



16 February 2022

Victoria's Central and Voluntary Registers and Donor Linking





VARTA's Information & Donor Registry Services Team

Manager

Claire McCole

Information Officers

- Carrie Farley-Roche
- Kath Herring

Information Assistant

· Bec Price

Counsellors

- Andrea Phillips
- · Lilian Rodan
- · Amelia McDermott
- Emily Hunter (maternity leave)





VARTA's Information & Donor Registry Services Team

Our Role

- record donor conception births on the Central Register and report to the Victorian Births Deaths & Marriages
- provide advice, education and support to people involved in donor conception
- process applications for information from the Central and Voluntary Registers

- provide counselling to people applying for information from the Registers
- outreach and support to subjects of Register applications and their families
- · connect donor families through donor linking

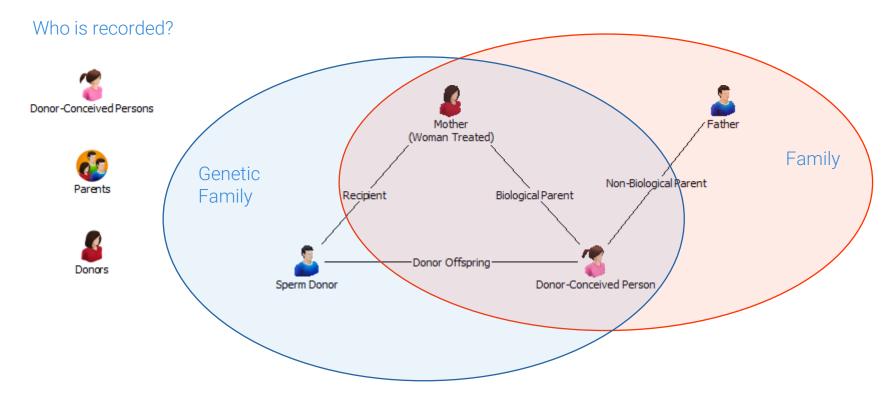
















Who is recorded?





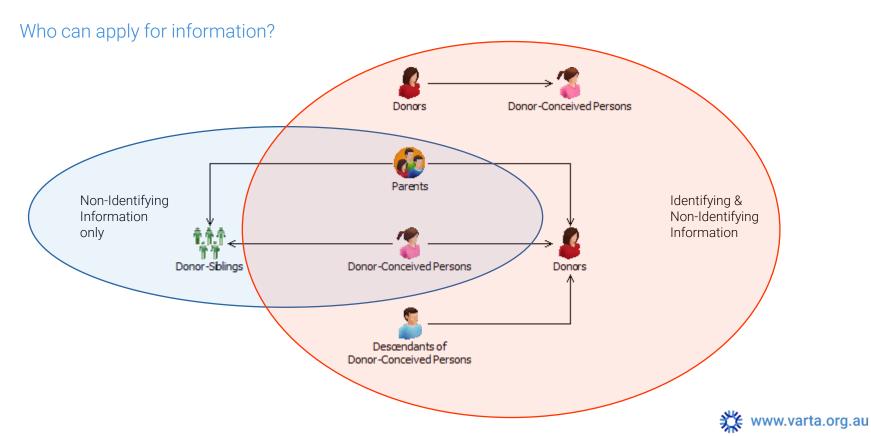


What information is recorded?

- Name
- DOB
- Contact detailsIdentifyingInformation
- · Treatment and birth details
- Gender
- · Donor details
- Non-Identifying Information
- Physical features
- Education, work and family background
- Interests and hobbies
- Genetic conditions









What's involved?





Non-ID information disclosure about a donor			
Sex	Male		
Month & Year of birth	Mar 1952		
Place of birth	Surrey, UNITED KINGDOM		
Hair colour	Medium Brown		
Eye colour	Blue/Green		
Height	5'7 (170 cm)		
Blood group	A Positive		
Genetic Abnormality	Type 1 Diabetes		
Number of women who have conceived using donor's donations	6		
Number of donor conceived persons born as a result of this donor's donations	8		
Occupation	Brick layer		
Clinics where the donor's donations were used in treatment	Prince Henry's Institute of Medical Research		
Other Information on the Central Register	Red beard, general colouring: fair, Caucasian		





ID Information release about a donor or donor-conceived person			
Given name(s)	John Robert		
Surname	SMITH		
Donor Code	A1		
Date of birth	01/03/1952		
Contact telephone number	0400 000 000		
Email address	jrsmith@gmail.com		





Non-ID Information Release – Donor Siblings or Offspring				
Total number of donor siblings / offspring		8		
Woman	Number of donor siblings / offspring born to that woman	Sex	Month and year of birth	
1	1	MALE	12/1978	
2	1	FEMALE	01/1980	
3	1 1	FEMALE MALE	04/1980 03/1982	
4	1 - Deceased	FEMALE	01/1981	
5	1	FEMALE FEMALE	04/1981 04/1981	
6	1	FEMALE	08/1981	





The Voluntary Register







The Voluntary Register

Who can apply?











What information is recorded?

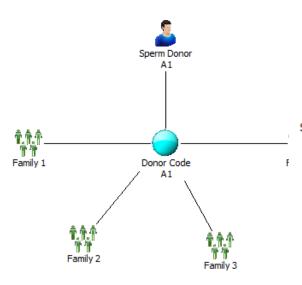
- Name
- · Contact details
- Donor ID
- · Any items the applicant wishes to register
 - Letters, photographs, videos, family trees, etc...
 - Interests and hobbies
 - · Medical conditions
- The applicants wishes about
 - Who they want to connect with
 - · What information they want to share

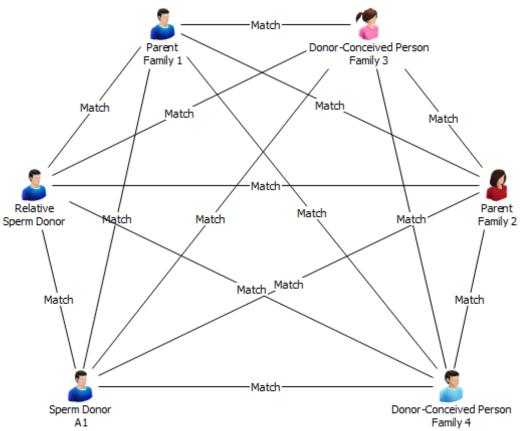




The Voluntary Register

What's involved?









Donor Linking

Who can participate?











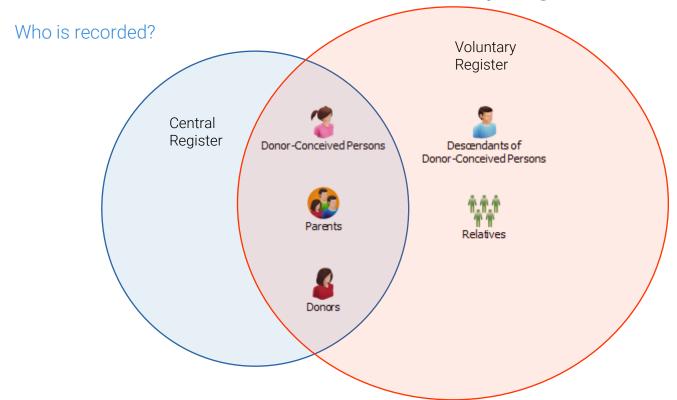
What is it?

- Exchange of information or correspondence
 - Facilitated email exchange
 - up to 5 items, first 6 months only
 - Non-identifying email address
- Arrange contact
 - Exchange emails, phone numbers
 - facilitated meeting with VARTA counsellor





Difference between Central and Voluntary Registers



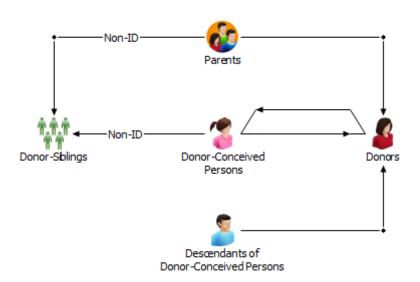




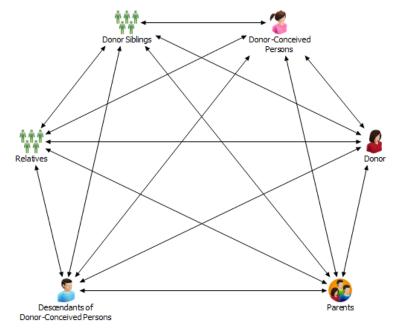
Difference between Central and Voluntary Registers

What information is available?

Central Register



Voluntary Register







Difference between Central and Voluntary Registers

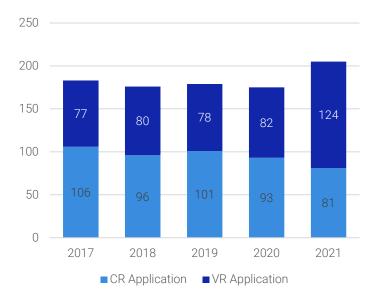
Other important differences

Option	Central Register	Voluntary Register
Recording on Register	Mandatory	Optional
What information is recorded	Prescribed by legislation	Name, contact details – all other information is voluntary
Family / genetic relationships	Must be satisfied before release (ie. medical records / DNA test results)	Donor code or other evidence
Update information	Contact details with consent Name and treatment details requires evidence	All information
Withdrawal from Register	Not allowed	Allowed
Cost	\$77.86 (Donor / DCP info) + \$77.86 (Donor Sibling non- ID info)	Free

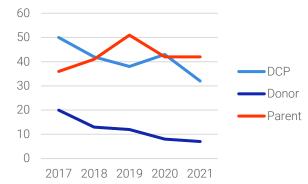


Application Trends

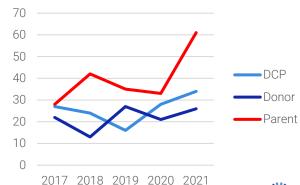
Central & Voluntary Register Applications 2017-2021



Central Register Applicants by Type



Voluntary Register Applicants by Type







Challenges & Opportunities

Managing expectations

- Outreaches
- Setting boundaries

DNA Testing

Importance of telling

Unregulated donor activity

- Health and legal risks
- No 'right to know'
- Not recorded on Central Register

Notices of Separation

Separated partner providing the gametes - now a donor

The Voluntary Register

- Changing purpose
- Potential growth
- Best option for
 - Donor-siblings
 - Parents to meet other parents
 - Treatment prior to official records





Questions?



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