

Donor conception and the search for information

- APPROACHES TO INFORMATION RELEASE AROUND THE GLOBE
- 2016



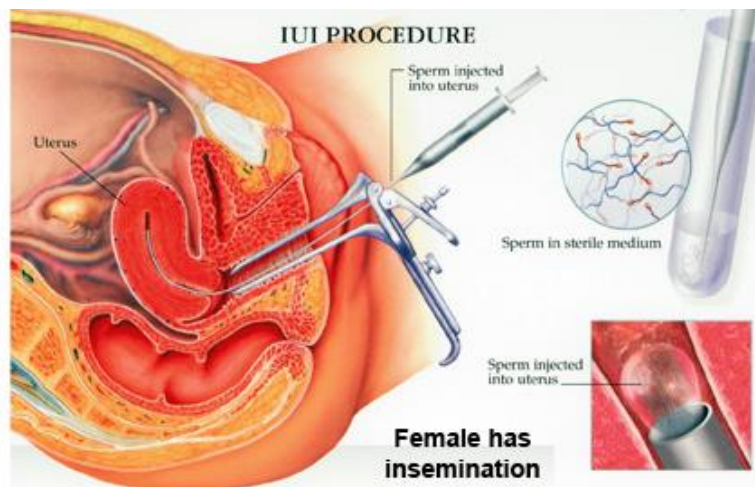
DONOR CONCEPTION: A LONG HISTORY OF SECRECY

'...the historical origins of assisted conception are clearly tainted by doubts about the morality of the acts involved [including **masturbation** and **instrumental substitution for sexual intercourse**] and their **legitimacy as medical treatment.**'

Simone Bateman Noveaus



Male has a date
with the cup



DONOR CONCEPTION: A LONG HISTORY OF SECRECY

- ▶ 1884: donor insemination by Professor William Pancoast (reported 25 years later)



- ▶ 1890s: Dr Robert L. Dickson (research reported 40 years later)

DONOR CONCEPTION: PRESERVING DONOR ANONYMITY

Donor Doctor Husband Wife



+ve result

DONOR CONCEPTION: PRESERVING DONOR ANONYMITY

- Adultery?
- Illegitimacy?
- Paternity?
- Inheritance of the child from the donor and/or husband?
 - 1960 UK interdepartmental committee, chaired by Lord Feversham:
 - DI '**undesirable**' and should not be practiced...
 - donation 'is an activity which might be expected to attract more than the usual proportion of '.



DONOR CONCEPTION: PRESERVING DONOR ANONYMITY

- ▶ Who/what is the focus of secrecy?
 - ▶ Donors; doctors; recipient parents...
 - ▶ Religion? (Against natural law)
 - ▶ Morality? (Adultery; Masturbation)
 - ▶ Shame? (Infertility)
 - ▶ Fears regarding parentage?
 - ▶ Fears regarding rights & responsibilities?
 - ▶ Fear of interference with family sphere (emotional/physical)
 - ▶ Commercialisation? (Supply and demand)

DONOR CONCEPTION: A SHIFT TO OPENNESS

- ▶ In some countries the focus shifted to the child. There was and continues to be discussion of:
 - ▶ Identity formation
 - ▶ Medical history
 - ▶ Consanguineous relationships
 - ▶ Human rights (identity; genetic heritage; private and family life)
 - ▶ Interests
 - ▶ Equality
 - ▶ Genetic relatives (i.e. siblings)
 - ▶ Truth/Openness/Honesty
- ▶ Shift also in who accesses donor gametes



Jurisdiction	Legislation	Date of implementation
Victoria (Australia)	Infertility (Medical Procedures) Act 1984; Infertility Treatment Act 1995; Infertility Treatment Regulations 1997; Assisted Reproductive Treatment Act 2008	1985; 1998; 2010; 2016; 2017 (respectively) Prospective; Retrospective
Sweden	Lag om insemination (Law on Insemination) 1984 (replaced by Genetic Integrity Act 2006)	18 March 1985 Prospective
Austria	Fortpflanzungsmedizingesetz. 275 Bundesgesetz.	1 July 1992 Prospective
Switzerland	Federal Act on Medically Assisted Procreation of 18 December 1998 – FF 1996 III, 197 (LPMA)	1 January 2001 Prospective; Retrospective

Jurisdiction	Legislation	Date of implementation
The Netherlands	Wet donorgegevens kunstmatige bevruchting, 2002 (1990- 2004) Dual track 'A' or 'B' donors	1 June 2004
Western Australia	Human Reproductive Technology Act 1991 (WA)	2004
New Zealand	Human Assisted Reproductive Technology Act	2004
Norway	Act on Biotechnology 2003	1 January 2005
UK	Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004	1 April 2005
Finland	The Act on Assisted Fertility Treatments (1237/2006)	September 2007

Jurisdiction	Legislation	Date of implementation
New South Wales (Australia)	Assisted Reproductive Technology Act 2007 1 January 2010	Prospective (retrospective with consent recommended, but pending) (register based)
South Australia	Assisted Reproductive Treatment Act 1988 (SA); Assisted Reproductive Treatment Regulations 2010 (SA). 1 July 2010	Prospective (clinic based)
Washington State (United States)	Wash Rev Code Ann §26.26.750 July 2011	Prospective (clinic Based) NB. Subject to veto by donor

Jurisdiction	Legislation	Date of implementation
Croatia	<i>ZAKON O MEDICINSKI POMOGNUTOJ OPLODNJI (Law on Medically Assisted Reproduction, 12 July 2012) (Croatia), No: 71-05-03 / 1-12-2</i>	12 July 2012 Prospective (Register Based)
Uruguay	Law Regulating Human Assisted Reproductive Techniques (22/11/2013 No 19.167):	22 November 2013 Based on application to the Court.
Argentina	Código civil y comercial de la nación (Civil and Commercial Code of the Nation), Title V, Ch2, approved by Law 26,994.	1st of October 2014 Prospective (Birth registration, and medical records)
Ireland	Children and Family Relationships Act 2015 Act No. 9 of 2015	6 April 2015 Prospective (Register)

Court Based

GERMANY

28 January, 2015, the German Supreme Court (Bundesgerichtshof) held that all children have a right of access information, regardless of age, and that that rights trumps any right the donor has to privacy. BGH, Urteil vom 28. January 2015 - XII ZR 201/13.

October 2016 – Hanover Court reaffirms that a ‘child's’ right to know about where they come from weighed more significantly than a sperm donor's right to determine how their personal information is shared. (Nb. Plaintiff 21 yr old female).

DUAL TRACK

- ▶ Not statute or court based
- ▶ Donors choose whether to be 'anonymous' or 'open-identity'
- ▶ Recipients choose whether to use anonymous or 'open identity' donor

Places that allow for 'anonymous' or 'open-identity' donations: Canada, Denmark, Iceland, Hungary and the United States.

But NOTE – where the emphasis lies...

Approaches to information Release

- ▶ **Mandatory Register (with/without notification)**
 - ▶ Held at birth records office (Victoria – notification since 2010) (management to be transferred to VARTA in 2017)
 - ▶ Held at Health Department (NSW, Netherlands, Switzerland (govt. dept), Croatia – notification (parents), Ireland – notification B/C, WA)
 - ▶ Run by Stand-alone body (UK, Finland)

Approaches to information Release

- ▶ **Clinic based**
 - ▶ Compulsory (Austria, Sweden, Switzerland (retrospective), Washington State*, Germany)
 - ▶ Determined by clinic (incl. open identity v anonymous)
- ▶ **Court Application**
 - ▶ Uruguay, Argentina – notification B/C,

Approaches to information Release

Voluntary Registers

(with/without DNA testing)

- ▶ United Kingdom
 - ▶ Voluntary DNA register pre 1991 donations/conceptions
 - ▶ Voluntary donor sibling registry run by HFEA
- ▶ Australia (NSW, Victoria (potential for DNA testing with new laws), Western Australia)
- ▶ Netherlands (DNA register)
- ▶ New Zealand (may voluntarily place information on HART register)

Retrospective?

▶ Australia

- ▶ Victoria (laws passed 23 February 2016, commence March 2017)
- ▶ South Australia (current inquiry)
- ▶ Tasmania (current inquiry)

▶ Switzerland

(Art 41 Federal Act on Medically Assisted Procreation of 18 December 1998 – FF 1996 III, 197 (LPMA) (pre 2001 must ask clinics; post 2001 on register).

- ▶ Netherlands (2004) United Kingdom (2005) optional

With or without support services?

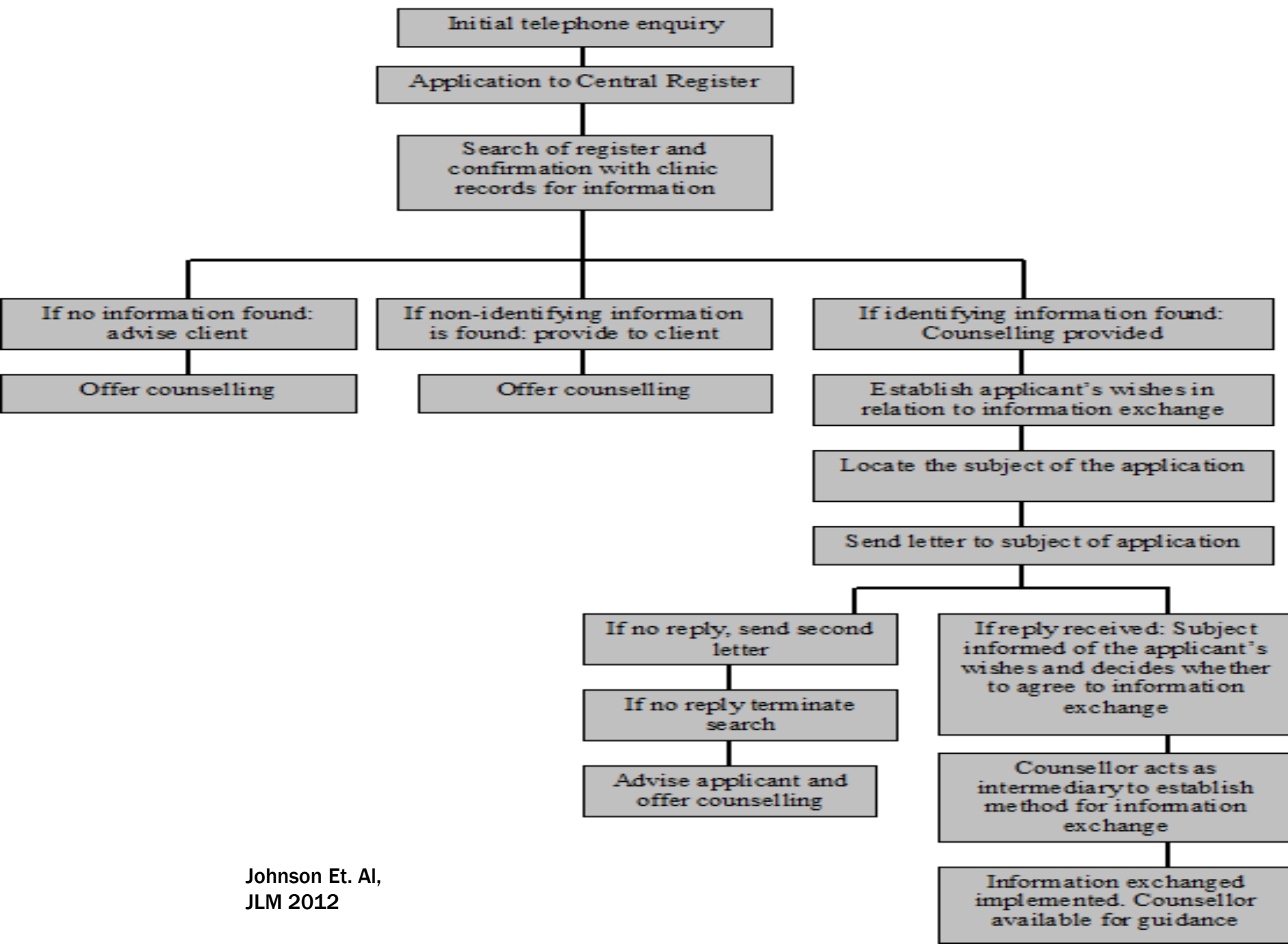
Information Release

- ▶ Notification?
- ▶ Counselling/support regarding access to information?

Contact:

- ▶ Intermediary services for example:
 - ▶ o liaise b/w donor and donor-conceived person regarding optional contact – (letters, meeting?)
 - ▶ Expectation counselling/support

Figure 1
ITA DONOR-LINKING SERVICE MODEL - APPLICATIONS TO THE CENTRAL REGISTER



Thank you....

DONOR CONCEPTION
AND THE SEARCH FOR
INFORMATION

FROM SECRECY AND ANONYMITY
TO OPENNESS

SONIA ALLAN

► Want to know more?

Contact:

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