



**ANZICA Guidelines for Professional  
Standards of Practice: Donor Conception  
Linking Counselling (DCL-C) 2024**

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## 1. **Preamble**

The Australian and New Zealand Infertility Counsellors Association (ANZICA) is the peak professional body involved in developing and maintaining psychosocial practice standards for individuals and couples affected by, and receiving treatment for fertility issues.

ANZICA strives to support all those with whom they work, including through promoting the welfare and best interests of any person born through assisted reproductive technologies.

## 2. **Purpose of these Guidelines**

- To provide a set of principles and guidelines for professional standards of practice, streamlining and supporting the process of successful and ethical donor conception linking.
- Counsellors will be guided in their professional practice by the specific needs and rights of the person making the enquiry, based on the legislation applying to that era and jurisdiction, and in recognition that the needs and feelings of those affected may change over time.
- Guidelines will reflect the spirit of the NHMRC guidelines and respect the interests of donor-conceived adults, recipient parents and donors, as well as individuals' needs regarding privacy.
- Prior practice has traditionally focused on donor-centred linking. The term 'donor conception linking' (DCL) is used in acknowledgement that linking occurs in a variety of ways and with a range of parties, and is not restricted to linking between the donor and DCP. This aligns with ANZICA's principles of using language that accurately reflects possible relationships in donor conception, and as such, this is reflected in the terminology used in the guidelines.
- These guidelines are deliberately responsive, offering general principles and guidelines for counsellors to apply to the variation of donor conception linking that may occur. The document is a living document and will be updated regularly.

## 3. **Definitions/Terminology**

**Ethical Donor Conception** - ethical donor conception refers to the practice of assisted reproduction involving donated gametes or embryos in a manner that upholds the principles of informed consent, transparency, provision of counselling and support, compliance with legal and regulatory frameworks, a child-centred approach, and consideration of the long term implications of donor conception for all parties. The three pillars of contemporary ethical donor conception are:

- early disclosure
- identity release donors
- donor conception linking

**Donor Conception Linking (DCL)** - donor conception linking refers to the practice whereby people connected through donor conception: donor-conceived persons, donors, recipient parents and siblings - seek access to information about each other, which may include the intention of making contact (Kelly et al., 2019a). DCL can include requests for information and linking between recipient parents who have used the same donor as other parents to conceive their children, and the partners and families of those affected by donor conception (e.g. donors' partners, extended family). It should be noted that ANZICA has chosen to move away from the historic term *Donor Linking* to adopt and reflect this more accurate terminology, recognising that linking that may occur in a variety of ways and should not be limited to linking with a donor.

**Donor conception linking counselling (DCL-C)** refers to the provision of counselling to assist the various parties affected by donor conception to explore and prepare for DCL, and to provide support during and after DCL occurs.

**Donor conception (DC)** - donor conception refers to the process of having a child using donated sperm, eggs or embryos, either through self-insemination or fertility treatment such as IVF. Donor conception involves a donor or donors (person/s donating sperm, eggs or an embryo) and recipient parent(s) who receive the donation.

**Donor-conceived person/people (DCP)** - a person born as a result of donor conception is known as a donor-conceived person (DCP) (VARTA, 2023). Note that the term 'donor-conceived person' is preferred over donor-conceived child, a term which risks infantilizing adult donor-conceived persons. 'Offspring' is commonly used in legislature as a term for DCP, even though DCP do not refer to themselves as 'offspring' but as individuals in their own right.

**Gametes** - reproductive cells: female gametes are called oocytes or eggs; male gametes are called sperm.

**Egg donation** - egg donation is the process whereby a person donates their eggs to enable another person/s who is not their partner to conceive through assisted reproduction treatment

**Sperm donation** - sperm donation is the process whereby a person donates their sperm to enable another person/s who is not their partner to conceive either through artificial insemination or other assisted reproduction treatment.

**Embryo donation** - embryo donation is the donation of embryo/s by an individual or couple who have "surplus" embryos following their own family formation via fertility treatment to others to build their family. Note that these embryos may have been created with donated eggs/sperm. The DCP born to recipient parent(s) of an embryo donation thus shares no genetic link with them and may have full genetic siblings raised in the donor's family or in other families who have conceived using embryos with the same genetics.

**Double donation** - double donation is the creation of embryos using separately donated eggs and donated sperm. This is different from embryo donation in which a couple has created embryos using their own or donated gametes and then donated 'surplus' embryos.

**On-donation** - refers to the further donation of embryos by the recipient(s) of donated embryos. In some jurisdictions this is only available under certain conditions.

**Donor/genetic/biological parent** - note that a variety of terms may be used by DCP to refer to individuals who donated sperm/egg or embryos.

**Genetic sibling** - genetic siblings are individuals who are related to each other through the donor's gametes or embryo/s (i.e. individuals share the same donor, or the DCP is a genetic sibling to the donor's raised child/ren). Genetic siblings can be half siblings or, in the case of embryo donation, full genetic siblings. The terms 'diblings', 'donor half-siblings' or 'same donor peers' (Indekeu et al., 2021) may be used by some to denote genetic siblingship through donor conception. The word 'diblings' is considered inappropriate by many donor-conceived people as it can be seen to minimise the significance of genetic siblings related through donor conception compared to those related by traditional conception.

**Identity release donors** - identity release donors are donors that have agreed to the release of their identifying information at some time point following the birth of the person conceived from those gametes/embryos. The age of the DCP at identity release and to whom the identifying information can be released varies between jurisdictions and/or fertility service providers (if no legislation applies). Whether additional consent is required prior to the release of the identifying information also varies between jurisdictions and/or fertility service providers (if no legislation applies). Note that the agreement for the release of identifying information is not a guarantee of agreement to contact with DCP and recipient parent/s.

**Recipient parent/s (RP)** - a recipient parent is a person becoming a parent through donor conception with donated eggs, sperm or embryo. Recipient parents are identified as the legal parents.

**Early disclosure** - early disclosure refers to the practice of informing a child about their donor-conceived origins at a young age. This should not be a one-off conversation and entails ongoing open and honest communication by recipient parent/s with their child about donor conception. Early disclosure aims to present donor conception as a normal and accepted part of the child's identity, and is associated with better outcomes for donor-conceived people (Ilioi et al., 2017; Lampic et al., 2021). Early disclosure, so that children have 'always known', is considered ideal (Daniels, 2020; Glidden et al., 2022).

#### **4. Background to donor conception practice and donor conception linking**

*ANZICA is firmly committed to the practice of Ethical Donor Conception. As such, we recognise that in order to move closer to this practice we must understand and acknowledge the history of donor conception to ensure lessons are learned from the past.*

##### ***Historical practices***

Early models of donor conception used anonymous donors, often with an absence of records, and secrecy and non-disclosure of donor conception were recommended to parents by fertility service providers (Daniels, 2005). At this time, anonymous donation was thought to be in the best interests of donors (protecting them from paternity, inheritance and succession issues), recipient parents (protecting them from the 'shame' of infertility, and concerns around parent-child bonding) and DCP (protecting them from potential stigma) (Newton, 2022). Donor conception linking from this era usually takes place when DCP are adults, often in the context of late disclosure by parents or late discovery through DNA testing. Both late disclosure of donor conception and late discovery through DNA testing or inadvertent disclosure (e.g., by others who are aware of the donation) can be very challenging and are associated with poorer emotional well-being than early disclosure (Glidden et al., 2022; Jadva et al., 2009). For example, disruption in identity formation, feelings of anger and betrayal and poorer self worth, and adverse parent-child relationships (Adams et al., 2022; Canzi et al., 2019; Macmillan et al., 2021) are commonly reported. Often donors from this era are now also elderly or have died, raising further issues for DCP. Research on the motivations for DCP seeking additional information about and contact with the donor parent(s) concludes that simply knowing the identity of the donor parent(s) may not be sufficient, and contact with the donor parent(s) may be necessary to satisfy the needs of DCP (Ravelingien et al., 2015).

Over time, disclosure of donor conception to children and teenagers by their parents became more common (Duff, 2022). DCP from this era may have had more time to accept being donor-conceived or may be coping with the impacts of late disclosure. Record keeping improved and donor identities and donor siblings were more frequently recorded but were still legally anonymous.

Donors of this era were not given the option of being known, although many are reported to be open to contact (Indekeu et al., 2021; Kelly et al., 2019b). However, DCL from the era of anonymous donation can be challenging as some donors who donated under the premise of anonymity are reluctant to engage in contact and may feel their privacy has been violated. Parents may also be reluctant for their DC child to search for and link with the donor, and DCP may be conflicted about possible reactions from their parents (Beeson et al., 2011; Hertz et al., 2013; Jadva et al., 2010; Newton, 2022). Some parents however, are reported to be supportive, even potentially taking an active role in the search for information and initiating DCL (Duff, 2023). Donor conception linking from this era takes a significant amount of negotiation to get consent from all parties and navigate contact. Moreover, donors and DCP may find that those DCP who are not

aware they are donor conceived cannot be contacted and known. An exception here is the Australian state of Victoria, which enacted legislation in 2015 allowing for the retrospective opening of donor records, thus giving DC adults who were conceived and donors who donated under conditions of anonymity before 1988 the right to apply for each other's identifying information (Dempsey et al., 2019). This means that VARTA (Victorian Assisted Reproductive Treatment Authority) can contact DCP and disclose donor conception to them directly in the process of DCL. In other cases, voluntary registers have been set up allowing anonymous donors and DCP born through anonymous donation to record their details and potentially facilitating linking (although the success of these has been limited) (e.g., Johnson et al., 2012 ;Te Tari Taiwhenua/ Department of Internal Affairs, 2022).

### ***Towards a new era***

Legislative changes in Australia and New Zealand now recognise the importance of donor identity release for DCP, and have established donor registries allowing access to this information for DCP conceived in these jurisdictions, usually at the age of 18 years (refer to legislation addendum - LINK to follow). In New Zealand, DCP born from gamete donations made after 21st August 2005 may request access to the identifying information of the donor once they reach 18 years of age. In addition, *parents* of DCP born from gamete donations made after this date may also request this access at any time from the birth of their child. Research highlights that DCP may be interested in knowing about their genetic heritage and want to link with the donor (Canzi et al., 2019; Lampic et al., 2021) and that parents may also see themselves as having a significant role to play in facilitating this process (Duff, 2023). Donors in these contexts may also donate not just with the expectation that they may need to 'be available' for future contact, but also with a desire to connect, and even engage in early contact (Goedeke et al., 2023; Volks, in preparation). In some cases, donors and recipients may negotiate information exchange and contact arrangements even before the donation occurs, which makes DCL possible from the outset. For example, in New Zealand, donors and recipients may meet at clinics prior to donation - In fact, this is mandatory for embryo donors and recipients, and required in the case of previously unknown recipients e.g. recruited through online media (Goedeke et al., 2023).

Early disclosure is now more common, although still not ubiquitous (Duff & Goedeke, under review), and while legislation makes provision for identity release, whether or not parents disclose (in the absence of mechanisms such as birth certificate annotation) remains an individual choice for parents. As already emphasised, early disclosure has a range of benefits, including an ability to more readily incorporate the knowledge of donor conception into identity and more positive family relationships (Daniels, 2020; Glidden et al., 2022). Donor conception is now open to a wider range of family types and demand for donor conception has significantly increased. LGBTQ+ families and single-mothers now account for the majority of donor conception (Trail & Goedeke, 2022) and some research suggests that disclosure is more common in these family types than in heterosexual two parent families where donor conception may be easier to conceal (Duff & Goedeke, under review; Indekeu et al., 2013). However, it should be highlighted to parents that even though donor conception may be 'obvious' to adults in these family types, it may not be 'obvious' to children. DCP in LGBTQ+ and single-mother families may not realise they are donor conceived if this has never been explicitly discussed, and this may lead to trauma from late-discovery of donor conception. Families of all types need to be encouraged to disclose donor conception early and often. Family limits for local donors have increased to try to improve access to donor gametes, although limits are important in consideration of the complexity of linkages that may occur and to reduce the risk of accidental incest/unknown consanguinity between DCP and their descendants.

International research on experiences of searching for and contact between parties varies, and while there is evidence of positive experiences (Blyth et al., 2017; Daniels et al., 2012; Hertz et al., 2015/2017; Jadva et al., 2011), disclosure, the release of identifying information, and the process of connecting can have wide-reaching and emotionally challenging effects for donor-conceived individuals, donors, parents and their wider families (Rodino et al., 2015). DCP may experience distress from learning about their origins in unplanned ways, disclosure may affect relationships with families, and disappointment may arise where contact between the parties is not possible or does not unfold as expected (Blyth et al., 2020; Daniels, 2020; Trail & Goedeke, 2022).

Furthermore, as demand for donor conception outstrips local supply of donors, families are sometimes sourcing gametes from overseas, often from jurisdictions where anonymous donation is offered or mandated. This raises a number of concerns, including that parents and DCP may not have access to identifying information about the donor, and even where information is provided, that the donor may not be open to contact (Rodino et al., 2015). Cross-border donation services also involve additional complexity for DCL-C as they often offer commercial rather than altruistic models, with payment constituting explicit financial reward for the supply of gametes. This leads to concerns about the commodification of human life as well as the depersonalisation of donation as a “one-off transaction” with possible implications for the willingness of donors to have their identity released to DCP (Goedeke et al., 2022). Further, overseas fertility service providers may or may not set family limits, and recipient parents may be unclear that global limits do not always apply, even if country based family limits do. This has resulted in same-donor sibling groups of 50-100 children or more becoming more common, with families based across the globe. Donor conception linking in this context has additional complexities due to the large numbers of families and widespread location of families in multiple jurisdictions (Indekeu et al., 2021).

With advances in technology including online DNA testing and reverse image searches, parents and DCP in many jurisdictions are now able to determine the identity of the donor independently, and despite any donor agreements of anonymity or identity release at 18 (Darroch & Smith, 2021). More parents are considering and engaging in earlier than 18 contact with the donor (e.g. Dempsey et al., 2019; Duff, 2023; Trail & Goedeke, 2022), and this introduces additional complexity if they are navigating contact outside of pre-existing donor agreements.

As awareness of the benefits of contact with genetic relatives (Goldberg & Scheib, 2015; Indekeu et al., 2021; Scheib et al., 2020) becomes more mainstream, more parents are also seeking to link with same-donor sibling families earlier than 18. This has a number of potential benefits for DCP and their parents e.g., forming new relationships, creating a sense of belonging, avoiding consanguineous relationships, and contributing to a healthy sense of identity (Indekeu et al., 2022), but does introduce additional considerations. Between families who have used the same donor, not all parents will agree on early/any contact with the donor/each other and this can lead to conflict between families. Families may have varying degrees of openness. For example, some families may be open to contact but are not willing to disclose to the donor siblings that they are genetically related (Freeman et al., 2009). The introduction of embryo donation and double donation means that DCP are being raised by entirely non-genetic parent/s. There is currently very little research addressing outcomes and well-being for people conceived by embryo donation and double donation. Current research reports positive adjustment up to middle school age (Jadva & Imrie, 2023; MacCallum et al., 2007; MacCallum & Keeley, 2008), although international research also suggests that parents may be less likely to disclose embryo donation than egg or sperm donation. Note that this finding has not been replicated in New Zealand, where donors and recipients meet prior to donation in joint counselling (Goedeke et al., 2015), nor in the case of the Snowflakes Embryo Adoption Program in the US (Blyth et al., 2019; Frith et al., 2017). In both cases, early contact was possible and often valued. DCL in these situations may involve negotiating complex ‘family’ structures given that in ED there are full-genetic siblings in other families, and in double

donation DCL includes linking with families on both the egg and sperm donation side. Existing research on donor conception using either egg or sperm donation suggests that teenagers and adults may have more complex and ambiguous feelings about donor conception than children (Best et al., 2023) and this will likely also be borne out in future research on double donation and embryo donation.

As the effects of current legislation come into play with people born under identity release programs reaching adulthood and parental awareness of the importance of meeting genetic relatives increases, the landscape of donor conception (DC) in Australia and New Zealand, as well as globally, is fundamentally changing and we are entering a new era of DCL. The combination of legislation in New Zealand and Australia, and increased openness and honesty from parents and donors, means that DCP making requests will have had significantly different DC experiences compared to previous generations, and DCL requests from DCP, parents and donors are likely to increase. A significant number of DCP with identity release donors can be expected to request identifying information, particularly within a few years of turning 18 (Scheib et al., 2017) or around major life events, such as partnering or having children. Both the types of requests and who makes these requests are likely to change.

### ***Ethical Donor Conception: The 3 pillars***

Early practices in donor conception showed little understanding and limited consideration for the psychosocial wellbeing of the children born from donation. Current practices are however, quite different from these early days of donor conception and there is now a significant body of research exploring the experiences and outcomes for DCP, donors, recipient parents and their families. This research continues to expand our understanding of what best practice in donor conception looks like. Best Practice in donor conception must be considered to be ever-evolving as our understanding grows.

The three pillars of contemporary ethical donor conception are:

- early disclosure
- identity release donors
- donor conception linking

However, counsellors must be aware that even with 'ideal' conditions of donor conception, there are a variety of experiences for DCP, donors and recipient parents.

### ***The Role of Counsellors***

Research suggests that many DCP, parents and donors desire professional support in DCL and may report a lack of confidence about how to initiate and negotiate contact, as well as the absence of established scripts to follow (Indekeu et al. 2021). Counsellors have significant influence on parent decision-making in all three aspects of donor conception and therefore play a key role in the health and well-being of DCP and their families (Goedeke & Gamble, under review).

The review of the ANZICA Guidelines document is timely as we enter this new era. By applying the principles outlined above, we expect counsellors to be able to offer a nuanced, emotionally sensitive and efficient approach to donor conception linking - one that can be tailored for each individual, rather than following a rigid set of guidelines that do not account for a multitude of variations. Counsellors must ensure they are familiar with relevant national and state legislation with respect to donor conception.



## 5. **Relevant Legislation/Guidelines and Developments**

See the [ANZICA Donor Legislation Addendum](#) for more detailed information regarding legislation for each state/country.

Jurisdictions may have different laws, policies and guidelines regarding donor conception.

However in general, Australian and New Zealand legislation/guidelines include:

- Altruistic donation (there may be no commercialisation of gametes i.e. outright payment constituting financial reward. Reimbursement of reasonable costs, such as medical costs, costs for time off work, transport etc. are usually considered as reasonable)
- Identity disclosure of donors
- Limits of the number of families created through each egg, sperm and embryo donation (variation across states/country). Note that there are no worldwide limits set by international gamete banks.
- Donor Conception Registers (Victoria, NSW, South Australia, Western Australia, New Zealand, Queensland and ACT - in process)

Across **Australia**, ART clinics are bound by NHMRC guidelines to record information about donors, recipients and children as a result of gamete donation. Some Australian jurisdictions have additional state legislation regulating Donor Registers. In **New Zealand**, assisted reproduction practices are regulated under the HART Act, 2004.

- **National Health and Medical Research Council (NHMRC)** - The *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* (ART guidelines) are used by professional organisations to set standards for the practice of ART. <https://www.nhmrc.gov.au/about-us/publications/art>  
Section 5.9 of the NHMRC Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2017 (updated 2023) specifically outlines the importance of information needs of those conceived through donor assisted conception. It states that: "Persons born from donated gametes are entitled to know the details of their genetic origins" (Section 5.9, p.34) This information includes:
  - identifying information about the gamete donor (see paragraph 5.9.1)
  - any identifying information that any person born from the gametes of the same donor has consented to being released (see paragraph 5.10.2).
- **New Zealand - Human Assisted Reproductive Technology (HART) Act 2004**  
The New Zealand HART Act 2004 has an underpinning principle that people conceived from donor gametes have the right to knowledge regarding their genetic origins. It states: "Donor offspring should be made aware of their genetic origins and be able to access information about those origins".

Clinics in Australia and New Zealand also need to adhere to the Code of Practice of the **Reproductive Technology Accreditation Committee (RTAC)** to be an accredited service provider.

- **Reproductive Technology Accreditation Committee (RTAC)** - RTAC is a professional group of the Board of the Fertility Society of Australia and New Zealand and reports directly to that Board. It is charged with the responsibility of setting standards for the performance of ART through an audited Code of Practice and the granting of licences to practice ART

within Australia. It further licences an International Version of the Code of Practice for the use by Certifying Bodies in countries outside Australia and New Zealand. <https://www.fertilitysociety.com.au/rtac-australia-new-zealand/>

- **Implications of Biotechnology: Direct to Consumer (DTC) DNA testing**

DTC DNA testing enables anyone affected by donor conception to potentially find and connect with donor relatives regardless of whether they have access to donor records. Increasingly with advances and consumer accessibility to biotechnology, ANZICA counsellors working in both private practice and ART units are likely to encounter clients impacted by DTC DNA testing.

These implications may include the unexpected discovery that:

- they are donor conceived and one or both parents is/are not their genetic parent(s);
- they have donor siblings (this could be a high number);
- their sibling has a different donor and thus they are not full genetic siblings and;
- their parent has donated gametes to a fertility clinic

## 6. Code of Conduct/Principles for Counsellors

- DCL-C is a specialist area of counselling - practitioners must be guided by their professional scope of practice, expertise and indemnity. Referral to colleagues should be made as appropriate, and counsellors are strongly encouraged to engage in regular professional supervision and seek continuing education in DCL-C.
- DCL-C should be conducted with due consideration of relevant national (e.g. [HART Act in NZ](#)) and state (e.g. Victoria) legislation, and professional and practice guidelines (e.g. [NHMRC](#), [RTAC COP](#); in New Zealand: Advisory Committee on Assisted Reproductive Technology - [ACART](#))
- DCL-C needs to be sensitive to the different aspects of DL across a range of contexts, e.g., where information is accessed via official records; through direct-to-consumer DNA testing; through voluntary registers; linking before the age of 18
- DCL-C should be made in the context of understanding and bringing to the fore the needs and perspectives of DCP as set out by Donor Conceived Aotearoa New Zealand (refer [Basic Principles for Understanding the Needs and Perspectives of Donor Conceived People](#))
- DCL-C should respect the individual needs and interests of DCP, recipient parents and donors, as well as individuals' sensitivities regarding privacy and information-sharing.
- DCL-C should assist clients in exploring and preparing for linking, and provide support before, during and after linking occurs, with due consideration of the following:
  - DCL-C should ensure that clients have agency over what they decide to do
  - DCL-C should entail sensitivity to the emotional impact of donor conception on DCP, recipient parents and donors (and their families)
  - DCL-C should ensure the clear provision of information, including with reference to DCL process and protocols. This should include an explicit description of the types of information that can be requested
  - DCL-C should be confidential, with careful, rigorous record-keeping around consent and the sharing of information across the various parties involved in DCL
  - DCL-C should explore clients' motivations to engage in DCL
  - DCL-C should support clients to explore the short and long term implications of donor linking
  - DCL-C should consider possible variations in and outcomes of DCL, including the possibility that DCL may or may not lead to direct contact or not unfold as desired
  - DCL-C should be neutral but encourage respect, sensitivity, goodwill and

- perspective-taking
- DCL-C involves support to all parties, including anyone important to the client. DCL may be more than DCP-to-donor contact e.g., it may include siblings, extended family, partners; may be family-to-family contact
- DCL-C should involve the provision of resources to support individual decision-making around DCL
- DCL-C should entail ongoing consent for facilitation and enable parties to move forward independently as they feel comfortable, and at a pace with which they are comfortable
- DCL-C requests should be attended to in a timely manner.
- DCL-C may be particularly important in the early stages, but may also be called for at later stages of DCL
- DCL-C is complex and multi faceted and the counselling role may include psychoeducation, mediation, advocacy, facilitation and relationship counselling (Generally DCL-C is not therapeutic intervention. If counsellors are aware of mental health or family issues they ideally need to be referred on for best outcome)
- DCL-C may involve balancing the needs of different parties. Separate counsellors for each may be advised where circumstances allow.

## **7. Donor Conception Linking - Counselling (DCL-C) Process/Protocol**

As already stated, DCL may occur in a variety of ways and depend upon the jurisdiction in which DCP, donors and/ or genetic siblings are located. The following is a suggested process for those working in an ART unit; however it should be noted that due to changes in legislation in some jurisdictions, linking may take place outside of the ART clinic unit and be conducted by an independent intermediary service. A reminder that the following are intended to be helpful guidelines - there is no one model of DCL. The suggested process below also details a protocol for ANZICA counsellors working in ART units who have access to donor records when receiving an enquiry. ANZICA counsellors working in private practice may have contact with one party only, so may not be able to follow this suggested process. They are advised however, to follow the principles of DCL and support the party(ies) with whom they have contact.

### ***Participants***

Participants to the donor conception linking process, including the enquirer and the subject of the enquiry (donor-conceived person, donor or recipient parent), should:

- Provide confirmation of their identity details e.g. 100 point identity check
- Be provided with clear information about the process and options, as well as the responsibilities of the counsellor
- Be provided with an explicit description of the types of information they can request e.g. number of DCP/siblings, year of birth/gender/location of DCP/siblings, whether the donor/recipient parents/DCP have contacted the clinic previously, updates to medical history
- Be offered the opportunity for discussion about the short and longer term implications and choices of potential DCL
- Be assisted with the process and in their adjustment to the outcome
- Have control over the decision-making and pace of the steps involved

### ***The Donor Linking Counsellor***

- Supports both the client who wishes to find information and the subject(s) of the enquiry throughout the process, but does not become the advocate for one party over another
- Supports the principle that people affected by donation may have an interest to request

information or make contact e.g. with the donor, genetic offspring, or genetic half-siblings, and such interest in information or contact is to be treated as normal and responded to positively

- Is respectful of an individual's right to privacy – thus subject to provisions in legislation, information must not be released to another person without the consent of the individual concerned unless otherwise required by legislation
- Best practice would entail the counsellor, as a courtesy, informing the donor that their identifying information has been released or will be released. The counsellor will offer support and advice about the potential implications for them and those close to them. Note that for identity release donors, additional consent for the release of identifying information at the time of the request is not required as this was already made at the time of donation.
- Provides information or referral about other mechanisms for donor linking e.g. NSW Health Voluntary Register, Donor Sibling Registry, Victorian Donor Registers, NZ HART Register, Health Department of WA Donor Conception Information Service
- Practitioners are reminded of the critical importance of managing their dual/multiple roles in DCL and ensuring they do not breach the confidentiality of each of their clients.

### 1. Initial Enquiry

A DCL counsellor should be appointed by the ART unit to manage all DCL cases. All initial enquiries and communication should be referred to the DCL counsellor to ensure consistent information is provided. The DCL counsellor should work closely with ART unit staff who have direct access to the donor records. At the time of the initial enquiry, the specific information needs and wishes of the client should be established. If their needs are not clear or there are issues pending further discussion a preliminary appointment for counselling should be offered. Provision of written information by ART units regarding policies, options and protocols in place for exchanging identifying and non-identifying information is optimal.

### 2. Request for information

Establish the type and nature of the request:

#### a. **Non-identifying information request (when information is available from ART unit records).**

Counselling should be offered for enquirers requesting non-identifying information. The request should be made in writing with verification of the identity of the enquirer (100 points identity). A search of ART unit records should then be made to establish whether there are any records pertaining to the request. If no records are located, the enquirer should be advised and counselling should be offered. In cases where information is available, after searching appropriate records, information is to be provided in writing. Routine, follow up counselling, should be offered.

#### b. **Identifying information and non-identifying information NOT requiring consent from the other party** (note that some of the protocol below relates to c. Note that many DCP now fall into the category of b. where additional consent from the donor is not required prior to release of identifying information - variations to the protocol need to be made for this scenario)

#### c. **Identifying information and non-identifying information request requiring consent from the other party.**

If the request is for identifying information or further specific non-identifying information not included in the records, an appointment for counselling should be arranged before any further steps are taken. See below steps.

### 3. Counselling

The enquirer should be advised that counselling is recommended, but not mandatory, and provided (in writing) with information on the steps that will be followed through the process of DCL, including realistic associated timeframes.

#### Counselling session (with the individual requesting information - the enquirer)

This session assists the enquirer to develop a clear understanding of their needs and motivation, and whether they wish to proceed with donor linking.

The counselling session should aim to address the following:

- Confirmation of the identity of the enquirer (e.g. 100-point identity check);
- Clarification of the specific request for information/contact for that person including their motivation and exploration of their needs, wishes and expectations of the possible outcome of the enquiry in the short and longer-term i.e., what specific information do they want to know e.g., medical, family tree, interests, personality, photographs, do they want to start by exchange emails/letters/meet? Where do they see the contact potentially going?
- Clarification of the types of information that may be available: (too often people aren't aware of what is possible and clinics only release exactly what has been asked for and do not disclose that there is other information available) identifying and non-identifying information about the donor, physical characteristics, written donor motivation's document, medical history, number of siblings including gender and year of birth, whether donor or siblings have contacted the clinic and if any are open to contact or have left information for release on their file, medical information from siblings
- Facilitate an understanding in the context of other life issues including the impact of the search to people close to the enquirer
- Provide clarification of the legal rights of all parties
- Discussion of possible outcomes of pursuing the request including case scenarios of positive and adverse outcomes e.g., where donors and donor-conceived individuals have exchanged information or made contact, the possibility the other party can't be located, does not consent to provide information, e.g. is incapacitated or has died
- Consideration of the possible implications for the other party and the possible impact on those close to them
- Discussion of the anticipated steps involved.

If the enquirer has decided after initial counselling to progress with the request, or counselling has been declined, the following steps should be followed:

#### 4. A search of records (for the contact details of the person who is the subject of the outreach).

- a. Clinic records (post legislation)
- b. Clinic records (prior to legislation)
- c. No clinic records (outside of legislative provisions)

This can be done by accessing client records in the case of a., or where contact details are not known or incomplete as in b. and c., the electoral roll, internet or enlisting the assistance of an organisation experienced in searching e.g. VANISH in Victoria. Extreme care needs to be taken to ensure that the correct person is identified before any attempt is made to contact them.

Note: In jurisdictions without retrospective access legislation, information may not be released without consent (currently only Victoria and South Australia have retrospective

access legislation). If the clinic consent form does not include permission for the release of identifying information (e.g. because the donation was made before the introduction of legislation regarding identity-release provisions), the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor, to contact the donor and obtain his or her consent to the release of information. If consent cannot be obtained, DCP may pursue online DNA testing in conjunction with genetic genealogy techniques to determine the identity of the donor and can seek support from independent counsellors if desired.

#### 5. Initiate search for subject of enquiry

- a. If the subject of the outreach is not located, the client is advised, and further counselling may be necessary.
- b. If the subject of the outreach is believed to have died, the client is advised and counselling offered. In this situation it *may* be possible to contact the deceased subject's spouse or next of kin who may be willing to provide information or to have contact.
- c. If the subject of the outreach is located, the counsellor should inform the enquirer and re-establish whether the enquirer wishes to proceed before any attempt is made to contact the other party.

Note: Some clients may have second thoughts as the possibility of contact moves closer to reality. This contact with the enquirer also prepares them that a response from the subject may occur in the near future.

#### 6. Formal (written) request (by the party wishing to initiate contact/information exchange).

The enquirer should provide in writing the information that they want communicated by the counsellor if/when contact is made with the outreached party, and how they would like to proceed if the subject of the outreach is willing to exchange information/have contact. This could be in the form of a personal letter which is not formal in nature or tone, introduces the enquirer and explains in their own words what they are seeking. e.g. motivations, specific information requested, interest in ongoing communication exchange/contact, non-identifying information about the person making the request. This information is useful for the subject of the enquiry to assist them to make decisions about potential information exchange/contact.

*See Appendix A: Sample letter by enquirer*

Care should be taken to ensure that only information that has been specifically consented to by the enquirer is passed on to the subject of the outreach. This should be notated and signed by the enquirer. This is particularly important as the subject of the outreach may not agree to further contact but may be prepared to answer specific questions outlined in the written request.

#### 7. Contact the subject of the enquiry (requesting that they contact the counsellor)

Contact may take a variety of forms and should be initiated on a case by case basis:

##### 1) *By letter:*

This is done using the letterhead of the unit/organisation. It should ideally be sent via person to person registered mail since this enables tracking and ensures the counsellor knows when and whether the letter has been received. The letter should contain information that will enable the person to recognise what it is about, however it should not include detailed specific information in case someone other than the subject of the enquiry reads the letter (see sample letter Appendix B).

## 2) *Via Phone:*

Historically written contact has been considered the most appropriate form of approach, however, empirical experience working in DC-Linking now informs us that contact via phone may well be a very useful, and often preferred form of first contact. Donors report appreciation of the opportunity to talk directly with a clinic counsellor about the approach. Moreover, DCP and recipient parents have also shared that they too welcome this form of contact since the immediacy of phone contact gives all involved a sense that direct action is being taken. While not all donors can be contacted in this direct way, this is a valuable option that the clinic counsellor should consider. Identity can be confirmed verbally, and an additional advantage is the fact that there is less opportunity for someone else to see an email or open a letter not meant for them – even if worded very generally. It is worth noting that phone is often a preferred way to contact linked recipient parents – since again, there is less risk of a privacy breach and often the very careful call has led to a conversation about “maybe it’s time to tell them, how do we do that?”

## 3) *Social Media:*

Some counsellors will feel nervous to use social media, however, if there is no postal address or phone number, it may be possible to contact the subject via email or social media e.g. Facebook messenger. Care needs to be taken to ensure that the correct person has been identified. This is also not the preferred means, as the person who is the subject of the outreach may think they are being scammed and may be less likely to respond.

- a. In situations when the letter/email/social media/Facebook message is received but there is no response - the counsellor could try sending a further outreach letter, or making contact in another appropriate way, ensuring there is confidence that the contact details are accurate.
- b. When contact is made with the outreached party, it is important to firstly check the subject’s identifying details i.e., full name, date of birth, ensuring that the person was involved in the donation situation. Once this has been established information may be passed on to the subject by the donor linking counsellor as authorised by the enquirer (e.g., the enquirer’s letter).
- c. The person (subject of the enquiry) should then be invited to attend counselling (as below) to help to clarify their feelings, thoughts, expectations, and wishes in relation to the enquiry and implications for themselves and those close to them.

## 8. Counselling (for the person who is the subject of outreach/enquiry)

Counselling should be offered to the person who is the subject of the outreach. If this person declines face to face counselling, these issues can be discussed via telephone. Specifically:

- Would they be prepared to exchange information?
- If so, what information would they be prepared to pass on to the enquirer?
- Would they be prepared to exchange emails/letters?
- Would they be prepared to meet etc? If so, on which neutral grounds would they like to meet?

During the counselling session, information may be provided by the subject of the outreach to the counsellor for reciprocal exchange to the enquirer however information, whether it be identifying or specific non-identifying, should only be exchanged with consent given by the person it pertains to.

## 9. Mediation and facilitation

The counsellor now acts as an intermediary to establish the preferred option for information exchange and contact.

- For information exchange, the counsellor may agree to provide a letterbox service in which letters/emails are forwarded confidentially by the counsellor between the parties so that the parties can write to each other without having to give identifying details about themselves. This can provide a safe mechanism for parties to get to know each other. This may continue for some time or the parties may choose to include identifying details in correspondence and discontinue using the letterbox exchange.
- The counsellor continues to act as a mediator between the two parties until either an agreement is reached to exchange further information or it becomes clear that an agreement cannot be reached. In the case that an agreement cannot be reached, it may be agreed instead to revisit the topic at a later date or to end the attempt at contact.
- If the person who is the subject of the outreach agrees to contact/information exchange, the counsellor assists to establish the first contact between the parties and may step out of the mediating role so the clients can establish their own relationship independently if they have agreed to do so.  
If the enquirer and/or the person who is the subject of the outreach would like further support in the early stages of contact the counsellor should clarify what form of support is requested - e.g., follow-up phone call/email and time frame.

#### 10. Further counselling support

Further support may be required by either party depending on outcomes/emotional reactions.

- The needs of others in the immediate families of each party should also be considered. It is possible that issues that were salient at the time of the treatment or donation may resurface and may need to be dealt with (e.g. marital conflict, dealing with infertility, grief, etc). Disclosure issues are also likely to need to be addressed if people close to either party are unaware of the donation
- Telephone or email support is provided as needed.
- (Extent and duration of care - this is currently unclear) Note that the HFEA (Human Fertilisation and Embryology Authority) in the UK offers/funds 2x individual sessions for donors/DCP/siblings, and one joint session with linking parties (HFEA, 2023). Unfortunately however, due to financial pressures, these arrangements are in place until September 2024 only, and while the HFEA will continue to provide information, funding for a commissioned support service will end (HFEA, 2024).
- Referral to external counsellors may be made. See the ANZICA list of registered counsellors. <https://www.fertilitysociety.com.au/professional-groups-anzica-australia-new-zealand/>

## 8. Resources

For DCL counselling processes:

- ANZICA is hoping to establish a donor conception linking peer support group
- Kramer, W. & Bertisch, H. (2022). Counselling Donor Family Members: A Guide for Mental Health Professionals

Useful links

- Human Fertilisation and Embryology Authority (HFEA) - the UK's independent regulator of fertility treatment <https://www.hfea.gov.uk/donation/>  
There are some good resources here including: 'Preparing to access identifying information about your donor' -<https://www.hfea.gov.uk/donation/donors/information-for-past-applicants/preparing-to-access-identifying-information-about-your-donor/>
- Connected DNA project - <https://sites.manchester.ac.uk/connecte-d-n-a/> (See the "preparing for contact" brochures)
- Vanish - a not-for-profit organisation for adults affected by adoption and donor-conceived



people. <https://vanish.org.au/about/about-us/>

- Victoria Assisted Reproductive Treatment Authority - VARTA provides independent information and support for individuals, couples, and health professionals regarding fertility, infertility, assisted reproductive treatment (ART) and the best interests of children born. <https://www.varta.org.au/>

Donor-conceived community organisations who provide a focus on understanding DCP and families and their lived experience:

- Donor Conceived Aotearoa New Zealand- <https://donorconceivedaotearoa.co.nz/>
- Donor Conceived Australia - <https://donorconceivedaustralia.org.au/>
- Donor Conception Network - <https://dcnetwork.org/> (a charity organisation of over 2200 mainly UK-based families with children conceived from donation, those thinking about donation and DCP)

Books/Resources

- See: <https://dcnetwork.org/catalog> for a list of books and resources, including for: donors, before having children, children/DCP, different family types (mum and dad, solo mothers, two mothers, two fathers) and the “Telling and Talking” series
- See also: <https://donorconceivedaotearoa.co.nz/parent-resources>
- Hertz, Rosanna & Nelson, Margaret (2020). *Random Families: Genetic Strangers, Sperm Donor Siblings and the Creation of New Kin*.
- Dingle, Sarah (2021). *Brave New Humans: The Dirty Reality of Donor Conception*.
- Nordqvist, P. & Gilman, L. (2022). *Donors: Curious Connections in Donor Conception*.
- Nordqvist, P. (2014). *Relative Strangers: Family Life, Genes and Donor Conception*

Webinars:

- DC Aotearoa: Connecting with same donor siblings: <https://donorconceivedaotearoa.co.nz/connecting-with-same-donor-siblings>
- Webinar on DC linking and legislation - see <https://www.fertilitysociety.com.au/professional-groups-anzica-australia-new-zealand/>

## **9. Authors**

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## **APPENDIX A: Sample letter by enquirer**

Sample letter from a donor-conceived person to a donor

### Considerations for letters:

- Make it clear that you are someone worth knowing
- Offer enough information to make them curious, without offering too much. You want to make them curious enough to want to know more and respond. Ensure you are comfortable with the amount of information you share while protecting your rights to privacy during these early communications.
- Make it clear that you will not be giving up your search easily
- Do not offer any restrictions (for example about the type of relationship you are seeking as feelings can change)

Dear Mr/Ms ABC,

My name is XYZ. As a child/adult, I learnt my parents had fertility issues and conceived me with help of a/n egg/sperm/embryo donor through Dr 123's clinic at LOCATION. I was born in YEAR and grew up in AREA. I completed my TRAINING/UNIVERSITY at the NAME. I am interested in/ describe a few traits/characteristics. I have a loving family (*or other details*) and am grateful for the life I have led so far (as relevant). Naturally, I am curious as to which of my traits and characteristics I have inherited from my donor. Further, I am curious to learn about who my donor is and what kind of person he/she is. It is important for me and any children I may have to know if there are any medical issues to be aware of from the donor side of my genetics.

Please take the time you need to formulate a response, as I understand that this might be somewhat of a surprise to you. I find genetic connections significant, however, my own mother/father and I have a strong relationship, and I am not looking to replace that (*or relevant variation*). I would appreciate a reply indicating you have received my message so that I don't need to pursue other avenues.

You can contact me: phone, email, postal address/fertility clinic

Best wishes,

XYZ

**APPENDIX B: Sample outreach letter to a donor**

Date xx/xx/xx

Dear x

Around (insert date) you very kindly assisted with a project which was run at (insert name of hospital). There are a few questions that have arisen which you may be able to assist us with and hence this letter to you. If you are willing to consider helping with these enquiries, I would be very happy to talk with you by telephone and provide more information about this at a time convenient to you. Please contact me on (insert telephone number) which is a direct line to my office to explore your thoughts regarding this matter. You are not obliged to contact me however it would be much appreciated if you choose to do so. Please be assured that I will respect your confidentiality and any personal wishes you have in regards to this enquiry.  
Thank you for considering this request.

Yours sincerely,

Name of counsellor

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