

# A right to know your identity

Giving donor-conceived people the right to access information identifying their donor



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## Summary

The Andrews Labor Government is committed to giving all donor-conceived people the right to access identifying information about their donors.

The Government believes all Victorians should have the right to know their genetic heritage, no matter when they were born.

For decades, the rights of donor-conceived people to obtain identifying information about their donors has been inconsistent and confusing – it has arbitrarily depended on when gametes (reproductive cells) were donated.

Prior to 29 June 2015,

- Those whose gametes were donated prior to 1988 cannot access any information identifying their donor
- Those whose gametes were donated between 1988 and 1998 can only receive identifying information with the consent of their donor
- And those whose gametes were donated after 1998 have unconditional access to information identifying their donor.

Amendments to the *Assisted Reproductive Treatment Act 2008* were passed in 2014 and came into effect on 29 June 2015. These amendments allow persons conceived as a result of donations made prior to 1988 to find out identifying information about their donors with the donor's consent.

While these changes are significant, they do not address the inequality between donor-conceived Victorians. They still limit some donor-conceived people's access to information about their identity depending on when their gametes were donated.

The Andrews Labor Government will legislate so that all donor-conceived people will have the same rights to access donor information regardless of when their gametes were donated.

Of course, in enabling donor-conceived people to find out identifying information about their donor, the Government recognises that it is imperative to support donors through the process of being identified.

A key component of the Government's proposal is to include "contact preferences" for donors to enable them to choose and manage what contact they have with their offspring. This recognises that donors who donated prior to 1998 did so with the expectation that they would remain anonymous.

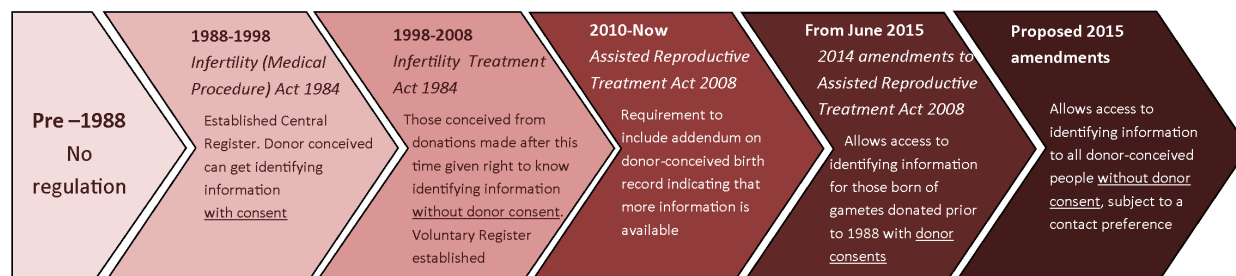
This Discussion Paper outlines a range of proposed measures to support donors through these proposed changes – such as contact preferences, as well as the proposed process for how information requests will be managed – and the Government welcomes feedback on these proposals.

## Background

### Regulation of Assisted Reproductive Technology and changing expectations

Prior to 1988, assisted reproductive treatment was not regulated in Victoria.

Legislation was introduced in 1988 and has developed over time as understanding about the impacts of donor conception has developed:



As reflected in the developments in legislation, assisted reproductive technologies continue to evolve rapidly, and community views about the rights and interests of participants in donor conception and those born of these technologies are also changing dramatically.

Prior to 1988, donor anonymity was considered crucial for the protection of the family formed through donor conception. Donors generally donated anonymously and recipient parents were advised not to tell their child of their donor origins.

It is understood that donors who donated prior to 1988 were assured of anonymity, not counselled about their donation, and likely expected that their details would not be retained or disclosed.

Legislative changes in the 1980s and 1990s reflected changing attitudes and a recognition that donor-conceived individuals should be aware that they were donor-conceived and may wish to know something about their donor.

Since 1 January 1998, anonymous donations have not been permitted. Now, donors must consent to their identifying information being retained and accessible to future offspring.

### Inquiry into Access by Donor-Conceived People to Information About Donors

In 2012, the Parliamentary Law Reform Committee *Inquiry into Access by Donor-Conceived People to Information about Donors* tabled its report.

The Inquiry received around 80 submissions, including from Narelle Grech who has sadly since passed away.

Narelle, who was conceived by an anonymous donor in the early 1980s, wrote in her submission to the Inquiry:

*“Not knowing is the hardest part. Not knowing who my biological father is, who his family is, my paternal family... whether he is still even alive! Does he want to know me? Does he think about the donations he made as a student all those years ago? Does he have a family of his own? The questions that whirl around my head are endless.*

*I believe very strongly that this information about my father and my paternal family should be accessible to me. I do not want money from them or to cause any one drama. I want what is an intrinsic part of me; answers that will help me to feel that I completely know myself. I can say without a shadow of a doubt that at the age of 27 I still do not know myself like I should.”*

The Committee made 30 unanimous recommendations, including that the rights of donor-conceived people should not differ depending on when a donation was made, and that the state has a responsibility to provide all donor-conceived people with an opportunity to access identifying information about their donors.

The Committee concluded that:

*“...providing all donor-conceived people with the opportunity to access identifying information about their donors, regardless of their date of conception, is consistent with the first guiding principle found in the Victorian legislation regulating donor-conception – that the welfare and interests of persons born as a result of assisted reproductive treatment procedures are paramount.”*

The Committee also recognised that there should be no unreasonable interference in donors’ lives, and recommended that donors and donor-conceived people should be able to veto contact from each other.

It also recommended that donors, and all of the people affected by donor-conception, are provided with comprehensive counselling and other support services.

The Government’s proposed amendments fulfil the Committee’s recommendations in full.

### **Access to information by donor-conceived people**

The following table summarises the information available and the rights of donor-conceived people to access information about their donors under current legislation. This includes changes which came into effect on 29 June 2015.

<b>Gametes donated before 1 July 1988</b>	<p>Registered ART providers are required commencing 29 April 2015 to provide a register of donors and births where this information exists. Individual practitioners are encouraged but not required to provide this information to the Central Register held by Births, Deaths and Marriages.</p> <p>Donor-conceived persons (and their parents) can obtain non-identifying information about their donor from the Central Register.</p> <p>Donor-conceived persons 18 years or over (or with their parent/guardian’s consent or written opinion from counsellor that they are sufficiently mature) can apply to the Central Register for identifying information about their donor. This information is only provided with the donor’s consent.</p>
<b>Gametes donated between 1 July 1988 and before 1 January 1998</b>	<p>All donations and births were required by law to be recorded on the Central Register.</p> <p>Donor-conceived persons (and their parents) can obtain non-identifying information from the Central Register.</p> <p>Donor-conceived persons 18 years or over (or under 18 with parent/guardian’s consent or written opinion from counsellor that they are mature enough to understand consequences) can apply to the Central Register for identifying information about their donor. This information is only provided with the donor’s consent.</p>
<b>Gametes donated 1998 or later</b>	<p>All donations and births were required by law to be recorded on the Central Register.</p> <p>Donor-conceived persons (and their parents), or donor-conceived persons under 18 with parent/guardian’s consent or written opinion from counsellor that they are sufficiently mature can obtain non-identifying and identifying information about their donor from the Central Register.</p>

## The Government's proposed amendments

The Andrews Labor Government has committed to legislate to give all donor-conceived people the right to access identifying information about their donors.

Under the Government's proposed changes:

	Source of information	Information that can be obtained	Information that will be available under the Government's proposed amendments
<b>Gametes donated before 1 July 1988</b>	<b>Central Register</b> (Since 2014, registered ART providers are required commencing 29 April 2015 to provide a register of donors and births, where this information exists. Individual practitioners are encouraged but not required to provide this information to the Central Register)	Donor-conceived persons (and their parents) can obtain non-identifying information.	Donor-conceived persons can obtain non-identifying information.
		Donor-conceived persons over 18 years (or with parent/guardian's consent or written opinion from counsellor that they are sufficiently mature) can apply for identifying information about donor. This information is only provided with donor consent.	Donor-conceived persons 18 years or over (or under 18 with parent/guardian's consent or written opinion from counsellor that they are sufficiently mature) can obtain identifying information about their donor.
	<b>Voluntary Register</b>	If the donor is registered on the Voluntary Register, the donor-conceived person can obtain non-identifying or identifying information in accordance with donor's wishes.	Not applicable. Donors and donor-conceived people will be able to lodge information on the Donor Linking Collection.
<b>Gametes donated between 1 July 1988 and before 1 January 1998</b>	<b>Central Register</b> (All donations and births were required by law to be recorded on register)	Donor-conceived persons (and their parents) can obtain non-identifying information.	Donor-conceived persons can obtain non-identifying information.
		Donor-conceived persons 18 years or over (or under 18 with parent/guardian's consent or written opinion from counsellor that they are sufficiently mature) can apply for identifying information about donor. This information is only provided with donor consent.	Donor-conceived persons 18 years or over (or under 18 with parent/guardian's consent or written opinion from counsellor that they are sufficiently mature) can obtain identifying information about their donor.
	<b>Voluntary Register</b>	If the donor is registered on the Voluntary Register, additional non-identifying information may be available.	Not applicable. Donors and donor-conceived people will be able to lodge information on the Donor Linking Collection.



<b>Gametes donated 1998 or later</b>	<b>Central Register</b> (All donations and births were required by law to be recorded on register)	Donor-conceived persons can obtain non-identifying information.  Donor-conceived persons 18 years or over (or under 18 with parent/guardian's consent or written opinion from counsellor that they are sufficiently mature) can obtain identifying information about donor.	No change.
	<b>Voluntary Register</b>	If the donor is registered on the Voluntary Register, additional non-identifying information may be available.	Not applicable. Donors and donor-conceived people will be able to lodge information on the Donor Linking Collection.

These proposed changes reflect community attitudes that knowledge about parentage and heritage contribute significantly to a person's sense of identity and can be vital to inform medical treatment and family planning.

This Government's proposed amendments will ensure that the rights of all donor-conceived people to obtain information are no longer determined by the date of a donation. It will ensure all donor-conceived people are treated equally.

It is important to note that changes in technology, especially information technology and social networking, mean that it is now possible in some cases, to identify people utilising selected or minimal information about them. With the advent of DNA testing and rise of direct-to-consumer genetic profiling, linked with the application of this technology to family/ancestral tracing and extensive public databases of information, donors can now feasibly be traced by individuals.

This suggests that even without changes to the law, many donors will be identified and this would occur without regulation and without protections for both donors and donor-conceived people.

Accordingly, it is necessary to provide a framework to ensure information exchange and contact occurs in a protective and appropriate manner, with a supportive system for all donor-conception stakeholders.

The Government's proposed amendments will not alter the rights of donors to access information about their donor-conceived offspring.

It is appropriate that such information access only be possible with the consent of the donor-conceived person, and records containing identifying information will continue to be held on a Central Register.

## Implementing the Government's commitment

It is important that the Government's commitment is implemented in a meaningful and sensitive way, and great care is being taken to consider all aspects of how these reforms will be implemented.

The following principles and considerations have been used to underpin the development of the Government's approach to implementing its commitment.

1. *The law should, as far as possible, treat all donor-conceived people consistently and equally, regardless of when the donations that led to their conception were made.*
2. *It is critical to the welfare and interests of donor-conceived people that they have the opportunity to know their genetic identity.*
3. *Consideration should be given to the impact of releasing donors' identifying information on donors and their wider families, as well as the impact donor recipient parents.*

4. *The rights conferred by the law on donor-conceived people should be meaningful and, as far as practicable, should be able to be exercised.*
5. *As far as practicable, legislation should not place undue regulatory burden on medical practitioners and health services.*

## Provision of services

In creating a statutory right to identifying information for donor-conceived people, the state will support the facilitation of access to this information and ensure that all parties are fully supported through the process.

To achieve this, it is necessary to have clear lines of responsibility and a comprehensive and easily navigable service system.

The Parliamentary Law Reform Committee found that the current service system is disjointed and that people do not receive adequate support when seeking and receiving information.

The Committee recommended that one agency provide all the services relating to donor-conception.

### **'One door in' service**

The Government's proposed amendments will establish the Victorian Assisted Reproductive Treatment Authority ('the Authority') as the 'one door in' service provider for any person seeking information about donor conception.

The Government has determined that the entity managing the disclosure of personal and health information should be a public statutory body, operating within a framework of strong public accountability.

The Victorian Assisted Reproductive Treatment Authority is an experienced, non-partisan statutory body already operating within the framework of the *Assisted Reproductive Treatment Act 2008*.

Under the Government's proposal, the Authority will access the expertise of specialist providers to deliver search and donor location services.

These providers will be 'approved agencies', identified by the Secretary to the Department of Health and Human Services.

For donor-conceived people seeking information identifying their donor, the following process is proposed:

- (i) All applications for information will be made to the Authority, and the Authority will inform applicants about the process.
- (ii) The Authority will access any relevant available records held on the Central Register.
- (iii) The Authority, or an approved agency, will undertake searches to supplement any incomplete records to attempt to identify a donor-conceived person's donor.
- (iv) The Authority, or an approved agency, will locate the donor.
- (v) The Authority will offer the donor counselling and the opportunity to lodge a contact preference indicating whether they agree to contact by their donor offspring, and if so, the form of contact they agree to.
- (vi) The Authority will provide counselling to a donor-conceived person and, prior to the release of identifying information, will require the donor-conceived person to sign an undertaking that they will comply with any contact preference.
- (vii) The Authority will provide ongoing support to the donor, donor-conceived person, and any family members.

In order to enhance the 'one-door in' service, and to enable better coordination of information, the Central Register will be transferred to the Authority.

With access to available information regarding pre-1988 donor conceptions, the Voluntary Register (a register of voluntarily supplied information currently maintained by the Registrar) will be largely redundant. Instead, it is proposed that a 'Donor Linking Collection' be established to perform a broader role.

The Donor Linking Collection, to be managed by the Authority, will enable materials such as photos and mementos to be shared between donor conception stakeholders and support donor conception stakeholders to share meaningful information. Importantly, it will allow donors to share information while being able to manage contact.

The Donor Linking Collection may also be used by the Authority to link people who have been involved in donor conceptions, for example, donor siblings with different recipient parents.

In addition to these direct services, the Authority will provide information and ongoing public education about donor conception and donor linking in the community.

## **Information disclosure and contact process**

The Government recognises that implementing these proposed changes will involve the retrospective release of identifying information about donors in circumstances where many donors considered that their identity would remain private.

To ensure that there is no undue interference in the lives of donors, contact preferences will be made available to all those who donated before 1998. Contact preferences will also be made available to all donor-conceived people.

### **Contact preferences**

Contact preferences will allow a person to nominate a preferred form of contact, such as email or telephone contact only. 'No contact' will also be an option under a contact preference scheme.

Under the Government's proposed amendments, after being informed that an applicant has sought their identifying information, a donor will have two months to decide whether or not to lodge a contact preference.

This recognises that parties may require some time to adapt – both donors and possibly other family members – to the changes that may follow the release of identifying information. For example, this period will give donors an opportunity to advise family members of their donations if they are unaware and if the donor chooses to tell them.

A significant flaw in the current arrangements is that pre-1998 donors are not offered supportive counselling. The Government will ensure the provision of counselling and support to all donors.

### **Undertakings**

Where a contact preference is lodged, and prior to identifying information being provided, the applicant will be required to sign an undertaking to the Secretary to the Department of Health and Human Services stating that they will comply with the conditions of the contact preference.

To protect donors, if an applicant refuses to sign an undertaking, information will not be provided.

Further, breaches of an undertaking to abide by a 'no contact' preference will be an offence and will incur a fine of up to 60 penalty units.

This ensures that donors can manage contact where information identifying them is released.

### **If the donor cannot be found**

Identifying information about a donor will be disclosed to an applicant when the donor cannot be located by the Authority after three months of searching. This is considered to be a reasonably sufficient time to seek to locate a donor

Prior to receiving identifying information, the applicant will be required to agree to and sign an undertaking to the Secretary of the Department to Health and Human Services that if they find or become aware of additional information that might allow the donor to be located they will not initiate contact with the donor.

Instead, the applicant must provide the new information to the Authority, who will use it to attempt to contact the donor and advise them that their identifying information has been released and offer counselling and the option of lodging a contact preference.

Once contacted, the donor will be given two months to decide whether they wish to lodge a contact preference. They will also be provided with counselling support.

Breaches of an undertaking not to initiate contact will also be an offence and will incur a fine of up to 60 penalty units.

## Locating and verifying records

As there was no requirement that doctors create or retain records of donations prior to 1988, it is believed that some doctors never kept records and that other records may have been lost or destroyed. Further, to the extent that information exists, it may be incomplete or inaccurate.

Unfortunately this means that not all donor-conceived people will be able to access information.

Under the Government's proposals, these donor-conceived people will be offered counselling and support.

### Locating records

The 2014 legislative amendments required that any records of pre-1988 assisted reproductive treatment procedures held by registered fertility clinics be provided to the Central Register.

There are, however, a number of procedures that were performed prior to 1988 at locations that are not now registered clinics or linked to these clinics. Unfortunately, very little is known about where records of these procedures may be, if they exist at all.

The Government's proposed amendments will require any person in possession of records to give them to the Central Register when requested to do so by the Authority and in the context of an application for information.

This will ensure that as much relevant information as possible is made available, consistent with the Government's commitment.

### Verifying records and filling in the gaps

Even where records are available, it is known that there may be gaps and inaccuracies. Anecdotally, it is understood that records may not always provide sufficient detail to conclusively match donors and their offspring.

The Authority will be given a new function to undertake searches to supplement a record that does not contain a unique code that identifies a donor and links them to a donor-conceived person.

Following searches, if the Authority is able to find the likely donor, the Authority may ask the donor to undertake a DNA test to determine whether or not they are the genetic parent of the donor-conceived person. The Authority may also approach a blood relative of the potential donor to obtain additional information or to ask them if they are willing to undergo a DNA test.

Anyone contacted by the Authority during the search will be subject to confidentiality requirements. If a donor, or their blood relative, consents to the test and it shows a match, identifying information will be released to the donor-conceived person in line with the provision of contact preferences.

## Conclusion

The Andrews Labor Government is committed to giving all donor-conceived people the right to access identifying information about their donors because everyone should have the right to know their genetic heritage, no matter when they were born.

The Government recognises that implementing these proposed changes may have a significant effect on many people's lives and so great care is being taken to ensure it is being done with extensive support and sensitivity.

The Government would be very interested to receive any feedback about the proposals outlined in this Discussion Paper.

Comments can be provided to the Assisted Reproductive Treatment Policy Manager, 50 Lonsdale Street, Melbourne, VIC, 3000 or via email to [artsubmission@dhhs.vic.gov.au](mailto:artsubmission@dhhs.vic.gov.au) by Friday 4 September, 2015. To receive a copy of this paper, please call (03) 9096 8750.