

Assisted Reproductive Treatment Act 2008

Guidelines under section 100A

Introduction

The *Assisted Reproductive Treatment Act 2008* (Act) has been amended by the *Assisted Reproductive Treatment Amendment Act 2016*. As a result of these changes all donor conceived people now have the right to access available identifying information about their donors regardless of the date of the donation leading to their conception. The Assisted Reproductive Treatment Amendment Act was passed by Parliament on 23 February 2016 and came into effect on 1 March 2017.

Those people conceived from donations made prior to 1998 can now, just like those who were conceived from later donations, receive identifying information held on the Central Register, about their donors without the consent of the donor.

Under the changes, the Victorian Assisted Reproductive Treatment Authority (the Authority) is the keeper of the Central Register and the Voluntary Register and manages applications for information from the registers.

There may be practical obstacles in locating and accessing records relating to donors who donated prior to 1998. Many doctors encouraged donors to donate anonymously and recipient families were encouraged to keep the manner of their donor-conceived children's conception a secret. There was also no legislative requirement to maintain and keep donor conception records before 1 July 1988 and record keeping depended on individual clinical practice. Some records were not retained, or may have been destroyed or damaged or may be incomplete. In light of this, the Authority has specific powers to request additional information or documents which are not on the Central Register in response to certain applications for identifying information about a donor. Where appropriate, the specialist expertise of an authorised search agency can be engaged to assist with locating relevant people.

The changes provide a number of support mechanisms and protections for donors, donor-conceived people and their families. The Authority manages the application process from initial contact by an applicant to any ultimate release of information, providing information, support and counselling to the parties. Donors who donated before 1998 may lodge contact preferences in response to an application for identifying information about them to prevent or manage contact by their donor-conceived offspring or other applicant. Donor-conceived people may also lodge contact preferences in response to an application for identifying information about them to prevent or manage contact by their donors where they have consented to release of their identifying information. Where identifying information about a pre-1998 donor is released in circumstances where the donor cannot be located, the donor-conceived applicant must have undertaken to the Secretary of the Department of Health and Human Services not to contact the donor and to provide any subsequently available information about the donor's location to the Authority.

The Authority must also comply with the Charter of Human Rights and Responsibilities in carrying out its functions and powers under the Act.

About these Guidelines

These guidelines are issued by the Secretary of the Department of Health and Human Services. Section 100A of the Act provides that the Secretary may issue guidelines to the Authority in relation to the

performance of its functions and exercise of its powers under the Act. The Authority must comply with the requirements set out in the guidelines when carrying out its functions and powers under the Act.

Included in this document are guidelines in relation to:

Part 1 — requests for additional information in order to identify a pre-1998 donor

Part 2 — requests for records relating to pre-1988 donor treatment procedures

Part 3 — request to pre-1998 donor, or blood relative of pre-1998 donor, to consent to undergo genetic testing

Part 4 — searching under the Act

Part 5 — establishing a link

Part 6 — identifying and non-identifying information

As required under s.100A(2) of the Act, the Health Complaints Commissioner has been consulted in the preparation of the guidelines which relate to the Authority's disclosure of identifying information about a pre-1998 donor or person conceived from a pre-1998 donation.

These guidelines will be periodically reviewed. Feedback for consideration as part of this review process can be directed at any time to:

The Assisted Reproductive Treatment Policy Manager
Department of Health and Human Services
50 Lonsdale Street
Melbourne VIC 3000

Part 1— requests for additional information in order to identify a pre–1998 donor

The guidelines in Part 1 set out requirements the Authority must comply with in the exercise of its powers under s. 56J of the Act to request additional information to identify a pre–1998 donor.

The powers in s. 56J provide a mechanism by which the Authority may seek to establish links between an applicant who is a person born as a result of a pre–1998 donor treatment procedure and their donor, where records on the Central Register may not be complete.

Relevant provisions of the *Assisted Reproductive Treatment Act 2008*

s56J Authority may request additional information in order to identify pre-1998 donor

- (1) This section applies if—
 - (a) an application has been made under section 56(1) by a person born as a result of a pre-1998 donor treatment procedure; and
 - (b) there is insufficient information on the Central Register to identify the donor of gametes used in the procedure; and
 - (c) the Authority is satisfied that records identifying the donor are not among records from Prince Henry's Institute of Medical Research in the custody of the Public Record Office; and
 - (d) the applicant consents to the Authority requesting information under this section.
- (2) Subject to subsections (4) and (5), the Authority may for the purposes of identifying the donor—
 - (a) request information relating to the donor or to the donor treatment procedure from any person (including a registered ART provider); and
 - (b) for the purposes of making a request under paragraph (a), disclose to any person information contained on the Central Register.
- (3) A request under subsection (2)(a) must be made in accordance with any guidelines issued under section 100A.
- (4) The Authority must not request information under subsection (2)(a) from a child of a person whose name is entered on the Central Register as a donor unless—
 - (a) the person whose name is entered on the Central Register consents to the Authority making the request; or
 - (b) the child has previously initiated contact with the Authority.
- (5) The Authority must not request under subsection (2)(a) records relating to pre-1988 donor treatment procedures.

s56K Offence to disclose that Authority has requested additional information relating to donor or donor treatment procedures

- (1) A person who receives a request from the Authority under section 56J(2) must not disclose, whether directly or indirectly, to any other person that the Authority has made that request unless—
 - (a) the disclosure is reasonably necessary for the purposes of locating the information that is the subject of the request; or
 - (b) in the case of records, the disclosure is made to the person to whom the requested records relate.

Penalty: 50 penalty units.
Subsection (1) does not apply to a disclosure of information if the Authority has not advised the person or the registered ART provider that it is a criminal offence to disclose to any other person that the Authority has made the request.

The Authority may only request information under s. 56J where there has been an application made under s. 56(1) to the Central Register by a donor-conceived person born of gametes donated prior to 1998; and

- there is insufficient information on the Central Register to identify the donor;
- the Authority is satisfied that records identifying the donor are not among the records from Prince Henry's Institute of Medical Research held at the Public Record Office; and
- the applicant has consented to the Authority requesting information under s56J.

The Authority cannot request information under s. 56J in the following circumstances:

- (a) in response to applications for information from the Voluntary Register;
- (b) to requests for records relating to pre–1988 donor treatment procedures as such requests are to be made under s. 56B; and

- (c) in response to an application made by the parent of a donor-conceived person, the sibling or descendant of a donor-conceived person or a donor.

The guidelines under Part 1 should be read in conjunction with the Act and the other guidelines including those related to requests for records (Part 2) and searching (Part 4). The searching guidelines under Part 4 provide information about the steps the Authority, or an authorised organisation, may take to identify and locate a person from whom the Authority may make inquiries under s. 56J.

The guidelines

Guideline 1

Context

Section 56J(1)(d) provides that, before initiating contact with a person for the purposes of seeking additional information under s56J, the applicant must consent to the Authority requesting information under that section.

Requirement

The full and informed consent of the applicant must be obtained in writing in an approved pro forma form created by the Authority and submitted by the applicant.

In obtaining the consent, the Authority should ensure that the applicant has had the opportunity to consider the implications of such a request being made. This includes:

- i. that in making the request, the Authority may disclose to a person from whom information is being sought that an application has been made for information from the Central Register.
- ii. that there is a possibility that, despite the information being requested, the Authority may be unable to obtain sufficient information to identify the donor
- iii. that any relevant information found in the search will be updated on the Central Register as permitted under the Act.

Guideline 2

Context

The Authority cannot make a request for additional information under s. 56J as a general fishing expedition.

Requirement

The Authority must only make a request under s. 56J where the Authority has reasonable grounds for considering that the person to whom it is proposed that a request be made may have information that will assist in identifying the donor who is the subject of a specific application.

The person to whom the request for information is made must be informed that they are not obligated to give information pursuant to the request.

Guideline 3

Context

The Authority cannot make a request for information under s.56J when no application has been made.

Requirement

The Authority must not request information under s. 56J where no application for information has been made under s. 56(1).

This includes circumstances where no application has been received but the Authority may believe that a person has information that would allow the Central Register to be updated or made more complete.

Guideline 4

Context

Family members may not be aware that their relative is a donor.

Requirement

The Authority should only seek information from a family member of a donor if all other practicable avenues to find information have been exhausted. The practicable avenues may vary depending on the particular circumstances, however, if it was considered that

another person may hold records, for example a doctor, the Authority should first request the records before approaching a family member. Where it is appropriate (see Part 3), consideration should be given to requesting that a potential donor consent to undertaking a genetic test prior to contacting a family member for information or documents so as not to intrude unnecessarily on family members. This should be read in conjunction with Part 4 – searching under the Act.

Guideline 5 **Context**

For some individuals being contacted by the Authority requesting additional information under s. 56J may be confronting. In some cases this may involve disclosure by the Authority that someone they know, possibly a family member, is named as a donor on the Central Register. If it is a potential donor being contacted this may be the first time they become aware that someone is seeking identifying information about them. It is therefore critical that this contact is managed sensitively and discretely by the Authority.

Requirement

Initial contact with a person for the purposes of seeking additional information under s. 56J should be as unobtrusive as practicable to achieve the objective of obtaining information to identify a donor. In general this will mean that initial contact is made in writing using unmarked envelopes. Subsequent contact will be tailored to the circumstances and take account of the preferred contact method of the person being contacted.

Where phone contact is to be made, the Authority should not disclose they are from the Authority and should take steps to ensure that the specific reason for the call is not disclosed, unless it is clear that the person being spoken to is the person identified as able to provide relevant additional information. It is not appropriate to seek information from an alternative person who answers a phone call unless they have also been identified as able to provide the relevant information.

If practicable within the time constraints imposed by the Act, the timing of requests for information should where possible seek to avoid coinciding with significant events such as birthdays or family or cultural celebrations (where known).

Guideline 6 **Context**

Record keeping procedures

Requirement

In accordance with the *Public Records Act (1973)*, the Authority should keep records setting out:

- i. the nature of any requests for additional information made under s. 56J;
 - ii. the basis for making the request; and
 - iii. the information that was disclosed and obtained as a result of the request for information.
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Guideline 7 **Context**

In most cases available pre-1988 records from registered ART clinics have now been included on the Central Register. However, the files belonging to doctors operating out of the Prince Henry's Hospital (later the Prince Henry's Medical Research Institute) were in the most part retained by the Prince Henry's Medical Research Institute and subsequently transferred to the Public Records Office Victoria where they are still held. The Act provides that these records may be accessed by the Authority if a request for information is made (s. 56A).

To ensure that requests for additional information are not made in cases where relevant records may be available, the Act states that the Authority may only make a request for additional information under s. 56J in circumstances where there is insufficient information on the Central Register to identify the donor of gametes used in the procedure; and the Authority is satisfied that records identifying the donor are not among records from Prince Henry's Institute of Medical Research in the custody of the Public Records Office Victoria.

Requirement

The Authority must examine the records from Prince Henry's Hospital and Prince Henry's Institute of Medical Research that are held at the Public Records Office before making a request under s. 56J unless the Authority is satisfied, on the basis of information provided by the applicant or through information gathered by the Authority that the donor conception procedure did not take place at Prince Henry's Hospital or Prince Henry's Institute of Medical Research.

Guideline 8**Context**

Section 56K makes it an offence for a person who receives a request from the Authority under s. 56J to disclose, whether directly or indirectly, to any other person that the Authority has made the request.

There are two exceptions to this. The person may disclose to another person that the Authority has requested additional information from them:

- i. if it is reasonably necessary to do so in order to locate the information that is being requested; or
- ii. if the information being requested is records, the disclosure is made to the person to whom those records relate.

The offence does not apply if the Authority has not advised the person that it is a criminal offence to disclose to any other person that the Authority has made the request.

Requirement

The Authority must document and retain records of the provision of this advice and provide a copy of the advice in writing to the relevant person where practicable.

Guideline 9**Context**

Section 66A of the Act provides that it is an offence for a member of the Authority (or a person or organisation engaged by the Authority) to disclose to any person, whether directly or indirectly, information recorded on the Central Register. The offence does not apply where the disclosure occurs in the following circumstances—to a court or Tribunal; as required in the course of disciplinary proceedings against a doctor; as required under any Act; for the purpose of law enforcement; or in the exercise in good faith of a power or a function under the Act.

To allow the Authority to exercise the power to request information under s. 56J, the Act expressly provides that the Authority may, for the purposes of making a request under s. 56J 2(a) disclose to any person information contained on the Central Register (s. 56J 2(b)).

Requirement

The Authority should only disclose information contained on the Central Register where making a request for information under s. 56J if that disclosure is reasonably necessary to obtain the information being sought.

Guideline 10**Context**

Information may only be requested that is directly relevant to the identification of the donor that is the subject of the specific application.

Requirement

The Authority must not request additional information for any other purpose, even if the additional information may assist in making the Central Register more complete.

Guideline 11**Context**

Contacting a person to request additional information relating to a donor, or a donor treatment procedure, under s. 56J will ordinarily involve the disclosure of some information from the Central Register.

Requirement

To minimise the need to disclose information and the number of individuals to whom information is disclosed, the Authority must make a request under s. 56J with respect to a specific application for information under s. 56(1) to only one individual at a time.

The Authority should identify the person it believes is most likely to be able to provide information to assist in identifying a donor and request information from that person.

Once this request has been responded to, and the Authority is satisfied that the person has provided all the information they are able and prepared to provide, the Authority may make an assessment as to whether subsequent requests are required.

After the initial information request the Authority may, if sufficient information has not been obtained to enable the donor to be identified, make a request for information from another person it believes is the next most likely to be able to provide information to assist in identifying a donor. This (and any subsequent information requests) must be finalised before another individual can be approached.

Guideline 12 **Context**

Section 56J(4) provides that the Authority may not make a request for additional information under s. 56J to a child (under 18 years of age) of a person named on the Central Register unless:

- i. the person named on the Central Register has consented to the request being made; or
- ii. the child has previously initiated contact with the Authority

Requirement

The consent of the person named on the Central Register must be obtained in writing and must be in respect of a particular request.

The relevant contact which the child initiated with the Authority is a request for information about whether their father is a donor or potential donor of gametes. There must be a written record (eg. file note), of the child's previous contact with the Authority to satisfy this second requirement.

Guideline 13 **Context**

54A provides that the Authority may use information or records obtained under section 56J to amend or correct information, or create a new entry, in the Central Register if in the Authority's opinion, the amendment, correction or new entry will make the Central Register more accurate or complete.

In considering whether a new entry will make the Central Register more accurate or complete, the Authority must have regard to the desirability of including in the Central Register as much as possible of the information required under the Act and regulations to be contained in the Central Register.

Requirement

If the information that the Authority obtains from its request for records or in response to a production order from the Magistrate's Court would make the Central Register more complete, and the information can be included on the Central Register under section 53 of the Act, the Authority should include this information on the Central Register

Part 2— requests for records relating to pre–1988 donor treatment procedures

The guidelines in Part 2 set out requirements the Authority must comply with in the exercise of its powers under ss. 56B to 56F of the Act to request records relating to a pre–1988 donor treatment procedure.

The powers to request records in ss. 56B to 56F provide a mechanism by which the Authority may seek to establish links between an applicant and a pre–1988 donor where records on the Central Register may not be complete.

Relevant provisions of the *Assisted Reproductive Treatment Act 2008*

56B Authority may request records—pre-1988 donor treatment procedures

(1) This section applies if—

(a) an applicant under section 56(1) requests information relating to a person born as a result of a pre-1988 donor treatment procedure; and

(b) records relating to the donor treatment procedure are not among records from Prince Henry's Institute of Medical Research in the custody of the Public Record Office.

(2) If the Authority believes on reasonable grounds that a person (other than a registered ART provider) is in possession of or has control of records relating to the donor treatment procedure, the Authority may, subject to subsection (3), request the person to locate and give the records to the Authority.

(3) The Authority must not request records under this section from a child of a donor unless—

(a) the donor consents to the Authority making the request; or

(b) the child has previously initiated contact with the Authority.

(4) A request under subsection (2) must be in writing and must set out the requirements of this section.

(5) A person who receives a request under subsection (2) must, within 60 days of receiving the request—

(a) make all reasonable efforts to locate the requested records; and

(b) provide a written declaration to the Authority stating—

(i) that the person has made all reasonable efforts to locate the requested records; and

(ii) whether the person is in possession of or has control of the requested records.

(6) If the declaration states that the person is in possession of or has control of the requested records, the person must, within 21 days after providing the declaration—

(a) give the records to the Authority; or

(b) give copies of the records to the Authority.

(7) A person is not liable for prosecution for an offence, or to a civil action, only for giving records, or copies of records, to the Authority under subsection (6).

56C Offence to disclose that Authority has requested records—pre-1988 donor treatment procedures

(1) A person who receives a request from the Authority under section 56B(2) must not disclose, whether directly or indirectly, to any other person that the Authority has made that request unless—

(a) the disclosure is reasonably necessary for the purposes of locating the records that are the subject of the request; or

(b) the disclosure is made to the person to whom the requested records relate.

Penalty: 50 penalty units.

(2) Subsection (1) does not apply to a disclosure of information if the Authority has not advised the person that it is a criminal offence to disclose to any other person that the Authority has made the request.

56D Authority may apply to Magistrates' Court for production order

- (1) The Authority may apply to the Magistrates' Court for an order requiring a person to produce records relating to a particular pre 1988 donor treatment procedure if—
 - (a) the Authority requested the person under section 56B to provide records relating to that donor treatment procedure; and
 - (b) the person, within 90 days of the Authority giving the request—
 - (i) did not provide the requested records; or
 - (ii) did not provide all the requested records; and
 - (c) the Authority believes on reasonable grounds that the person is in possession of or has control of the requested records.
- (2) The Authority may make an application under subsection (1) whether or not the person has made a declaration under section 56B(5) stating that the person is not in possession of or does not have control of the records.
- (3) An application under subsection (1) must be—
 - (a) supported by an affidavit made on behalf of the Authority stating—
 - (i) the particulars of the request that the Authority has made under section 56B; and
 - (ii) whether the person complied with any part of the request under section 56B; and
 - (iii) the grounds on which the Authority considers that the person against whom the order is sought is in possession of or has control of the records that are the subject of the request; and
 - (b) accompanied by any declaration made by the person under section 56B(5).
- (4) As soon as practicable after the Authority makes an application under subsection (1), the Authority must serve a copy of the application and the supporting affidavit on the person against whom the production order is sought.

56E Hearing of application for production order

- (1) The Magistrates' Court hearing an application under section 56D(1) may require the Authority to give the Court any additional information that the Court requires concerning the grounds on which the order is sought.
- (2) The respondent is entitled to be present at any hearing of an application under section 56D(1).
- (3) Despite anything to the contrary in the Open Courts Act 2013, an application under section 56D(1) must be heard in closed court.

56F Magistrates' Court may make production order

- (1) If the Magistrates' Court is satisfied that there are reasonable grounds for believing that the person is in possession of or has control of records relating to the pre-1988 donor treatment procedure to which the application relates, the Court may make a production order requiring the person to produce to the Authority before a day specified in the order—
 - (a) the records specified in the order; or
 - (b) copies of the records specified in the order.
- (2) The Authority must serve a copy of an order made under this section on the person against whom it is made.

These guidelines apply in circumstances where there has been an application made to the Central Register regarding a pre-1988 donor treatment procedure; and records relating to the donor treatment procedures are not among records from Prince Henry's Institute of Medical Research in the custody of the Public Record Office. The application for information from the Central Register may be made by a donor-conceived person, the parent of a donor-conceived person, the descendent of a donor-conceived person or a donor.

The powers in ss. 56B to 56F cannot be used to request that records held by a registered ART provider, as s. 52A of the Act requires registered ART providers to forward information relating to pre-1988 donor treatment procedures to the Authority.

The guidelines do not apply to applications for information from the Voluntary Register.

The guidelines should be read in conjunction with the Act and other guidelines issued under s100A of the Act, including those related to requests for further information (Part 1) and searching (Part 4). The guidelines related to searching under the Act (Part 4) provide information about the steps the Authority or an authorised organisation may take to identify and locate a person from whom the Authority may request records under s. 56B.

The guidelines

Guideline 1	<p>Context</p> <p>The Authority cannot make a request for records under s.56B as a general fishing expedition.</p> <p>Requirement</p> <p>The Authority must only make a request under s. 56B where the Authority believes on reasonable grounds that the person to whom it is proposed that a request be made has control or possession of records relating to the pre–1988 donor treatment procedure that is the subject of the application.</p> <p>Ordinarily it will be the responsibility of the applicant to provide the Authority with all necessary information to enable the Authority to assess whether there are grounds to form a reasonable belief that a person has control or possession of relevant records. There may, however, also be circumstances where the Authority makes inquiries under s. 56J of the Act and thereby obtains sufficient information to form this belief.</p>
Guideline 2	<p>Requirement</p> <p>The Authority may not request records under s. 56B for any purpose other than responding to an application under s. 56(1) for information.</p> <p>The Authority may not make a request under s. 56B in circumstances where no application has been received even if the Authority believes that a person has control or possession of records that would allow the Central Register to be generally updated or made more complete.</p>
Guideline 3	<p>Requirement</p> <p>In accordance with the <i>Public Records Act 1973</i>, the Authority should keep records setting out:</p> <ol style="list-style-type: none">i. the nature of any requests for records made under s. 56B;ii. the basis for making the request;iii. the grounds for believing that the person to whom the request is made has control or possession of the records;iv. the information that was disclosed as a result of the request for records;v. any declaration provided to the Authority in response to a request for records;vi. what, if any, records were provided to the Authority in response to a request made under s. 56B;vii. details of any application made to the Magistrates court under s. 56D; andviii. the details of the service of the copy of any application made under s. 56D or any order made under s. 56F.
Guideline 4	<p>Context</p> <p>In most cases available pre–1988 records from registered ART clinics have now been included on the Central Register. However, the files belonging to doctors operating out of the Prince Henry’s Hospital (later the Prince Henry’s Medical Research Institute) were in the most part retained by the Prince Henry’s Medical Research Institute and subsequently transferred to the Public Records Office Victoria where they are still held. The Act provides that these records may be accessed by the Authority if a request for information is made (s. 56A).</p> <p>To ensure that requests for records are not made in cases where relevant records may already be available, the Act states that the Authority may only make a request for records under s. 56B in circumstances where the records relating to the donor treatment procedure are not among records from Prince Henry’s Institute of Medical Research in the custody of the Public Records Office.</p> <p>Requirement</p> <p>The Authority must examine the records from Prince Henry’s Hospital or Prince</p>

Henry's Institute of Medical Research that are held at the Public Records Office before making a request under s. 56B unless the Authority is satisfied, on the basis of information provided by the applicant or through information gathered by the Authority, that the donor conception procedure did not take place at Prince Henry's Hospital or Prince Henry's Institute of Medical Research.

Guideline 5

Requirement

A request for records by the Authority under s. 56B must be made in writing. The request must specify the records being sought and about whom they relate and the grounds on which the Authority has formed the reasonable belief that the person to whom the request is made has the records or has control of them.

The written request should also advise the person to whom the request is being made of the following:

- (a) the person must within 60 days of receiving the request provide a written declaration to the Authority stating that the person has made all reasonable efforts to locate the requested records and whether the person is in possession of or has control of the requested records;
- (b) if the person is in possession of the requested records, they must provide the records or copies of the records to the Authority within 21 days of providing the declaration;
- (c) the person is not liable for prosecution for an offence or to a civil action only for the giving of the records under s. 56B;
- (d) the power of the Authority under s. 56D to apply to the Magistrates' Court for an order requiring the person to produce records if the Authority believes, on reasonable grounds, that the person is in possession of, or has control of, the records that are the subject of the request; and if the person does not provide all of the requested records within 90 days of the request; and
- (e) it is a criminal offence under s. 56C to disclose whether directly or indirectly to any other person that the Authority has made the request except in the following circumstances:
 - i. if it is reasonably necessary to do so in order to locate the records being requested; or
 - ii. the disclosure is made to the person to whom those records relate.

To assist the person from whom records are being requested to comply with their obligations, the Authority should provide a blank form of declaration which they may complete in order to meet the requirements of s. 56B(5)(b).

Guideline 6

Context

Section 56C makes it an offence for a person who receives a request from the Authority under s. 56B to disclose, whether directly or indirectly, to any other person that the Authority has made the request.

There are two exceptions to this. The person may disclose to another person that the Authority has requested additional information from them:

- i. if it is reasonably necessary to do so in order to locate the records being requested; or
- ii. the disclosure is made to the person to whom those records relate.

The offence does not apply if the Authority has not advised the person that it is a criminal offence to disclose to any other person that the Authority has made the request.

Requirement

The Authority must document and retain records of the provision of this advice and provide a copy of the advice in writing to the relevant person.

Guideline 7**Context**

Section 66A of the Act provides that it is an offence for a member of the Authority (or a person or organisation engaged by the Authority) to disclose to any person, whether directly or indirectly, information recorded on the Central Register. This offence does not apply where the disclosure occurs in the following circumstances—as required by a court or Tribunal; as required in the course of disciplinary proceedings against a doctor; as required under any Act; for the purpose of law enforcement; or in the exercise in good faith of a power or a function under the Act.

Section 56B does not make specific provision for the disclosure of information on the Central Register, however, it is anticipated that, in order to make a request for records under s. 56B, it may be necessary for the Authority to disclose to a person information contained on the Central Register. Such disclosure is permitted where it is in the exercise in good faith of the power conferred by s. 56B.

Requirement

The Authority should only disclose information from the Central Register when making a request for records under s. 56B where the disclosure of that information is reasonably necessary to obtain the information being sought.

Guideline 8**Context**

Records of donor treatment procedures will contain sensitive health information.

Individuals who are required under section 52B to provide these records, or copies of these records, to the Authority are not liable for prosecution or civil action for doing so under s. 52B(7)).

However, the legal obligations to maintain the confidentiality of records and protect the privacy of the health information of an individual remain.

Requirement

The Authority should liaise with persons to whom a request for records are made to arrange a method for providing the records that minimises the risk of privacy breaches and protects confidentiality. The appropriate method for transmissions should be assessed on a case by case basis but may, for example, include the use of registered person to person mail, encrypted email transmission or personal collection or delivery.

Guideline 9**Context**

The Authority may not request records under s. 56B from a child (under 18 years of age) of a donor unless:

- i. the donor consents to the request being made; or
- ii. the child has previously initiated contact with the Authority.

Requirement

The Authority must obtain the consent of the donor to the request in writing and the consent must be in respect of the particular request. The relevant contact which the child initiated with the Authority is a request for information about whether their father is a donor or potential donor of gametes. There must be a written record of the child's previous contact with the Authority to satisfy this second requirement.

Guideline 10**Context**

Section 54A provides that the Authority may use records obtained under section 56B to amend or correct information, or create a new entry, in the Central Register if in the Authority's opinion, the amendment, correction or new entry will make the Central Register more accurate or complete. In considering whether a new entry will make the Central Register more accurate or complete, the Authority must have regard to the desirability of including in the Central Register as much as possible of the information required under the Act and regulations to be contained in the Central Register.

Requirement

If the information that the Authority obtains from its request for records or in response to a production order from the Magistrate's Court would make the Central Register more complete, and the information can be included on the Central Register under section 53 of the Act, the Authority should include this information on the Central Register.

Part 3 – request to pre–1998 donor, or blood relative of pre-1998 donor, to consent to undergo genetic testing

These guidelines set out requirements the Authority must comply with in making a request, under s. 56L and s.56M of the Act, that a person named on the Central Register (or in certain circumstances a blood relative of such a person) consent to undergo genetic testing for the purposes of establishing if they are genetically linked to a pre-1998 donor-conceived person who has applied for information from the Central Register.

The powers and procedures set out in s. 56L and s. 56M provide a mechanism by which the Authority may seek to establish links between an applicant and a pre–1998 donor where records on the Central Register may not be complete. Section 53(ac) and (ad) of the Act allows for results of genetic testing undertaken under these provisions to be included on the Central Register.

Relevant provisions of the *Assisted Reproductive Treatment Act 2008*

56L Authority may request genetic test results of suspected donor

(1) This section applies if—

(a) an application has been made under section 56(1) by a person born as a result of a pre-1998 donor treatment procedure; and

(b) there is insufficient information on the Central Register to determine whether a person whose name is entered on the Central Register as a donor is the donor of gametes used in the procedure.

(2) The Authority may, for the purposes of establishing a genetic link between the person whose name is entered on the Central Register and the applicant, request that the person whose name is entered on the Central Register—

(a) undergo genetic testing at a place specified by the Authority; and

(b) consent to the comparison of the results of the genetic testing described in paragraph (a) with a DNA profile or genetic test results relating to the applicant; and

(c) consent to the results of the comparison described in paragraph (b) being given to the Authority.

56M Authority may request genetic test results of relative of suspected donor

- (1) This section applies if—
- (a) an application has been made under section 56(1) by a person born as a result of a pre-1998 donor treatment procedure; and
 - (b) the Authority reasonably believes that a person whose name is entered on the Central Register as a donor may be the donor of gametes used in the procedure; and
 - (c) the Authority has—
 - (i) made a request under section 56L(2) of the person whose name is entered on the Central Register; or
 - (ii) made all reasonable efforts to locate the person whose name is entered on the Central Register for the purposes of making a request under section 56L(2).
- (2) Subject to subsection (3), the Authority may, for the purposes of establishing a genetic link between the person whose name is entered on the Central Register and the applicant, request that an adult blood relative of the person whose name is entered on the Central Register—
- (a) undergo genetic testing at a place specified by the Authority; and
 - (b) consent to the comparison of the results of the genetic testing described in paragraph (a) with a DNA profile or genetic test results relating to the applicant; and
 - (c) consent to the results of the comparison described in paragraph (b) being given to the Authority.
- (3) The Authority may make a request under subsection (2) only if—
- (a) the person whose name is entered on the Central Register is deceased; or
 - (b) the person whose name is entered on the Central Register is considered to be a missing person by Victoria Police, the police force of any other State or a territory or the Australian Federal Police; or
 - (c) the Authority considers that there are exceptional circumstances that justify making a request under subsection (2) in the particular case.
- (4) If the Authority intends to make a request under subsection (2) on the basis that there are exceptional circumstances that justify making the request, the Authority must make all reasonable efforts to give notice of the intended request to the person whose name is entered on the Central Register.
- (5) If a person is given notice under subsection (4) of an intended request, that person may apply to VCAT for a review of the decision of the Authority to make the intended request.
- (6) An application to VCAT must be made—
- (a) if the person does not request reasons for the decision under section 45 of the *Victorian Civil and Administrative Tribunal Act 1998*, within 28 days of receiving the notice under subsection (4); or
 - (b) if the person does request reasons for the decision under section 45 of the *Victorian Civil and Administrative Tribunal Act 1998*, within 28 days of receiving the written reasons under that Act.
- (7) If notice of an intended request is given under subsection (4), the Authority may make that request only if—
- (a) the person does not apply for a review of the decision of the Authority to make the intended request within the period set out in subsection (6)(a) or (b); or
 - (b) VCAT has reviewed the Authority's decision to make the intended request and has confirmed the Authority's decision.

The Authority may only request genetic testing under these provisions where there has been an application made to the Central Register by a donor-conceived person regarding a pre-1998 donor treatment procedure; and there is insufficient information on the Central Register to determine the identity of the donor.

The guidelines in Part 3 do not apply to applications for information from the Voluntary Register.

These guidelines should be read in conjunction with the Act and other guidelines issued under s. 100A of the Act, including the guidelines in relation to requests for additional information in order to identify a pre-1998 donor (Part 1), searching (Part 4) and establishing a link (Part 5). The searching guidelines in Part 4 provide information about the steps the Authority, or an authorised organisation, may take to identify and locate a person the Authority may request consents to genetic testing under ss. 56L or 56M.

The guidelines

Guideline 1

Context

Under the Act, genetic testing can only be used for establishing links between individuals when the two individuals consent to providing a genetic sample and agree to their comparison.

For some individuals, being contacted by the Authority to request that they undertake a genetic test may be confronting. Therefore, before making such a request, the Authority must confirm that the applicant is prepared to participate in order to establish a link.

Requirement

Before making contact with a potential donor, or the blood relative of a potential donor, the Authority must obtain the written agreement of the applicant that, if the donor or potential donor consents to genetic testing under s. 56L, the applicant will also consent in writing to:

- i. undergo genetic testing at a place specified by the Authority;
- ii. consent to the comparison of the results of the genetic testing with the test results of the possible donor, or the donor's relative; and
- iii. consent to the result of the comparison being given to the Authority.

Guideline 2

Context

The Act confers specific powers on the Authority to allow for a mechanism by which the Authority may seek to establish links between an applicant and a pre-1998 donor where records on the Central Register may not be complete. This includes the powers in ss. 56L and 56M to request that individuals undergo genetic testing. The scope of these powers is defined in the Act.

A request that a person consent to genetic testing cannot be made as a general fishing expedition or to establish a DNA database to facilitate the matching of individuals.

Requirement

The Authority must only make a request under s. 56L or s. 56M where the Authority forms a reasonable belief that the person named on the Central Register is the donor about whom information is being sought in a specific application.

The Authority may not make such requests in other circumstances to improve information on the register, to establish a database of genetic profiles to facilitate matching, or for any other reason.

Guideline 3

Context

The Act does not allow for any individual to be required or coerced to participate in genetic testing. Any genetic tests undertaken under the Act will be on voluntary basis, with the consent of both parties.

Requirement

The Authority should ensure that, in requesting that a potential donor, or the relative of a potential donor, consent to genetic testing, it is explained that agreeing to participate is voluntary and that there is no legal consequence for the person approached in not agreeing to participate.

A potential donor should be advised in writing where practicable that the Authority may, in exceptional circumstances, request that a blood relative agree to genetic testing where the potential donor has refused to undergo such testing. The Authority should also advise the potential donor in writing where practicable that they will be given notice if such a request is to be made and will have the right to apply to the Victorian Civil and Administrative Tribunal for a review of the decision of the Authority to make the request. VARTA must advise that the application for review is to be made within 28 days of receiving the notice under s.56N(4) that the Authority intends to make a request.

Guideline 4**Context**

The consequences of determining that a genetic link exists between a donor and a donor-conceived person may be significant and it is, therefore critical that a high threshold of scientific reliability is met - both in the protection of the chain of custody of samples and technical accuracy of undertaking and reporting the test.

Requirement

Genetic testing undertaken for the purpose of establishing a link under s. 56N(4)(b) must be undertaken by a facility accredited by the National Association of Testing Authorities (NATA) and must, as far as possible, follow the parentage testing procedure provided for under the *Family Law Act 1975 (Cwth)*.

This will ensure that the facility meets a range of criteria in relation to the collection of bodily samples; the storage and transport of samples; the timeframe for testing; and the format of the parentage testing report. In that way both parties can be confident that the results are accurate.

When genetic testing involves an adult blood relative of the potential donor (rather than the potential donor themselves), the Authority, in consultation with representatives of genetic testing facilities with appropriate scientific knowledge and expertise, should in each case assess the validity and usefulness of particular tests, including whether more than one test may be required to establish a link.

Guideline 5**Context**

The Act sets out clear requirements in relation to the disclosure of information from the Central Register. The scheme established by the legislation aims to ensure that when information is disclosed in accordance with the Act, support can be provided to both the applicant and the donor who donated before 1998 where their information is being released.

Requirement

The Authority must have in place processes to enable genetic testing to be undertaken (with consent) without the identity of either party being disclosed to the other.

The processes for genetic testing must also allow for the result of comparisons to be disclosed from the testing agency to the Authority so that the results can be communicated to the applicant and the potential donor (or blood relative of the potential donor) by counsellors engaged by the Authority.

To achieve this, it is expected that the Authority will enter into agreements with NATA approved genetic testing laboratories to enable comparisons to be undertaken without need to disclose the identity of those being tested and to allow for the results of the tests to be disclosed to the Authority for the purposes of advising the individuals and recording the information on the Central Register under s. 53(ac) or s. 53(ad).

Guideline 6**Requirement**

In accordance with the Public Records Act 1973, the Authority should keep records setting out:

(a) for requests made under s. 56L:

- (i) the basis for any requests for genetic tests made;
- (ii) the written consent obtained from applicants, the response to the request including any written consent to testing obtained from the person named on the Central Register; and
- (iii) the results (if any) of the genetic testing.

(b) for requests made under s. 56M:

- (i) the basis for any requests for genetic tests made;
 - (ii) the details of the relevant request made under s. 56L or the search undertaken in attempting to locate the person named on the Central Register for the purpose of making a request under s. 56L;
 - (iii) where relevant to the grounds for the request being made, evidence that the person who is named on the Central Register is deceased or considered missing (it is expected that this would ordinarily be a death certificate provided by the Registry of Births Deaths and Marriages or a missing persons report
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- provided by a relevant authority (e.g. the Victoria Police);
 - (iv) where the request is to be made to a blood relative of a person named on the Central Register on the basis that there are exceptional circumstances that justify making the request (s. 56M(3)(c), the grounds on which the Authority considers that such circumstances exist and the efforts made to give notice of the intended request as required under s. 56M(4);
 - (v) any applications made by a person to VCAT under s. 56M(5) and the outcomes of any review by VCAT;
 - (vi) the response to a request including any written consent to testing obtained from the adult blood relative of the person named on the Central Register; and
 - (vii) the results (if any) of the genetic testing.
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Guideline 7

Context

For some individuals being contacted by the Authority requesting that they consent to genetic testing under s. 56L or s. 56M may be confronting. For a person named on the Central Register, this may be the first time they become aware that someone is seeking identifying information about them. If it is a blood relative being contacted this request may involve disclosure by the Authority that their relative is named as a donor on the register. It is therefore expected that this contact be managed sensitively and discretely by the Authority.

Requirement

Initial contact with a person for the purposes of requesting that they consent to genetic testing under s. 56L or s. 56M should be as unobtrusive as practicable to achieve the objectives of obtaining information to identify a donor. In general this will mean that initial contact is made in writing using unmarked envelopes. Subsequent letters may be sent using registered person-to-person mail.

Where phone contact is to be made, the Authority should take steps to ensure that the specific reason for the call is not disclosed unless it is clear that the person being spoken to is the person to whom the request to consent to genetic testing is to be made.

If practicable within the time constraints imposed by the Act, the timing of requests under s. 56L and s. 56M should, where possible, seek to avoid coinciding with significant events such as birthdays or family or cultural celebrations (if known).

Guideline 8

Context

Section 66A of the Act provides that it is an offence for a member of the Authority (or a person or organisation engaged by the Authority) to disclose to any person, whether directly or indirectly, information recorded on the Central Register. Section 66B makes it an offence for a member of the Authority (or a person or organisation engaged by the Authority or an authorised search organisation) to disclose to any person, whether directly or indirectly, any information contained in records provided to the Authority under s. 52B or in response to a request made under s. 56B or in the records transferred to the Public Records Office from Prince Henry's Hospital. It is also an offence to disclose information obtained through a request for additional information made under s. 56J. These offences do not apply where the disclosure occurs in the following circumstances—to a court or Tribunal; as required in the course of disciplinary proceedings against a doctor; as required under any Act; for the purpose of law enforcement; or in the exercise in good faith of a power or a function under the Act.

Sections 56L and s. 56M do not make specific provision for the disclosure of information, however, it is anticipated that, in order to request that a person consents to genetic testing under these provisions, it may be necessary for the Authority to disclose to that person information contained on the Central Register. Such disclosure is permitted where it is in the exercise in good faith of the powers conferred under s. 56L or s. 56M.

Requirement

The Authority should only disclose information on the Central Register where that disclosure is reasonably necessary to make the request that a person consent to genetic testing.

Guideline 9**Context**

Contacting a person to request that they consent to undergo genetic testing, under s. 56L or s. 56M will ordinarily involve the disclosure of some information from the Central Register.

Requirement

To minimise the need to disclose information and the number of individuals to whom information is disclosed, the Authority must make a request under s. 56L or s. 56M with respect to a specific application for information under s. 56(1) to only one individual at a time.

Once this request has been responded to, and test results are known (if consent was given), the Authority may make an assessment as to whether subsequent requests are required.

Guideline 10**Context**

Where the person considered by the Authority to be the donor does not consent to undergo a genetic test, section 56M(3)(c) allows the Authority, in exceptional circumstances, to make a request that an adult blood relative of that person consent to genetic testing to establish whether that named person is the person that is the subject of an application for identifying information. A person may not have consented to undergo a genetic test in circumstances where a request has been made or, despite all reasonable efforts, they have not been located by the Authority. These are different circumstances from where a person considered to be the donor is deceased or officially identified as a missing person. In these latter sets of circumstances, the Authority may approach a blood relative whether or not exceptional circumstances exist.

Requirement

'Exceptional circumstances' is a high threshold and as such, it is anticipated that such circumstances will arise infrequently. It is not possible to identify all the sets of circumstances that will be 'exceptional' because by their nature, they are special in the context of the particular case. However, they may arise in circumstances of particular urgency or medical necessity or need for example. By their nature, they will be circumstances that warrant approaching the blood relative of the potential donor even though that potential donor has not consented to undergo genetic testing. Requests under s. 56M(3)(c) cannot be made *only* on the basis that the potential donor has not consented to testing or that it is not possible to establish a link through any other means. This will not be sufficient to meet the 'exceptional circumstances' threshold.

By way of example but without limiting the circumstances where there may be 'exceptional circumstances', it is envisaged that 'exceptional circumstances' may exist, if a donor conceived applicant were suffering from a terminal illness of known genetic origin and was seeking to identify their donor as a means of being able to alert any donor-conceived siblings of their potential genetic predisposition to this condition. Any such determination by the Authority must be made on the merits of each individual case however.

Guideline 11**Requirement**

If the Authority finds that the person named on the Central Register does not have capacity to consent, a sample cannot be obtained from that person for the purposes of genetic testing. This lack of capacity does not in itself amount to exceptional circumstances under s. 56M(3)(c).

In such circumstances the Authority may consider whether, in the particular case, there are exceptional circumstances that warrant seeking consent from an adult blood relative of a person named on the Central Register to genetic testing to establish whether that named person is the person that is the subject of an application for identifying information. As outlined in guideline 13 above, 'exceptional circumstances' is a high threshold and it is anticipated that such circumstances will arise infrequently and in relation to matters particular to a given case.

Guideline 12**Context**

The Act recognises that, given the time that has elapsed since the donation was made, there may be practical difficulties in locating people named on the Central Register as pre-1998 donors.

Provision has therefore been made that, when the Authority has made all reasonable attempts to locate a person named on the Central Register, but the donor is deceased or is a missing person or there are exceptional circumstances, the Authority may request that an adult blood relative of a potential donor consent to genetic testing s.56(3) .

Requirement

In order for the Authority to make a request on this basis, the Authority must be able to demonstrate, and must retain records documenting, that all reasonable efforts have been made to locate the person named on the Central Register. In determining what would constitute 'all reasonable efforts' in these circumstances, the Authority should give regard to the Guidelines made in Part 4 which outline the types of searches and enquires it is expected that the Authority will undertake.

Part 4 — searching under the Act

The guidelines in Part 4 set out requirements which the Authority must comply with when taking steps to identify and locate a person being sought for the purposes of the Act. The Authority may undertake searches to locate a person in order to provide notices required under the Act or to locate a person for the purposes of exercising powers with the aim of identifying an individual who is the subject of an application to the Central Register.

Relevant provisions of the Assisted Reproductive Treatment Act 2008

67B Authorisation of organisations

- (1) The Secretary may, by written notice, authorise an organisation to assist the Authority in obtaining—
 - (a) information relating to the identity of persons from whom the Authority may request information under section 56J; or
 - (b) if the disclosure of identifying information relating to a person has been applied for under section 56(1), information from which that person may be located.
- (2) A notice of an authorisation under this section, and notice of any revocation or suspension of an authorisation under this section, must be published in the Government Gazette.
- (3) The Authority may disclose information recorded in the Central Register to an organisation authorised under this section to enable that organisation to exercise a function under this section.

An organisation authorised under s. 67B of the Act may only undertake searches in accordance with that authorisation to assist the Authority in:

- obtaining information relating to the identity of a person from whom the Authority may request information under s. 56J; or
- locating a person about whom an application for identifying information from the Central Register has been made under s. 56(1).

The guidelines in Part 4 apply to the Authority, and to any organisation authorised by the Secretary to assist the Authority under s. 67B. The Authority and any authorised organisation is subject to confidentiality obligations in s. 66A to s. 66C of the Act.

The guidelines under Part 4 should be read in conjunction with the Act and the other guidelines issues under s. 100A, including those related to requests for additional information in order to identify a pre-1998 donor (Part 1), requests for records relating to pre-1998 donor treatment procedures (Part 2) and genetic testing (Part 3).

The guidelines

Guideline 1

Context

Search activities to locate an individual may only be undertaken by the Authority, or on behalf of the Authority, in response to an application for information under s. 56(1) or to fulfil obligations under the Act.

Requirement

The Authority may not initiate a search for any person on the Authority's own initiative for any purpose, including to facilitate matches in the absence of an application or to make the Central Register more complete.

Guideline 2

Context

Searches undertaken to locate a donor, or potential donor, should be sufficiently comprehensive to:

- allow maximum opportunity for the donor or potential donor to receive the support and protections available under the Act; and
- satisfy an applicant that all reasonable efforts have been made to find the person relating to their application for information under section 56(1).

A number of provisions in the Act require the Authority to make all reasonable efforts to provide notice of certain actions being taken. This includes providing notice to a person:

- named on the Central Register where the Authority intends to make a request that a blood relative of that person undergo genetic testing on the basis of exceptional circumstances (s. 56M(4))
- about whom identifying information is to be disclosed under Division 3, Part 6 of the Act (s. 62)
- whose identifying information has been released under s. 63 (s. 63A(2)).
- who has lodged a contact preference to advise them of the date that the contact preference will expire (s. 63D(4), s. 63K(3) and s. 64L(3))

Furthermore, the Act allows the Authority to exercise certain powers if all reasonable efforts have been taken to locate a person but that person has not been able to be located. This includes:

- requesting, in exceptional circumstances, that a blood relative of a suspected donor undergo genetic testing (s. 56M); and
- the disclosure of identifying information about a pre-1998 donor without giving notice under s. 62(2) (s. 63)

Requirement

For the Authority to demonstrate that “all reasonable efforts” have been made as required by these sections of the Act, the Authority must ensure where a person has not been located that the following minimum searches have been conducted to the extent the information is accessible:

- i. consultation with the Victorian Registry of Births Deaths and Marriages and request for a search of any relevant registers including marriage, birth, death and change of names
- ii. inspection of the current non-public Victorian electoral roll
- iii. inspection of the current public Australian electoral roll, if person not identified on current non-public Victorian electoral roll
- iv. search of the White Pages directory
- v. basic internet search
- vi. search of publicly available information on prominent social media sites (including facebook, linkedin)

In demonstrating that ‘all reasonable efforts’ have been made, the Authority should also ensure that the following searches are undertaken if the circumstances of the case indicate they are relevant and to the extent the information is accessible:

- i. search of online death indexes (newspapers, Ryerson index, Australian Cemeteries, Births Deaths and Marriages public indexes)
- ii. search of accessible historical electoral rolls and other public records including those held by the Authorised search agency
- iii. inspection of probate/wills/letters of administration held at the Public Records Office of Victoria
- iv. search of accessible missing persons registers
- v. inspection of immigration files, military registers and any other national archives
- vi. Land Titles searches.

Guideline 3**Requirement**

These searches described in guideline 2 above may be undertaken:

- by the Authority; or
- on referral from the Authority, by an organisation authorised by the Secretary under s. 67B if the search relates to
 - i. obtaining information relating to the identity of a person whom the Authority may request information under s. 56J; or
 - ii. locating a person about whom an application for identifying information from the Central Register has been made under s. 56(1).

It is expected that the Authority will make use of the expertise of any authorised search organisation. However, only the Authority will be able to receive information from the Registry of Births Deaths and Marriages or inspect the current non-public Victorian electoral roll.

Guideline 4**Requirement**

In accordance with the *Public Records Act (1973)*, the Authority should keep records setting out:

- i. all search activities undertaken and the results of these searches;
 - ii. the rationale for undertaking or not undertaking particular search steps; and
 - iii. documentation of notices provided under the Act.
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Guideline 5**Requirement**

The Authority must not, under any circumstances, misrepresent itself or the purpose of search activities.

Guideline 6**Context**

Section 67B(3) allows the Authority to disclose information to an organisation authorised by the Secretary under s. 67B to enable the authorised organisation to exercise a function under that section.

It may also be necessary for the Authority to share personal information with other agencies (such as the Registry of Births Deaths and Marriages) to enable searches to be undertaken.

Requirement

The Authority should ensure that appropriate security and confidentiality measures are in place to protect personal information where it is necessary to share such information with another agency for the purposes of undertaking a search.

Guideline 7**Requirement**

The Authority must enter into a written arrangement with any organisation authorised by the Secretary to assist the Authority under s. 67B.

This agreement must include details about:

- i. how information will be shared;
- ii. how sensitive information will be transferred between the organisations to ensure it is protected;
- iii. timeframes for searching;
- iv. the searching tasks that will be undertaken by each organisation, taking into consideration resourcing and expertise; and
- v. how searches undertaken by the authorised organisation will be documented and communicated to the Authority.

The agreement must also clarify that:

- i. the authorised search organisation must not make contact with the subject of a search. Once the subject has been identified/located this information is to be given to the Authority who will initiate contact if appropriate; and
 - ii. the authorised search organisation must not, under any circumstances, misrepresent itself or the purpose of search activities.
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Guideline 8**Context**

Social media can be a very valuable tool for searching, however, it is not a preferred means for making contact with individuals.

Requirement

In general the Authority should avoid making contact with individuals via social media unless there is no alternative to contacting that person. In the rare cases that contact is made via social media any approaches made via this method should be by direct private message and never be in a public posting and should be in accordance with any best practice standards. This guideline is to be read in conjunction with Part 1, Guideline 4.

Part 5 — establishing a link

The guidelines in Part 5 set out requirements the Authority must comply with when determining whether there is a genetic link between two people for the purposes of releasing information in accordance with the Act from the Central and Voluntary Registers.

The Authority manages two donor treatment registers – the Central Register and the Voluntary Register. These were established for different purposes and are subject to different powers and controls.

The Central Register, which is established under s. 53 of the Act, records information about donor treatment procedures. This information is submitted to the Authority by registered clinics which provide donor treatment procedures and by doctors who perform donor treatment procedures independently of a registered clinic.

The information held in the Central Register is prescribed in the Act and includes information about the parties to a donor treatment procedure including the:

- child who was born as a result of the treatment procedure
- woman who received the treatment procedure
- sperm donor (if any)
- egg donor (if any)

The Central Register holds the names and dates of birth of all parties. It may also contain additional details about the donor, including the donor's physical attributes (such as blood group, hair colour or eye colour). All available records from registered Assisted Reproductive Treatment providers (including those related to pre-1988 donor conception procedures) are now required to have been included on the Central Register (or are accessible by the Authority in the case of the records of the former Prince Henry's Hospital which are held at the Public Records Office). Nonetheless, given the lack of regulation in relation to record keeping prior to 1988, the Central Register will not contain all records from this time and the information may not be sufficiently complete to establish links between individuals in all cases.

The Authority may only release information from the Central Register to eligible applicants under specific circumstances. Only a donor-conceived person, the parent of a donor-conceived person, the descendant of a donor-conceived person or a donor may apply for information. The Act specifies the circumstances under which identifying and non-identifying information may be disclosed from the Central Register. Section 56N stipulates that no information be released by the Authority from the Central Register unless the Authority is satisfied that the person named on the Central Register and the person born as a result of the donor treatment procedure are genetically linked. Section 56N sets out the circumstances under which the Authority may be so satisfied.

Relevant provisions of the Assisted Reproductive Treatment Act 2008

s56N Authority to be satisfied of relationship before disclosing information

(1) The Authority must not disclose information (whether identifying or non-identifying) under this Part about a person whose name is entered on the Central Register as a donor to a person born as a result of a donor treatment procedure or a parent or descendant of a person born as a result of a donor treatment procedure unless satisfied under subsection (4) that the person whose name is entered on the Central Register and the person born as a result of a donor treatment procedure are related.

(2) The Authority must not disclose information (whether identifying or non-identifying) under this Part about a person born as a result of a donor treatment procedure to a person whose name is entered on the Central Register as a donor unless satisfied under subsection (4) that the person whose name is entered on the Central Register and the person born as a result of a donor treatment procedure are related.

(3) The Authority must not disclose information about a donor sibling under section 60A to a person born as a result of a donor treatment procedure or a parent of that person unless satisfied under subsection (4) that—

(a) the person whose name is entered on the Central Register as a donor and the person born as a result of donor treatment are related; and

(b) the donor sibling—

(i) is a person born as a result of a donor treatment procedure; and

(ii) is related to the person whose name is entered on the Central Register referred to in paragraph (a).

(4) The Authority may be satisfied that a person whose name is entered on the Central Register as a donor and a person born as a result of a donor treatment procedure are related if—

(a) a unique donor identifier recorded in the Central Register links the person whose name is entered on the Central Register and the person born as a result of a donor treatment procedure; or

(b) a comparison of genetic testing results provided to the Authority establishes that the person whose name is entered on the Central Register and the person born as a result of a donor treatment procedure are genetically related; or

(c) the Authority, having regard to all available information and any guidelines issued under section 100A, reasonably believes that—

(i) the person whose name is entered on the Central Register and the person born as a result of a donor treatment procedure are genetically related; and

(ii) there is no reasonable likelihood that any other person may be the donor of the person born as a result of a donor treatment procedure.

(5) In this section—

unique donor identifier means a unique identifier used by a registered ART provider or a doctor carrying out artificial insemination other than on behalf of a registered ART provider for the purposes of identifying an individual donor.

The Voluntary Register, which is kept by the Authority under s. 70 of the Act, contains information that eligible people (donor-conceived people, descendants of donor-conceived people, donors, recipient parents and relatives of any of these people) voluntarily give to the Authority.

The Voluntary Register was established in recognition of the lack of mandated record keeping in relation to pre-1988 donor treatment procedures and at a time when the legislation did not allow for the release of identifying information about pre-1988 donations. The Voluntary Register was primarily a mechanism by which pre-1988 donors and donor conceived people could link and share information. Changes made to the Act in 2014 and 2016 mean that the reliance on the Voluntary Register to make these links has been significantly reduced as pre-1998 donor treatment records held by clinics were required to be transferred to the Central Register for access. The Voluntary Register also offers a means by which donor siblings and others can exchange information that cannot be obtained from the Central Register and, for those for whom a link has been established, to share information which includes a much broader range of matters than those available on the Central Register. Information on the Voluntary Register may include any information that a person asks to have recorded in the register, including photographs, and other items of a personal nature. When a person provides information for inclusion on the Voluntary Register they must also provide a statement as to their wishes regarding obtaining information about, or having their information released to, another person named on the Voluntary Register. The Authority is not permitted to release information from the Voluntary Register other than in accordance with these stated wishes.

Section 56N of the Act sets out the circumstances in which the Authority is to be satisfied of a relationship before disclosing information from the Central Register. Section 56N does not apply to the disclosure of

information from the Voluntary Register. These guidelines, however, are intended to also apply in circumstances where the Authority is required to determine whether a link has been sufficiently established to allow for the release of information from the Voluntary Register in accordance with the wishes of the person who lodged it.

The guidelines in Part 5 should be read in conjunction with the Act and other guidelines issued under s. 100A of the Act, including those related to powers of the Authority to assist in establishing links such as those in relation to requests for additional information in order to identify a pre-1998 donor (Part 1), requests for records relating to pre-1988 donor treatment procedures, genetic testing (Part 3) and searching (Part 4).

The guidelines

Guideline 1

Context

Section 70(2) of the Act requires that the Voluntary Register must be kept separately to the Central Register and is not part of the Central Register.

The Central Register is the definitive record, created to allow genetic links between people to be established.

The Voluntary Register is kept primarily as a mechanism to allow the exchange of information where a link between individuals has been identified or to facilitate links between individuals who cannot be linked through the Central Register (for example donor siblings).

Requirement

In establishing a link, the Authority will only access the Central Register when a specific application for information has been made to the Central Register. The Voluntary Register must be used in accordance with Part 7 of the Act. The Voluntary Register may be used for example, to establish a link when the applicant has expressed an interest in receiving information about genetic relatives and disclosure of information is in accordance with the wishes of the person who placed their information on the Voluntary Register.

Guideline 2

Context

The Voluntary Register must only be used by the Authority to assist in establishing a link for the purposes of a Central Register application in certain circumstances.

Requirement

Where there has been an application to the Central Register, the Authority may look to information held on the Voluntary Register to assist in contacting a person for the purposes of –

- i. requesting additional information (under s. 56J);
 - ii. requesting a genetic test (under s. 56L);
 - iii. providing notice of intended disclosure of identifying information (under s. 62);
 - iv. satisfying the requirement to release information without the provision of notice (under s. 63) or;
 - v. to satisfy the wishes of the person lodging the information on the Voluntary Register.
-

Guideline 3

Requirement

The Authority may not disclose information from the Voluntary Register to another person without the consent of the person who lodged it.

Guideline 4

Context

The Central Register is the definitive record, created to allow genetic links between people to be established. The Voluntary Register contains information provided voluntarily by individuals to be used only in accordance with their expressed wishes.

It is therefore critical that there is appropriate rigour applied to amending or including any information on the Registers.

The Act (s. 54A) allows for the Authority to correct or include additional information on the Central Register in specific circumstances if, in the Authority's opinion, the

amendment, correction or new entry will make the Central Register more accurate or complete. These circumstances do not include relevant information being provided to the Authority for inclusion on the Voluntary Register. Such information may only be included on the Central Register at the written request of the person to whom the information relates and if, in the Authority's opinion, the amendment, correction or new entry will make the Central Register more accurate or complete (s. 54).

Requirements

In forming an opinion that the inclusion or amendment of specific information will make the Central Register more accurate or complete, the Authority should have regard to the particular circumstances of the case and must reasonably believe that the information is accurate.

The Authority may only make changes to the Voluntary Register with the consent of the person to whom the information relates.

In practice, this may mean that the Authority seeks the consent of an individual to update the Voluntary Register if new information comes to light as a result of a Central Register application. Conversely, if an individual updates their details on the Voluntary Register the Authority may encourage that person to request that the change also be made to the Central Register. In each case it is wholly at the discretion of the individual about whom this information relates if they wish to take these steps.

Guideline 5

Context

Section 56N(4) provides the basis on which the Authority may be satisfied that a donor conceived person and a person named as a donor on the Central Register are linked.

Requirements

In applying section 56N(4), the Authority must consider the particular facts of the case, to determine whether they are satisfied that the named donor and the donor-conceived applicant are related.

In the event that the Authority is not satisfied that two individuals are linked, information (whether identifying or non-identifying) should not be released on the basis of the possible link. This applies even if one of the conditions of s. 56N(4) is met (for example there is a unique donor identifier recorded in the Central Register that links the person whose name is entered on the Central Register and the person born as a result of a donor treatment procedure) if the Authority has other information that casts doubt on the link.

Guideline 6

Context

The Act recognises that there may be instances in which the Central Register does not contain a unique donor identifier and it is not possible to obtain genetic test results to confirm a genetic link, but nonetheless there is clear evidence that establishes that two individuals are linked.

Section 56N(4)(c) allows for the release of information in accordance with the Act in these circumstances. Given the significant implications of releasing information in these circumstances the Act sets a high threshold for the Authority to be satisfied of a link in such cases. Having regard to all the available information, the Authority must hold a reasonable belief that

- (a) the person whose name is entered on the Central Register and the person born as a result of a donor treatment procedure are genetically related (s. 56N(4)(c)(i)); and
- (b) there is no reasonable likelihood that any other person may be the donor of the person born as a result of a donor treatment procedure (s. 56N(4)(c)(ii)).

The guidelines under Part 4 are to be read in conjunction with guidelines issues under s. 100A, including those related establishing a link (Part 5).

(c)

Requirement

For the Authority to form a reasonable belief on the second of these two points it is anticipated that the Authority may need to undertake enquiries that allow the possibility of any other potential donors to be excluded.

If the Authority cannot form a reasonable belief in relation to both s. 56N(4)(c)(i) and s. 56N(4)(c)(ii), it cannot be satisfied that a link exists and therefore information may not be released on the basis of this link.

Guideline 7

Requirement

In accordance with the Public Records Act 1973, the Authority should keep records setting out the grounds for decisions made as to whether two individuals are linked and any action, including the release of information, made on the basis of such decisions.

Guideline 8

Requirement

In order to satisfy the requirements of s. 56N(4)(b), genetic testing results must meet the quality standards described in the Guideline relating to genetic testing (Part 3).

Guideline 9

Context

The Act confers on the Authority specific powers to assist in establishing links between individuals in responding to applications for information from the Central Register. These powers (which are the subject of related Guidelines) are intended to assist in establishing the identity of donors who are the subject of an application in circumstances where information is not contained in the Central Register or available information is incomplete. For this purpose, the Authority may seek additional information from third parties (s. 56J), request records in relation to pre-1988 donor treatment procedures (s. 56B) and/or request that a suspected donor undergo genetic testing (s. 56L).

These powers do not apply in relation to applications to the Voluntary Register.

Requirement

The Authority must not seek to facilitate genetic testing to establish links between persons whose names are entered on the Voluntary Register, nor will the Authority seek additional information or records from third parties under sections 56J and 56B in order to establish links through the Voluntary Register.

Part 6 — identifying and non-identifying information

The guidelines in Part 6 set out requirements the Authority must comply with in carrying out its functions and powers under the Act regarding the release of identifying and non-identifying information.

The Act draws a distinction between identifying and non-identifying information. Different requirements and protections apply to the release of information depending on whether it is identifying or non-identifying. The Act provides special protections for the release of identifying information. For example, there are legislative requirements for the applicant to be provided counselling and a donor who donated prior to 1998 who is the subject of an application to be offered counselling when identifying information is to be released. In the case of pre-1998 donations, a person about whom identifying information is to be released may make a contact preference, as can all donor conceived people whose information is applied for. In other circumstances, such as when an applicant seeks information about a donor conceived person or when a parent applies for identifying information about a donor, the Act requires the consent of the person who is the subject of the application before identifying information can be released. The same provisions do not apply to the release of non-identifying information.

Relevant provisions of the *Assisted Reproductive Treatment Act 2008*

3 Definitions

In this Act – ...

identifying information means information that will or may disclose the identity of a person;

non-identifying information means information other than identifying information;

The guidelines in Part 6 are applicable in any circumstances where the Authority is to release information in response to an application for information on the Central Register or Voluntary Register.

The Guidelines should be read in conjunction with the Act and other Guidelines issued under s. 100A of the Act, including those related to establishing a link (Part 5). The guidelines in Part 5 provide information about the steps the Authority may take in attempting to establish a link and the requirements that must be met by the Authority to be satisfied of a relationship for the purposes of releasing identifying or non-identifying information in accordance with the Act.

The guidelines

Guideline 1

Requirement

The unique donor identifier is also known as the 'donor code'. Section 56N(5) of the Act defines *unique donor identifier* as "a unique identifier used by a registered ART provider or a doctor carrying out artificial insemination other than on behalf of a registered ART provider for the purposes of identifying an individual donor".

Identifying information about a person, as defined in the Act, is information that will or may disclose the identity of a person. This includes the person's:

- Name
- Address
- Telephone number
- Email address; and
- Any unique donor identifier or unique patient identifier

Date of birth in combination with some or all of the above information will usually constitute identifying information. Careful consideration should be given to its release.

As the unique donor identifier could lead to the identity of a donor, it is identifying information for the purposes of the Act and may only be released by the Authority when the legislative requirements for the release of identifying information are met.

Guideline 2

Requirement

The following information about a person will generally be considered non-identifying information – the person's:

- Sex
- Year of birth
- Place of birth
- Hair colour, eye colour, build, height, blood group
- Marital status, occupation, education and interests
- Country of birth and the country of birth of their mother, father and grandparents.

However, there will be circumstances in which combinations of this information could lead to the identification of a person and in such circumstances this information would be identifying. The Authority must consider the release of information on a case by case basis and not release information that may lead on its own or when in combination altogether to the identification of an individual unless the conditions for the release of identifying information are met.

The following information relating to a donor treatment procedure is also considered to be non-identifying:

- The location at which a treatment procedure was carried out
 - The name and address of the registered ART provider or doctor who carried out the procedure
 - The outcome of a treatment procedure (whether a birth, a pregnancy or unknown)
 - Whether the donor donated gametes other than to the registered ART provider or doctor who carried out the treatment?
 - Any genetic abnormality of the donor?
 - The number of women who have children conceived using the donor's gametes or an embryo formed from the donor's gametes, including the donor and any current or former partner of the donor
 - The number of children born as a result of treatment procedures carried out by the registered ART provider or the doctor using the donor's gametes or embryo
-

Guideline 3**Context**

The Act allows donors who donated prior to 1998 to lodge a contact preference if their identifying information is to be released. The contact preference will not stop the release of the donor's identifying information but will allow the donor to specify the contact, if any, they wish to have with a donor-conceived person (or a descendent of a donor conceived person who makes an application) or that they permit the donor conceived person to have with the donor's child. This can include, for example, an email-only contact preference.

A donor conceived-person who consents to release of their identifying information to a donor may also lodge a contact preference, as may a donor who consents to the release of their information to the parent of a donor-conceived person.

When a contact preference is lodged, identifying information will not be released to an applicant until that applicant has signed an undertaking that they will comply with the conditions of the contact preference.

A contact preference is valid for 5 years.

Requirement

As a further comfort to those who have specified, through a contact preference, that they do not want any contact with the applicant, the Authority should, while the contact preference is in place, withhold from the applicant the address, telephone or email contact details of a person who has made a 'no contact' preference.

If a contact preference states that contact is only wanted through a particular method (e.g. email), the other contact details (e.g. address and telephone contact details where contact is only to be by email) should not be released. In this way the risk of unwanted or inadvertent contact is minimised.

Prior to the expiry of the contact preference, the Authority will contact the individual whose information was disclosed seeking their advice as to whether they want to extend (whether or not in an amended form), the contact preference.

Guideline 4**Context**

The Authority may only release information from the Central or Voluntary Registers in accordance with the Act.

The definition of health information in s. 3 of the Health Records Act clarifies that information relating to a person's donation of body substances is the person's health information. The donor code is therefore the donor's health information.

Requirement

To the extent that any part of the register might constitute a health record, it cannot be released under the *Health Records Act 2001* as the Act provides the basis for access to the Central Register. It should also be noted that the unique donor identifier does not form part of the health information of the recipient parent or the donor conceived child.

If you have any comments or queries about the application of these guidelines please contact the Authority in the first instance. In relation to matters regarding the guidelines themselves or the exercise by the Authority of powers and functions under these guidelines please write to:

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To receive this publication in an accessible format please contact the Victorian Assisted Reproductive Treatment Authority on 03 8601 5250 using the National Relay Service 13 36 77 if required, or email dcrs@varta.org.au

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