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## Searching for and making genetic connections: recommendations for practice from donor conceived adults in the UK

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### Abstract:

**Research question:** What are the support needs of donor conceived individuals who are searching for or open to matching with genetic connections?

**Design:** 88 donor conceived adults in the UK participated in an online survey open between January and August 2022. Participants were asked about their level of awareness of current resource provision; recommendations for resources to support the process of searching for genetic connections; and resources to support with feelings about searching or being found by genetic connections.

**Results:** Participants were found to have varying levels of awareness of the resources available. Their recommendations for practical and emotional resources also varied. The most recommended resources for practical support were DNA testing and changes to UK law. The most recommended resources for emotional support were counselling and peer and other support groups.

**Conclusions:** The impact of legal and technological changes such as direct-to-consumer DNA testing and the legal transition to identifiable donation may be felt by donor conceived individuals irrespective of their year of birth. The wishes of donor conceived individuals for different support resources should be borne in mind by practitioners, regulatory bodies, and policymakers going forward.

**Introduction:** The rise of direct-to-consumer DNA testing and the legal transition to identifiable donation in several jurisdictions have each brought forward questions about the future of donor information provision. Existing research provides important insights into the connections that may result from these legal and technological changes, between both donor conceived individuals and donors, and donor conceived individuals conceived through the same donor. However, considerably less attention has been given to how donor conceived individuals who are searching for genetic connections, or have themselves been found, might be best supported by different stakeholders.

Existing support for donor conceived individuals who are searching for and matching with genetic connections differs country by country. In the UK, access in law to information about the donor and others conceived using the same donor is stratified by birth date. Primarily for those who were conceived or donated prior to 1991, the voluntary, DNA-based Donor Conceived Register (DCR, formerly UK Donor Link) currently provides a platform and support for donors and donor conceived people who wish to make genetic connections (Hodson et al., 2022). This resource has been an important source of support, counselling, and information, including providing support with information exchange between genetic connections (Crawshaw et al., 2016). Support for donor conceived people with identifiable donors, who will be able to request their donor's identity from the Human Fertilisation and Embryology Authority from 2023 onwards, is currently being developed.

Given the rate of change, this is an especially timely issue that warrants close and immediate attention.

**Methods:** 88 participants were recruited via support groups, social media and snowballing to take part in an online survey. Ethical approval for the study was granted by the UCL IOE Research Ethics Committee.

Participants ranged in age from 18-70 (Mean= 34.2, S.D.= 10.95). In terms of gender, participants were female (n=65, 74%), male (n=19, 22%), non-binary (n=4, 5%) and transgender (n=1, 1%) (multiple options could be selected). In terms of donation type, 79 (90%) participants had been conceived by sperm donation, 7 (8%) by egg donation, and 2 (2%) by embryo donation. In terms of searching for genetic connections, 39 (44%) participants were actively searching for genetic connections, 44 (50%) were open to connections but not actively searching, and 5 (6%) were not searching for connections.

The survey was live between January and August 2022. All participants were asked the following closed question: Are you aware of any resources available to donor conceived people, such as those from the HFEA? Participants who stated that they were either actively searching for, or open to, connections were asked the following open-ended questions: 1. Are there any resources that you think would help you in the process of searching for donor connections? 2. Are there any resources that you think would help with how you feel about searching or being found? Open-text responses were coded using qualitative content analysis (Schreier, 2014), with responses coded more than once where appropriate.

**Results:** 34 (39%) participants said they were aware of resources available to donor conceived people, such as those from the HFEA, 36 (41%) participants described themselves as partly aware, and 18 (21%) participants stated that they were unaware of such resources.

64 participants responded to the question about resources to help in the process of searching. DNA testing, including funding for access to tests by those who are donor conceived, was most frequently mentioned, followed by changes to the law, including the retrospective removal of donor anonymity and the release of all available information to donor conceived people (for a list of all resources suggested, see Table 1).

60 participants responded to the question about resources to help with feelings about searching or being found. Counselling, particularly independent, specialist counselling, was most frequently mentioned, followed by peer and other support groups (see Table 1).

**Discussion:** Findings suggest that donor conceived individuals who are searching for, or open to, genetic connections may have varied practical and emotional resource needs. It is noteworthy that the forms of practical support most frequently recommended were DNA testing and retrospective changes to UK law, suggesting that the impact of legal and technological changes may be felt by donor conceived individuals irrespective of their year of birth. Practitioners, regulatory bodies, and policymakers should bear this in mind when considering changes to the law or practice that will only affect individuals conceived by donation in the future.

The recommendation for emotional support in the form of counselling echoes the recent work of the ESHRE Working Group on Reproductive Donation and others (2022). That this recommendation has now been made by donor conceived people in both the present and prior research (e.g., Schrijvers et al., 2019) should be taken seriously.

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**Table 1: Resources recommended by donor conceived individuals**

Resources to support the process of searching for connections	Number of times mentioned	Illustrative quotation
DNA testing	19	"Free access to all the commercial genetic testing sites for donor conceived people."
Changes to the law	11	"Really there should be an end to donor anonymity so we don't have to search."
More guidance and support on how to search, interpret information and make contact	10	"DNA guide would have been very helpful or some assistance with working out DNA sites."
Awareness campaign	7	"An awareness campaign by the HFEA for example targeting donors and giving them information that they have the opportunity to remove their anonymity would be hugely helpful."
Peer and other support groups	6	"The DCR group on Facebook seems to be fantastic for support, a lot of good people helping each other out and a place of warmth."

Counselling	3	"Some free counselling offered - some of these interactions can be traumatic and difficult to manage i.e., when matching with a sibling and they don't know they are donor conceived. This has happened to me twice now... the guilt is awful."
Non-DNA based registries	2	"The following all helped: We used Ancestry and a few other genealogy websites, public records (birth certs and wills). Facebook, Companies House, Land Registry, local planning dept, LinkedIn, census info and family trees plus a lot of general use of search engines."
Only so much can be done	2	"Ultimately the main issue is that if my dad / donor doesn't consent then there isn't anything I can do."
No or don't know	12	
<b>Resources to support with feelings about searching or being found</b>		
Counselling	13	"A counsellor/therapist with specialist expertise in this area."
Peer and other support groups	7	"Support groups for donor conceived people."
DNA testing	4	"Free DNA tests on all commercial sites."
Support with searching and making contact	4	"A professional who is allocated to you to guide and support your search."
Examples of personal experiences	3	"Hearing from other donor conceived adults who have found donor connections."
Awareness campaign	3	"For the scandal of sperm donation and the lack of regulation in the past to be highlighted heavily in the media."
More information (both specified/unspecified)	3	"I think DNA testing sites could give more helpful information. So for example, having a link when you receive DNA results that says "Not what you were expecting? Click here for more information". And then it gives some examples of why a DNA match might be unexpected, including the possibility of donor conception, and then a UK specific resource to organisations like the HFEA to find out more."
Changes to the law	1	"Everyone has the right to know their genetic identity."

Resources for parents	1	“Resources for parents of adult donor conceived people to adjust to changes in law, genetic testing developments etc and what this means for searching.”
Identifying a connection	1	“[To] know half siblings.”
Compensation	1	“Compensation.”
No or don't know	19	



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