steadily, but what about families after sperm donation? I miss a paragraph on <i>the change</i> in population (increase in single mothers, Isingle and lesbian mothers being largest group of SD families in countries that allow it], older women in treatment). And a sentence on how this also create different challenges for support. | We have integrated sperm donation in the paragraph |
| Bryan Woodward/BFS | 2 | 29- 31 & 33- 35 | Past tense needed rather than present to report findings from IFFS 2019 | This was adapted |
| Stichting Donorkind | | 41 | How come records of sperm donation are still so sloppy? | Thank you for this comment. ESHRE advocates for mandatory registries, and will remain doing so. However, this discussion and the need for registries is outside the scope of the current paper |
| Marilyn Crawshaw | 2 | 42 | I'm not sure there are data either on the no of surrogacy pregnancies where a donor was also used | We have added a sentence stating that surrogacy is not reported by EIM |
| Juliana Pedro | 2 | 43- 45 | Can we have here a more detailed information regarding the improvement and references supporting it? | We have added a reference to the EIM data collection, |
| HFEA | 2 | 44 | 'survival rates' It may be clearer to say 'oocyte survival rates,' assuming this is what is meant. | This was adapted |
| Jose Antonio Castilla | 2 | 45 | Recipients should be warned about certain information which they can find on the websites of some centres which create unrealistic expectations, such as the success rate of ARTs with and without donated gametes, for example (Wilkinson et al., 2017; Sauerbrun-Cutler et al., 2021). It is recommended to suggest to patients that they should only access information on websites which are audited by reliable organisms. | The discussion on success rates and commercial information is important, but outside the scope of the current project that focusses on reproductive donation and DNA testing |
| Jose Antonio | 2 | 46 | Sauerbrun-Cutler MT, Brown EC, Huber WJ, Has P, Frishman GN. Society for Assisted Reproductive Technology advertising guidelines: How are member clinics doing? Fertil Steril. 2021;115:104-109. Wilkinson J, Vail A, Roberts SA. Direct-to-consumer advertising of success rates for medically assisted reproduction: a review of national clinic websites. BMJ Open. 2017;7:e012218. Change "import and export" to "distribution". We recommend the author reads the European | This was adapted |
| Castilla | _ | 40 | directive about this topic because "import and export" are not the same as "distribution". | |

| Stichting Donorkind | | 47- 48- 49 | The increasing number of people travelling across international borders is not a 'neutral trend'. This is because of marketing and it is a threat to the rights and well being of the resulting people. | We have listed a number of factors that could impact on cross-border reproduction, which may or may not be driven through marketing. It is outside the scope of the current paper to elaborate on the reasons for cross border care. |
|--|----|------------------|---|---|
| Jose Antonio Castilla | 2 | 48 | Include "to cheaper treatments, shorter waiting times, better quality. ". According to Shenfield et al. (2010) another important reason for CBRC is the better quality in the centre of the destination country. Please include this reference: Shenfield F, De Mouzon J, Pennings G, Ferraretti AP, Andersen AN, De Wert G, Goossens V. Cross border reproductive care in six European countries. Hum Reprod 2010;25:1361–1368. | We have adapted the sentence and included the reference |
| HFEA | 2 | 49- 51 | 'for oocyte donation' It may be clearer to change this to 'for treatment using oocyte donation.' | This was adapted |
| Stichting Donorkind | | 55- 65 | It should be noted how problematic this is for many children born this way. Although understudied. Could we note here that we know now how important it is to tell children about their conception and biological family? Keeping secrets within families is a bad thing for forming good relations and not telling children about their genetic identity is a violation of their rights. | We acknowledge your point of view, and we think this opinion is included in the section on disclosure, as well as the studies on the topic. The scope of the current paper is to define recommendations for information provision, not to recommend for or against anonymity or disclosure. |
| Astrid Indekeu | 3 | 56- 65 | It should mention that historically professionals advised secrecy (see Novaes) | We have added this to the text |
| Marilyn Crawshaw | 3 | 56 | I think the earliest published account was a medical procedure (in the 1800s) so maybe say 'it's more frequent use'? | This was adapted |
| Astrid Indekeu | 3 | 56- 57 | Sentence is unclear | We have revised the sentence, but consider it appropriate as an introductory sentence which is explained in more detail in the following lines |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P3 | 57 | In 1884, the first registered insemination with donor semen was done by William Pancoast, an American physician. This case was published in Medical World in 1909. REF: Hard, D. A. (1909). Artificial impregnation. Medical World, 27, 163-164. | We have corrected this sentence and added the reference for Pancoast |
| Bryan Woodward/BFS | 3 | 58 | Change "England" to "the UK". Also the reference to the 1930s is questionable, e.g. what about William Pancoast? | We have corrected this sentence and added the reference for Pancoast |
| Petra Nordqvist and Leah Gilman | | 59 | Line 59 – consider replacing 'safeguarding' with 'anonymising' as former implies donors necessarily want(ed) this information to be withheld. | This was adapted |
| Nina Barnsley & Yael Ilan-Clarke | 3 | 61 | Secrecy and anonymity were also a response to a lack of clarity about the legal status of the donor, with regards to the child. E.g. would a sperm donor be considered the legal father and therefore have rights and responsibilities towards the child? | We have added this to the text |

| Nina Barnsley & Yael Ilan-Clarke | 3 | 64 | It's an odd connection to say that people who had fertility treatment were more likely to tell about that, than people who had used donor conception to be open about the use of a donor. At DC Network we would see fertility treatments and the use of a sperm/egg donor as different topics. We see a lot of blurring of language, e.g. saying IVF when people mean egg donation, which is unhelpful and confusing. | The sentence reports the outcome of a review reporting on studies evaluating disclosure to children conceived via autologous versus donor ART and illustrates that there seems to be more secrecy around donor ART compared to non-donor ART. In fact, the review highlights that these are 2 separate entities, and does not seem to contradict the position of the reviewer |
|-------------------------------------|---|-----------|---|---|
| Astrid Indekeu | 3 | 66 | This sentence seems out of place: there is only 1 sentence in relation to donor anonymity and the rest of the paragraph is about (non-)disclosure. Disclosure and donor-anonymity is not the same and therefore confusing | This was adapted |
| Stichting Donorkind | | 66- 74 | How can the whole human rights development be missing from this text? The Convention on the Rights of the Child has been a driving force for legislation in countries banning donor anonymity. | We have added a reference to the UN Convention on the Rights of the Child in the text |
| Nina Barnsley & Yael Ilan-Clarke | 3 | 66 | It would be helpful to distinguish between secrecy and donor anonymity. For example, our organization was founded when donors were completely anonymous and there was no prospect of that ever changing, however parents wanted to be honest with their children about how they were conceived. Of course, anonymity and secrecy feed each other to some degree, but the fact of having used a donor is separate to the details of who that donor is, and what potential contact / information may be available. | We have added a sentence clarifying the difference between secrecy and donor anonymity and have checked appropriate use of both terms throughout the paper. |
| HFEA | 3 | 66- 74 | It could be useful to add to this paragraph some information about the level of parental 'disclosure' in reality (or explain why data on that is not readily available), as what happens in practice may differ from what is recommended by professional bodies. Guidance Note 20 of our Code of Practice states: 20.7 The centre should encourage and prepare patients to be open with their children from an early age about how they were conceived. The centre should give patients information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children. | This comment was made in reference to the introduction, but disclosure is included further down in the paper. The recommendations on disclosure are in line with the suggested ones. |
| Nina Barnsley & Yael Ilan-Clarke | 3 | 68 | The experience and the lessons learned from the adoption world fed into this change of view. | Although we agree with this comment, we decided not to add adoption to the text, as not to further complicate the paper |
| Nina Barnsley & Yael Ilan-Clarke | 3 | 68 | DC Network played no minor role in voicing the experiences of parents and donor conceived people in the UK and showing that openness was not only possible but also beneficial in many families. | Thank you for this comment, which does not seem to request an adaptation to the paper |
| Juliana Pedro | | | Direct-toconsumer genetic testing and donor registries, sibling registries: The majority of these "tools" to find donors or donor conceived relatives are not well known or disseminated in some countries. For this reason, I think it might be beneficial to explain, in a more detailed way, how these tools work as this knowledge might be new for some people even working in this field. | This is covered in the introduction. A lay version to be prepared will also be helpful |

| Astrid Indekeu | 3 | 76- | I would prefer this paragraph at the end of the 'trends' section to follow a bit the time-evolution in | The paper focusses on information provision to |
|------------------|---|-----|---|---|
| | | 151 | the 'trends-section'. I think the paragraph should mention not only DTCGT but also more explicitly | all parties involved in donor-assisted |
| | | | the impact of the internet more general- see: | conception, and focusses on direct-to- |
| | | | Mechanick Braverman A. (2010) How the internet is reshaping Assisted reproduction: From donor | consumer genetic testing (combined with social |
| | | | offspring registries to Direct-to-consumer genetic testing. | media and internet). We have not expanded on |
| | | | Woodward J.T (2015). Third-party reproduction in the internet age: the new, patient-centered | further issues related to internet and its impact |
| | | | landscape. Fert Steril 104:525-529. | on third-party reproduction |
| | | | As the internet (and its' possibilities) had a huge impact on who has access to information | |
| Stichting | | 76- | And can be kept out of the personal private information of the resulting donor conceived persons. | The sentence commented on "In the healthcare |
| Donorkind | | 77 | Taking away possibilities for informed consent and correct medical information for DCP's. | system, information about donors is still |
| | | | | considered strictly confidential and kept in a |
| | | | | secure manner where only a few people will |
| | | | | have access. " relates to GDPR regulations, and does not relate to donor-conceived offspring. |
| | | | | The section explains the impact of Direct-to- |
| | | | | consumer genetic testing. Implications for |
| | | | | donors and offspring are explained in the |
| | | | | respective sections. |
| Petra Nordqvist | | 77- | Line 77-79 text here implies that known non-clinic donation has not been practiced for a long time | The recommendations are prepared for |
| and Leah Gilman | | 79 | (esp in gay and lesbian communities, e.g. (Weeks, Heaphy and Donovan, 2001; Nordqvist, 2011) but | donation within a MAR centre. In donation |
| | | , 0 | also doesn't acknowledge the growing rate at which people find known donors over social media | outside the clinic, there is no professional |
| | | | etc. | caretaker involved who could provide |
| | | | | information or has the professional |
| | | | | responsibility to do so. Still, the considerations |
| | | | | in the paper would still apply. We have clarified |
| | | | | the relevance of the paper for donation outside |
| | | | | the clinic in the introduction. |
| Marilyn Crawshaw | 3 | 90 | This is one of the places where you exclude donors' non DC offspring | We have replaced "same-donor offspring" by " |
| | | | | genetic siblings or family". |
| Nina Barnsley & | 4 | 97 | Although one aspect of the DNA test is that they potentially match with unexpected relatives, for | The sentence states the genetic testing could |
| Yael Ilan-Clarke | | | DC parents who are not telling, the bigger and more likely situation is that the DC person discovers | make donor offspring aware of their donor- |
| | | | either that their ethnic heritage doesn't match their family, and/or that their mum or dad is not their | assisted conception, irrespective of whether a |
| | | | genetic mum or dad. This is true even if no other genetic family matches are made. This is not just | donor is identified. This is exactly what the |
| | | | about the impact of unexpected matches, but more fundamentally the test will reveal the lack of | reviewer is suggesting, but we have added |
| | | | genetic connection within the family. | some further clarification |
| Sarah Norcross | 4 | 98 | may pose a threat'- We think the word threat is too strong here as for some people it is an | This was adapted |
| | | | opportunity to make a connection, a more neutral word or phrase such as - may give rise to | |
| | | | different issues to the parties involved. | |
| Petra Nordqvist | | 98- | Lines 98-113: some of the vocabulary here (threat, exposed, unfortunately) seems quite alarmist | This was adapted |
| and Leah Gilman | | 113 | and moralising. Again this section ignores known non-clinical donation practices | |

| Verein Spenderkinder | 4 | 98 | "Genetic testing within the context of ancestry databases or registries may pose a threat to all parties". Although genetic testing may be a threat from the perspective of parents and reproductive physicians, for many DCP it is a great opportunity (often their only opportunity) to learn about their medical and ancestral history, and to change existing power relations. Recommendation: Change the phrase "Genetic testing within the context of ancestry databases or registries may pose a threat to all parties" to "Genetic testing within the context of ancestry databases or registries may pose a threat to reproductive physicians, genetic and legal parents while it is a great opportunity for DCP to learn about their medical and ancestral history and to | This was adapted |
|--|----|------------|--|---|
| Stichting Donorkind | | 98- 101 | change existing power relations". This is an incorrect statement. It is not a threat to the parties but a threat for the secret, if one would choose for the word 'threat'. It is part of medical scientific progress and a tool for donor-conceived people to get the withheld information about their genetic identity. Which they are often desperately looking for to feel whole as a person. Parents should by now know it is not a good thing to keep these big important secrets from their children. Donors should realise that a human being is born out of their donation. A human being with needs and feelings. | This was adapted |
| HFEA | 4 | 104 | 'relatives who direct-to-consumer genetic testing' There is a typo here. | This was adapted |
| Marilyn Crawshaw | 4 | 106 | Cousins? I know of many whose contact with cousins is important to them | We added "cousin" to the list |
| Marilyn Crawshaw | 4 | 109 | Apart from the fact that you repeat here about anonymous donors being exposed, I'm not sure why you would only refer to them and not DC people – suggest leave it out | We added "or donor-conceived offspring" to the sentence |
| Stichting Donorkind | | 110 | It is stated that 'unfortunately' the anonymity of donors and family is no longer tenable. This is not scientifically backed and there is much evidence from experience that this indeed a very good fortune. | The word 'unfortunately' referred to the anonymity of relatives, but we have removed it from the sentence as we acknowledge this may be seen very differently by different involved, |
| Nina Barnsley & Yael Ilan-Clarke | 4 | | The discovery can come by different routes: i) a relative of a donor matches with a DCP (this could be one of their own children) and that person was unaware of the family member having donated; ii) A DCP matching with another DCP who doesn't know they are donor conceived, and iii) A DCP discovering they are donor conceived unexpectedly. All these three routes mean the burden of knowledge and disclosure falls on the wrong person. The donor's relative or the DCP is then responsible for making a decision about who else they tell (e.g. sibling, parents, partner, other DCP). | We have highlighted the different options in the text, by adding a sentence reading that Direct-to-consumer genetic testing can both reveal i) the lack of a genetic link between the parent and the offspring, ii) the knowledge that a family members has donated gametes/embryos or iii) identify genetic relatives (a donor, siblings, family). |
| Nina Barnsley & Yael Ilan-Clarke | 4 | 111 | "Is no longer tenable"-should be "no longer guaranteed" (we do know of people desperately using DNA sites who have not found a single match, even distant cousins, possibly because the donor is from a country where DNA testing is not common). | This was adapted |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P4 | 114 | The authors write "donor who have donated anonymously can themselves share", but also non-anonymous donors can share their genetic information at a DNA bank. | This was adapted |

| HFEA | 4 | 118 | '68.4% of the 118 respondents in this study stated that they were not concerned that they would be identified as someone's biological parent' This wording does not make clear whether 'concerned' in this context means a) The donors did not think they would be identified; or b) The donors were ok with being identified if it happened. | The sentence states "they were not concerned that they would be identified as someone's biological parent by a direct-to-consumer genetic test", i.e. they were not concerned on being identified. For more details, the reviewer is referred to the study, |
|------------------------|---|---|--|---|
| Stichting Donorkind | | 121 | The topic might be understudied but from our experience (800 dutch donor-conceived people/donors) the well-being of all parties is improved rather than worsened after getting to know each other, in most cases. | In the text, we have left it open whether it would affect well being positively or negatively. |
| | | | See for example: V. Jadva, T. Freeman, W. Kramer, S. Golombok, Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring, Human Reproduction, Volume 26, Issue 3, March 2011, Pages 638–645, https://doi.org/10.1093/humrep/deq364 And: Blyth, E., Crawshaw, M., Frith, L., & Jones, C. (2012). Donor-conceived people's views and experiences of their genetic origins: a critical analysis of the research evidence. Journal of law and medicine, 19(4), 769. | |
| Marilyn Crawshaw | 4 | 124 | Technically the DCR stopped being govt funded some time ago when financial responsibility was transferred to the HFEA. May be more correct to say 'publicly funded'? | This was adapted |
| Marilyn Crawshaw | 4 | 125 | It's also for donors who are searching | This was adapted |
| Marilyn Crawshaw | 4 | 127 | I don't think this is true – I'm not aware of a supportive network for DTC testing (or are you referring to DCR and FIOM here? If so they don't offer DTC testing per se). DCR and FIOM offer some time-limited professional support/counselling but I don't think this extends to families and is not a network | We have adapted the sentence clarifying that support is available in some cases. |
| Astrid Indekeu | 4 | 132 | Correct reference for the Dutch DNA database= Fiom KID DNA Database . Please also correct at all places mentioned + check sentence people who were conceived prior June 2004 and donors who donated prior to June 2004 | This was adapted |
| Astrid Indekeu | 5 | 136- 145 corr ecti on nee ded | Please add that in half of the population of donors also donor-oriented motives were present: see p4 of paper Bolt: "Two donors (1.1%, n=2) reported only donor-oriented motivations, 97 donors (54.2%, n=97) reported only child-oriented motivations, and 80 donors (44.7%, n=80) reported both donor-oriented and child-oriented motivations.' Also other research (see ESHRE presentation annual meeting Vienna, Indekeu) showed that donors have an own interest in contact/searching. This is important for counselling as donor's have own needs as well. Recent research (cfr Nordqvist's research, see: Nordqvist, P., (2019). Un/familiar connections: On the relevance of a sociology of personal life for exploring egg and sperm donation. Sociology of Health and Illness. 41, 601-615.) focuses on the impact of donation for the donor and his personal network. (see also comments in Review van de Broeck et al 2013(p49), "The donor has not been studied as an actual stakeholder but rather as a means to an end". To provide good care, the donor should be seen as an actual person • if interested in more recent numbers of the Fiom KID DNA database: April 2021 846 donors and 2289 DCP are registered | We corrected the sentence, now reading "Their motivations were mostly children-oriented, or both donor-oriented and child-oriented." |

| Verein Spenderkinder | 5 | 145 | The wording "children of their own" is used in relation to donors. Biologically, DCP are also the "own" children of the donor. A better wording would be "children who they raised and for whom they have legal responsibility". | This was adapted |
|--------------------------|---|-------------|--|---|
| | | | Recommendation: Change the wording "children of their own" to "children who they raised and for whom they have legal responsibility". | |
| HFEA | 5 | 146- | Where you write about the Donor Conceived register (DCR) it could be useful to add that the HFEA | We have added the link to the DCR and FIOM |
| | | 151 | now commissions the DCR service and add a link to our web content which covers the DCR and/or the DCR website. | databases |
| Bryan Woodward/BFS | 5 | 148 | Past tense needed rather than present to report findings from the DCR | This was corrected |
| Anne Schrijvers, | 5 | | Legislation, anonymity and donor quota ; The authors describe the differences in legislation – | The requested information has recently been |
| Marja Visser, | | | donor anonymity, maximum number of children born from a donor, information shared with the | published by ESHRE. It was decided not to |
| Monique Mochtar | | | offspring – and refer to some counties, for example see line 162, 165, 168, 207. We feel an outline of | duplicate this information |
| | | | legislation per country would be more appropriate for this guideline than only refereeing to some | |
| | | | countries. For example, this could be summarized in a table. | |
| Bryan Woodward/BFS | 5 | 154 | Change "does not" to "may not" | This was corrected |
| Marilyn Crawshaw | 5 | 155 | Should be 'consequences for all affected' – maybe also make clear that DC offspring minors can be traced even tho the legislation about identity release may say they have to reach a certain age | We consider this as a relevant example of the impact of direct-to-consumer testing, and have added it in the introduction. |
| Stichting Donorkind | | 155 | It also does not take into consideration the importance of human rights of donor-conceived persons to have knowledge about their family history and genetic identity, as in some countries anonymous donation is still possible. | Thank you for this comment. Donor anonymity is still possible by law in many countries. This paper does not advocate for or against donors anonymity, but merely explains the impact of direct-to-consumer genetic testing on donor |
| | | | | anonymity |
| Stichting Donorkind | | 156 | Should add: and the consequences for the infringement of the private family-and medical information of donor conceived persons. | We have changed the sentence to now read 'the consequences for all affected", which covers this comment as well |
| Astrid Indekeu | 5 | 158- 159 | EUTCDs were created for tissue traceability, not to protect the health and not to increase equal availability(?) | We have corrected the aim of the EUTCDs |
| Verena Ehrbar | 5 | 162- | Regarding the legislation in Germany: I am not fully aware of all possibilities in Germany, but what I | We have removed the incorrect reference to |
| | | 169 | read in this paragraph is new to me. So maybe I didn't know or maybe it would be worth to recheck this information just to be sure. | Germany |
| Jose Antonio Castilla | 5 | 162 | Instead of "In some countries", we believe more "In the majority of countries " o "in almost half European countries" to be more specific and exact. In this reference, you can see the percentage of different donation criterion in European countries: Calhaz-Jorge C, De Geyter CH, Kupka MS, Wyns C, Mocanu E, Motrenko T, Scaravelli G, Smeenk J, Vidakovic S, Goossens V. Survey on ART and IUI: legislation, regulation, funding and registries in European countries: The European IVF-monitoring Consortium (EIM) for the European Society of Human Reproduction and Embryology (ESHRE). Hum Reprod Open. 2020 Feb 6;2020(1):hoz044, doi: 10.1093/hropen/hoz044. | We have added the reference to the paper and corrected the information accordingly |

| Cryos International sperm and egg bank | | 162 and follo win g. | A tissue establishment should not give any donor the assumption that his donation is completely anonymous, hence no legislation should support this. Promising "anonymous donation" is in 2021 a misrepresentation of the donor and it is possible that it could constitute a breach of contract for the tissue establishment, promising this when knowing that it is not in fact possible to promise anymore, or at least knowing that whether or not the tissue establishment will be able to keep this promise is out of their hands. So the term "anonymous" should be removed from legislation, and focus should be on informing the donor thoroughly about this issue. Legally, there should merely be the possibilities "ID-release" and "Non-ID-release", describing the agreement between the donor and the TE about whether or not the TE will hand out the donor's ID to offspring and/or intended parents. These terms would be much more representative for what is actually taking place and what is controllable for the parties. What information is handed out to the offspring should be left totally to the parties involved to agree upon as they wish. | Thank you for this comment. This paper does not advocate for or against donor anonymity, not do we speculate on whether there should be ID-release. The aim of the paper is to explain the impact of direct-to-consumer genetic testing on donor anonymity, and to ensure that donors are informed of possible consequences at the time of donation |
|--|---|----------------------------------|---|---|
| Nina Barnsley & Yael Ilan-Clarke | 5 | 162 | As far as we understand, the legal position regarding sharing half-sibling information is unclear in some countries, e.g. Czech Republic even though legally the donor should remain anonymous | This paper does not advocate for or against donor anonymity, or recommended preference of a certain system over another. The aim of the paper is to explain the impact of direct-to-consumer genetic testing on donor anonymity, and to ensure that parties are informed of possible consequences. We also recommend that parties are informed of relevant legislation. More information on country-specific variations in legislation are described in Calhaz-Jorge 2020 |
| Astrid Indekeu | | 163 | Please correct to: No right to access the identity of the donor/ancestry information | This was adapted |
| Juliana Pedro | 5 | 165 | If pertinent, add "at 18 years old, in Portugal" | The information on Portugal was added |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | | 165 | After Finland add 'and UK' | This was adapted |
| Astrid Indekeu | 5 | 170 | Change: the prohibition of donor treatment or certain type of donors/donation (it is not about gametes, people are involved) | This was corrected |
| Marilyn Crawshaw | 2 | 47-8 | What you say here is also my understanding of current evidence (which is anyway limited) but at a later point (e.g. p5 line171-4) you say that it's primarily driven by people seeking anonymous donation and I don't think there is robust evidence for the latter | In line 47, we list "ethical and legal restrictions" as a motivation for cross border care, in line 171 we provide further information on these motivations, "use certain type of gametes", or "secrecy", based on published data. We do not consider this a contradiction, |
| Bryan Woodward/BFS | 6 | 175- 191 | In this section on the maximum number of children born via a single donor, can you include a sentence about donor sperm purchased from big international sperm banks? For example, a single donor can be used in numerous countries. Whilst individual countries may have their own laws, how many recipients are informed that beyond their own country's legislation, a donor-conceived offspring could have 1000s of half-siblings created from the same donor? | We have considered this comment, but have not included a comment on the sperm banks. We did add a sentence that donors should be informed that potentially a large number of offspring could be born from their donation. |

| Astrid Indekeu | 6 | 175 | the word "patients": not all intended parents have an infertility issue, so preferable use recipients | This was adapted |
|------------------------------------|---|-------------|---|--|
| | | 175 | throughout the whole document. | |
| Astrid Indekeu | 6 | 175- 191 | With international spermbanks and the impact of the internet a donor may be confronted with much more than 10 DCP. Vice versa a DCP may be confronted with much more donor-relatives(same-donor offspring). I suggest to stipulate this more in this paragraph | We have considered this comment, but have not included a comment on the sperm banks. We did add a sentence that donors should be informed that potentially a large number of offspring could be born from their donation. |
| HFEA | 6 | 177 | 'Again, these restrictions may be based on legislation (e.g. UK, Germany)' | This was corrected |
| | | | This is not entirely correct as the UK 10-family limit is not a legal requirement. It is a policy position taken by the HFEA which is reflected in the guidance in our Code of Practice and with which we expect all centres to comply. It is not required by the Human Fertilisation and Embryology Act 1990 | |
| | | | The HFEA Code of Practice (Guidance Note 11) states that clinics must ensure that sperm or eggs from a donor are used to create no more than 10 families, although donors can specify a lower limit if they wish. There is no limit on the number of children within each family. | |
| Verein Spenderkinder | 6 | 177 | "Most legislations on donor treatment include a paragraph on quotas; the number of patients that can be treated with a single donor or the maximum number of children born (or families created) from a single donor. Again, these restrictions may be based on legislation (e.g. UK, Germany) or relevant professional guidelines (e.g. Hammel et al. 2015)." In Germany, the number is not legally limited. Although there were guidelines in the past that physicians had given themselves, the number of identified half-siblings indicates that they were not considered legally binding. Recommendation: Delete "Germany" | This was corrected |
| Stichting Donorkind | | 181- 185 | How strangely one-sided saying nothing about the need of donor conceived siblings to have meaningful relationships with each other. | We have changed the sentence to focus on psychological considerations in the donors and the offspring |
| Petra Nordqvist and Leah Gilman | | 182 | Lines 182 It is interesting to note that in our recent study of donors (Nordqvist and Gilman, Forthcoming) some of the donors we spoke to who donated as known donors, felt that the ten family limit was too much, and that they would choose to be a known donor, because they wanted to donate to one or a smaller number of recipients. | We have given a recommendation that donors should be informed on whether they themselves can set a lower limit on the number of families created. Unfortunately, there is currently no conclusive data on what this limit should be. The forthcoming study may be of help. |
| Stichting Donorkind | | 182 | I do not see any research supporting this 200 offspring per donor in a world that is everyday more globalized. 200 people who do not know they are family, who will have children and grandchildren The possibility of meeting each other without knowing that they are family will only grow every generation. And now we are just talking about genetics. Not even about the psychosocial impact of having to live with the idea that 199 half brothers and sisters live all around the world. | We have explained this in the text, based on genetic considerations and the risk for consanguinity, a limit of 200 is okay (which was calculated in the study by Janssens), and we clarified that based on psychosocial considerations, the limit would need to be much lower. We consider no further information is needed. |

| Marilyn Crawshaw | 6 | 184 | I think it said so that each party could form a meaningful relationship if desired, not just donors! Did it really say (line 182) only in social minority situations? I thought it also acknowledged situations where donors and recipient parents lived in fairly close proximity? | We have corrected this to "isolated communities". We have also added that this could be one example, reducing the need to add more examples, such as the donor and recipients living in close proximity |
|-------------------------------------|---|-------------|---|---|
| Verein Spenderkinder | 6 | 184 | The wording "if necessary" is used regarding "donors" forming a meaningful relationship with DCP. What does "if necessary" mean? Who determines the need? The neediness of the DCP? No human being wants to be needy and have a genetic parent who establishes a relationship only out of "need". Recommendation: Delete "if necessary" and change the phrase to "so that it is possible for DCP and genetic parents to have a meaningful relationship." | We have removed "if necessary" from the sentence |
| Stichting Donorkind | | 186- 191 | How come the lack of regulation on how many children of one donor and the possibility of adding international quotas is not stated as a threat to all parties involved? | We have added that due to the lack of (inter)national rules and quotas, potentially large numbers of offspring can be born from the donation. |
| Verein Spenderkinder | 6 | 190 | "however, most other countries have less regulation and consequently no national registry, and therefore it is hard to track numbers of offspring produced per donor and enforce any restrictions on numbers." DCP should not be referred to using words which suggest commodification, or that we are a merely "product". Recommendation: Instead of "track numbers of offspring produced per donor" use "track numbers of DCP per genetic parent". | This was corrected |
| Nina Barnsley & Yael Ilan-Clarke | 6 | 190 | Even with a regulator, the numbers rely on trusting parents to report pregnancies and births honestly and donors to responsible. | We have added a sentence, and confirm that this information was already included as a recommendation for recipients. |
| Astrid Indekeu | 6 | 192 | Better to say Global perspective ? as European perspectives is also international | This was corrected |
| Petra Nordqvist | | 202- | Lines 202-204: claim that donors only 'rarely' access information about donor offspring at odds with | The sentence states that providing information |
| and Leah Gilman | | 204 | our own research –donors often do choose to find out basic info about offspring (Nordqvist and Gilman, Forthcoming). | about the offspring to the donor is rarely allowed and practised, which is not contradicting the point made by the reviewer |
| HFEA | 6 | 204 | 'the UK allow donors to know the number, sex, and year of birth for any offspring.' This could me be more specific e.g. 'donors who donated after 1 August 1991' | This information was added |
| Jose Antonio Castilla | 6 | 206. | Instead of "A number of countries", we believe "A very small number of European countries" to be more realistic and precise. Also, please exclude Australia from this list, because this is a completely different situation to the European situation which is not comparable. Include this reference Calhaz-Jorge C, De Geyter CH, Kupka MS, Wyns C, Mocanu E, Motrenko T, Scaravelli G, Smeenk J, Vidakovic S, Goossens V. Survey on ART and IUI: legislation, regulation, funding and registries in European countries: The European IVF-monitoring Consortium (EIM) for the European Society of Human Reproduction and Embryology (ESHRE). Hum Reprod Open. 2020 Feb 6;2020(1):hoz044. doi: 10.1093/hropen/hoz044. | We adapted to a small number of countries and added the reference. |
| Juliana Pedro | 6 | 207 | If pertinent, add "Portugal in 2018" | This information was added |
| Bryan Woodward/BFS | 6 | 211- 214 | Past tense needed rather than present to report findings. | This was corrected |

| Nina Barnsley & Yael Ilan-Clarke | 7 | 218- 222 | Should we be clear that if removing anonymity results in less donors coming forward, that does not give grounds for not removing anonymity? As there are other important principles to take into consideration. | In the section highlighted by the reviewer, we have listed the data from the literature. Further considerations, in addition to those discussed in the studies are mentioned in the next paragraph, and we decided it was not needed to expand on this. |
|--|----|-------------|---|---|
| Petra Nordqvist and Leah Gilman | | 222 | Line 222-226: very important point which could be flagged earlier. Also need to include here the rise of online matching websites and rise in known non-clinical donation practices. One such matching service, Pride Angel in the UK, report a steep rise in membership numbers in recent years. Recipients and donors also meet on social media, on places such as Facebook and Instagram. Moreover, many of the UK identity-release donors we interviewed in our recent study, were keen for some level of contact with their recipient (parent and child), and the option to make that known to the recipient family (Nordqvist and Gilman, Forthcoming). | The recommendations are prepared for donation within a MAR centre. In donation outside the clinic, there is no professional caretaker involved who could provide information or has the professional responsibility to do so. Still, the considerations in the paper would still apply. We have clarified the relevance of the paper for donation outside the clinic in the introduction. We agree that there is a need for much more knowledge on the experience of donors |
| Stichting Donorkind | | 225 | Writing in this manner makes it seem like it is very easy and immediate to find a donor through genetic testing. This is not the case. It can take people up to years of building family trees to find their donor. And even if one finds the donor it is a very big step to get into contact with someone who is not prepared to hear from their offspring. | Our recommendation states that "Recipients should be informed about the possibilities of donor-conceived offspring connecting through direct-to-consumer genetic testing with their donor or other genetic relatives" Providing this information would include more details on the time it may take, the option that no link is found etc, but these details are not included in the recommendation |
| HFEA | 6 | 230- 31 | 'i.e. a relative may access and submit DNA to an ancestry database.' It could be made clearer whether this means a relative may submit another's person's DNA to an ancestry database, or whether it means a relative may submit their own DNA. | This was corrected |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P7 | 231 | We feel that the term "psychosocial implications" would be more suitable, as donor conception involves not only psychological implications but also social implications. | This was corrected |
| Stichting | | 232- | This should've always been the case. Even before genetic testing was available. | We agree with this comment, but do not think |
| Donorkind | | 233 | | the current sentence contradicts the reviewers' comment |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P7 | 234 | We suggest to use "fertility clinics" instead of "IVF clinics" as not every clinic that offers donor sperm treatment also offers IVF treatment. | This was corrected |
| Stichting Donorkind | • | 239 | And the impact on the unborn child! | Donor-conceived offspring was added here |

| Astrid Indekeu | 7 | 239- 240 | ASRM guidelines exist. There were no ESHRE guidelines until now. | We have identified the recent ASRM guideline, which briefly touches upon direct-to-consumer genetic testing. We have slightly rephrased the sentence which stated there are no recommendations. |
|------------------------------------|--------------------|--------------|---|--|
| Juliana Pedro | <u>-</u> 7 | 244 | Replace "provides" for "provided" | This was corrected |
| Petra Nordqvist and Leah Gilman | | 260 | Line 260: figure 2 seems to be very much based on heterosexual couple using an identity-release donor in a clinic, where disclosure is planned. Also implies identity release is about the donor and not about donor siblings. Also ignores situation (mentioned elsewhere) where donors and recipients might meet prior to donation, known donation and non-clinic donation. State that this is one possible scenario in which donor conception can take place, and list other possibilities? | The figure represents an overview of the different steps in the process, and it does not intend to be directive towards one option of donation, or a specific type of donor or recipient. Still, we have adapted the figure, inserting also non-heterosexual couples and single parents, We have also inserted at several points 'if applicable" to allow the figure to fit for other types of donation as well. |
| Bryan Woodward/BFS | 8 | Figu re 2 | Suggest changing the images of the recipients from a man+woman, since recipients can be many combinations, e.g. woman+woman, single woman, man+man, etc. | The figure was pictorial, showing examples, but has now been adapted to be complete. |
| Verein | 33, | | Additional point regarding the number of children per genetic parent: Genetic parents should be | All points made by the reviewer are already |
| Spenderkinder | Tabl | | informed that, according to the UN Convention on the Rights of the Child, DCP have a right to know | included in the recommendations. We did, |
| | e 1 | | who their genetic parents are and that most donor conceived people who are informed will want to contact their unknown parents sooner or later. They should take this into account with regard to their social family, i.e. also talk about it with their partner or children. Recommendation: Please add this point to the recommendations regarding the number of children. | based on other comments, make some clarifications to the recommendations. |
| Verein | 34, | | Additional point regarding information provision: Genetic parents should be informed that they | The scope of the paper is to provide |
| Spenderkinder | Tabl | | should subsequently report any diseases or disease dispositions that come to their knowledge, in | recommendations on information provision. |
| | e 1 | | order to be able to inform affected DCP, if necessary. Recommendation: Please add this point to the recommendations regarding information provision. | Even if donors should be informed how they can update their information, there is no legal framework for enforcing disclosure of any future medical/genetic information. |
| Verein Spenderkinder | 34. Tabl e 1 | | Regarding psychosocial aspects and psychosocial counselling: "Donors who are known to the recipients (i.e. known donation) should have access to counselling on their own and with recipients in order to clarify roles and relationships and disclosure plans and preferences." - As mentioned above, counselors and donors should be aware that relationships cannot be predetermined. You cannot set boundaries to another human being's feelings or even "clarify" what their parents mean to them. The child should be informed about its genetic parents and should be free to identify for itself the importance of the genetic parents in its life. Recommendation: Please change the phrase to "If genetic and legal parents are known to each other, legal parents should have access to counselling on their own and together with the genetic parent counselling should cover clarifying that relationships cannot be predetermined and there cannot be set boundaries to another human being's feelings. All parents must be made aware that the child should be informed and be free to identify for itself the importance of its genetic parents in its life." | Our recommendation "Donors who are known to the recipients (i.e. known donation) should have access to counselling on their own and with recipients in order to clarify roles and relationships, disclosure plans and preferences" is consistent with the comment of the reviewer. Specific recommendations for counselling and what should be included is outside the scope of the paper. |

| Petra Nordqvist and Leah Gilman | | 263 | Line 263-265 This is very brief, and could usefully be unpacked to say that recent research shows that also those connected to donors, such as their partners, children, parents, siblings and so on, and can feel implicated in the donation, that it is also 'their story' (Nordqvist and Gilman, Forthcoming) | We do understand this comment, and have touched upon the social circle, but decided not to expand on this too much, also as professionals in the field are not necessarily involved with the social circle |
|--|----|-----|--|---|
| Nina Barnsley & Yael Ilan-Clarke | 8 | 269 | Do you mean by this statement that the wider social context of the donor might change, e.g. new partner, they have children in the future, or do you mean the wider social context of society, e.g. secrecy no longer the norm; donor conception more widely accepted? | We have adapted the sentence, stating the "societal context" |
| Nina Barnsley & Yael Ilan-Clarke | 8 | | Donors should be encouraged to be open with their immediate family so that there are no shock discoveries for them. | We have added a recommendation: q Donors should be considering potential future impact of the donation on their close family. Whether or not they should disclose their donation to their family is outside the scope of the paper |
| Nina Barnsley & Yael Ilan-Clarke | 8 | | The implications for donors should include the feelings of family members and future family members. Grandparents, partners and children can feel differently to the donor about the meaning of his/her donation and the connection to any subsequent children born in other families. | We have added a recommendation: q Donors should be considering potential future impact of the donation on their close family. |
| Marilyn Crawshaw | | | Private/informal donations: Somewhere I wonder if it should be made clear that arrangements involving donation also appear to be on the rise, and that some 'donors' may donate within and outside formal settings? In keeping with this, the sentence on pg 271-3 could also come earlier rather than under the section on 'Information for Donors' | We have included the discussion on private donation in the introduction and expanded it. |
| Petra Nordqvist and Leah Gilman | | 271 | Line 271: We don't think the best practice guidelines are necessarily 'not relevant' to non-clinic donor conceptions. Could acknowledge instead that circumstances will be different but may be helpful for individuals and organisations to think about how they can implement recommendations in their setting, and also support known donation practices. | The recommendations are prepared for donation within a MAR centre. In donation outside the clinic, there is no professional caretaker involved who could provide information or has the professional responsibility to do so. Still, the considerations in the paper would still apply. We have clarified the relevance of the paper for donation outside the clinic in the introduction. |
| Anne Schrijvers, Marja Visser, Monique Mochtar | Pg | 271 | Although fertility clinics are not involved in private donation, we feel it is still important to inform donors and intended parents as best as possible. To reach out to this population, general practitioners and network organizations in the field of donor conception dan refer intended parents and their own donors to platforms such as DCNetwork, LIDC and ANZICA to find themselves a specialized counsellor to discuss implications of donor sperm treatment and to find a specialized notary to establish a donor contract. | The recommendations are prepared for donation within a MAR centre. In donation outside the clinic, there is no professional caretaker involved who could provide information or has the professional responsibility to do so. Still, the considerations in the paper would still apply. We have clarified the relevance of the paper for donation outside the clinic in the introduction. |

| Jose Antonio Castilla | 9 | 271 | We believe that this document should make ESHRE's position on two aspects clear, and that this information should be given to recipients. Users should be dissuaded from searching for donated gametes outside the medical system (contact on the internet) and also from at-home insemination with donated gametes (direct to consumer or "kitchen insemination"). | The recommendations are prepared for donation within a MAR centre. In donation outside the clinic, there is no professional caretaker involved who could provide information or has the professional responsibility to do so. Still, the considerations in the paper would still apply. We have clarified the relevance of the paper for donation outside the clinic in the introduction. |
|--|----|-----|--|--|
| Astrid Indekeu | 9 | 272 | Recommendation are not relevant as they only <i>apply to donation within the medical system</i> (not because there is no caretaker involved) | The recommendations are prepared for donation within a MAR centre. In donation outside the clinic, there is no professional caretaker involved who could provide information or has the professional responsibility to do so. Still, the considerations in the paper would still apply. We have clarified the relevance of the paper for donation outside the clinic in the introduction. We did rephrase the sentence |
| Nina Barnsley & Yael Ilan-Clarke | 9 | 274 | Many donor conceived people don't like the thought that the donor's motivation was financial and they don't like to feel like they are a product of a transaction. | The research focussed on the motivations for donors, and was presented as such. The impact of the motivation on the offspring are not discussed here, and to our knowledge have not well studied. Still, we have, based on another comment, included a study mentioning that sperm donors considered the effect on the offspring in their opinion towards payment. |
| Astrid Indekeu | 9 | 275 | Please add limitations of Van de Broeck in how question are asked in surveyas at donors, so interpretation should be done carefully | We have added a sentence on the general limitations of research included in the paper. |
| Verein Spenderkinder | 9 | 275 | "Financial issues" regarding "donor" recruitment and compensation – Additionally it should be pointed out in this section that the sale of gametes is prohibited in the EU. Only compensation for expenses is permitted. Recommendation: Please add this point. | We have added this information to the text |
| Anne Schrijvers, Marja Visser, Monique Mochtar | P9 | 276 | Many studies suggest that a mix of altruism, financial compensation and knowing one's fertility status lead men and women to donate gametes. "Nine of 13 studies looked at the motivation of potential donors to donate. In general, four different types of motivation could be distinguished: altruism, financial compensation, procreation or genetic fatherhood and finally questions about the donors own fertility." REF: van de broeck, 2013 A systematic review of sperm donors: demographic characteristics, attitudes, motives and experiences of the process of sperm donation | Other motives are covered further down in the text, and we decided not to repeat this information |
| Astrid Indekeu | 9 | 283 | And what about donating at commercial sperm banks? | We have not specifically addressed commercial sperm banks in this section, as these have not been addressed specifically in the studies. |

| Petra Nordqvist and Leah Gilman | | 288 | Line 288: another argument for payment is that donors can end up being out of pocket or that claiming back expense can be administratively arduous compared to fixed payments.(Machin, 2012). | We did not include the difference between payment and compensation. Although a relevant argument, this type of discussion would need to consider legislation and was not included in the paper |
|------------------------------------|---|-------------|--|---|
| Marilyn Crawshaw | 9 | 298- 9 | I wasn't aware of different payments being made acc to whether donor was identifiable or not but I am aware of recipients being charged different amounts acc to donor attributes – should that be referred to anywhere? | This section relates to donor compensation, not payment by recipients |
| Jose Antonio Castilla | 9 | 299 | We suggest including this idea in this paragraph: "Most recipients are in favour of compensating donors as it serves as a symbolic acknowledgement of the donor's contribution and helps secure the type of relationship they expected from their donor (Ravelingien et al., 2015)" Ravelingien A, Provoost V, Wyverkens E, Buysse A, De Sutter P, Pennings G. Recipients' views on payment of sperm donors. Reprod Biomed Online. 2015;31:225-31. | We have added this sentence as suggested. |
| Petra Nordqvist and Leah Gilman | | 299 | Line 299: on the other hand, evidence that UK id-release donors consider that donating 'for the money' is problematic in context of potentially meeting donor offspring (Gilman, 2018). In addition, a group of donor conceived delegates at a UN meeting to commemorate the UN convention on the rights of the child United Nations 2019 Donorkinderen | We consider that identifiable donors require better information and counselling to candidate donors, not more money. We have added the study of Gilman to provide context to this topic |
| Verein Spenderkinder | 9 | 299 | Discussing issues on financial compensation for genetic parents, the perspective of the child is missing and should be added: What does it feel like for a human being to know that a genetic parent did it just for the money? Recommendation: Please add the child's perspective on financial compensation for genetic parents. | The research focussed on the motivations for donors, and was presented as such. We have added a sentence on the study of Zadeh, adding the offspring perspective towards the motivation for donation. |
| Jose Antonio Castilla | 9 | 299 | After this sentence "may also drive differences in commercial pricing", please include this sentence "This suggests that using identifiable donors encourages the commercialization of gamete donation." | We don't agree with this interpretation – identifiable donors require better information and counselling to candidate donors, not more money. |
| Astrid Indekeu | 7 | 302- 303 | Seen the difference in collecting sperm or oocytes I miss a sentence on the influence of gender on donation (see papers from Rene Almeling on gender and donation) I miss the review paper of Purewal & van den Akker: Systematic review of oocyte donation: investigating attitudes, motivations and experiences, PMID: 19443709 DOI: 10.1093/humupd/dmp018 "in conclusion": this is based on? As not in line wth review on sperm donation by Van de Broeck et al 2013 about primary and secondary motivations that play a role | The first point has been addressed in the text. The suggested additional review was outside the range of included studies (2014-2019) and not considered a necessary addition by the working group. The conclusion was clarified. |
| Jose Antonio Castilla | 9 | 308 | Delete this recommendation, as the donor should be informed about compensation and its basis, but we do not believe that the ethical debate related with this compensation should be included in the doctor-donor relationship. We believe that these ethical aspects should be addressed in various arenas: ethical committees, social councils, conferences, etc. If in the end this recommendation is included, why not also inform the donor about the ethical aspects of the national donor registers, the maximum number of children per donor, anonymity and thousands of other ethical debates which exist in gamete donation? | We have adapted the recommendation as suggested by the reviewers |
| Marilyn Crawshaw | 9 | 309 | Have you really made the case for saying 'especially for oocyte donation'? I'd favour this being deleted | We have adapted the recommendation |

| HFEA | 9 | 309- | 'Donors should be made aware that there is debate regarding the ethics of payment and | We have adapted the recommendation, in line |
|-------------------------------------|----|-------------|--|--|
| | | 10 | compensation especially in the area of oocyte donation.' Our Code states at 13.5 The centre should ensure that donors understand that donating gametes and embryos is voluntary and unpaid and that they may be compensated only in line with relevant HFEA Directions. | with the suggestions of the reviewer |
| | | | We do not require clinics to discuss the ethics of compensation with donors. Compensation levels for donors seeking to donate at UK licensed clinic are set by the HFEA. This followed a policy | |
| | | | review we carried out in 2011 which explored ways in which we could remove unnecessary barriers to donation. The Authority set the compensation at a level that it felt provided a balance between ensuring donors are treated fairly and are not out of pocket, while not attracting individuals to donate who are merely financially motivated. | |
| Verein Spenderkinder | 9 | 309f | "Donors should be made aware that there is debate regarding the ethics of payment and compensation especially in the area of oocyte donation". Recommendation: continue the sentence with "and that they should consider what it would mean for the child if they did it just for the money." | We have rephrased the recommendation, but have not included the suggested phrase. |
| Marilyn Crawshaw | 10 | 314& 317 | I think you have to define what you mean here by 'independent'! | An independent professional is not defined in the paper, but is assumed to be somebody who does not work for the clinic to avoid a conflict of interest! It is clear that doctors should not counsel as they have a financial interest in having as much donors as possible. We did not add this in the text, but we did add a recommendation on independent counselling |
| Bryan Woodward/BFS | 10 | 317 | Suggest changing the sentence "Informed consent does not remove the requirement for independent counselling". The offer of counselling should be a requirement. Even with this, some donors may not wish to have counselling, even when it is recommended. Could you add in the recommendation that "Donors should be offered independent counselling beyond that information provided by the clinic or donor bank"? | We have included this suggestion in the recommendations and added the sentence that Informed consent does not remove the requirement for independent counselling |
| Nina Barnsley & Yael Ilan-Clarke | 10 | 321 | As far as we understand, the legal position regarding sharing half-sibling information is unclear in some countries. For example, we think that in Czech Republic even though legally the donor should remain anonymous there are no rules about half sibling contact. It's worth noting that a donor's own children are excluded from the register of half siblings. | We have not included specific situations like the situation in the Czech republic, as the differences of national legislation and registries are outside the scope of the paper and addressed elsewhere |
| Marilyn Crawshaw | 10 | 322 | Here and in various other places you need to say 'country(ies)' as otherwise it implies that there may only be one other country involved – see also line 336. | We corrected this |
| Astrid Indekeu | 10 | 329 | Centre of origin? Strange word | We have adapted the centre of origin to "MAR centre/gamete bank" |
| Marilyn Crawshaw | 10 | 339 | Inappropriate use of 'to be counselled' here – to differentiate from psychosocial counselling, suggest you say 'need to be advised/informed' | We corrected this |
| Marilyn Crawshaw | 10 | 340- 1 | The important point is that they may be found, not that it will result from offspring and their families searching. Every opportunity should be taken to reinforce that it's the presence of the DNA of a close relative (2nd cousin and above) that can lead to identification even if the person themselves has not deposited a sample | we agree with the reviewer and have revised this sentence. |

| Stichting Donorkind | | 342 | Donors should be informed that a growing number of organizations of donor conceived people are lobbying for their human rights to know their biological family and medical history. | We thank the reviewers for their suggestion, but have decided not to copy the recommendation in the text. We did include signposting to support groups, etc. |
|--|----|-----|---|--|
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 10 | 342 | Section on Recommendations could also include points such as: Donor should be made aware of their rights of information on knowing /not knowing the outcome of their donation and their feelings and potential implications about this explored Donors need to be aware of the implications for their own children or children they may have in the future. • Should be aware of the risks of consanguinity. • Whether they would they tell their children of the donation and any resources available to help them with this • Will their children want to know if children have been born as a result of any donation? • How will it be for them as a family in the future if the child/children does, or doesn't make contact with them? • Should they decide not to tell their children, their children could still be contacted in the future via / following DNA testing | We already included a recommendation that donors should be informed of the consequences of the donation on their relatives. Furthermore, we already included a recommendation stating that donors should ideally be allowed at any point in time to request information on the number of families, pregnancies and live births resulting from their donation. "which addresses the comment of the reviewer. |
| Jose Antonio Castilla | 10 | 345 | Delete this recommendation as the donor should be informed about the legal framework of the country where the donation is carried out and the European legislation, but not that of each country where it may be used. This is a recommendation which is logistically difficult to comply with as even the bank itself does not know where the sample will be used when the donor makes a donation. This recommendation would oblige centres to contact the donor each time their gametes were distributed in a new country. | We have rephrased this sentence, now reading that donors should be informed that "legislation may be different in other countries". It would indeed not be feasible to explain legislation of dozens of countries |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 11 | 358 | Could add something like: 'Neither the donor nor the donor-conceived person themselves necessarily need to be signed up to such a service for a genetic link, and possibly even their identity, to be inferred. Additionally, the use of DNA testing is increasing all the time and so may mean matches are more likely in the future'. | Both points are explained in the introduction |
| Nina Barnsley & Yael Ilan-Clarke | 11 | 353 | Donors should also be made aware that with DNA testing earlier contact may be initiated. We do know that some single mothers are putting their children's DNA online to search for half-siblings and/or the donor. | We already included a recommendation reading "Donors should be informed about the implications of direct-to-consumer genetic testing in combination with social media and online information. They need to be fully aware that their genetic identity could be revealed through DNA testing by themselves or one of their family members at any point, even if they were granted anonymity by the legislation of their home/donating country." which addresses the comment by the reviewer |

| Verein Spenderkinder | 11 | 364 | "In general, the number of gametes from oocyte donors is smaller than for sperm donors, as oocyte donation involves medical treatment" – Wording: It is rather an intervention, not a medical treatment when a healthy person is hormonally stimulated. Recommendation: Use the term "intervention" instead of "treatment" | We corrected this |
|--|----|-------------|--|--|
| Bryan Woodward/BFS | 11 | 372 | Remove double bracket | We corrected this |
| Nina Barnsley & Yael Ilan-Clarke | 11 | 384 | It might be worth considering recommending that donors are educated on the rationale behind the offspring limits, to discourage those who might want to donate in addition privately or in other countries and bypass the limits. We are aware of this happening. | We have added that donors should be informed of the rationale behind donor quota |
| Astrid Indekeu | 11 | 390 | Can donors set limits based on families? Shouldn't the initiative be made by policy makers – professionals? On what is this based? | The idea is that donors can adapt the limits of the number of offspring/families within the legal limits. We consider it is indeed relevant for policymakers to set clear legal limits and considered adding a recommendation for policymakers stating this. |
| Bryan Woodward/BFS | 12 | 392 | Suggest expanding the recommendation "Donors should be informed of possible extent of use of their donation nationally and internationally" to add the sentence "This should emphasise that some countries may not have limits, so potentially hundreds of donor-conceive offspring could be born using a donor gametes" | We have added the suggested sentence, although we have rephrased it slightly. |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 11 | 392 | Could add something like: and the implications for them any people conceived as a result of their donation discussed | We have added "and the implications thereof" to the recommendation |
| HFEA | 11 | 399- 400 | 'Some countries have legislative restrictions on the maximum duration of storage of donated gametes 400 (e.g. 10 years in the UK). ' 10 years in the standard storage period in the UK. However, please note that The Human Fertilisation and Embryology (Statutory Storage Period) Regulations 2009 allow gametes or embryos to be stored for longer than the 10 year standard storage period, up to a maximum of 55 years, provided that the conditions set out in those regulations have been met. There are two statutory criteria that must be met: the first is that the relevant person(s) have provided written consent to the gametes or embryos being stored for treatment purposes for longer than 10 years. The second is that, on any day within the relevant period, a registered medical practitioner gave a written opinion that the person who provided the gametes (or in the case of embryos, one of the persons whose gametes were used to create the embryos), or the person to be treated, is prematurely infertile or likely to become prematurely infertile. For more details please see the 'Extension of storage' section of Guidance Note 17 of our Code of Practice. Please also note that The Human Fertilisation and Embryology (Statutory Storage Period for Embryos and Gametes) (Coronavirus) Regulations 2020 (Coronavirus Regulations) came into force on 1st July 2020. These extended by 2 years the 10-year storage limit for embryos and gametes already in storage on 1 July 2020 if certain conditions were met. Full details can be found here. | We have removed the example from the text |

| Astrid Indekeu | 12 | 401 | And what about the large age difference between DCP and ancestor/donor. Does he still wants to exchange info/meet DCP at a high age? | We have added this suggestion in the text |
|--|----|--|--|---|
| Jose Antonio Castilla | 12 | 401 | Include " reducing the risk of consanguinity between half-siblings" | This section related to the duration of storage, the risk of consanguinity is related to the number of offspring and discussed in another section in the paper |
| Petra Nordqvist and Leah Gilman | | 414 | Line 414-415: Donors should also be informed if and how they can update their information as required with relevant organisations | We have added this suggestion in the text |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 12 | Choi ce of a reci pien t - pag e 12 | In The Netherlands the Equal Right for humans issued the statement: not to endorse to discriminate. https://mensenrechten.nl/nl/nieuws/spermabanken-ga-niet-op-discriminerende-voorwaarden-donoren | We have referred to the UN Convention, which we think is more appropriate from an international perspective, but thank the reviewers for the information on the Netherlands |
| Marilyn Crawshaw | | | Clarity that there are a range of recipients; The prevailing assumption in the document is that DC is used by heterosexual couples, especially in the earlier parts of the document. Can I suggest it instead routinely refers to heterosexual couples, same sex couples and single people? It then follows that you need to identify where what is said only refers to heterosexual couples (as is sometimes the case) and can be amended. For example, grief is not always a dominant experience for same sex couples; same sex couples and single people may seek DC because of involuntary childlessness and so on | We have discussed this comment within the working group. The recipients in the paper are heterosexual couples, same-sex couples and single women. This is explained in the introduction, and we have used the terms "recipients" or "(intended) parents", rather than "couples", to ensure inclusiveness. Off course, when studies investigated a certain subgroup, we have reported accordingly. We have not adapted our terminology used, even if we did double-check the entire paper. |
| Bryan Woodward/BFS | 12 | 420 | Is the word "fetter" correct? | We have checked and "to fetter consent" is a correct term in legal language. We state that where this is an option (with regards to the legal framework), donors should be informed that they can restrict access to their donation for certain recipients, We do not make any judgement on whether it should be allowed or be common practice, |
| Petra Nordqvist and Leah Gilman | | 424 | Line 424: Add acknowledgement that clinics may decide not allow donations from those who place certain limitations as the restrictions may be deemed impractical or at odds with equalities legislation. Perhaps also acknowledge that there is a financial interest of sperm/egg banks to get maximum use out of an approved donor, and so not to allow donors to select particular recipients. | We have added to the paper that "in other situations, the clinic may not facilitate recipient selection/exclusion." |
| Astrid Indekeu | 12 | 425 | Prefer more accurate phrasing: they are <i>known</i> to each other <i>prior to start of treatment</i> | We corrected this |
| | | | | |

| Petra Nordqvist and Leah Gilman | | 425 | Also, the paragraph on known donation in the context of embryo donation (lines 425-432) do I think require some engagement with making some recommendations for known donation, even if that is to say that this is an issue that require further investigation. This is especially important given the rise of various forms of known donation, and direct-to-consumer genetic testing. They could for example include the recommendation that people in known donation can access counselling services and support to discuss options in terms of how donors and recipients envisage their relationship to unfold. Another recommendation here could be that donors are informed about the possibility of finding a known recipient or (where applicable) of any possibilities to make contact with recipients prior to, or after, donation. | This aspect is covered in a specific section on known donation, and was not repeated here, |
|--|----|-----|--|---|
| Sarah Norcross | 12 | 435 | '(i.e. fetter their informed consent)' We don't think this phase is correct and think it should be deleted. We think that what is meant here is that donors may as part of the consent process place restrictions on how their donation may be used. Also to use fetter in this context suggests that the donor's autonomy is restricted when it is not, it is the reverse, they are being given more say over what happens with their gametes. If you agree please also remove it from the glossary. | We have checked and "to fetter consent" is a correct term in legal language. We state that where this is an option (with regards to the legal framework), donors should be informed that they can restrict access to their donation for certain recipients, We do not make any judgement on whether it should be allowed or be common practice, |
| Petra Nordqvist and Leah Gilman | | 435 | Line 435: add also depends on clinic policies to first recommendations. Also recommend that donors are told that placing restrictions does not guarantee that their donations will definitely only be used by a certain 'type' of person (e.g. married couples may divorce, opposite sex couples can find new same-sex partner, people may convert religion etc.). | The recommendation states that donors should know if they have a legal right to limit use of their gametes, in which case it is assumed that the clinics apply the law. If this is a concession of clinic, the donor cannot be sure that the limit they wish will be adhered to. This last point is not covered in the recommendation. |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 13 | | Withdrawal of consent - Donor should be informed that a withdrawal of consent is not possible in case the sperm is used for cryo preserved embryos. | The text states that this withdrawal of informed consent is likely limited to any point in time before insemination/fertilization. We have added some further clarification in the recommendation |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 13 | 437 | Withdrawal of consent: Could add something about UK donors have the right to withdraw their consent up to the point of transfer and thus recipients may already have a child via their donation and unable to use stored gametes for a sibling pregnancy if donor withdraws consent. | There is no clear data up to which point consent can be withdrawn, and it seemed that in most cases this is possible up to the time of fertilisation. We consider adding a suggestion that this needs to be clarified fi in the EDQM guide |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 13 | 439 | After word clinics add /countries as it is not always a clinic decision | We have adapted this in the text |
| Bryan Woodward/BFS | 13 | 441 | Is there a reference to support this third group considerations? | This third group was also covered in the review by Kool. We have moved the reference to the end, |

| Cryos International sperm and egg bank | | 444- 446 | They should be able to withdraw up until right before the donation. But when the donation to the TE has taken place, a gift has been given and the right of ownership has been transferred and a processing of the sperm has begun that cannot be undone. To the contrary this independent work effort changes the sperm irrevocably into a product owned by the TE who is the seller on the invoice to the customer. The sperm in its original form does not exist anymore, and it is a well-established principle within the legal areas of property that the transfer of ownership by gift cannot be regretted. For these reasons it is questionable that the donor can withdraw his consent (that merely applies to the extraction of the sperm not the gift) after the donation has been completed. This should be cleared and standardized. | The text states that in some cases ownership is transferred to the clinic/bank, while in others donors keep ownership of their donation. We assume this point is covered. |
|--|--------|-------------|---|--|
| Petra Nordqvist and Leah Gilman | | 448 | Line 448-450: Would add that donors should also be informed, in advance, what the consequences could be of withdrawing consent down the line (e.g. if an embryo has already been created, or a child born) | We have clarified in the recommendation that the timeframe relates to the use of donation (fi whether fertilisation has occurred). |
| Marilyn Crawshaw | 13 | 452- 458 | Without double checking, I'm not sure there's an equivalent recommendation for prospective parents' to be informed if a donor they are considering has died – and if they and/or of the offspring should be informed if the donor they have used later dies. These are tricky situations but they have arisen (see also my comment about transmission of genetic. Information at a later stage) and maybe there could be a recommendation about including it in recipients'consents so that the door is open? | We did already include a recommendation stating that "Regarding post-mortem use of donated gametes, the recipients should be informed that the local legislation and the donor's preferences should be respected." |
| Petra Nordqvist and Leah Gilman | | 462 | Line 462: Our research show that partners, parents and other family may have feelings about the donation, and the donor-conceived people (Nordqvist and Gilman, Forthcoming). Another recommendation might therefore be that donors should be encouraged to tell their next of kin what their wishes would be in relation to their gametes post-mortem and how to enact these (i.e. who would they need to notify and how of their death). Alternatively, such arrangements could be made via a will(?). | We have added a recommendation, as suggested |
| Bryan Woodward/BFS | 13 | 473- 475 | If a potential donor is screened and discovered to be azoospermic/have male infertility, can you add a recommendation that such people should be informed of their result and offered counselling? Some banks may simply say that the person is not suitable to be a donor and leave it at that. | We have added that "where required, offered a follow-up consultation to explain the results and potential implications" |
| Astrid Indekeu | 13 | 473- 475 | Second sentence however, medical and/or also applies to oocyte donation (and is not mention in the section on OD). Suggest adding | We agree with this comment and have reversed the sentences. |
| Petra Nordqvist and Leah Gilman | | 476 | Line 476-489: We found in our research that egg donors experienced very varied follow-up from clinicians following donation. Some had no follow-up post egg collection. | We Added a recommendation stating that "A follow-up consultation with oocyte donors shortly after donation is recommended" |
| Marilyn Crawshaw | 14 | 478 | I find it odd that 'excellent' used here (and nowhere else) as it seems rather strong! Neither does it say what they are satisfied about either here or at line 482! | The referenced paper by Bracewell-Milnes reports "excellent post-donation satisfaction", so we do not consider it required to adapt |
| Verein Spenderkinder | 14 | 480f f | "7.2% had OHSS or immediate bleeding, 11.5% experienced unsuccessful attempts to become pregnant following donation, and 4.9% were diagnosed with gynaecological conditions." - OHSS is due solely to hormonal stimulation. A 7.2% risk for an intervention that is not medically beneficial to | We stated the numbers, without any judgement. Women should be informed of these risks |
| Tim Bracewell- | 14 | 485- | the woman is quite high! This is a surprising finding and may well stem from the country the study was performed in, and the | We have included that the study was |
| Milnes | | 489 | legislation and guidelines in that country | performed in Cyprus |
| | | | | |

| Juliana Pedro | | 400 | | We have added that "where required, offered a |
|-------------------------------------|----|-------------|--|--|
| Juliana Pedro | 14 | 498- 499 | I would say that they should be informed about unanticipated results and, if it happens, an appointment with a reproductive doctor/geneticist should be part of the protocol to explain the | follow-up consultation to explain the results |
| | | | results and the implication for their health/reproductive project | and potential implications" |
| Petra Nordqvist | | 500 | Line 500: Additional recommendation would be that all egg donors have a follow-up consultation | We have added the suggested |
| and Leah Gilman | | | after their egg collection to review their health and any side-effects. | recommendation to the paper |
| Petra Nordqvist and Leah Gilman | | 506 | Line 506-518: Really important to include that donors consider the way in might impact on their own relationships with partners, parents and so on, and consider disclosure, particularly in a context of identity-release donation | We included a section on items to be explored in counselling, and this includes "Donors intention (or not) to disclose that they have donated to their partner, children, family, and friends". We consider there is no further adaptation required. |
| Marilyn Crawshaw | 14 | 513 | Are you sure it didn't say 'including' rather than 'especially'? | The sentence is correct as is it |
| Marilyn Crawshaw | 15 | 526 | I think this should include 'children' and 'current and future' and whether they would like any help in thinking about how to do so | We have added children to the list, but did not think it would add clarity if we added 'current and future" |
| Petra Nordqvist and Leah Gilman | | 526 | Line 526: (current and future) partner, family, own children and friends. Make donors aware that they might have their own understanding of what the donation means, and how they are themselves connected to the recipient family, and that tensions may emerge in families where different people may see these connections very differently. We found for example, that it could give rise to secrets and sensitivities, because family members did no necessarily agree with the donation and yet felt unable to 'have a say' (Nordqvist and Gilman, Forthcoming). Whether they decide to tell or not, these things are important to consider. | We have added children to the list. |
| Nina Barnsley & Yael Ilan-Clarke | 15 | 526 | Perhaps it would be worth expanding this a little bit more – maybe to include the fact that being a donor is likely to be exposed and to consider who would be impacted, how they might feel about it and to encourage openness. | We included a section on items to be explored in counselling, and this includes "Donors intention (or not) to disclose that they have donated to their partner, children, family, and friends". We also added in the recommendation that donors should be considering potential future impact of the donation on their close family. |
| Marilyn Crawshaw | 15 | | Neither set of Recommendations includes any reference to whether any other party affected should be included, if the donor so wishes (e.g. their partners) | We added a recommendation that "Donors should be considering potential future impact of the donation on their close family". However, donors' relatives and social circle are not considered the parties involved in reproductive donation, and information provision is not the responsibility of the professionals in the clinic or donor bank. Therefore, further specific details on donors' relatives and social circle were not added. |

| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 15 | 536 | Add after word identity 'and implications for the donor and any children they may have now or in the future,' | We included a section on items to be explored in counselling, and this includes "Donors intention (or not) to disclose that they have donated to their partner, children, family, and friends". We also added in the recommendation that donors should be considering potential future impact of the donation on their close family. |
|--|----|-------------|---|--|
| Astrid Indekeu | 15 | 536- 537 | Would suggest phrasing it more clearly "Information <i>on the consequence of the increase o</i> f direct to consumer genetic testing" | We have adapted the sentence as suggested |
| Petra Nordqvist and Leah Gilman | | 538 | Line 538-541: Recommendations should also include enabling discussion of implications for donors' current and future partners and families and allowing donors option to have joint or separate counselling sessions for partners or significant others who may feel themselves to be implicated, or who donors feel are implicated. | We included a section on items to be explored in counselling, and this includes "Donors intention (or not) to disclose that they have donated to their partner, children, family, and friends". We also added in the recommendation that donors should be considering potential future impact of the donation on their close family. However, donors' relatives and social circle are not considered the parties involved in reproductive donation, and information provision is not the responsibility of the professionals in the clinic or donor bank. Therefore, further specific details on donors' relatives and social circle were not added. |
| Nina Barnsley & Yael Ilan-Clarke | 15 | 538 | Perhaps worth adding that donors should be provided with support on telling their partner, natural children and potentially other close family and what regulations apply to them in terms of contact and access to information about half siblings outside the family. | We included a section on items to be explored in counselling, and this includes "Donors intention (or not) to disclose that they have donated to their partner, children, family, and friends". We also added in the recommendation that donors should be considering potential future impact of the donation on their close family. |
| Verein Spenderkinder | 15 | 538 | Additional point regarding recommendations for "donors" (genetic parents)): They should be informed that more than 80% of informed children would like to make contact sooner or later, and that it would be important for those to be interested in the child when that happens. (And not just agree to meet as a favor). Recommendation: Please add this point to the recommendations. | The scope of the paper is to provide guidance on information provision to donors. Instructing donors on how to act is outside the scope. |
| Tim Bracewell- Milnes | 15 | 541 | Should fertility treatment involving donor gametes not have mandatory counselling. Counselling is mandatory in the UK, for example. | We clearly recommend counselling for the different parties at different timepoints. We state that "Counselling should be available before, during and after donating gametes" Whether or not this is mandatory would be included in the national legislation and is outside the scope of a good practice paper. |

| Petra Nordqvist | | 541 | 541. As with recipients parents, donors also need support in telling their own children about their | We included a section on items to be explored |
|--|----|-----|--|--|
| and Leah Gilman | | 341 | donation (Nordqvist and Gilman, Forthcoming). Such support should also be made available to their significant others. For example, we have found that both family of recipient families (Nordqvist, 2021) and family of donors (Nordqvist and Gilman, Forthcoming) can struggle with knowing how to talk to children in the family (for example, the cousins of donor-conceived child, or the niece or nephew of the donor). Also include in recommendations that these services are extended to donors who donate in known non-clinic settings. | in counselling, and this includes "Donors intention (or not) to disclose that they have donated to their partner, children, family, and friends". We have not added this details in the recommendation, |
| Astrid Indekeu | 15 | 545 | Suggest changing "defining" into "discuss"as it is a process and may change as life continues | This was adapted in the text |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 15 | 550 | In case of known donations, do the authors have any ideas about contracts between known donors and recipients? In our clinic we recommend donors who are known to the recipients to go to a notary or a lawyer to develop a donor contract incl. information as frequency of donor-child contact, inherit money, etc. Suggestions of the authors of this guideline would be helpful. | We have added a sentence in the text stating that "A (legal) agreement between the donor and recipient can be considered.' We consider this is implicitly covered under the recommendation to clarify roles and relationships, disclosure plans and preference |
| Verein Spenderkinder | 15 | 545 | "If donors and recipients are known to each other (intra-familial donation, known or personal donor) counselling should cover clarifying roles and defining the boundaries between the donor and the recipient family" - Counselors and donors should be aware that relationships cannot be predetermined. You cannot set boundaries to another human being's feelings or even "clarify" what their parents mean to them. That sounds absolutely manipulative and patronizing – and naive. The child should be informed about its genetic parents and should be free to identify for itself the importance of the genetic parents in its life. Recommendation: Change the phrase to "If genetic and legal parents are known to each other (intra-familial transfer, known or personal "donor") counselling should cover clarifying that relationships cannot be predetermined and there cannot be set boundaries to another human being's feelings. All parents must be made aware that the child should be informed and be free to identify for itself the importance of its genetic parents in its life." | We have addressed this comment by mentioning that "boundaries should be discussed" rather than "defined" |
| Petra Nordqvist and Leah Gilman | | 551 | Line 551: Similarly add option for partners and significant others to be included in counselling process (jointly and/or separately). Also recommend that non-clinic donors and their significant others have access to some support, e.g. counselling | We have adapted the recommendation, now reading "Donors (as well as partners/family members) who are known to the recipients (i.e. known donation) should have access to counselling on their own and with recipients in order to clarify roles and relationships and disclosure plans and preferences" We did not include the detail on whether such counselling should be separately. With regards to donation outside of the medical system, considerations are included in the introduction, but not in the recommendations, |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 15 | 553 | In some countries, where a sperm donor is donating to a single woman or same sex couple, the donor and recipients should be encouraged to consult a fertility lawyer | We have added a sentence in the text stating that "A (legal) agreement between the donor and recipient can be considered.' We consider this is implicitly covered under the recommendation to clarify roles and relationships, disclosure plans and preference |

| Tim Bracewell- Milnes | 16 | 563 | Blyth, 2004. This is quite an old reference, and prior to the legislative change in the UK surrounding anonymity and donor gametes. I would suggest using a more up to date references, and also stating the country of origin, to these important findings. | Blyth 2004 explains the possible interpretations and implications from the UN conventions on the right of the child. This was clarified in the sentence. A more recent reference was added for the legislative changes |
|--|----|-------------|--|---|
| Cryos International sperm and egg bank | | 564- 565 | Agree, however, more likely that it might impair the element of voluntariness in the consent. | This was adapted in the text |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 16 | 567 | Could maybe also include here that if the egg sharer did successfully have children, her children would not have the same rights to information and sibling register as the donor conceived children | Throughout the text, we have focussed on donor-conceived offspring, restricting information on the donor's own children. Hence, we did not include this information |
| Tim Bracewell- Milnes | 16 | 568- 570 | Is more detail needed here? What would someone's motives to sperm share be? | Although relevant for completeness, sperm sharing was not considered in detail, and no further information was added |
| Petra Nordqvist and Leah Gilman | | 568 | Line 568: Worth noting here that no evidence that recipient conceiving heightens distress of egg sharers who don't conceive. Our own research (Nordqvist and Gilman, Forthcoming) found that egg sharers in this situation took some comfort from the knowledge of the recipient's success in such circumstances. However, more research is needed. Also consider that sperm sharing is also practiced now in the UK (although is less common) | We have mentioned in the introduction that we have considered egg sharers in so far they are to be considered donors. Specific issues related to the outcome of the egg sharer's own treatment are outside the scope of the current paper. |
| Petra Nordqvist and Leah Gilman | | 570 | Line 570: ethics of gamete sharing needs to be understood in context of limited options available e.g. restrictions on NHS funding | We consider the most relevant ethical aspects of gamete sharing in the context of the paper have been covered. |
| Bryan Woodward/BFS | 14 | 571- 575 | Should a recommendation be that oocyte sharing should means sharing of the oocytes from one cycle, rather than asking the woman to have one full cycle to donate eggs followed by a second cycle for her own use, with the additional risks of a second stimulated cycle? | This option was added to the definition of oocyte sharer. |
| Marilyn Crawshaw | 16 | 571- 5 | I wasn't clear what the potential repercussions were that might be the result of sharing – do you mean less eggs to freeze or something else? | The sentence reads "potential repercussions for their own chances of having a child.", which is indeed less oocytes and lower chance of pregnancy |
| Tim Bracewell- Milnes | 16 | 572- 573 | What do the authors mean by repercussions? We have studied the last 10 years of data for egg share donors in our clinic (pending publication) and found a slightly higher IR, PR, LBR for ES donors compared to standard IVF patients matched for age, AMH and BMI. This is supported by the majority of studies on the outcomes with ES donation cycles. | We acknowledge "potential repercussions" is a bit vague, but we consider that knowledge may increase in the next years. Whether or not reassuring data are/will be available, the potential repercussions to the patients own chances of success are still to be discussed, fi in case of very few oocytes. |

| Petra Nordqvist and Leah Gilman | | 574 | Line 574: 'should be informed about' -> 'should be given the opportunity to discuss'. This needs to be an option for all donors, not just egg-sharers. | We have revised the sentence, but still consider the "implications if their treatment is unsuccessful" specific for the context of gamete sharers |
|--|--------------------|--|---|---|
| Marilyn Crawshaw | 17 | | Top para – focus here is heterosexual couples only and again on line 639 | the paragraph was rewritten to focus on the different recipients |
| Marilyn Crawshaw | 16 | 577 | Do you mean Counselling with regard to contact? | The heading was adapted |
| Tim Bracewell- | 16 | 596- | Why would this not also impact women's social networks if they donated their oocytes? | The sentence related to a study of semen |
| Milnes | | 598 | | donors, so only a conclusion on men could be derived from that study |
| Verein Spenderkinder | 16 | 601 | "Donors and their family should also be able to access counselling before, during and after organized contact with offspring (donor and family) occurs." — Counseling should also be available (especially) when the offspring has initiated contact for which the genetic parent was not prepared. Recommendation: Delete "organized". | We have removed 'organised" as suggested, but as the recommendation includes "before" contact, we consider this prevents the situation where the genetic parent is not prepared, |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 17 | Infor mati on for reci pien ts – pag e 17 | It is usually the same counsellor who offers psychosocial counselling as well as screening of recipients for parental suitability. It would be helpful if the authors share information about this. Do the authors have any recommendations on how to make a clear distinction between counselling and screening? And do they have any recommendations for screening? | We consider that screening of the parents for suitability (welfare of the child assessment) is only performed in case of concerns, and independent on whether the treatment involves donor gametes or not. We consider it outside the scope of the current paper to discuss this issue. |
| Astrid Indekeu | | Proc esse s and patt erns of discl osur e | Instead of mentioning numbers it might be more valuable to refer to factors that might influence disclosure. I miss following reference: Indekeu, A., Dierickx, K., Schotsmans, P., Daniels, K., Rober, P., D'Hooghe, T. (2013). Factors contributing to parental decision-making in disclosing donor conception: a systematic review. Human Reproduction Update, 19 (6), 714-733. Data are mentioned from Chez republic as well as Iran: pointing out the impact of culture is needed. More and more discussed is the fact that disclosure is an an interactive, ongoing process between all family-members. And how support (Crawshaw & Montuschi 2014. It said what it did on the tin) is needed. See also Nordqvist (2021. Telling Reproductive Stories: Social Scripts, Relationality and Donor Conception Sociology. DOI: 10.1177/0038038520981860) how social scripts are needed. So even when single and lesbians are open they also experience a lot of challenges. | We have considered this comment, but many of the references were not included as they fell outside the inclusion limits. We do recommended that "Disclosure should be an ongoing process, rather than a one-off event." and "Families often need support and guidance in this area and tailored support is needed for different family types and cultural settings." which actually addresses the comments made |
| Verein Spenderkinder | 35, Tabl e 2 | | Regarding transition to "donor-assisted conception "Recipients should be provided support and information on how they can talk age appropriately with their children about their conception" - Parents should also be informed about their child's rights. Recommendation: Please add "and about the fact that according to the UN Convention on the Rights of the Child, the child has a right to know his or her genetical parents." | We have referred to the UN Convention, but we did not include the suggestion in the recommendation |

| Verein | 35, | Regarding information provision and informed consent: "Recipients should be informed on the | We acknowledge there are different |
|-------------------------|-------------|--|---|
| Spenderkinder | Tabl e 2 | different forms of donation available to them where they are having treatment, and - if there is a choice - the advantages and disadvantages of 'known', 'anonymous', and 'identity-release' | legislations and opinions about anonymous donation. This paper aims to look at the impact |
| | | donations" We note the recommendation for recipient parents as being informed to the pros/cons of known vs anonymous donations - this suggests there are pros to anonymous donations. Are | of direct-to-consumer testing on anonymous donation but not to advocate for or against |
| | | there any? | anonymous donation |
| | | Recommendation: Please add the pros if there are any or delete the term "advantages and". | |
| Verein | 35, | Additional point regarding information provision and informed consent: Such terms should be used | We are not clear what the comment of the |
| Spenderkinder | Tabl | in the consultation that all participants are perceived as human beings. Misleading terms such as | reviewer refers to, but can confirm that we have |
| | e 2 | "treatment" should be avoided. It should be clear to everyone from the outset that this is a different | been careful in terminology and have double |
| | | form of family formation. There are one or more other genetical parents and usually several (half) | checked |
| | | siblings. | |
| | | Recommendation: Please adjust the wording. | |
| Verein | 35, | Additional point regarding information provision and informed consent: Recipients should also be | We did already include the medical risk for the |
| Spenderkinder | Tabl | informed of the health risks posed by the egg delivering woman or surrogate mother, as the case | oocyte donor. With regards to surrogacy, we |
| | e 2 | may be. Recommendation: Please add this point to the recommendations. | have clarified at the start of the paper that |
| | | | surrogacy is only considered from the |
| | | | perspective of the donation, and further |
| | | | aspects are considered outside the scope of |
| | | | the paper |
| Verein | 36, Tabl | Regarding psychosocial aspects and psychosocial counselling: "Counselling should address the decision of whether or not to disclose to the child." | This paper aims to be non-directive, also towards disclosure. Still, we have revised the |
| Spenderkinder | | | |
| | e 2 | - The question is no longer if, but how parents inform their child. Recommendation: Delete "whether or not" and replace with "how". | section on disclosure taking into account this and other comments |
| Verein | | | Our recommendation "Donors, who are known |
| verein Spenderkinder | 36, Tabl | Regarding psychosocial aspects and psychosocial counselling: "In known donation, recipients should have access to counselling on their own and together with the donor in order to clarify roles | to the recipients (i.e. known donation) should |
| Speriderkirider | e 2 | and relationships, boundaries and disclosure." | have access to counselling on their own and |
| | e 2 | - As mentioned above, counselors and donors should be aware that relationships cannot be | with recipients in order to clarify roles and |
| | | predetermined. You cannot set boundaries to another human being's feelings or even "clarify" what | relationships, disclosure plans and preferences" |
| | | their parents mean to them. The child should be informed about its genetic parents and should be | is consistent with the comment of the reviewer. |
| | | free to identify for itself the importance of the genetic parents in its life. | Specific recommendations for counselling and |
| | | Recommendation: Please change the phrase to "If genetic and legal parents are known to each | what should be included is outside the scope of |
| | | other, legal parents should have access to counselling on their own and together with the genetic | the paper. |
| | | parent counselling should cover clarifying that relationships cannot be predetermined and there | тте рарет. |
| | | cannot be set boundaries to another human being's feelings. All parents must be made aware that | |
| | | | |
| | | the child should be informed and be free to identify for itself the importance of its genetic parents | |

| Verein | 36, | | Regarding legal parents and contact with genetic parents and halfsiblings: "Recipients should be | We have adapted this recommendation based |
|------------------------------------|-------------|-------------|---|---|
| Spenderkinder | Tabl e 2 | | informed about the possibilities of donor or donor-siblings making a link and the importance of support and counselling for all the parties involved." - As mentioned above the desire for contact with the genetic parents and possibly half-siblings is a | on this and other comments. We did not think it was necessary to include that most donor-conceived offspring want to contact their donor. The relevance of this additions seems limited |
| | | | central point. Recommendation: Please insert here: "should be informed that most informed donor conceived people at some point want to contact their genetic parents and often also their (half-)siblings and" and continue with "about the possibilities of donor or donor-siblings making a link and the importance of support and counselling for all the parties involved." | The relevance of this additions seems limited |
| Sarah Norcross | 17 | 603 | We suggest a different word is used than transitioning. Transitioning is now so strongly connected to gender reassignment that a different word or phrase should be used to avoid any confusion. Eg Moving from, Switching from | The heading was adapted |
| Petra Nordqvist and Leah Gilman | | 603 | Line 603-630: Idea of 'transitioning' from ART to DC excludes same-sex couple and single women, as well as some heterosexual couples who always know they will require donated gametes. Better to talk about 'decision to use DC' unless specific focus on this sub-group is what is being discussed. (Also line 612) | The heading was adapted |
| Astrid Indekeu | 17 | 603- 624 | The introduction on this section is still very unstructured, seems to miss a clear focus. Recommendation P 17: I miss support on making the transition from genetic to social parenthood? (see ESHRE CC jan 2021) | We state that "When moving from ART with own gametes to ART with donor gametes, pathways to parenthood should be discussed", The papers main focus is on donor conception, donor anonymity and DNA testing. As information on these issues is relevant from the point of considering donor conception, the transition is discussed, but not explored in detail. |
| Anne Schrijvers, Marja Visser, | 17 | 604- 605 | We recommend to remove the last part of this sentence "even though their chances of a life born baby are much higher". This suggest that having a baby would be more important than having a | We have made the sentence less strong |
| Monique Mochtar Astrid Indekeu | | L60 | baby from once own – or partners' – genes, which we feel is incorrect. In L 605 it is mentioned that donor conception 'is their <i>only</i> option to achieve a family' and L 610 it is | The sentence was adapted |
| Astria maekeu | 17 | 5 & 610 | said 'to discuss <i>other options</i> ? this is a contradiction. Donor conception is one of different options to build a family. | me sentence was adapted |
| Verein Spenderkinder | 17 | 605f | "In other recipients, using donated reproductive material is their only option of achieving a family." This formulation gives the impression that there is a right to have one's own child. Of course, such a right does not exist. Also, note that the definition of a family is highly personal and does not always include the presence of children. Recommendation: Delete "In other recipients, using donated reproductive material is their only option of achieving a family." | The sentence was adapted |
| Sarah Norcross | 17 | 605 | In other recipients, using donated reproductive material is their only option of achieving a family.' We think this sentence should either be deleted or rephrased to something such as this: Some recipients will have been aware using donated reproductive material is their only option of achieving a family. | We have copied in the sentence as suggested |
| Astrid Indekeu | 17 | 606 | What is the purpose/value of this sentence on half-siblings in an introduction paragraph for parents? An introduction regarding donor conception for recipients would focus on how DC (with | We have integrated the sentence to a section on donor quota |
| | | 609 | the involvement of a donor) is different than their dreamed family | |

| Anne Schrijvers, Marja Visser, Monique Mochtar | 17 | 611 and 626 | We feel these two sentences should be expanded: Pathways to parenthood should be discussed which include other options such as fostering, adoption or continuing life without children. | We have adapted the sentences accordingly, but we did not expand on counselling for childlessness or other parenting options. |
|--|----|---|---|--|
| | | | When transitioning from ART with own gametes to ART with donor gametes, pathways to parenthood should be discussed which include other options such as fostering or adoption or continuing life without children. | |
| Petra Nordqvist and Leah Gilman | | 611 | Line 611 and 626: Should also discuss option to not have (any more) children. But also be mindful here that recipient families may live in families, cultures or society where disclosure could lead to significant negative consequences, such as loss of vital family relationships (Dempsey, Nordqvist and Kelly, forthcoming). Counsellors need to be sensitive to the idea that disclosure might not always be a viable option for recipient families. | We have adapted the sentences, but we did not expand on counselling for childlessness or other parenting options. |
| Nina Barnsley & Yael Ilan-Clarke | 17 | 611 626 | Could also include support for childlessness. | We have adapted the sentences accordingly, but we did not expand on counselling for childlessness or other parenting options. |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 17 | Tran sitio n to don or- assi sted con cept ion | Intended parents in heterosexual relationships expressing their interest in family building through donor conception, may be in a state of grief about being unable to conceive with their own gametes within a traditional nuclear family. Grief may take shorter or longer and its intensity between partners may vary. In case couples opting for donor sperm treatment, both may have different feelings towards donor conception. A final decision should not be rushed, but rather be supported by both partners. We feel this should be added to the recommendations (line 625): Counsellors pro- actively should ask intended parents about their experiences with grieve and - if necessary - offer support to this process, so that the decision to opt for donor sperm treatment can be well-considered. Exploring their motivation can strengthen intended parents' trust about their decision, or can make clear the contrary. REF: Cousineau, T. M., & Domar, A. D. (2007). Psychological impact of infertility. Greenfeld DA. Effects and outcomes of third-party reproduction: parents. 2015 | We have addressed the transition to donorassisted conception from the perspective of having to consider a number of extra considerations related to information provision such as disclose of using a donor, possible future contact with the donor. Grief and the relevance of counselling when moving to donor-assisted reproduction, is outside the scope of the current paper. |
| Petra Nordqvist and Leah Gilman | | 622 | 622 There are leaflets available to parents and grandparents in lesbian and heterosexual donor conception families, that show stories of how others have experienced the process. These build on the large scale qualitative study of recipient families (Nordqvist and Smart, 2014) and are freely available online (https://www.socialsciences.manchester.ac.uk/morgan-centre/research/research-themes/kinship-and-relatedness/relative-strangers/information-for-families-with-donor-conceived-children/) | Thank you for this information, very helpful |
| HFEA | 17 | 626- 627 | When transitioning from ART with own gametes to ART with donor gametes, pathways to parenthood should be discussed which include other options such as fostering or adoption. The HFEA's Code states: 20.8 If it is possible that the question of treatment with donated gametes or embryos may arise, the centre should raise this with the person or couple seeking treatment before their treatment starts. The centre should allow people enough time to consider the implications of using donated gametes or embryos, and to receive counselling before giving consent. Our expectation is that the discussion of implications should be delivered by a qualified counsellor. | Thank you for this information, we consider this is covered in the paper |

| Verein Spenderkinder | 17 | 627 | "When transitioning from ART with own gametes to ART with donor gametes, pathways to parenthood should be discussed which include other options such as fostering or adoption." - Adoption and fostering are not "easy solutions" and come with their own set of complications. Adoption and fostering are not about parents wanting a child, but about finding suitable parents for a child in need. This is a crucial difference in perspective. Recommendation: Change the phrase to "When transitioning from ART with own gametes to ART with donor gametes, other pathways, even a life without own children, should be discussed." | We have adapted the sentence, but we did not expand on childlessness or other parenting options. |
|--|----|-------------|--|--|
| Marilyn Crawshaw | 17 | 628 | Not only children but also others, e.g. family members. There are only two studies cited here: I realise there's not a lot out there but, for example, the De Lacey et al should be included and maybe Crawshaw and Daniels? | Further down, we already included a recommendation stating that "Counselling should include exploration of how to handle questions from family, friends and others about their a-typical road to parenthood." We consider this sufficiently addresses the comment of the reviewer |
| Nina Barnsley & Yael Ilan-Clarke | 17 | 628 | The support and information could just be signposting if the person hasn't even gotten pregnant yet. It may be helpful to distinguish between the support needed for people whilst they are having treatment and the support needed for people once they become parents. | We agree that support is needed before and after pregnancy, but information should be given before pregnancy. |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 17 | 630 | Please add the recommendation: Counselors should discuss the difference between nature and nurture and how parents reflect on this. See Visser et al line 622-624. | we have added this recommendation to the paper, although we have slightly rephrased it. |
| Stichting Donorkind | | 631- 638 | recipients should be informed about the medical risks for the resulting donor conceived person/their child of secrecy (missed screening during pregnancy of grandchildren because of giving information about the recipient father instead of the biological father) and informed of the medical risks for the donor conceived person/their child of missing updated medical issues within the wider family of the donor/ | We have added a sentence reading "It should also be noted that if donor-conceived offspring are unaware of their genetic origin, they may fail to benefit from any updates on genetic risks available from the MAR centre/gamete bank." Furthermore, we added a recommendation reading "Recipients should be informed if and at what age their children can access identifiable information about of the donor. They should also be provided information about how any medically relevant updates could occur" |
| Nina Barnsley & Yael Ilan-Clarke | 17 | 633 657 | Should this include what information will be available for the resulting child? | We have discussed this comment within the working group, but we consider additional information on non-identifying biographical information outside the scope of the current |
| | | | | paper |
| Tim Bracewell- Milnes | 17 | 640- 641 | Does this mean the number of babies that will be born from the donor? I think it could be phrased more clearly. | paper The sentence was adapted |

| Nina Barnsley & Yael Ilan-Clarke | 18 | 643 | Recipients with anonymous donors ideally should have it explicitly clarified that the donor will not be expecting to be found and won't have had counselling to prepare them. | We have added a recommendation reading that "Recipients and donor-conceived offspring with anonymous donors should be encouraged to consider that the donor may not expect to be found and will not have had counselling to prepare them." |
|--|----|-------------|--|--|
| Stichting Donorkind | | 644- 648 | Recipients should be informed about the Convention of the rights of the child, especially article 7 and 8. | We have added a reference to the convention, but have not included it in the recommendations |
| Marilyn Crawshaw | 18 | 646 | Another place where you should say country(ies) | In the recommendation we mention the country of the recipient and the country of the donor. Therefore this did not need adaptation |
| Petra Nordqvist and Leah Gilman | | 649 | 649 Donors could also be informed about the advantages and disadvantages of all of these options | The sentence already stated that recipients should be informed of the options and the advantages and disadvantages. No need to adapt |
| Stichting Donorkind | | 650- 656 | This is not an advantage/disadvantage question. Caring for a child brings responsibilities. | the advantages related to the type of donation, not the care for the child |
| Stichting Donorkind | | 652 | recipients should be informed about the lack of quotas and how many children there can be with international gametes and operating clinics. | We have added a sentence, similar to the one for the donors "Recipients should be informed about the lack of (inter)national rules and quotas, and possible consequences thereof." |
| Petra Nordqvist and Leah Gilman | | 656 | Line 656: and don't' include births from non-clinic donations. We found in our recent study (Nordqvist and Gilman forthcoming) that many donors transition between known and identity-release donation, and, for sperm donors, between clinic and non-clinic donation. | We have clarified at the start of the paper that we focus only on reproduction within the clinic and have therefore not adapted the sentence |
| Verein Spenderkinder | 18 | 657 | Additional point from the child's perspective regarding recommendations for recipients: The recipients' desire for clear boundaries is understandable, but nevertheless the child will most likely want to make contact. Recipients should take this into account when making their decision. Recommendations: Please add this point to the recommendations. | We have added a sentence reading "recipients should be informed that their child may is likely to want to contact the donor." |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 18 | 657 | In the Netherlands, children can obtain non-identifiable information about the donor from the age of 12 and identifiable information about the donor from the age of 16. In our opinion, the difference between obtaining non-identifiable information and obtaining identifiable information should be made. We recommend to say: Recipients should be informed at which age their child can obtain identifiable information about the donor and at which age their child can access identifiable information of the donor. | Thank you for this information:, We have added a reference to a recent ESHRE paper presenting the different European Legislations in detail, and therefore have not added this information to the current paper |

| Petra Nordqvist and Leah Gilman | | 662 | 662 In the UK, there seems to be some confusion around who 'owns' the information about the donor conception, with recipient parents being told by their fertility counsellor that the child should be in charge of sharing this information (Nordqvist, 2014). However, with parents feeling the need for support as they go through the process of trying to conceive, this approach can and do have as consequence that grandparents (grandmothers especially) are told but then sworn to secrecy, and so secrets then develop in family networks. The grandparents that we spoke to in this study found this to be a very heavy burden. A better approach would be to recognise that donor conception brings a large number of people into relation, and that many may feel themselves to have a stake in the donor conception, and so feel they too 'own' the story (Nordqvist, 2021). | We acknowledge the different parties being affected by donor-conception and secrecy, but have focussed on the parties that are "attending" the clinic/donor bank, and therefore for which professionals have a responsibility towards |
|--|----|---------------------------------|--|---|
| Stichting Donorkind | | 672 | Again this should be refreshed in name of the rights of the child. | These recommendations refer to the gametes and embryos and therefore it is not relevant to bring the child into this recommendation |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 18 | Choi ce of a don or | Parents' rationale for choosing a known donor or a donor from the sperm bank – anonymous or identifiable – may be driven by feelings of fear that the child will be drawn towards the donor once he/she is aware of their biological link, considering the non-biological parent to be secondary and eventually will reject the non-biological parent during puberty. On the other hand, their preference for a known donor may be driven by the opportunity to meet the donor, to obtain information about him and that the child can know the donor from the beginning and not from – in the Netherlands – the age of sixteen. When making the decision between a known donor or a donor from the sperm bank, intended parent(s) should reflect upon their motivations for this choice and by taking the child's perspective into account. In counselling, the advantages and disadvantages for parents and their children should be discussed as well as parents feelings towards a known donor and a donor from the sperm bank. Counselling can assist in their decision making as well as contact with peers to discuss their experiences. REF: Schrijvers et al., 2019b. Chabot JM, Ames BD. It wasn't lets get pregnant and go do it: Decision making in lesbian couples planning motherhood via donor insemination. (2004). | The message presented by the reviewer is similar to the conclusion of the review by Somers (2017), which has included the study by Chatot. As such, no further modifications were made in reply tot his comment. |
| Stichting Donorkind | | 685- 688 | Of course it should be clear these people use the rationale of 'protection' about imagined threats. this should be a topic in counselling | We consider the reviewer confirms the presented text and no amendments were made |
| Tim Bracewell- Milnes | 18 | 687 | This seems a strange finding/ statement. Why would the child be disappointed in the sperm donor? | The sentence was derived from the study by Somers 2017, and it was not deemed relevant to rephrase the outcomes of the study |
| Petra Nordqvist and Leah Gilman | | 688 | 688-710 It would seem as though relevant qualitative studies into recipient parents are not included here, such as (Almack, 2006; Nordqvist, 2010, 2011, 2015; Nordqvist and Smart, 2014) | We included studies retrieved from the literature search and the experts and selected them based on relevance to the topic and availability if the full text. We did not use any inclusion criteria on whether the studies were quantitative or qualitative. in fact, most of the studies suggested by the reviewers are not retrievable through PUBMED |
| Petra Nordqvist and Leah Gilman | | 692 | line 692: recipients may also want to choose a donor who is similar to one or other or the intended parents as part of the process of creating kinship and connection with their child (not necessarily because they intend to 'pass' as a genetically related parent(s) (Thompson 2005). | We have added this information to the text |

| Tim Bracewell- Milnes | 19 | 694- 695 | I think these 3 references should be in the same bracket. | This was corrected |
|--|----|--|--|---|
| Jose Antonio Castilla | 19 | 696 | Recipients should be warned about the false guarantee of a perfect phenotypic similarity between recipient and donor-conceived offspring if facial biometric data are used for selecting donors, since this does not take into account the genetics of normal-range variation in facial morphology (Xiong et al., 2019; Murillo-Rincón and Kaucka, 2020; White et al., 2021). Looking like someone does not mean sharing the same genes and even less so that all similarities are inherited. Siblings who do not look alike share many genes and people who look alike do not necessarily share genetic information. In addition, recipients should be informed that selecting donors based on catalogues which show donor behaviour, preferences and skills ("Amazon"-style catalogue) which are difficult to inherit is not advisable, because this trivialises the situation and creates false expectations in recipients, commercialising the process of gamete donation and receiving games which is none other than a reproductive health problem which may also encourage solidarity among the members of a society. | We have considered this comment, but consider it outside the scope of the current paper to go into detail on matching strategies. |
| | | | Xiong Z, Dankova G, Howe LJ, Lee MK, Hysi PG, de Jong MA, et al. Novel genetic loci affecting facial shape variation in humans. Elife. 2019;8:e49898. | |
| | | | Murillo-Rincón AP, Kaucka M. Insights Into the Complexity of Craniofacial Development From a Cellular Perspective. Front Cell Dev Biol. 2020;8:620735. | |
| | | | White JD, Indencleef K, Naqvi S, Eller RJ, Hoskens H, Roosenboom J, et al. Insights into the genetic architecture of the human face. Nat Genet. 2021;53:45-53. | |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 19 | Heal th and med ical risk | Some suggestions on the occurrence of a genetic disease: Professionals should ask the recipients to inform the health care professionals on the health of their donor child. Professionals should inform all parents sharing the same donor, if a notification has reach them of genetic disease in a donorchild, the donor should be put on hold until the genetic testing is completed. For a second child the parents can be tested. Donors should inform the professionals if a (genetic) disease becomes known to him/her or in his/her family. Parents should inform the professionals if their child is diagnosed with a genetic disease and subsequently take appropriate action genetic disease in a donor child should be notified at TRIP. | We have added a recommendation reading "Donors should be encouraged to update their information in the MAR centre/gamete bank should relevant medical history appear in the donor or their family." |
| Marilyn Crawshaw | 20 | 735 | I find it surprising that there's no recommendation about choice of donor only about medical risk given that there was a section on what recipients look for in donors. | We have added a sentence that this is considered in medical donor selection, and not necessarily the choice of the donor |
| Tim Bracewell- Milnes | 20 | 735 | Should there be a recommendation that, even if the donor has been genetically screened, the patient still needs to participate in routine antenatal screening for genetic abnormalities? | Antenatal screening is outside the scope of the current paper, as well as details on genetic screening, |
| Verein Spenderkinder | 20 | 738 | Additional point from the child's perspective regarding recommendations for recipients: Recipients should be encouraged to reflect what their choice criteria will communicate to the resulting child. Recipients should take this into account when making their decision. Recommendations: Please add this point to the recommendations. | We have considered and discussed the suggestions and made additions where the working group considered it relevant |

| Marilyn Crawshaw | 20 | 740- 741 | This sentence contradicts itself about how much evidence there is! I also found the ending of this para rather strange as you've already said elsewhere that professional bodies' advice has moved towards recommending openness? | We have adapted the first sentence of the paragraph. |
|--|----|--|--|--|
| Petra Nordqvist and Leah Gilman | | 745 | Lines 745-748 and 784-5 seem at odds with the recommendations for this section | We acknowledge in the sections and the quoted sentences that there is no convincing evidence either way. Still, the working group considered it appropriate to recommend openness and early disclosure |
| Tim Bracewell- Milnes | 20 | 746- 747 | Certainly in the UK, counselling sessions strongly encourage disclosure to the offspring. | We also advise disclosure, which is in line with the comment of the reviewer |
| Astrid Indekeu | 20 | 747- 748 | Please add recommendations of Nuffield report (disclosure at young age is recommended) | We have removed the statement that "There is not enough evidence to recommend disclosure at a certain age, but data suggest that later unplanned finding out can be traumatic", and adapted the recommendation with insertion of the Nuffield Bioethics document |
| Susan Golombok | 20 | 748 | The Nuffield Council on Bioethics 2013 report, "Donor Conception: Ethical aspects of information sharing" concluded that it will usually be better for children to be told, by their parents and at an early age, that they are donor-conceived. | We have removed the statement that "There is not enough evidence to recommend disclosure at a certain age, but data suggest that later unplanned finding out can be traumatic", and adapted the recommendation with insertion of the Nuffield Bioethics document |
| Juliana Pedro | 20 | 751 | "which can be demonstrated empirically" –Is that possible to add some references | We have removed "(which can be demonstrated empirically)". Both arguments are further explained in the referenced paper of Ravitsky. It was not found helpful to put too much details in our paper, and the information is there only to illustrate the discussion on the topic |
| Astrid Indekeu | 20 | 756 | Change to effect on family-relationships? Seems more accurate. | We have adapted the heading as suggested |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 20 | Effe cts of discl osur e on the chil d | Donor-conceived offspring want open conversations with their parents about donor conception. Open conversations with parents from birth on had helped them to talk about their own feelings and thoughts on donor sperm treatment. We feel the following need to be added to the recommendations (line 823): Counsellors can inform parents about the child's perspective and make them aware of child's preference to be informed about donor conception from birth on. REF: Schrijvers et al., 2019a | We consider the suggestions by the reviewers are covered in the recommendations "disclosing to children that they were conceived using donated gametes is advised. In line with other guidance documents, seem to advise suggests that disclosing is preferably done when children are young [Nuffield Council on Bioethics, 2013 #7549]." and "Disclosure should be an ongoing process, rather than a one-off event." |
| Tim Bracewell- Milnes | 20 | 757- 763 | This contradicts the statement in line 740 that there is a lack of evidence regarding the benefit of disclosure. I am aware of numerous studies reporting this finding. | We have adapted the first sentence of the paragraph as this was indeed unclear and could be misinterpreted. |

| | | . <u>.</u> | | |
|-------------------------------------|-----------|-----------------|---|---|
| Susan Golombok | 20 | 757 | A longitudinal study that compared family relationships in disclosing families, non-disclosing families, and those formed by spontaneous conception, found no overall differences between the disclosing and other families. However, within the disclosing group, children who had been told about their donor conception in their preschool years had more positive relationships with their mothers at adolescence (Ilioi, et al., 2017). Another study found little difference between those children who knew and those who did not in terms of family functioning and child well-being (Kovacs, et al, 2015). If have deleted the 'however' in the sentence about the Kovacs study as it doesn't make sense. The Kovacs study did not look at the impact of age of disclosure on later outcomes as the longitudinal study did] | We have corrected the sentence as suggested |
| Marilyn Crawshaw | 20 | 757 on | See my earlier comments about the need to make clear the complexity of the findings and the limitations of research, including the ages of the children involved | The paper provides a broad overview of the published data aimed at explaining and supporting the recommendations. For more details, the interested reader is referred to the original studies/papers |
| Nina Barnsley & Yael Ilan-Clarke | 20 | 759 | The way we feel about it in the Network is that although there is no empirical evidence for harm of not telling, there is evidence of potential harm from late telling and particularly accidental discovery. Given that this document was in part motivated by the realization that DNA testing means that most DCPs will discover that they are donor conceived whether their parents tell them or not, we do feel the potential harms of secrecy cannot be disregarded. We try to make the impact of DNA testing integral to the message of openness as the basis for a positive choice. | Thank you for this comment. We have added a sentence in the document explaining the relevance of direct-to-consumer genetic testing in the context of disclosure. |
| Susan Golombok | 20/ 21 | 766 /76 7 | References would be helpful | References were added to the selected sentence |
| Marilyn Crawshaw | 21 | 768 | Are you sure that caution has been expressed or simply that understanding in the early stages will be limited? | The section includes the sentence "While some parents adopted the seed planting strategy of very early disclosure, caution was expressed that very young children may show little understanding of it, thus emphasizing the importance of disclosure as an ongoing process rather than a one-off event." which we consider addresses this concern |
| Susan Golombok | 21 | 770 /771 | Sentence beginning, 'The age of' repeats paragraph on previous page | We checked but could not find a duplication in the paragraph. |
| Marilyn Crawshaw | 21 | 772- 4 | This is not quite what this study found – it found that even some of those told during childhood could find it hard to come to terms with which, if anything, reinforced that starting in infancy may be better | We have checked the paper and confirmed with the first author. The sentence is correct as stated in the paper, and actually is similar to the reviewers comment. |
| Marilyn Crawshaw | 21 | 781 | The caveat should be that these were all DI families and it's not yet clear whether it was the gender of the parent or the lack of genetic connection that may have been a factor | We agree with the addition suggested by the reviewer |
| Marilyn Crawshaw | 21 | 784 | Should be 'later or unplanned' rather than 'later unplanned' | This was corrected |

| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 21 | 784 | Perhaps add something about no research indicating differences in childs reaction if known/unknown donor | We have considered this comment, but this is outside the scope of the current paper. We consider it unlikely that there is a significant population using a known donor but not disclosing |
|--|----|-----|--|---|
| Petra Nordqvist and Leah Gilman | | 786 | 786-791 Consult addition literature: Nordqvist and Smart 2014, Nordqvist 2014, Dempsey et al 2021. This section also needs to highlight that when early disclosure is encouraged that also requires parents to tell significant others, such as their own parents, siblings and so on (Nordqvist and Smart 2014) | We have added a recommendation stating that "q Recipients should be encouraged to reflect on informing those immediately around and close to their child on their disclosure to the child", |
| Tim Bracewell- Milnes | 21 | 786 | Should this section include the importance of when known donation is performed, or anonymous donation where friends/ family are aware, and the couple plan to not disclose to the child of the nature of conception. This means multiple parties are involved in secrecy and the chances of inadvertent disclosure higher, with potential psychological harm to the child. | We consider that the scenarios described represent a minority. We consider that the bigger picture is sufficiently covered in the paper |
| Nina Barnsley & Yael Ilan-Clarke | 22 | 809 | Same sex couples and solo parents will obviously have had help from an outside person (donor or otherwise) and will therefor have no choice about being open about that. It would perhaps be a better comparison to understand about openness in solo parent and same-sex couple households who have used double donation. Anecdotally within the Network, we know being open about the egg donation side, can be hugely challenging. | We acknowledge that the data form the literature are biased by the type of recipient, and information on double donation in single mothers is for instance not available. We have addressed this issue in the section on future research. |
| Marilyn Crawshaw | 22 | 811 | And there are others that have found the same among male same sex intended parents | We consider that we may have selected the most relevant studies on the topic. Still, we could not find the reference the reviewer refers to and hence have not adapted the paper ² |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 22 | | Intended parents and openness and disclosure The relevance of peer support should be clearly described: Intended parents value contact with peers – others in the same situation or who have gone through the same situation - on how telling their child about the donor conception and how their children reacted on this information. Parenthood-preparation workshops are found to be helpful to get in contact with other (intended) parents. REF: Schrijvers et al., 2019b. Crawshaw, M., & Montuschi, O. (2014). It 'did what it said on the tin' – Participant's views of the content and process of donor conception parenthood preparation workshops. Daniels, K., Thorn P., & Westerbrooke, R. (2007). Confidence in the use of donor insemination: an evaluation of the impact of participating in a group preparation programme | We do refer to literature stating that patients appreciate contact with former patients in the beginning of section on recipients. We have inserted peer support in the recommendation. |
| Astrid Indekeu | 22 | 815 | The title and content are not consistent. The paragraph goes beyond intended parents | We have adapted the heading |

| Marilyn Crawshaw | 21 | 21 | In my experience, lots of such studies do talk about the potential difference between intention and action And I'm rather surprised that you include a study of 3 families so suggest you rethink! There are several studies that report differences between intention and action too Funnily enough, in the next para you yourselves conflate intention and actual disclosure when referring to the French study and that of Rumpkiova et al | We would like to clarify that we do not only refer to the study by Hershberger (which is indeed small, but very recent), but also to the larger study by Applegarth 2016. The second paragraph is not about intention versus action, but on participation in research and its impact on any conclusions. We have not adapted the section. |
|--|----|-----|---|---|
| Anne Schrijvers, Marja Visser, Monique Mochtar | 22 | | Intended parents and openness and disclosure Although disclosure may seem obvious in two-mother households or single mother families, these families also seek for when and how to disclose, and scripts about disclosure should also be discussed in counselling these parents. We feel that this could receive some more attention in the recommendations. Line 827. Families often need guidance in this area and tailored support and scripts on how to disclose donor conception is needed for intended parents of different family types: heterosexual couples, lesbian couples and single women. | The recommendations are written toward all recipients, and therefore could and should be applied for single parents or same sex couples, similar as for heterosexual couples. We do not think it is necessary to clarify that counselling should be tailored to the recipients. |
| Marilyn Crawshaw | 22 | 818 | And I think it was the Ravilengen review that found an association with couple's security in their relationship and disclosure | We are aware that we prepared a broad overview and have not included all details from all studies, as the one mentioned |
| Petra Nordqvist and Leah Gilman | | 824 | 824 Include here recipients should be aware of that disclosure to the child also means disclosure to wider networks, and be invited to discuss what that might mean for them, their child, and their family now and in years to come. | We have already a recommendation reading that "counselling should prepare recipients from questions of family" and consider that no further information is needed on the topic |
| Angela Pericleous- Smith (BICA) | 22 | 825 | Perhaps also add about the "story" needs to be consistent between parents | We recommend support and guidance in disclosing, which should cover aspects like the one suggested by the reviewer. |
| Marilyn Crawshaw | 22 | 829 | The research evidence is fairly limited (but it does exist) that access to peer support is also very important | We have inserted peer support in the recommendation |
| Sarah Norcross | 22 | 829 | 'Access to literature' – this seems a little old fashioned in the age of the podcast, animation, and vlog so perhaps this can be expanded, also we think access to is a little week, perhaps 'signposting to resources such as' may work better | We have adapted the sentence as suggested |
| Nina Barnsley & Yael Ilan-Clarke | 22 | 829 | Perhaps it's worth noting that the idea of openness before having a baby can be overwhelming and daunting, whilst it's obviously very important, we would encourage people at this early stage to simply be told that it is important and that there is support available, not to have too much pressure, and to signpost to organisations such as ours. Maybe integrating the message that in the long run, books, peer support and a DC community can be valuable resources, can be helpful. The message should be: "of course it may be scary and daunting, but there is plenty of time. Don't neglect doing it of course, but don't worry about 'the how or when' at this early stage". | We have adapted the recommendation to "signposting to resources", but have not included the details on the timing of discussions on disclosure |

| Anne Schrijvers, Marja Visser, Monique Mochtar | 22 | | Psychosocial aspects and psychosocial counselling We suggest the authors to expand this section with information about the consequences of unmet needs for psychosocial counselling. Fifty-two women (55%) reported unmet counselling needs. Women in heterosexual relationships mostly had unmet counselling needs on the topics of the decision to opt for DST (n = 11, 58%) and non-genetic parenthood (n = 11, 58%); women in lesbian relationships (n = 10, 40%) and single women (n = 14, 27%) mostly had unmet needs on the topic of choosing a sperm donor. In general, women had good mental health, but 13 (14%) met the criteria for clinical mental health problems. Women with more unmet counselling needs also had more mental health problems. REF: Schrijvers et al., 2020. Psychosocial counselling in donor sperm treatment: unmet needs and mental health among heterosexual, lesbian and single women | We do acknowledge that there are unmet needs for counselling and hope the current paper and the recommendations for counselling at different timepoints will support future donors, parents and offspring |
|--|-----------|-------------|--|--|
| Astrid Indekeu | 22- 23 | 833- 866 | The sections on "Fear of not being" and "the relative importance of genetic parenthood": These data should be integrated, it is not only something of parents, parents do not live in vacuum but in a social context in which a certain norm is hold (society but also the clinic -logically- first aim is a genetic child. | We have removed the subheadings to combine both sections |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 22 | | Fear of not being considered normal by the outside world: If men and women discuss their considerations about donor sperm treatment within their social network, they may be confronted with rejection and stigmatizing reactions, as donor conception is still associated with a taboo. During the counselling process, acceptance of donor conception by extended family and social network should be discussed. Through psycho-education counsellors can help parents anticipate potential reactions and manage societal responses by strengthening parents' coping skills. This could be added to recommendation line 871. | We included the recommendation that "Counselling should prepare recipients for questions from family, friends and others about their a-typical road to parenthood." which covers the comment from the reviewer |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 22 | | Fear of not being considered normal by the outside world: In single women, social support in terms of emotional support and practical support from friends and family should be discussed, as these are important considerations for those contemplating single parenthood. REF: Graham, S. (2019). Being a 'good' parent: single women reflecting upon 'selfishness' and 'risk' when pursuing motherhood through sperm donation. | The paper discusses donor-conception, mainly in respect to direct-to-consumer genetic testing. The considerations of lesbian parenthood are outside the scope of the paper. |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 22 | | Fear of not being considered normal by the outside world We recommend to add some information about the impact of stigmatization in lesbian couples: Contact with other parents in the same situation is helpful and can reduce feelings of "being different" and to understand how others cope with societal rejection. REF: Bos, H. M. W., & van Balen, F. (2008). Children in planned lesbian families: Stigmatization, psychological adjustment and protective factors. | The paper discusses donor-conception, mainly in respect to direct-to-consumer genetic testing. The considerations of single parenthood are outside the scope of the paper. |
| Astrid Indekeu | 22 | 846- 850 | The first 2 lines fit the topic of this paragraph. After "besides the following topics: this is odd to mention here as it is not linked to the title". | By removing the subheadings (based on another comment), this issue is resolved as well |
| Petra Nordqvist and Leah Gilman | | 849 | 849 Also questions about if the donor has children of their own, and what that might mean | We consider this is included in half-siblings, so we have not adapted the text |

| Anne Schrijvers, Marja Visser, Monique Mochtar | 23 | | The relative importance of genetic parenthood We recommend to expand this section on information about the importance of genetic parenthood in lesbian couples. In case of women in lesbian relationships, the intended mothers have to make a decision on who will be the biological mother of the child. Despite practical considerations - as age and work schedules - the emotional considerations should be carefully explored with both women and where needed, also individually. REF: Chabot JM, Ames BD. It wasn't lets get pregnant and go do it: Decision making in lesbian couples planning motherhood via donor insemination. (2004). | The paper discusses donor-conception and genetic parenthood, but specific considerations of lesbian parenthood are outside the scope of the paper. We did add a comment in the paper on the fact that evidence is mainly related to heterosexual couples and that the conclusions may not be generisable to non-heterosexual couples |
|--|----|-----------------|--|--|
| Petra Nordqvist and Leah Gilman | | 851 | 851-866 Include Nordqvist and Smart (2014) for discussions about the paradoxical role of genetics in families by donor conception. | As stated in the methodology, we focussed on peer-reviewed papers. The reference Nordqvist and Smart (2014) is a book. |
| Susan Golombok | 23 | 859 /86 0 | Study by Imrie, et al., 2020 found that some mothers of children conceived by egg donation took some time to bond with their babies, but most had done so by the end of the first year. Imrie, S., Jadva, V., & Golombok, S. (2020). "Making the child mine": Mothers' thoughts and feelings about the mother-infant relationship in egg donation families. Journal of Family Psychology, 34(4), 469-479. | The sentence and reference were added to the text |
| Petra Nordqvist and Leah Gilman | | 859 | 859 Note that this might be very different for same-sex couples and single women ((Nordqvist, Petra Thorn and Boivin, 2021). E.g. for lesbians, it might be associated with opportunity rather than loss. There is a tendency of couple-based heteronormativity here. | We have added a comment in the paper on the fact that evidence is mainly related to heterosexual couples and that the conclusions may not be generisable to non-heterosexual couples |
| Marilyn Crawshaw | 23 | 860 | Het couples | We have corrected this |
| Marilyn Crawshaw | 23 | 861 | This is one study; I can't immediately think of others that report otherwise but practice experience is that fear about bonding is very present and, for some, can continue afterwards | Thank you for this insight. We have softened the sentence and included a further recent study on bonding, |
| Nina Barnsley & Yael Ilan-Clarke | 23 | 861 | Is there a way to soften this finding, e.g. this loss however, for most people does not result | We have softened the sentence |
| Nina Barnsley & Yael Ilan-Clarke | 23 | 866 | Parents can grieve the loss of the genetic connection – its worth remembering that children can also grieve that loss of genetic connection to a much-loved parent/grandparents and extended family/culture. | This is not considered relevant in the section on the intended parents |
| Petra Nordqvist and Leah Gilman | | 867 | 867 counselling should be open to significant others too, such as e.g. parents, siblings | We have not included evidence with regards to support services for family and friends, and consider this outside the scope of the current paper which focusses on donors, recipients and offspring |
| Marilyn Crawshaw | 24 | 871 | Can this be reworded to make clear that it's a shared endeavor Counselling should include exploration of how to handle questions from' | We have adapted the recommendation as suggested by the reviewers |
| Sarah Norcross | 23 | 876 | 'Counselling should address the decision of whether or not to disclose to the child'. We suggest how is included. 'Counselling should address the decision of whether or not to disclose to the child and if they choose to disclose, how to go about this.' | In the section on disclosure, we already included support and guidance regarding disclosure and we did not repeat this information |

| Tim Bracewell- Milnes | 23 | 877- 878 | The donor should also have a counselling session alone | This recommendation was included twice, once also in the donor section, and there include the suggestion of the reviewer |
|-------------------------------------|----|-------------|--|---|
| Verein Spenderkinder | 23 | 879 | Additional point from the child's perspective regarding recommendations for recipients: Intended parents should be informed that social relationships cannot be planned and that genetic parents and (half) siblings may also be important to their children. Recommendations: Please add this point to the recommendations. | We have discussed this suggestion, but have decided not to incorporate this in the recommendations. |
| Astrid Indekeu | 23 | 881 | Meaning of the donor: I suggest more explicitly state from the start that all type of Dc families somehow struggle with the meaning of the donor cfr Nordqvist work as well as Zadeh's work. More important, this is also a process and people can change in how they view the donor: Indekeu et al, 2014b. When sperm becomes a donor | We added a sentence to the start of this section, as suggested by the reviewer. |
| Petra Nordqvist and Leah Gilman | | 881 | 881 Nordqvist and Smart (2014) found that the donor could require an absent presence in recipient families. Overall, we found that the donor figures in much more complex ways that it is alluded to here. | Unfortunately, we did not pick up the book by Nordqvist and Smart (2014) when searching for literature |
| Tim Bracewell- Milnes | 23 | 889 -891 | Should this be actively discouraged amongst same sex couples? If they have this thought process they could be psychologically harmed if there was contact between the offspring and the donor in the future. | We have found no evidence to back this up, and hence decided not to adapt the text |
| Petra Nordqvist and Leah Gilman | | 889 | 889 See also Nordqvist 2011 | This study was published before the limit of inclusion of studies from the literature |
| Astrid Indekeu | 24 | 896 | Indekeu 2014b is not about lesbian or single couples. So incorrect reference at the end of this phrase. The main message of Indekeu et al., 2014 b is that in a longitudinal study (heterosexual) parents can change their view of the donor over time due to feeling more confident as parent | We removed the reference |
| Astrid Indekeu | 24 | 901 | Psycho-social health : Please change to psycho-social well-being Also a strange place for this paragraph as this is one of the first questions that was asked in this field (see Golombok 2015). I suggest to move it more upfront | We adapted the heading |
| Marilyn Crawshaw | 24 | | 3rd para – see my earlier comments about these studies | Both the comment and the section referred to were unclear, so no action was taken |
| Nina Barnsley & Yael Ilan-Clarke | 24 | 904 | Should motherhood be changed to parenthood, or motherhood and fatherhood? | we adapted to parenthood which is indeed more appropriate |
| Susan Golombok | 24 | 909 | This isn't quite right as parents of sperm donor conceived children are ART parents | It was clarified that ART parents refers to those using their own gametes |
| Petra Nordqvist and Leah Gilman | | 910 | g10 note that questions about the donor may remain, as the child grows up (Nordqvist and Smart 2014), and as the child start to show particular characteristics, likes or dislikes. This is a very real aspect of parenthood (and grandparenthood) through donor conception, and need to be considered too. | The questions of offspring with regards to the donor in different ages is covered in the offspring section |
| Nina Barnsley & Yael Ilan-Clarke | 24 | 910 | Is it worth acknowledging the limitations of these studies? Small numbers, large drop out rates, wide variation in family circumstances and children/young people still young (under 20). | The paper provides a broad overview of the published data aimed at explaining and supporting the recommendations. For more details, including the limitations, the interested reader is referred to the original studies/papers. The limitations of the evidence in general is considered in the section "lack of research" |

| Susan Golombok | 24 | 914 | Imrie & Golombok (2018) is on egg donation only. The sentence beginning, 'During infancy' and the following sentences that reference Imrie & Golombok (2108) in this paragraph are about egg donation only. | We have clarified that the study is on oocyte donation |
|------------------------------------|----|-----------------|---|--|
| | | | For a review that includes families formed by sperm donation as well as families formed by egg donation see Imrie & Golombok (2020) Impact of new family forms on parenting and child development. Annual Review of Developmental Psychology, 2,295-315. | |
| Petra Nordqvist and Leah Gilman | | 925 | Line 925: This should also be discussed with donors, particularly the implications for their own current and future children who may not necessarily have access to the same services as donor-conceived siblings from the same donor. | We have mentioned that donors should be informed on the implications for their relatives and children, but discussing these implications and how to resolve them in detail is outside the scope of the current paper |
| Susan Golombok | 24 | 929 /93 0 | Reference should be: Golombok, et al., 2017. Golombok, S., Ilioi, E., Blake, L., Roman, G., & Jadva, V. (2017). A longitudinal study of families formed through reproductive donation: Parent-adolescent relationships and adolescent adjustment at age 14. Developmental Psychology, 53(10), 1966-1977. | The reference was corrected |
| Susan Golombok | 24 | 930- 932 | This finding has been reported in previous paragraphs – see Ilioi, <i>et al.,</i> (2017) reference | This was indeed a repetition and has been removed |
| Susan Golombok | 25 | 933- 943 | See also: Freeman, T., Jadva, V., Kramer, W. & Golombok, S. (2009) Gamete donation: Parents experiences of searching for their child's donor siblings and donor. Human Reproduction, 24, No. 3, 505-516. Jadva, V., Freeman, T., Kramer, W. & Golombok, S. (2009) The experiences of adolescents and adults conceived by sperm donation: Comparisons by age of disclosure and family type. Human Reproduction, 24, No 8, 1909-1919. | Both papers were published prior to 2014 and therefore not discussed in the paper |
| Petra Nordqvist and Leah Gilman | | 933 | Line 933 Consider Deborah Dempsey's current study of contact in Victoria, Australia | Difficult to include a current study, so we have not adapted the text |
| Astrid Indekeu | 25 | 934- 950 | Difference should be made between parents searching themselves (either for themselves or their child), - parents whose children search. There are differences in emotions. Please see: Indekeu, A., Maas, A., McCormick, E., Benward, J., Scheib, J. (2021). Factors associated with searching for people related through donor conception among donor-conceived people, parents and donors: a systematic review. F & S Reviews, 2 (2), 93-119. doi: 10.1016/j.xfnr.2021.01.003 | We have checked the paper, but as it is too recent, it was not found in the literature search. We decided not to add it to the paper. T |
| Marilyn Crawshaw | 25 | 952- 3 | I struggled to understand what was meant here | We have clarified the recommendation |
| Sarah Norcross | 25 | 952 | Recipients should be informed about the possibilities of donor or donor-siblings making a link and the importance of support and counselling for all the parties involved. We weren't clear what is meant by make a link – do you mean make contact? If so, it may be better to say so. | We have clarified the recommendation |
| Petra Nordqvist and Leah Gilman | | 952 | 952 Also consider the role of donors' family and especially own children here. | This recommendation is formulated towards the recipients. We included a connection with the donor or other genetic relatives |

| Verein Spenderkinder | 25 | 954 | Additional point from the child's perspective regarding recommendations for recipients: Intended parents should be clearly told that the "donor" is a person whom the child will probably want to meet sooner or later. The child does not exist without its other genetic parent. In order for the parents to fully accept the child, it is important that they can accept this person as such. The way the parents talk about him/her transmits to the child the needs of its parents. The child feels, for | Our paper focusses on information provision to recipients and offspring. We refrained from making any recommendations towards disclosure and hence, we did not add the suggested points to the recommendations |
|-------------------------------------|--------------|------|---|--|
| | | | example, whether it is allowed to express interest in this person at all or not. Recommendations: Please add this point to the recommendations. | |
| Verein | 37, | Tabl | The word "children" is repeated. | We could find a duplication of the word |
| Spenderkinder | 5 , 1 | e 3 | Recommendation: We strongly recommend "people" instead of children. | 'children" in table 3, but we will perform a proofreading of the final paper. |
| Verein | 37, | Tabl | "When not available, the treating clinics/gamete banks should ideally have relevant support | We have made this correction |
| Spenderkinder | | e 3 | structures available." | |
| | | | - As mentioned above, transferring gametes to a fertile woman is no medical treatment. | |
| | | | Recommendation: In the sentence "When not available, the treating clinics/gamete banks should ideally have relevant support structures available." "treating clinics" should be replaced with "mediating clinics". | |
| Verein | 38, | Tabl | "Donor-conceived children/adults should be able to access counselling when considering trying to | We have adapted to donor-conceived offspring |
| Spenderkinder | | e 3 | find donors and/or siblings through direct-to-consumer genetic testing" Recommendation: Please replace "children/adults" with "donor conceived people". | throughout, |
| Verein Spenderkinder | 25 | 960 | "in some countries, fertility clinics are being confronted with new demands such as the request for information about donors by donor-conceived adults (Beeson, et al., 2011)." | Adapted as suggested |
| | | | - Not only donor-conceived adults, but also children/minors demand information. | |
| | | | Recommendation: Change the phrase to "During the last twenty years, in many countries, fertility | |
| | | | clinics are being confronted with new demands such as the request for information about donors | |
| | | | by DCP (e.g. Beeson, et al., 2011)." | |
| Tim Bracewell- | 25 | 967- | Who should provide this? | We have included in the paper a sentence |
| Milnes | | 968 | | stating that "Fertility clinics and donor banks should have in place resources and training to ensure the relevant staff groups are available and can provide informed support to donors, intended parent(s) and offspring. "This addresses the comment of the reviewer. |
| Nina Barnsley & Yael Ilan-Clarke | 25 | 967 | Could you add resources (websites, books) as well as opportunities to connect with others, as part of the recommendations? | We have added a recommendation for signposting to relevant resources |
| Astrid Indekeu | 26 | 974 | I don't see the added value of this sentence? Either add Scheib, J. E., & Ruby, A. (2009). Beyond consanguinity risk: Developing donor birth limits that consider psychosocial risk factors. Fertility & Sterility, or Indekeu, A., Bolt, S., Maas, A. (2021). Meeting multiple same-donor offspring: psychosocial challenges. Human Fertility. doi: 10.1080/14647273.2021.1872804 | We have considered this comment and others on the same paragraph and decided not to adapt the sentence. |
| Susan Golombok | 26 | 975 | Jadva figure is out of date. There have been newspaper reports of larger numbers. | We are aware of anecdotal reports of larger groups, but this has not been mentioned in published data |

| Nina Barnsley & 2 Yael Ilan-Clarke | 26 976 | Are these referring to informing 'children'? What age do you mean? Who would be responsible for informing them? Our feeling is that under the age of 16 the parents should be used as the conduit. If you are actually referring to donor offspring, 18+, then certainly they should be informed. We would recommend that parents are informed, and parents should be supported in working out what age this would be appropriate for them to share this information with their child, for some this | We did include a recommendation that recipients should be provided support and information on how they can talk age- |
|---------------------------------------|--------------|--|---|
| | | would be earlier and for some later. | appropriately with their offspring about their conception. We clarified in the offspring section that all information provision to children and young adults should be done through the parents. |
| Marilyn Crawshaw 2 | 26 976 on | I'm not sure why the recommendations refer to children rather than DC offspring or people? At what stage are you recommending that they be informed and by whom for the first two recommendations. The 3rd recommendation assumes info will only be released at age of majority; some countries allow at age of maturity; some at 16; some allow non-identifying info to be released to them earlier than identifying and so on | We have used "offspring" throughout |
| Sarah Norcross 2 | 26 976 | Recommendations – could a recommendation be added that donor-conceived people who do not have an identity-release donor should be signposted to the any voluntary registers that may exist in their jurisdiction. Having read further we see this recommendation is made in a different section. We assume you don't want to include it twice. | We did include a reference to donor registries. We hope that overview tables will facilitate reading, |
| Stichting Donorkind | 976- 987 | Should be informed about the possibility to reach out to organizations of donor conceived people. | We have discussed this option, but as we already mentioned in the following section "Signposting to resources such as literature (books), websites, peer support groups, dedicated counsellors and organisations may assist donor-conceived offspring." we decided not to make further amendments |
| Petra Nordqvist and Leah Gilman | 977 | Line 977-981: change 'children' to 'people' as these are not particular to under 18s (I think) | We have adapted to donor-conceived offspring throughout |
| Verein 2: Spenderkinder | 26 982 | "Donor-conceived children born after the lifting of anonymity should be informed from an early age about the type and content of information that will be released to them when they reach the age of majority." In some countries, there are no age limits or age limits other than the age of majority. Recommendation: Replace "that will be released to them when they reach the age of majority." with: "which they can receive (possibly from a legally defined age)." | We thank the reviewers for this suggestion, and have adapted the sentence accordingly |
| Astrid Indekeu 2 | 26 983 | 'Age of majority' change to ' <i>eligible age'</i> cause in some countries they can receive information much sooner | We have rephrased this sentence based on another comment |

| Astrid Indekeu | 26 | 984 | Last recommendation: it should entail that DCP should also be informed that they might have more donor-relatives as the international donor quota says, as this quota is defined per country. With international sperm banks a DCP can still have many other donor-relatives in other countries. With the internet, (blogs, facebook groups,) people can be confronted with much more donor relatives. | We agree with the reviewer, and this is what is stated in the recommendation "Besides being informed about the maximum known number of same-donor offspring / families that they can be genetically related to, donor-conceived offspring should be informed that there is no guarantee that this number will not be surpassed." |
|--|----|--------------|---|--|
| Verein Spenderkinder | 26 | 987 | Additional point regarding recommendations for DCP: DCP should be informed about possibilities to contact their (half-)siblings. Recommendation: Please add this point to the recommendations. | This is covered in the section 'Searching and contacting genetically related people' |
| Astrid Indekeu | 26 | 989- 1013 | I suggest switching order of paragraphs: Start with "From early childhoodMurray et al., 2006) and then "being a DCP" L 1005-1006: belongs to paragraph on 'contact' " | We have switched the paragraphs, as suggested |
| Marilyn Crawshaw | 26 | 998 | whose families disclose later or who find out unplanned I'm also concerned that in several places it implies that disclosure per se is protective of well-being whereas there is also evidence that it's more to do with openness and ongoing interactive dialogues. Some studies show that disclosure as a one-off events especially with instructions to the child to keep it secret can be harmful etc | We have discussed disclosure in more detail in the other sections, and here we focus on the psychosocial health of donor-conceived offspring, The recommendations formulated in the disclosure section seem to be in agreement with the comments of the reviewer |
| Anne Schrijvers, Marja Visser, Monique Mochtar | 26 | | The psychosocial health of donor-conceived offspring In 1986, the first longitudinal study (National Longitudinal Lesbian Family Study) to provide follow-up data on the social, psychological and emotional development of the first generation of lesbian families who conceived through donor sperm treatment was started. Data were collected during the treatment phase and when the children were 2, 5, 10, 17 and 25 years old (Gartrell et al., 1996, 1999, 2000, 2005, 2010, 2018). The overall findings were that donor-conceived offspring raised in two-mother families had good mental health equal to that of their peers. Some children were challenged by stigmatization and homophobic reactions because of the sexual orientation of their parents and this had a negative impact on their mental health (Bos et al., 2013). Specifically, more than sixty percent of the children in lesbian families was ever confronted with annoying questions, abusive language, jokes, gossip and/or exclusion because of their mothers' sexual orientation. Factors such as positive relationship with the parents, contact with other children in two-mother families and supportive schools and communities protected children from the negative effects of stigmatization (Bos et al., 2008). We feel information about the wellbeing of donor children in lesbian families as well as the role of stigmatization should be added to this paragraph. | The paper provides a broad overview aiming to guide practice. We acknowledge that a number of issues have not been covered in detail, due to indirect relevance to the topic, or for MAR professionals to be informed about/act upon. As such the topic of stigmatization was not discussed in detail. |
| Nina Barnsley & Yael Ilan-Clarke | 26 | 100 6 | The word 'stronger' – what does that mean in this context? | We have removed this sentence |
| Nina Barnsley & Yael Ilan-Clarke | | 1010 | Are the findings of that study/group of studies sufficiently robust to justify the statement in line 1007-1013? | We considered that the studies are relevant to be included. This section outlines the available data, and does not make any strong recommendations/interpretations |

| Susan Golombok | 26 | 1011 | The publications cited are from two separate longitudinal studies: The European Study of Assisted | We removed this details from the text as this is |
|------------------|----------|-----------|---|---|
| | | -13 | Reproduction Families and the UK Longitudinal Study of Assisted Reproduction Families. Please | redundant considering the references |
| | | | could you insert and the UK Longitudinal Study of Assisted Reproduction Families into the sentence. | |
| Astrid Indekeu | 27 | 1017 | I do not agree with the recommendation: This is not a counsellors job, but the job of the parents. | We have adapted the recommendation in reply |
| Asiria iriaekea | ۷/ | 101/ | But counsellors should support parents in how to discuss this with them. See Indekeu, A., Lampic, | to this comment |
| | | 1019 | C. (2018). The interaction between donor-conceived families and their environment: parents' | to this comment |
| | | 1019 | perceptions of societal understanding and attitudes regarding their family-building. Human Fertility, | |
| | | | 1-11. doi: 10.1080/14647273.2018.1533256 Open Access | |
| Nina Barnsley & | 27 | 1018 | This could be better achieved, potentially, through parents getting peer support or emotional | We have adapted the recommendation in reply |
| Yael Ilan-Clarke | , | | support and them giving children access to resources and guidance (for example DC Network's | to this comment, and added a second |
| | | | primary school materials). | recommendation on signposting to resources |
| Petra Nordqvist | | 1018 | Line 1018: there should also be the option to have counselling with parents, siblings or others. | Support services for family and friends are not |
| and Leah Gilman | | | | explicitly stated, as there is also no evidence for |
| | | | | this. In this context, it would be up to the |
| | | | | individual situation whether counselling with |
| | | | | the parents, siblings or others would be helpful |
| Petra Nordqvist | | 1019 | 1019. Some recognition here that once the story is out, it cannot be taken back. 'Unwanted | We have adapted the recommendation in reply |
| and Leah Gilman | | | questioning' is not the only thing that needs to be taken into consideration, but also: What if | to this comment |
| | | | teachers don't understand about donor conception, or do not know how to talk about it? What if | |
| | | | communities and schools are judgemental about it. How can young children cope with embedding | |
| A = 4.2.3 1 | | | this information in their lives in a positive way? | W/s because death at the death at the |
| Astrid Indekeu | 27 | 1021 | Perceiving (I would suggest 'Perception) the relationship with parents and Disclosure: This is | We have adapted the heading. Indeed, the information was provided here because it |
| | | - 1034 | information that should be given to parents not to DCP. It is mentioned here probably because it reflects experience of DCP, but this is information that is important that parents know. | reflects experience of DCP. There are no |
| | | 1034 | reflects experience of DCP, but this is information that is important that parents know. | recommendations, as these are covered in the |
| | | | | parents section |
| Susan Golombok | 27 | 1022 | This should be the UK Longitudinal Study of Assisted Reproduction Families | We removed this details from the text as this is |
| Cuban dolonibon | _/ | 1022 | This should be the extensition at the extensition to the extensition to the extensition of the extensition and the extensition of the extensition | redundant considering the references |
| Susan Golombok | 27 | 1031 | Insert Ilioi, <i>et a</i> l., (2017) | We inserted the reference |
| Tim Bracewell- | <u>:</u> | 1034 | 'is described above', it would be helpful for readers to have it stated specifically which sections | We inserted the reference |
| Milnes | , | 0. | this is available | |
| Marilyn Crawshaw | 27 | 1036 | Although I suspect this is now true, I'm not sure that we know it to be the case? | We removed the word "mainly" as we know |
| • | | | | they use "direct-to-consumer genetic testing" |
| | | | | but not whether this is the main pathway |
| Marilyn Crawshaw | 27 | 105 | I think this is 'trait resemblances' but do check Interestingly the VARTA studies suggest different | We have corrected "resemblance" to "trait |
| | | 0 | motivations. Consanginuity should also be here anyway and desire for medical information | resemblance". With regards to medical history, |
| | | | | the next sentence covers this, it reads "Other |
| | | | | reasons for searching the donor include |
| | | | | |
| | | | | wanting to learn about their medical history ", |
| | | | | |

| Nina Barnsley & Yael Ilan-Clarke | 28 | 1062 | "small percentage" – very interesting that it's not zero. We would be curious what sort of numbers this refers to and what the context was. | We suggest the reviewers check out the study for more data. The paper provides a comprehensive overview, and it was not feasible for readability to include that level of detail |
|-------------------------------------|----|-------------|--|--|
| Nina Barnsley & Yael Ilan-Clarke | 28 | 1064 | The finding from Zadeh's study that "search for their donors to learn about their motivation to donate" – should be ploughed back into the recommendations for donors when thinking about donating and what they are going to say to any DCP that may contact them in the future | We have added the study of Zadeh in the section on donors and their motivation to donate |
| Susan Golombok | 28 | 106 6 | This doesn't make sense. Children aged 1 can't have a clear understanding of conception – they can't even talk! It's not my study, but I thought I should point it out. | This sentence reports the findings from the study, but we agree with the relevance and have adapted to <6years |
| Marilyn Crawshaw | 28 | 106 8 | But didn't the Carone study show that some were not told about the egg donor? | The study reports on 31 children who were aware of the surrogate, of which 25 children who were also aware of the egg donation. We have adapted the information in the text. |
| Verein Spenderkinder | 28 | 1079 f. | "When asked about the three most important pieces of information to give to future donors, almost half of donor-conceived offspring recommended that donors should make themselves known, one quarter reported that they should take responsibility for their actions, and one fifth think it is important that donors know that future offspring might want to contact them (Hertz, et al., 2013)." Recommendation: These two points should be added in these recommendations. At line 1079, the paper says that just 20% of DCP people feel "donors" should know their "offspring" might want contact. But the We Are Donor Conceived (WADC) survey reports: • "66% of respondents believe that donors 'have a moral responsibility to their donor conceived offspring"; • 70% of respondents believe they have been harmed by not knowing the donor's identity; • 80% believe they have been harmed by not knowing the donor's medical history. "The explanation for these feelings of harm is perhaps best understood by how survey participants responded to statements regarding the donor's identity and family health history, such as "The identity of my donor is information that belongs to me" (86% agree), "My donor is 'half of who I am'" (77% agree), and "It is important for me to have a health history for myself/my children" (96% agree / 95% agree)." Recommendation: Please refer to the WADC survey results as a more recent source. | We did not include the report, as the evidence was restricted to peer-reviewed published data. The recommendations that donors should be aware that offspring may want to contact them is more or less covered in the donor section where we state that donors should be aware of the implications of their data being shared with offspring, through the clinic, direct-to-consumer testing or donor registries |
| Marilyn Crawshaw | 28 | 1083 -93 | See my comment above about use of 'children' and also the need to say when this should happen | We have adapted to "offspring" in all recommendations. Regarding when information should be provided, we have no information and could not add this to the recommendations |
| Sarah Norcross | 28 | 1084 | We are not certain that the first bullet should be at the top of the list and the way it is written could be taken as that using DCT to find a donor / donor-siblings is a good and necessary thing to be done. | We have adapted the order of the recommendations |

| Nina Barnsley & Yael Ilan-Clarke | 28 | 1084 | The reference here to 'children', perhaps needs to be changed? As per our comment on page 26, line 976. Perhaps the use of the word counsellor should be replaced with the term 'family support services', to include professional support where needed, as well as the wider support from peer support organisations and other resources available. | We have adapted to "offspring" in all recommendations. We did not use counsellor in this section, but have considered the comment to use "family support services" rather than counsellor in the recommendations |
|--|----|----------|---|---|
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 28 | 1093 | Perhaps also include Donor conceived children should be informed any information received may have changed over time i.e. the possibility the donor has changed gender | We have added "and that this information may have changed since provided by the donor" in the recommendation |
| Marilyn Crawshaw | 29 | 109 6 | This contradicts what you said on p27 (see my comment above) – it's important to be alert to the date of publications – the Beeson et al study gathered its data well before DTC companies took off! | We removed the sentence as it repeated earlier stated information and indeed the references was not appropriate |
| Nina Barnsley & Yael Ilan-Clarke | 30 | 1138 | These recommendations could benefit from the inclusion of peer support for families and DCPs and appropriate resources, as well as the access to professional counselling services. | We already mentioned that counselling should be available, and based on another comment, we have added that "Signposting to resources such as literature (books), websites, peer support groups, dedicated counsellors and organisations may assist donor-conceived offspring." We think both recommendations cover the comments of the reviewer |
| Sarah Norcross | 30 | 1143 | When not available, the treating clinics/gamete banks should ideally have relevant support structures available.' We are curious as to why the word ideally has been used here. We think it should be removed. | We have removed the word "ideally" |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 30 | 1150 | As above (1093): Perhaps also include Donor conceived children should be informed any information received may have changed over time i.e. the possibility the donor has changed gender | We felt it was not required to repeat this information here |
| Petra Nordqvist and Leah Gilman | | 1153 | Line 1153: possible additional recommendation that donor conceived people should be informed that not all donors will have told their partners and/or all of extended families that they have donated. | We included the recommendation* If donor-conceived offspring are able to contact the donor (and start a relationship), counselling should be available so they can discuss their expectations and inclusion of the donor in their personal lives.", which includes, among other aspects, that donor conceived people are informed that not all donors will have told their partners and/or all of extended families. We have not added this information to the recommendation |

| Verein Spenderkinder | 30 | 1153 | Additional point regarding recommendations for DCP: Counselors should also provide legal assistance to DCP when there are problems with doctors and clinics who do not want to provide information even though they are required to do so. It is therefore important that counselors operate independently of reproductive physicians and can act in an unbiased and neutral way." Recommendation: Please add this point to the recommendations. | We included the recommendation" q Clinics should be prepared to manage the requests of donor-conceived offspring to access information about their donors and act according to national legislation." We do not want to expand on legal issues |
|-------------------------------------|----|-------------------|--|--|
| Marilyn Crawshaw | 30 | 1155 on | As we are now seeing multiple siblings who share a donor, this evidence looks rather dated as it doesn't include this (see recent paper by Indekeu et al) but is an important feature, especially for those conceived through DI | We have checked the paper by Indekeu, which was not included as published after the inclusion deadline. We are not sure what additional information the reviewer suggests to add. |
| Verein Spenderkinder | 30 | 1163 | Regarding searching and contact with half-siblings and other relatives it is mentioned that "of those who report neutral or negative experiences, there is a greater proportion from heterosexual and single-parent families compared to lesbian parent families (Jadva, et al., 2010). There is also the speculation that single children might be more prone to wanting to contact or establish a relationship with same-donor offspring (Jadva, et al., 2010), but no comparative study has been done so far." - Additional hypothesis following the findings of Beeson et al. (2011): It may also be easier for single children to make contact because they do not have to consider the feelings of siblings they grew up with. Just as it may be easier for children of single mothers because they do not think they have to consider the feelings of the social father. Recommendation: Add the hypothesis "Following the findings of Beeson et al. (2011), it might be easier for single children to make contact because they do not feel responsible to consider the feelings of siblings they grew up with. Just as it is easier for children of single mothers because they do not feel responsible considering the feelings of the social father." | We have rephrased the sentence to incorporate this information |
| Nina Barnsley & Yael Ilan-Clarke | 30 | 1174 | When and by whom would the DCP be informed and offered counselling? Parents should be supported to prepare their children for the occasions mentioned in these recommendations (e.g. expectation management) The recommendations are great for counsellors and other professionals, should they be contacted by DCPs when they embark upon this process of discovery. | We have added a statement at the start of the paper stating that the recommendations are formulated towards fertility clinics and donor banks, who should have in place resources and training to ensure the relevant staff groups are available and can provide informed support to donors, intended parent(s) and offspring. |
| Marilyn Crawshaw | 30 | 1177 | As in an earlier comment, if you're talking about psychosocial counselling, you shouldn't say 'be counselled' so this needs rewording | We have adapted the recommendations accordingly |
| Sarah Norcross | 31 | 1180 | 'Donor-conceived offspring should be cautioned before making links that this reveals their identity and that this is an irreversible move' Again we are not sure about the word links here. | We have adapted the recommendations accordingly |
| Astrid Indekeu | 31 | 1188 - 1206 | This paragraph is not about counselling but about 'contact and the impact on family relationships.' (such as responsiveness) It should also include feelings of loyalty (see review Indekeu et al 2021: Factors associated with searching for people related through donor conception among donor- conceived people, parents and donors: a systematic review). | We have adapted the heading for the section. The paper was not included as too recent to be included in the literature search. |
| Marilyn Crawshaw | 31 | 1206 | Suggest this should say 'does not necessarily affect' – in a later paper from the same study, we concluded that disclosure and searching could disrupt and rupture existing relationships, some could be repaired others not It follows that the lines 1207-8 need revising! | We have removed the sentence from the paper |

| Marilyn Crawshaw | 31 | 1214 | Can I suggest replacing 'particularly' with 'including'. I don't think you should be suggesting that one parent is more important to include than the other | We have adapted the recommendations accordingly |
|--|----|-----------------------------|--|--|
| Astrid Indekeu | 31 | 1215 | Recipients? I think parents is meant | We have adapted the recommendations accordingly |
| Tim Bracewell- Milnes | 32 | 1221 | In this section I think the lack of research in ethnic minorities should be highlighted. The vast majority of studies investigate western and Caucasian populations. | We have extended the lack of research section |
| Astrid Indekeu | | Lac k of rese arch | It is absolutely correct to say that more research is needed, to better understand all the consequences and processes involved in donor conception. But for whom is this recommendation? | The paper is written towards professionals, who may incorporate these recommendations for future research in their research agenda |
| Sarah Norcross | 32 | 1222 | 'has been practiced' – should be practised if you are not using American English | This was corrected |
| Susan Golombok | 32 | 1226 -7 | That's not correct. There are several studies of children born though egg donation, embryo donation and surrogacy. | We have corrected to state that there is 'much less research on oocyte donation, embryo donation, in reply to this comment |
| Angela Pericleous- Smith (British Infertility Counselling Association – BICA) | 32 | 1230 | Little is also known about the impact on children who discover at an older age and who were not told at an early age that a family member/known donor was their genetic donor despite knowing the family member/known donor their whole life | We have added that little data are available on late disclosure |
| Susan Golombok | 32 | 1236 | Long-term follow up studies do exist. | We have not stated that there are no studies, so we think this is appropriate |
| Verein Spenderkinder | 32 | 1241 | The recommendations use the term "forming families" - This might be a more appropriate term than the technical approach of family-building. Recommendation: Use the term "forming families" instead of "family-building". | We have removed the term "family building" from the paper |
| Verein Spenderkinder | 32 | 1250 | "We hope that the recommended information provision allows donors, recipients, and DCP to experience donor-assisted conception in a constructive way and forestall any surprising or negative outcomes." - This is unrealistic. Gamete transfer cannot be done "right". It is always associated with special challenges, especially for the resulting people. The possibility that some DCP reject this form of family formation cannot be eliminated. Recommendation: Change the phrase to "We hope that the recommended information provision allows genetic and legal parents as well as DCP to experience this kind of family forming as well-informed as possible." | We have adapted the sentence according to the suggestion |
| Verein Spenderkinder | 32 | 1253 f. | "Therefore, providing opportunities for all parties in donor conception to have access to counselling and the current best evidence and information is critical, to ensure the ethical and safe practice of donor conception." Comment: It is not possible to eliminate ethical concerns regarding "donor conception" (e.g. Weinberg, 2008). Recommendation: Replace "to ensure the ethical and safe practice of donor conception" with: "to ensure the minimum standard of ethical and safe" | We have adapted the sentence according to the suggestion |

| Stichting | | 1265 | -counselling for donor conceived people should be offered but never mandatory. Topics regarding | The recommendation states that counselling |
|-------------------------|-----|---------------|---|--|
| Donorkind | | tabl e III | expectation and inclusion regarding donor and family should be done for parents toward the child. - Counselling cautioned since making contact is irreversible, Yes this is a irreversible move but cautioned is completely the wrong word. It is far too much influencing in one direction. Informed would be just acceptable. No one is cautioned before meeting their family members for the first time. Even if they never met before. You see this happening before weddings or funerals? Cautioning is an absurd word. One is born into a family and does not have to be warned. - regarding similarities this should also be part of counselling for parents. - is there any sign that DCP's do not realise that meeting the donor does not guarantee a good relationship? Is this some form of projection, since it is clearly the case that many parents think having a child guarantees a good relationship although they plan to hold secrets. - regarding secrets this should be part of counselling for parents. This is not the responsibility of the resulting donor conceived person. | should be offered, hence it is not mandatory. We have replaced "cautioned" by "informed" and removed the last recommendation on forming a good relationship. |
| Verein Spenderkinder | 37, | Tabl e 3 | "Counsellors should discuss with donor-conceived offspring the implications and consequences of revealing to others (e.g. peers) their conception, and how to deal with unwanted questioning." - The current wording comes across as if DCP should be prepared for the fact that openness may be a problem and follow-up questions may make them feel uncomfortable. Recommendation: Change the phrase to "Counsellors should address whether the donor-conceived person experiences problems related to talking to others regarding the way he or she came into being." | We have adapted the recommendation in reply to this comment |
| | | | Apart from that it is noticeable that the recommendation says that dcp should be "informed about the implications of using direct-to-consumer genetic testing." So when the recommendations are talking to recipient parents and their choices in terms of advantages vs disadvantages, whereas dcp must think only in terms of "implications"? Recommendation: We strongly recommend making the language more neutral and consistent - pros and cons please, not just "implications". | |
| Verein Spenderkinder | 37, | Tabl e 3 | "Donor-conceived children should be informed that the information that will be available to them in due time may not satisfy their curiosity" - The word "curiosity" suggests a sort of optional need to search. Recommendation: We recommend to say, "DC people should be informed that the information that available to them via both official and unofficial routes (e.g., direct-to-consumer DNA testing) may not be enough to give them a full picture of their identity, medical history and heritage and sometimes may not be according to their rights. Then legal support should be offered." | Curiosity is based on studies showing this is the main driving source for searching for genetic relatives. Still, we have adapted the recommendation stating that the information may not match offspring's expectations. We decided not to recommend legal support. |
| Verein Spenderkinder | 38, | Tabl e 3 | "Counsellors should discuss with donor-conceived offspring the implications and consequences of revealing or hiding to parents and other relatives their search for their donor" The person mentioned as a donor did not donate anything to the offspring! Recommendation: "donor" should be replaced with "genetic parent" (please adjust the wording in general). | We consider that the parents are the recipients and donors are not parents. As for the parents creating an environment of trust, this is covered in the section for recipients. |
| | | | We further recommend a wording here that clarifies that the parents should aim to create an environment of openness and trust, where the dc person is free to find their own path without judgement. Parents should not place this weight on their child. The current wording places the responsibility again on the dc person. | |

| Marilyn Crawshaw | | | Definition of counselling: There is no definition of counselling – a thorny subject! I think it needs one! There is also no distinction between [psychosocial[counselling and professional support. This is probably too complex a distinction to make in a document such as this but is nevertheless important so could be included in a definition? For example, there is evidence that those seeking information and/or contact with donor relatives want support in navigating the searching process and intermediary services for help with the contact process. Neither of these are counselling but could be included under the banner of counselling if your definition uses the right set of words. | The glossary includes a definition of counselling, referring to the APA dictionary |
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| Juliana Pedro | 2/5 | 29- 35 | I would suggest to present a table with legislation regarding donor-conceived treatments and respective countries (just a suggestion) | There is a recent ESHRE paper presenting the different legislations (Calhaz-Jorge 2020) for |
| | | 162- 169 | | which the reference was added to the paper |