

ANZICA GUIDELINES FOR PROFESSIONAL STANDARDS OF PRACTICE: DONOR LINKING COUNSELLING

Introduction

The 2007 NHMRC Ethical Guidelines on the Use or Assisted Reproductive Technology in Clinical Practice and Research state that,

'Persons conceived using ART procedures have a right to know their genetic parents (Part B, 6.1:25)'

'Voluntary exchange of information between persons conceived using donated gametes, gamete donors and gamete recipients, with the consent of all parties, is desirable. Access to further information may occur only with the consent of all parties involved or as specified by the law.' p25

If the consent form does not include permission for release of identifying information (because the donation was made before the introduction of these guidelines and the gamete donor has not come forward in response to the public information campaign outlined in paragraph 6.1.3), the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor, to contact the gamete donor and obtain his or her consent to the release of information.' 6.13.1

Definition of Donor Linking:

These guidelines pertain to requests for exchange of information between a donor-conceived adult or recipient parent and their donor, as well as between donor-conceived half genetic siblings and recipient parents who have used the same donor. These exchanges may or may not lead to direct contact depending on the wishes of the parties involved.

Guiding Principles:

As always counsellors will be guided by client individual need. These are guidelines and not regulations. This document aims to provide guidelines for professional standards of practice which will reflect the spirit of the NHMRC guidelines and both respect the interests of donor-conceived adults, recipient parents and donors as well as individual's sensitivities regarding privacy by utilising a model of mediation and facilitation.

The clients including the enquirer and the subject of the enquiry (donor conceived person, donor or recipient parent) should:

- Provide confirmation of their identity
- Be provided with clear information
- Be offered the opportunity for discussion
- Be treated with respect
- Be assisted with the process and in their adjustment to the outcome
- Be clearly informed of the choices available to them
- Have control over the pace of the steps involved
- Make informed decisions about each step taken

The donor linking counsellor:

- Takes on the role of the mediator
- Does not become the advocate for one party over another but supports both the client who wishes to find information and the subject of the enquiry throughout the process.
- Supports the principle that people affected by donation may have an interest to request information or make contact with their 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. Information must not be released to another person without the consent of the individual concerned
- Maintains confidentiality at all times.
- Provides information about other mechanisms for donor linking e.g. NSW Health Voluntary Register, Donor Sibling Registry, Victorian Donor Registers

Suggested Procedure/Protocol:

Figure 1. Process Map Donor Linking Counselling

1. Initial Enquiry

Provision of written information by clinics regarding policies and protocols for exchanging identifying and non-identifying information is optimal.

The donor linking counsellor is the person appointed by the ART clinic to manage these cases. All initial inquiries and communication should be referred to the donor linking counsellor. The counsellor will need to work closely with staff of the ART clinic who have direct access to the donor records.

At the time of the initial inquiry, the specific information needs of the client should be established. If their needs are not clear or there are issues needing further discussion an appointment for counselling should be offered.

2. Non-identifying information request (when information is available from clinic records.)

Counselling should be offered with requests for non-identifying information. The request should be made in writing with verification of the identity of the enquirer (driver's license suggested). A search of clinic records should then be made to establish whether there are any records pertaining to the request. If no records are able to be 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 by the counsellor in writing. Follow up counselling should be offered.

3. 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.

4. Counselling session with party requesting information (enquirer)

The counselling should address the following:

- Confirmation of the identity of the enquirer (e.g. driver's licence check)
- Clarification of the specific request for information/contact for that person including their motivation and clarification of their needs and expectations of the possible outcome of the enquiry i.e. what specific information do they wish to know e.g. medical, do they want to exchange emails/letters/meet?
- Understanding the context of other life issues including the impact of the search to people close to the enquirer
- Clarification of the legal rights of all parties
- Discussion of the anticipated steps involved
- 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 does not consent to provide information,
- Consideration of the possible implications for the other party and the possible impact to those close to them.
- This session assists the client to develop a clear understanding of their needs and motivation, and whether they wish to proceed.

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

5. A formal (written) request should be made by the party wishing to initiate contact/information exchange.

The client should also provide in writing the information that they want communicated by the counsellor if/when contact is made with the outreached party, and ideally how they would like to proceed if the subject is willing to exchange information/have contact. The subject of the search is likely to ask the counsellor about the reasons for the enquiry (e.g. motivations, specific information requested, interest in ongoing communication exchange/contact, non-identifying information about the person making the request).

The only information that should be passed on is that which was consented to by the client. Also establish in writing what the client wants the counsellor to ask the subject of the search. This is particularly important as the subject may not agree to further contact but may be prepared to answer some questions.

6. A search is initiated for the contact details of the subject of the outreach. This can be done by accessing the electoral roll, or enlisting the assistance of an organisation experienced in searching e.g. VANISH in Victoria. It may be possible to locate the party via the internet but extreme care needs to be taken that the correct person is identified before any attempt is made to contact them.

7. If the subject of the outreach is not located, the client is advised and further counselling may be necessary.

8. If the subject of the outreach is located, inform the enquirer and re-establish whether the client wishes to proceed before any attempt is made to contact the other party. 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.

The counsellor then adopts the role of **mediator/facilitator**.

9. The counsellor then may contact the subject requesting that they contact the counsellor. If by letter, it should ideally be sent by person to person registered mail and should contain information that will enable the person to recognise what it is about. However it should not give out detailed information in case someone other than the subject reads the letter. See sample letter Appendix A

10. If the letter is received but there is no response The counsellor could try sending a further letter, or making contact in any other appropriate way.

11. When contact is made with the outreached party, information may be passed on to the subject by the donor linking counsellor as authorised by the inquirer. The subject should be invited to attend counselling.. The counselling session assists to clarify the subject's feelings, thoughts, expectations, and wishes in relation to the enquiry and implications for themselves and those close to them. 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? During the counselling session, information may also be provided to the counsellor to pass on to the enquirer

Information, whether it be identifying or specific non-identifying, should only be exchanged with consent given by the person it pertains to.

12. 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. *When this has occurred the counsellor assists to establish the first contact between the parties and then steps out of the mediating role so the clients can establish their own relationship independently if they*

have agreed to do so. The counsellor may agree to provide a **letterbox service** in which letters are forwarded confidentially by the counsellor between the parties so that the two 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.

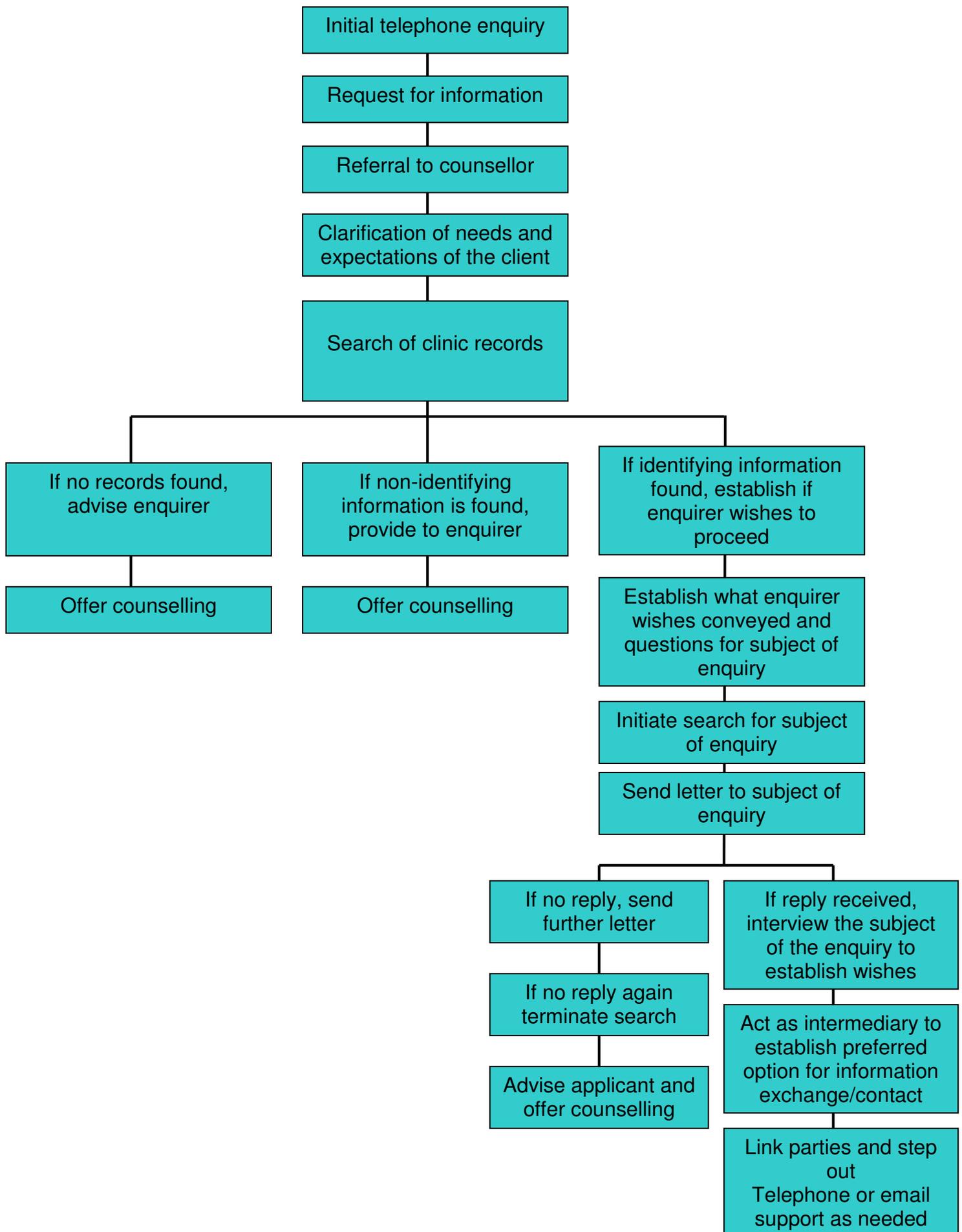
13. Further counselling may be required by either party depending on outcomes and emotional reactions. The needs of others in the immediate families of each party should also be considered. It is likely that issues that were salient at the time of the treatment or donation will resurface and will need 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.

See over for:

- Figure 1 - Process Map of Donor linking counselling.
- Appendix A - Sample outreach letter to donor

ANZICA would like to acknowledge the original authors of this document, Jenny Blood and Helen Kane, who pioneered donor-linking counselling practice in Australia. These guidelines have been updated in January 2012 by Kate Bourne and Liz Hurrell.

FIGURE 1. PROCESS MAP- Donor Linking Counselling Process



Appendix A: Sample outreach letter to a donor

Date xx/xx/xx

X

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 were willing to consider helping us with these enquiries, I would be very happy to talk with you by telephone at a time suitable to you. You could contact me on **(insert telephone number)** which is a direct line to my office. You are not obliged to contact me however it would be much appreciated if you choose to do so.

Thank you for considering this request.

Yours sincerely,

Name of counsellor