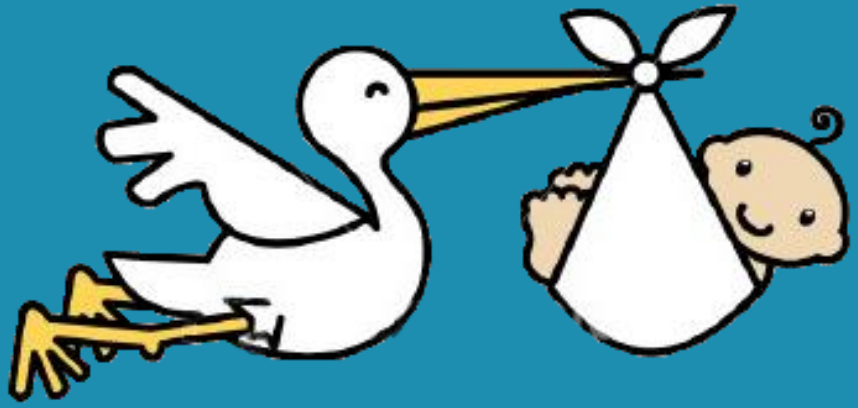
KU LEUVEN

The right to access information about one's genetic origins in the context of medically assisted reproduction: comparative overview



Elodie Decorte

RETHINKIN Expert Seminar

The Right to Identity and Access to Information on Genetic Origin and Parentage

16 April 2021

ART in Europe

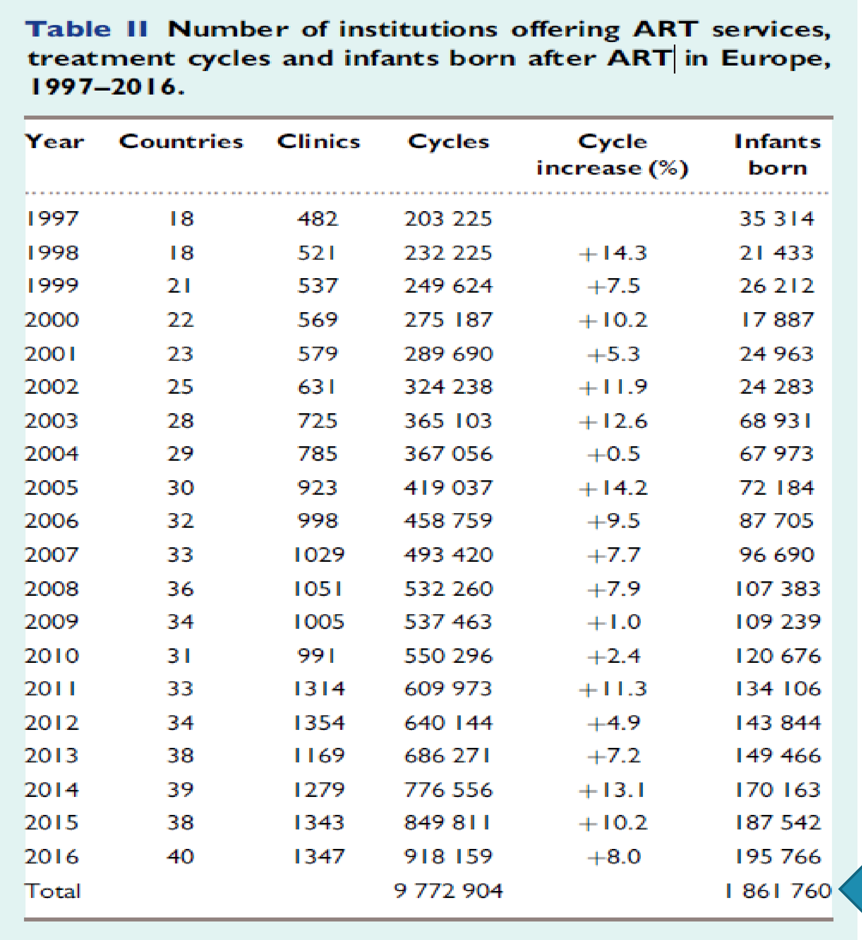
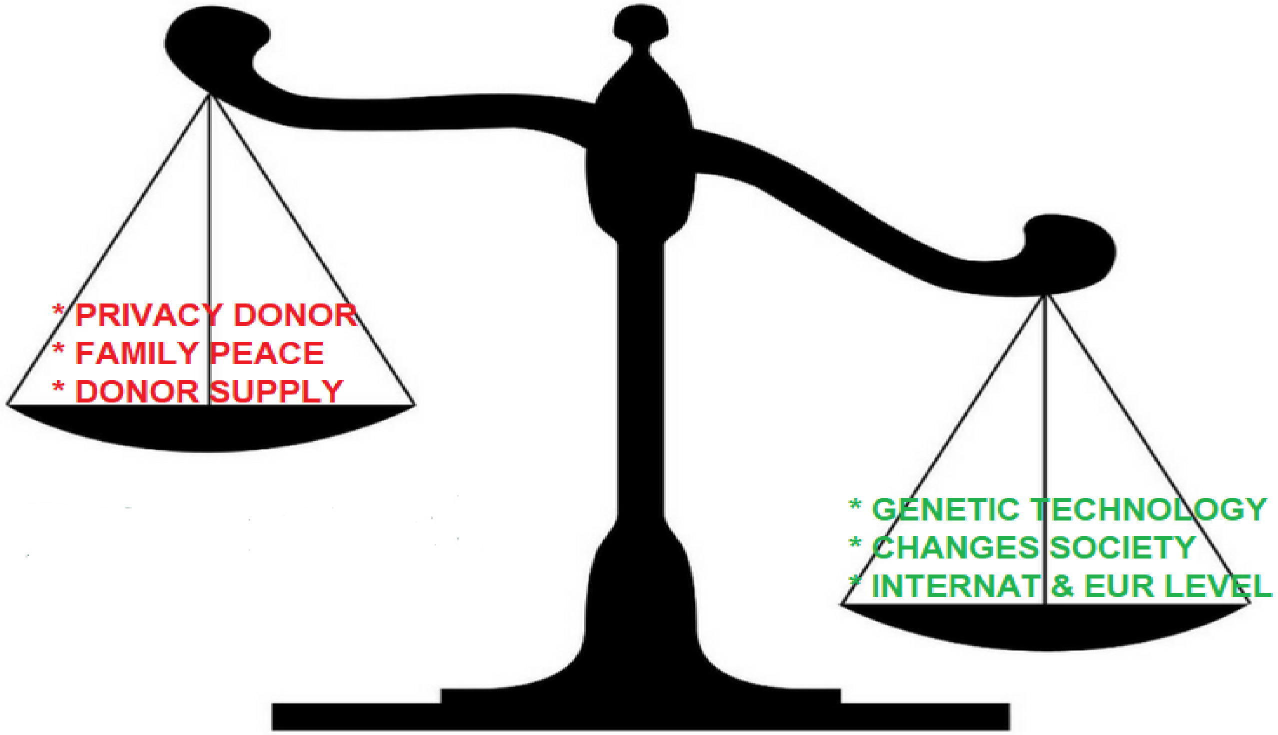


Table II Number of institutions offering ART services, treatment cycles and infants born after ART in Europe, 1997–2016.

Year	Countries	Clinics	Cycles	Cycle increase (%)	Infants born
1997	18	482	203 225		35 314
1998	18	521	232 225	+14.3	21 433
1999	21	537	249 624	+7.5	26 212
2000	22	569	275 187	+10.2	17 887
2001	23	579	289 690	+5.3	24 963
2002	25	631	324 238	+11.9	24 283
2003	28	725	365 103	+12.6	68 931
2004	29	785	367 056	+0.5	67 973
2005	30	923	419 037	+14.2	72 184
2006	32	998	458 759	+9.5	87 705
2007	33	1029	493 420	+7.7	96 690
2008	36	1051	532 260	+7.9	107 383
2009	34	1005	537 463	+1.0	109 239
2010	31	991	550 296	+2.4	120 676
2011	33	1314	609 973	+11.3	134 106
2012	34	1354	640 144	+4.9	143 844
2013	38	1169	686 271	+7.2	149 466
2014	39	1279	776 556	+13.1	170 163
2015	38	1343	849 811	+10.2	187 542
2016	40	1347	918 159	+8.0	195 766
Total			9 772 904		1 861 760

Source: https://www.eshre.eu/Data-collection-and research/Consortia/EIM/Publications

From anonymity to openess

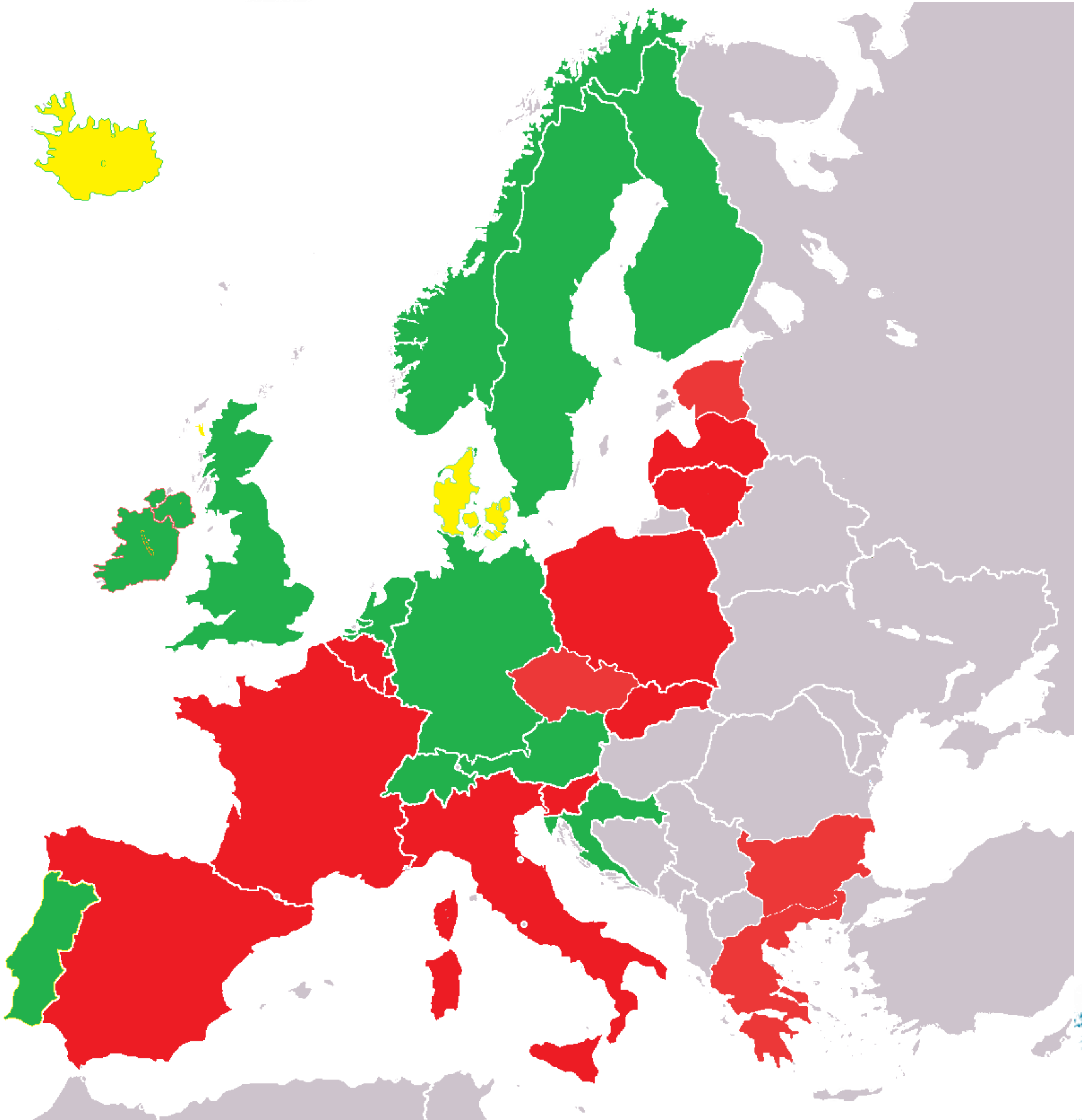


* PRIVACY DONOR
* FAMILY PEACE
* DONOR SUPPLY

* GENETIC TECHNOLOGY
* CHANGES SOCIETY
* INTERNAT & EUR LEVEL

Different approaches

- 🟩 Jurisdictions granting access to identifying information
- 🟨 Jurisdictions enabling both open-identity and anonymous donation
- 🟥 Jurisdictions holding on to anonymity



Different approaches: Belgium - Absolute anonymity

- Act 6 July 2007 Medically Assisted Reproduction
- Arguments in favour of anonymity:
  - avoid decrease number of donors
  - protect family peace
  - best interests of the child (!?)
- Future?

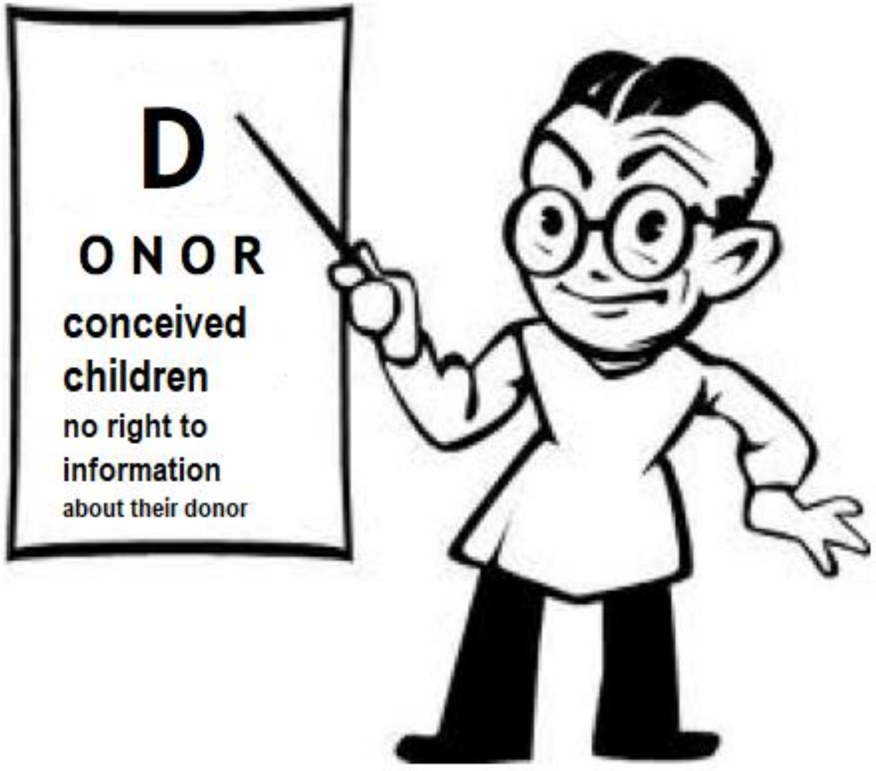
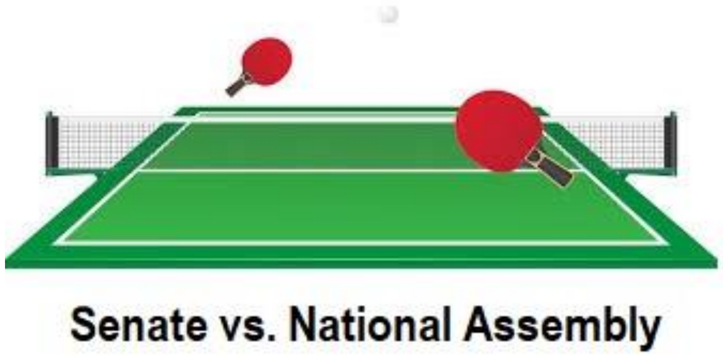


Illustration https://donorkinderen.wordpress.com/

Different approaches: France - Absolute anonymity

- Lois Bioéthiques 1994
- Revision Lois Bioéthiques 2018-2019?



National Assembly:

« Le consentement exprès des personnes souhaitant procéder au don de gamètes ou d'embryon à la communication de ces données et **de leur identité** dans les conditions prévues au premier alinéa du présent article est recueilli avant qu'il soit procédé au don. En cas de refus, ces personnes ne peuvent procéder à ce don. »

Senate:

« Elle peut également, si elle le souhaite, accéder à sa majorité à **l'identité** du tiers donneur, sous réserve du consentement exprès de celui-ci exprimé au moment de la demande qu'elle formule en application de l'article L. 2143-5. ».

Protection of the right to know one’s genetic origins

Comparative analysis of the Netherlands, Germany, the United Kingdom and Ireland:

- Legal framework
- Collection and registration of information
- Access to information about donor for donor-conceived persons
- Access to information about genetic siblings
- Access to information for donor and parents
- Duty to tell donor conceived-persons about the donor conception
- Donations from the past

Legal framework

2004

Netherlands

Wet donorgegevens 2002

2005

UK

Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004

2018

Germany

Gesetz zur Regelung des Rechts auf Kenntnis der Abstammung bei heterologer Verwendung von Samen vom 17.07.2017’

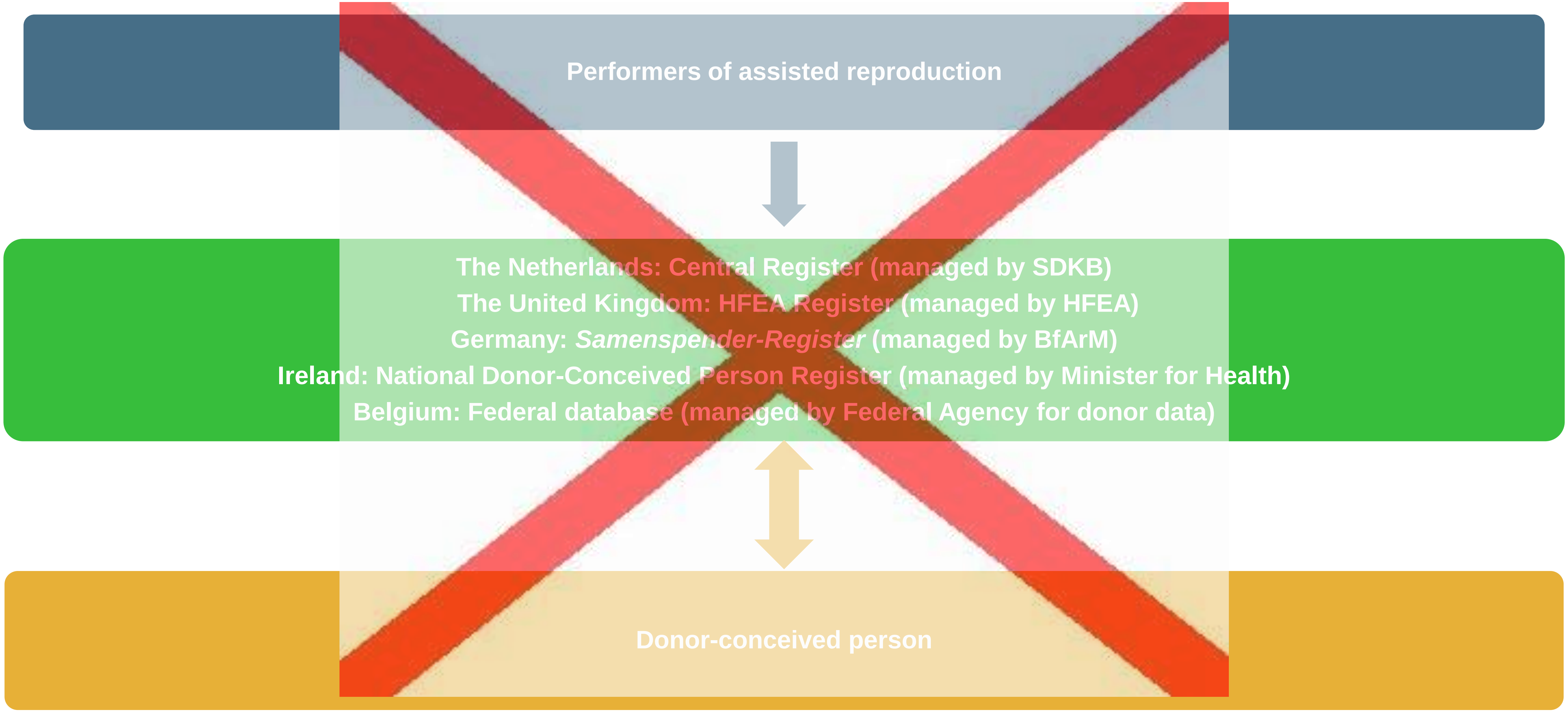
2020

Ireland

Children and family relationships act of 2015

Belgium?

Data collection and registration



Performers of assisted reproduction

The Netherlands: Central Register (managed by SDKB)
The United Kingdom: HFEA Register (managed by HFEA)
Germany: *Samenspender-Register* (managed by BfArM)
Ireland: National Donor-Conceived Person Register (managed by Minister for Health)
Belgium: Federal database (managed by Federal Agency for donor data)

Donor-conceived person

Storage time

The UK: ∞

Germany: **110** years

The Netherlands & Belgium: **80** years

Seed for a good deed?

Illustration by Sameer Ranjan Bakshi, https://bangaloremirror.indiatimes.com/bangalore/cover-story/sperm-bank-scam/articleshow/22167838.cms

What kind of information

	The Netherlands	**Germany**	**The United Kingdom**	**Ireland**	**Belgian law proposal**
Non-identifying information (e.g. medical, physical and social information)	Mandatory	**On a voluntary basis**	Mandatory	Mandatory	Mandatory
Identifying information (e.g. name, adress, date of birth)	Mandatory	Mandatory	Mandatory	Mandatory	Mandatory

Updating important medical information

- DIRECTIVE 2004/23/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells
- RATC report 2018: *“The **twenty-five alerts from Denmark**, encoded as quality and safety defects, concerned sperm donors identified as posing a risk for transmission of genetic disease. Authorities limited further distribution and use of the donations concerned.”*

	The Netherlands	Germany	The United Kingdom	Ireland	Belgian law proposal
Non-identifying information	**12 years**	16 years	16 years	18 years	**12 years**
Identifying information	**16 years**	**16 years**	18 years	18 years	18 years

Access to information about the donor: participation donor

	The Netherlands	Germany	The United Kingdom	Ireland	Belgian law proposal
Non-identifying information	X	**Right of veto**	X	X	X
Identifying information	**Written consent ‘Weighty interests’**	X	X	**Donor can make representations ‘Sufficient reasons’**	**Donor can make representations ‘Weighty interests’**

Access to information about the donor: support

What are your expectations about making contact and what are your hopes and fears?

A SPERM DONOR'S NIGHTMARE

How might your request for information or contact impact on the donor and their family (if they have one)?

What are you expecting to find out?

What if your donor is totally different to you?

What if your donor or donor-conceived siblings want to meet your family or have a closer relationship with you? How will you handle that if it’s not something you’re expecting?

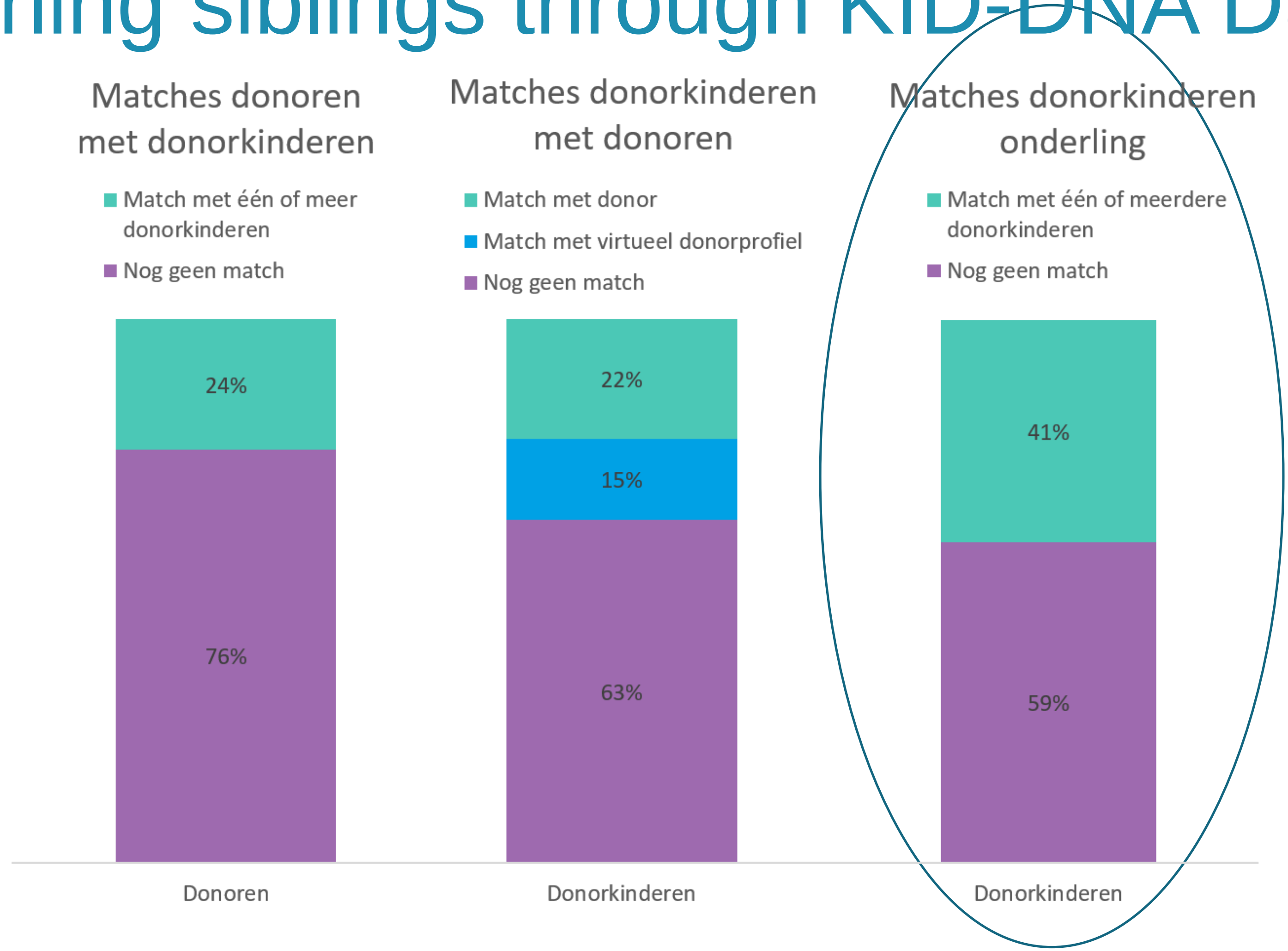
A family portrait: brothers, sisters or strangers?

Illustration by Eli Baden-Lasar

Access to information about genetic siblings

The Netherlands	Germany	The United Kingdom	Ireland	Belgian law proposal
X	X	- 16 years: number, sex, year of birth - 18 years: id. information by mutual acceptance - Request for information as to intended spouse etc.	18 years: number, sex, year of birth & id. Information if approving statement	X

Matching siblings through KID-DNA Databank

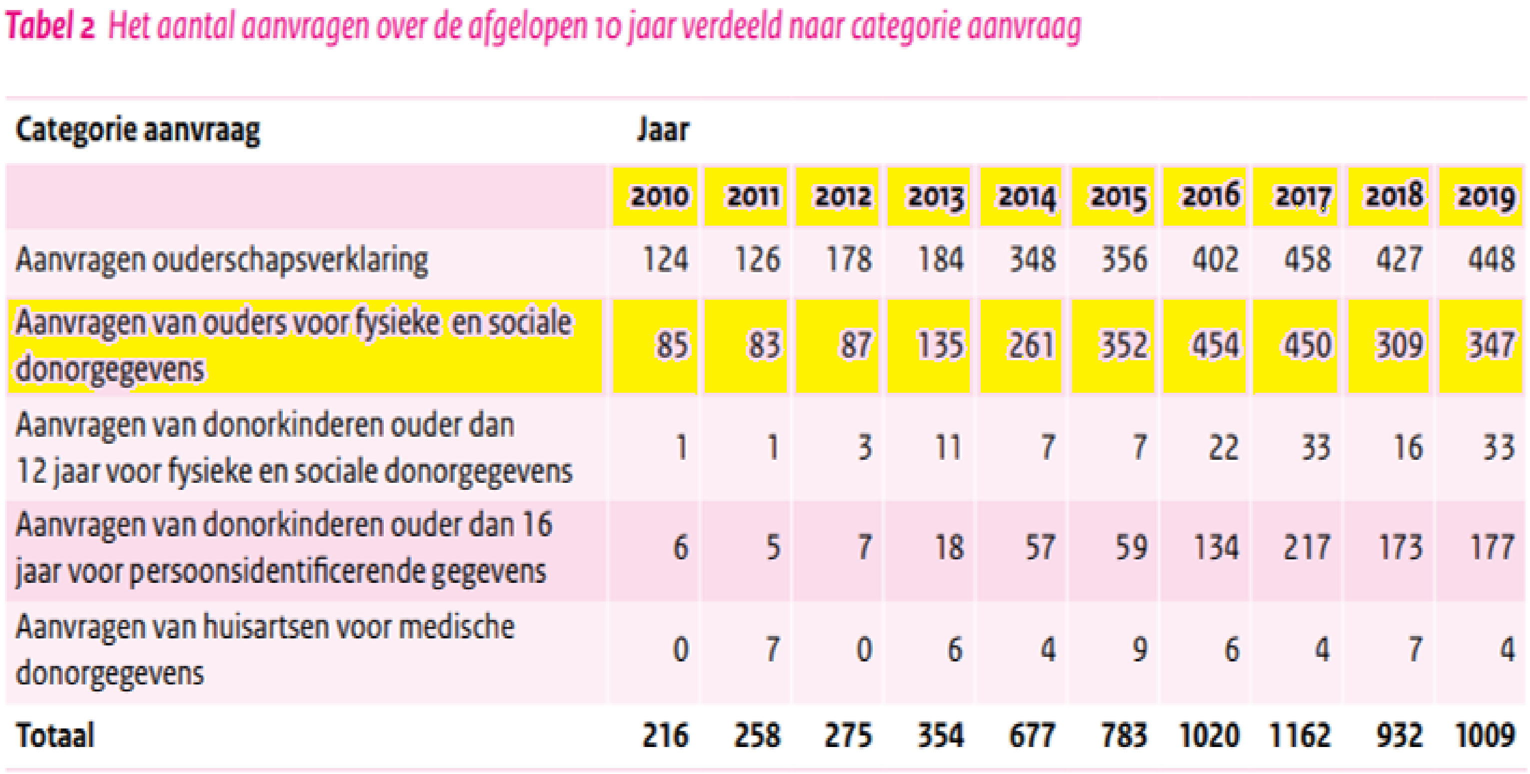


https://fiom.nl/afstammingsvragen/donorconceptie/praktische-informatie-over-fiom-kid-dna-databank

Access to information for parents & donor

	The Netherlands	Germany	The United Kingdom	Ireland	Belgian law proposal
Donor	No access	No access	Number, sex and year of birth	*Number, sex and year of birth ***Identifying information**	No access
Parent	Non-identifying information when child <12 years	(Non-)**identifying information** when child <16 years	Non-identifying information & number, sex and year of birth of the children from the same donor	Non-identifying information & number, sex and year of birth of the children from the same donor when child <18 years	Non-identifying information when child <18 years

Requests of parents in the Netherlands



Tabel 2 *Het aantal aanvragen over de afgelopen 10 jaar verdeeld naar categorie aanvraag*

Categorie aanvraag	Jaar									
	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Aanvragen ouderschapsverklaring	124	126	178	184	348	356	402	458	427	448
Aanvragen van ouders voor fysieke en sociale donorgegevens	85	83	87	135	261	352	454	450	309	347
Aanvragen van donorkinderen ouder dan 12 jaar voor fysieke en sociale donorgegevens	1	1	3	11	7	7	22	33	16	33
Aanvragen van donorkinderen ouder dan 16 jaar voor persoonsidentificerende gegevens	6	5	7	18	57	59	134	217	173	177
Aanvragen van huisartsen voor medische donorgegevens	0	7	0	6	4	9	6	4	7	4
Totaal	**216**	**258**	**275**	**354**	**677**	**783**	**1020**	**1162**	**932**	**1009**

Annual report 2019 Foundation for Data on Artificial Insemination Donors

Right to be told? Sooner rather than later

Right to be told?

	The Netherlands	Germany	The UK	Ireland	Belgian law proposal
Legal duty?	No	No	No	No	No
Consensus on importance?	Yes	Yes	Yes	Yes	Yes
Other?	**Supreme Court: part of parental authority**	/	/	**Note in the register of births**	/

Donations from the past: no retroactivity?

Donations from the past: retroactivity

Victoria, Australia

“While the release of identifying information to donor-conceived people may potentially cause discomfort and distress to donors (although this will not always be the case), it is certain that donor-conceived people are actually suffering from their lack of knowledge about donors.” (Victorian Law Reform Committee)

Switzerland

“Articles 18 and 24–27 also apply if sperm cells have been donated before, but are only used after, the commencement of this Act. In all other cases, physicians who have used assisted reproductive techniques using donated reproductive cells must provide information, with the provisions of Article 27 applying mutatis mutandis.” (Art. 41 Federal Act on Medically Assisted Reproduction)

juncto

“Every person shall have access to data relating to their ancestry.” (Art. 119, 2, g Federal Constitution)

Donations from the past: other solutions

Voluntary registers

- Fiom KID-DNA Database (NL)
- UK Donor Conceived Register
- Flemish centre of parentage (+ Federal DNA Database)

Release non-id. & id. after consent

- Transition period in the Netherlands
- Removing anonymity (1991-2005) in the UK