



Deposited via The University of Sheffield.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/id/eprint/192154/>

Version: Published Version

Article:

Pennings, G., Mocanu, E., Herrmann, J.R. et al. (2021) Attitudes of sperm donors towards offspring, identity release and extended genetic screening. *Reproductive BioMedicine Online*, 43 (4). pp. 700-707. ISSN: 1472-6483

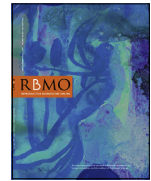
<https://doi.org/10.1016/j.rbmo.2021.06.025>

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) licence. This licence only allows you to download this work and share it with others as long as you credit the authors, but you can't change the article in any way or use it commercially. More information and the full terms of the licence here: <https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



ARTICLE

Attitudes of sperm donors towards offspring, identity release and extended genetic screening

**BIOGRAPHY**

Guido Pennings is full Professor of Ethics and Bioethics at Ghent University (Belgium) where he is also the director of the Bioethics Institute Ghent (BIG). He has published extensively on ethical problems associated with medically assisted reproduction and genetics.

Guido Pennings^{1,*}, Edgar Mocanu², Janne Rothmar Herrmann³, Anne-Bine Skytte⁴, Corey Burke⁵, Allan Pacey⁶

KEY MESSAGE

ID-release and non-ID-release donors differed significantly on numerous aspects of donation, including relationships with the offspring, information sharing with others and wanting information about offspring. Most non-ID-release donors would no longer donate if this option were eliminated.

ABSTRACT

Research question: What is sperm donors' attitude towards offspring, anonymity and extended genetic screening?

Design: An online questionnaire for sperm donors was administered at Cryos International in the USA and Denmark between 9 and 30 September 2020. A total of 233 donors (37 in the USA and 196 in Denmark) completed the questionnaire. This study is unique because it was performed in a setting that allows donors to choose to be either ID-release or non-ID-release donors.

Results: Most donors had two motives to donate: helping childless people and/or financial compensation. ID-release donors differed significantly from non-ID-release donors in numerous aspects of the donation, including relationships with the offspring, information sharing with others and wanting information about offspring. In general, donors had a very positive attitude towards genetic testing and extended genetic screening.

Conclusions: Offering the possibility for donors to be either ID-release or non-ID-release allows more donors to be recruited than if only one option were available. The multiple differences between the two donor types suggests that these are groups with profoundly different attitudes towards donation. The general attitude of donors towards genetic testing and expanded genetic screening is very positive but further studies on the attitude of candidate donors are needed.

¹ Bioethics Institute Ghent (BIG), Ghent University, Department of Philosophy and Moral Science, Gent, Belgium

² Rotunda Hospital, Royal College of Surgeons in Ireland, Dublin, Ireland

³ Centre for Advanced Studies in Biomedical Innovation Law, University of Copenhagen, Copenhagen, Denmark

⁴ Cryos International – Denmark, Aarhus, Denmark

⁵ Cryos International – USA, Orlando FL, USA

⁶ Department of Oncology and Metabolism, The Medical School, The University of Sheffield, Sheffield South Yorkshire, UK

KEY WORDS

Donor anonymity
Donor offspring
Expanded carrier screening
Genetic testing
Sperm donor

INTRODUCTION

Sperm donation has been around for several decades. The expansion of the sperm bank industry started with the development and use of sperm freezing in the 1970s (*Ombelet and Van Robays, 2010*). However, the practice still raises a number of recurring ethical questions related to anonymity, financial compensation and altruism.

The characteristics of the sperm donor population are constantly changing. This is a consequence of changes in regulation in some countries and new developments in society in general. One such development is the possibility for all participants (donor-conceived offspring, recipients and donors) to track the other parties by means of large genetic databases (*Harper et al., 2016; Pennings, 2019*). Another significant change is the growing application of expanded carrier screening on gamete donors. The introduction of expanded carrier screening raises both legal issues (i.e. different legal rules about the use of known carriers) and ethical issues (i.e. possible consequences for the donor of the composition of the panels) (*Mertes et al., 2018; Payne et al., 2021*).

These changes may have a large impact on past donors and also on the recruitment of new donors. Of concern is the introduction of the latter intervention without consultation with donors and candidate donors. Most countries are struggling to cover the demand for donor spermatozoa. This shortage reveals itself in patients crossing borders to get access to spermatozoa (in 2017, more than 5000 cycles of sperm donation were performed in Spain for foreign patients) and in countries importing spermatozoa from abroad (Belgium imports approximately 60% of its donor spermatozoa from Denmark) (*Sociedad Espanol de Fertilidad 2017; Thijssen et al., 2014*). Given the overall shortage of donors, it is important to seek the opinion of this population on the different aspects of the procedure. With this goal in mind, this study aimed to measure a number of demographic and psychosocial parameters and compare anonymous (non-ID-release) and non-anonymous (ID-release) donors using a dedicated questionnaire.

MATERIALS AND METHODS

Study setting

The survey was conducted on a population of donors attending the sperm bank Cryos International in Denmark and the USA. At the start of the donation, all donors choose to provide either a basic profile or an extended profile. The basic profile contains the following characteristics: race, ethnicity, eye colour, hair colour, height, weight, blood type and profession/education. Sperm donors with an extended profile are registered with additional details including background, physical characteristics, education, profession, personality, health and family history, photos, handwritten greeting, voice sample, staff impression and emotional intelligence tests.

Donors have to be physically and mentally healthy men between 18 and 45 years old. Beside selecting a profile, donors also have to choose between ID-release and non-ID-release. The non-ID-release donors were formerly known as anonymous. Due to developments in genetic testing and the possibility of looking for DNA matches in large genetic databases, it is no longer possible to guarantee the anonymity of donors. Donors are clearly informed about this development in the donor agreement and during counselling. Therefore, Cryos International chose to change the terminology to avoid confusion in candidate donors. In the case of non-ID-release donors, the sperm bank will never reveal the identity of the donor to anyone, but donors know that recipients or offspring may trace them through other means. ID-release donors accept that their identity can be revealed, upon request, to the child at the age of 18 (depending on the country) and they have agreed to be contacted. Donors are compensated for their time, expenses and inconvenience. In Denmark, they receive extra compensation if they choose to provide an extended profile and if they accept to be ID-release donors. They can receive up to €65 (500 DKK) per donation. Donors in the USA receive up to \$70 per donation.

Methodology

All active donors received an e-mail with the link to the questionnaire. Data collection was carried out between 9 and 30 September 2020. The questionnaire was available for 3 weeks

and a reminder was sent after 2 weeks. The questionnaire consisted of 30 questions that covered six domains: (i) demographic characteristics; (ii) psychosocial aspects; (iii) motivation for sperm donation; (iv) attitude towards anonymity; (v) attitude towards the children; and (vi) attitude towards genetic testing. The questionnaire was partly based on previous surveys conducted at the same sperm bank in 1992, 2002 and 2012 (*Bay et al., 2014*). Some questions were updated to fit changes in policy in the sperm bank. The section on genetic testing was new as no expanded carrier screening was performed before 2012.

Statistical analysis

The questionnaire was created and distributed using the MS Customer Voice application. The software used to perform the statistical analysis was partly MS Excel and partly the open-source tool R (The R Foundation, Austria). A two-sided Fisher's exact test was used to determine the significance of the association between variables. For age (a continuous variable), an analysis of variance test was performed. *P*-values <0.05 were considered to be statistically significant.

Ethical approval

According to the Danish Act on Research Ethics Review of Health Research Projects, questionnaire surveys and health science research projects must only be notified to an ethics committee if the project includes human biological material. The donors consented to participate in the research by filling out the questionnaire. They were free to participate and were informed that the data were anonymous. The study was approved on 18 February 2021 by the University Research Ethics Committee of the University of Sheffield (reference number 038425) and on 09 March 2021 by the Ethics Committee of Faculty of Arts and Philosophy of Ghent University (reference number 2021-09).

RESULTS

A total of 393 donors were invited by e-mail to participate, of whom 233 completed the questionnaire (a total response rate of 59.3%), 196 in Denmark (response rate of 60.7%) and 37 in the USA (response rate of 52.9%). Statistically significant differences between the US and the Danish samples were sought but only four were found:

TABLE 1 DEMOGRAPHIC CHARACTERISTICS

Characteristic	Total (n)	Total (%)	ID-release (n)	ID-release (%)	Non-ID-release (n)	Non-ID-release (%)	P-value ^a
Mean age (years) ^b	28.57		29.54		26.72		<0.001 ^{a,*}
Partner							0.008 [*]
Yes	113	48.5	84	54.9	29	36.2	
No	120	51.5	69	45.1	51	63.8	
Period of donation							0.199
Less than 1 year	106	45.9	64	41.8	42	52.5	
Between 1 and 2 years	87	37.3	64	41.8	23	28.8	
Between 2 and 3 years	24	10.3	15	9.8	9	11.3	
More than 3 years	16	6.9	10	6.5	6	7.5	
Children of their own							0.181
Yes	51	21.9	38	24.8	13	16.3	
No	182	78.1	115	75.2	67	83.8	
Occupational status							0.027 [*]
Student	105	45.0	63	41.2	42	52.5	
Skilled worker	52	22.3	43	28.1	9	11.3	
Academic worker	28	12.0	20	13.1	8	10.0	
Self-employed	21	9.0	14	9.2	7	8.8	
Unskilled worker	14	6.0	7	4.6	7	8.8	
Other	4	1.8	1	0.7	3	3.8	
Unemployed	9	3.9	5	3.3	4	5.0	
Country of donation							0.667
Denmark	196	84.1	126	64.3	70	35.7	
USA	37	15.9	27	73.0	10	27.0	

^a Fisher's exact test was used to compare ID-release donors with non-ID-release donors.

^b Mean age in years. Analysis of variance was used to compare age as a continuous variable between ID-release and non-ID-release donors. SD 6.745 years.

^{*} Significance level <0.05.

no longer wanting to donate if they could not be ID-release donors ($P = 0.036$); wanting information on the gender of the offspring ($P = 0.013$); thinking about potential children ($P = 0.019$); and wanting to know the results of genetic testing ($P = 0.050$). As no clear explanation could be offered for these differences, they will not be mentioned in the country comparison of the results.

Demographic characteristics

The majority of the donors (78.1%) had no children of their own at the time of donation (TABLE 1). Their mean age was 28.57 (SD 6.74) years. About half of them (45.9%) had been donating for less than 1 year, 37.3% between 1 and 2 years, 10.3% between 2 and 3 years, and 6.9% for longer than 3 years. There was an almost equal distribution between donors who had a partner (48.5%) and those who did not (51.5%). The most frequent occupations of the donors were student (45.0%), skilled worker (22.3%), academic worker

(12.0%) and self-employed (9.0%). There were considerably more skilled workers (45.9% versus 17.8%) and considerably fewer students (18.9% versus 50.0%) in the USA than in Denmark. The variable 'current occupation' was significantly different between the two countries ($P = 0.027$), but differences at the level of individual occupations were not statistically assessed.

Psychosocial aspects

Of those donors with a partner, 85.8% had told their partner about the donation. The influence of the partner on their decision was fairly limited: 64.9% said the partner had had no influence at all, 21.6% said a little, and 13.4% a lot. The large majority of the partners (84.5%) felt positive about the donation (as reported by the donor). Regarding talking to others about being a sperm donor, 16.3% never talked to others about this, 51.5% mentioned it to selected others, and 32.1% were completely open about it. On the

question of whether they intended to tell their own current or future children about being a sperm donor, 39.4% were uncertain, 15.4% did not plan to tell, and 45.0% intended to tell. On the last two questions, there was no significant difference according to the donor type (ID-release or non-ID-release).

Motivations for sperm donation

Respondents could select one or more of the following options: 'curiosity', 'to earn money', 'to get a health check', 'to have my sperm quality tested' and 'to help childless people' (TABLE 2). The variables 'only earn money' and 'only help childless people' count those who marked only this option and none of the other options. There was no significant difference between ID-release and non-ID-release donors on the reasons to donate.

The majority (60.5%) were not and had never been a blood donor. There were significantly more blood donors in the US

TABLE 2 SPERM DONORS' REASONS TO DONATE

Reasons to donate ^a	n	%
Earn money	146	62.6
Only earn money	11	4.7
Help childless people	210	90.1
Only help childless people	53	22.7
Earn money + help childless people	126	54.0
Get health check	43	18.5
Curiosity	53	22.7
Other	4	1.7

^a Donors could indicate more than one reason to donate.

sample than in the Danish sample (56.8% versus 36.2%, $P = 0.027$).

If they would no longer receive a financial compensation for their sperm donation, 20.6% would continue to donate, 45.5% would stop and 33.9% did not know what they would do.

Donors were also asked how many children they thought could acceptably be created with their sperm worldwide. We recorded the answers in five categories: (i) ≤ 10 (18.8%); (ii) between 11 and 99 (15.8%); (iii) ≥ 100 to unlimited (48.5%); (iv) limits per country (5.5%); and (v) 'don't know' (11.1%). No significant difference was found between ID-release and non-ID-release donors for this item.

Information sharing

Most donors (65.2%) would like to be informed if their donation resulted in a pregnancy but 21.9% did not want this information. Regarding information about the children, 69.3% wanted to know the number of children, 41.3% the gender, and 62.7% the children's health. The latter largely corresponds with their wish to be informed if a child resulting from their donation was found to have a hereditary disease (67.3%). The information provision from donor to offspring depends on the donor profile. The majority of the donors (79.4%) had an extended profile and thereby demonstrated that they accepted that a lot of information about themselves would be shared with the recipients and the offspring.

ID-release versus non-ID-release donors

The ID-release versus non-ID-release donors were systematically compared for all characteristics and items (TABLE 1 and TABLE 3). ID-release donors

were significantly older than non-ID release donors (29.54 years versus 26.72 years, $P = 0.001$). The ID-release donors were significantly more likely to have a partner (54.9% versus 36.2%, $P = 0.008$) and had more frequently informed their partner about their donor status than had non-ID-release donors with a partner (90.5% versus 72.4%, $P = 0.027$). However, the two groups were not significantly different in the degree to which their partner had influenced their decision to become a donor or about the feelings their partner had towards the fact that they were sperm donors. In line with informing their partner, ID-release donors reported that they would be significantly more likely to tell their own children about their donations (57.5% versus 21.2%, $P = 0.001$).

ID-release donors did not differ significantly from non-ID-release donors in their motivation to donate. Nor was there any significant difference between these groups in the intention to stop donating if no financial compensation was offered. ID-release donors were much more likely to have an extended donor profile (93.5% versus 52.5%, $P = 0.001$), thought significantly more about their potential donor children (56.2% versus 35.0%, $P = 0.002$) and were significantly more likely to want information on whether a pregnancy had occurred from their donation (70.6% versus 55.0%, $P = 0.017$). In addition, they also were significantly more likely to want information about the children conceived with their spermatozoa: the number of children (64.0% versus 50.0%, $P = 0.048$), their gender (40% versus 26.2%, $P = 0.042$) and their health (59.3% versus 42.5%, $P = 0.018$). The non-ID-release donors were much more likely than the other type to want no information (32.5% versus 19.3%,

$P = 0.034$). This general attitude is extended to the wish to be informed if a child with a hereditary disease was born after using their spermatozoa. The ID-release donors were significantly more likely to want to be informed if the offspring was diagnosed with a genetic disease (73.9% versus 55.0%, $P = 0.003$).

There is an interesting asymmetry between ID-release and non-ID-release donors in their response to the question of what they would do if their ID choice was no longer available. A total of 23.7% of non-ID-release donors answered 'don't know', 22.5% would continue as an ID-release donor and 53.75% would stop donating. From the ID-release donors on the other hand, 17% answered 'don't know', 73.8% would continue as a non-ID-release donor and 9.1% would stop donating. When compared with ID-release donors, non-ID-release donors were significantly more likely to think that a child should not be able to find out that it was donor conceived, for example through a genetic database (73.9% versus 28.8%, $P < 0.001$).

Genetic testing

Since 2018, sperm donors have been tested for 46 common recessive disorders. This is the first survey among donors since the introduction of this testing panel. The attitude of the donors towards genetic testing in general and towards extended carrier screening is shown in TABLE 4.

In general, donors have a positive attitude towards genetic testing. Only 6.0% preferred no genetic testing and 13.7% preferred the panel to be restricted to only lethal diseases. A very large majority (86.7%) also agreed with extended carrier screening. The positive attitude towards genetic testing is expressed in the acceptance of more testing in the future. Still, about 1 in 6 (14.7%) did not know what they would do if genetic testing were to be expanded in the future. Most donors (82.5%) wanted to know all results and less than 10% would put restrictions on the information they would like to receive.

DISCUSSION

The possibility of identifying donors through large genetic databases generates a number of problems with the concept of anonymity. Many people seem to have an absolute concept in

TABLE 3 DONOR CHARACTERISTICS AND ATTITUDE ACCORDING TO DONOR TYPE

Donor characteristics and attitude	Non-ID-release (n)	Non-ID-release (%)	ID-release (n)	ID-release (%)	P-value (Fisher's exact test)
Partner knows about donation ^a	21	72.4	76	90.5	0.027*
Positive feelings of partner ^a	19	90.5	63	82.9	0.512
Influence of partner on decision to become donor ^a					0.752
No influence	11	52.4	52	68.4	
Little influence	7	33.3	14	18.4	
Much influence	3	14.3	10	13.2	
Been a blood donor	32	40.0	60	39.2	1
Child should not be able find out about donor conception	23	28.8	113	73.9	<0.001*
Extended donor profile	42	52.5	143	93.5	<0.001*
Likes to know about pregnancy	44	55.0	108	70.6	0.017*
Wants information on number of children ^b	40	50.0	96	64.0	0.048*
Wants information on gender of children ^b	21	26.2	60	40.0	0.042*
Wants information on health of children ^b	34	42.5	89	59.3	0.018*
Wants no information on children ^b	26	32.5	29	19.3	0.034*
Information on children: don't know	5	6.3	6	4.0	0.521
Would like to know if a child is born with a hereditary disease	44	55.0	113	73.9	0.003*
Thinks about potential children	28	35.0	86	56.2	0.002*
Regrets donating	5	6.3	7	4.6	0.293
Talks to others about donating					0.226
To no one	15	18.8	23	15.0	
Only to selected others	45	56.3	75	49.0	
Completely open	20	25.0	55	35.9	
Intends to tell his own children					<0.001*
Yes	17	21.2	88	57.5	
No	24	30.0	12	7.8	
Don't know	39	48.8	53	34.6	

^a Question only asked to donors who had a partner.

^b Three ID-release donors did not answer this question.

* Significance level <0.05.

mind: nobody at any point in time will ever find out the identity of the donor. However, anonymity is a continuum on different dimensions: who knows (medical staff, recipients), when (never, after 18 years) and how likely is it that they will find out (high or low risk). Before the use of genetic databases, there was also a chance of finding the donor with the information available in an extended donor profile (Emon, 2016). The present development of genealogical databases has multiplied the probability of identifying the donor but it does not mean that all donors will be identified by their donor offspring. The concept of anonymity can be maintained in the future in relation to two specific meanings. First, the term refers to the fact that clinics or sperm banks will

not reveal the identity of the donor. Second, the term refers to the degree of contact the donor wants in the future. By opting for anonymous or non-ID-release donation, the donor declares that he wishes not to be traced or contacted. Recipients who select such a donor should honour this wish (Pennings, 2019).

The current study is unique as there is no other study the authors identified in which it was possible to compare donors who had been given the choice between anonymity and identifiability. Although this double-track system has been around for decades, few countries allow or apply the system (Pennings, 1997). A longitudinal prospective cohort study has shown that psychological adjustment of adult donor offspring in lesbian

families is not affected by donor type (Bos et al., 2020; Carone et al., 2021). Since the choice of donor type has no negative influence on the psychosocial development of the children, the positive effects on the intentional parents (e.g. feeling secure in their parental role) plead in favour of such a system (Pennings, 1997).

In the earlier cross-sectional study of Danish donors from 2012 (the Bay study) in which donors were also given the possibility to choose, the answers were not analysed according to whether the donors were anonymous or identifiable. In that sample, 70% opted for anonymous donation (Bay et al., 2014). In the current study, this percentage was almost reversed, with 64% opting for

TABLE 4 ATTITUDE TOWARD GENETIC TESTING AND EXTENDED CARRIER SCREENING

Parameter	ID release (n)	ID release (%)	Non-ID-release (n)	Non-ID-release (%)	Total sample (n)	Total sample (%)	P-value ^a
Attitude toward genetic testing in general							0.017*
I am pro testing for all diseases which can affect the quality of life of potential children	114	74.5	47	58.8	161	69.1	
I am pro testing only for serious diseases which can be deadly for potential children	21	13.7	11	13.8	32	13.7	
I would prefer no genetic testing	5	3.3	9	11.2	14	6.0	
The more genetic testing the better	13	8.5	13	16.2	26	11.2	
Attitude toward extended carrier screening (46 common recessive diseases)							0.007*
I am positive about it	139	90.8	63	78.7	202	86.7	
I don't care	8	5.2	4	5.0	12	5.1	
I don't know	4	2.6	11	13.8	15	6.4	
I would prefer not to be tested	2	1.3	2	2.5	4	1.7	
Reaction if more testing were to be required ^b							0.560
I would stop being a donor	4	2.6	3	3.8	7	3.0	
I would continue being a donor	128	84.2	63	78.8	191	82.3	
Don't know	20	13.2	14	17.5	34	14.7	
Attitude toward the results of additional genetic testing ^c							0.487
I would want to know all results	121	84.0	58	79.5	179	82.5	
I would want to decide what information to receive	13	9.0	6	8.2	19	8.8	
I would not want to know unless there is a high risk for my future children's health	3	2.1	4	5.5	7	3.2	
I would not want to know the results unless there is a high risk for my health	7	4.9	5	6.6	12	5.5	

^a Fisher's exact test was used to compare ID-release donors with non-ID-release donors.

^b One ID-release donor did not answer this question.

^c Due to a technical error, 11 ID-release and seven non-ID-release donors ticked more than one option and were excluded from the data.

* Significance level <0.05.

ID-release (solely considering the Danish donors). There have been several studies in countries with donor anonymity about the number of donors who would still be willing to donate if anonymity were to be abolished. Two Belgian cross-sectional studies found percentages of 20.1% and 26% (Mahieu et al., 2019; Thijssen et al., 2017). These percentages are close to the 22% in this study. It will be interesting to see how the practice of gamete donation will evolve when donors in countries with legal donor anonymity come to realize that their anonymity can no longer be guaranteed. The continued existence of non-ID-release donors as a category will depend on whether recipients and offspring will honour the wish for anonymity in the future. Still, regardless of the legal conditions, it seems that all countries will need to step up their efforts to recruit if they want to preserve a sufficient supply of donors.

The number of items on which ID-release donors differed from non-ID-release donors suggests that two very different groups are present. There are several possible explanations for the differences: (i) a different attitude towards the offspring; (ii) a different view of their own role; (iii) a wish to have future contact; or (iv) a combination of these. Donors who want to prepare for possible future contact probably want more information (number, gender, health) on the donor offspring. In line with the openness towards the recipients and offspring, ID-release donors were also much more likely to have an extended profile. Non-ID-release donors, on the other hand, were much more likely to have a basic profile and not to want any information about the offspring.

The answers to the question of what they would do if their preferred option were

not available indicated that the attitude and position of non-ID-release donors was the least flexible: the majority would stop donating if they could no longer be anonymous. The large majority of the ID-release donors would continue as a non-ID-release donor, thus indicating that ID-release was not a necessary condition to donate. The wish of non-ID-release donors to remain anonymous was supported by their rejection of the possibility of any children finding out about their donor conception through a database. They may fear that finding out about the donor conception might also increase the likelihood of finding their identity. An interesting question is why these men were still donating. Based on the experience of the counsellors, several explanations can be offered: (i) they believed that the risk of being identified was low; (ii) they hoped that their preference for non-identification would

be respected by the recipients; and/or (iii) they believed that as a consequence of their choice they were under no obligation to accept any contact with donor offspring and that the impact on their life would be limited.

No significant difference was found regarding the number of children that could be created with a donor's spermatozoa between ID-release versus non-ID-release donors. Non-ID-release donors were more likely than ID-release donors to accept the creation of more than hundred children (and frequently set no limits) (56% versus 44%) but the difference with ID-release donors was not statistically significant. The authors have no idea how ID-release donors think they will handle future contact with that many offspring or how many children they believe will contact them. It seems reasonable to assume that the (intended) openness towards the partner and their own offspring are largely in anticipation of this future contact. As some offspring may want to make contact in 18 years or earlier, their own family may find out about their donor status at that point. At the moment, donors are not informed about how many children are born from their donations. The lack of information about this may make the numbers more abstract and the possible practical difficulties in the future less obvious.

Previous studies have shown that most donors have both a financial and an altruistic reason for donating (Mahieu et al., 2019; Nikou et al., 2020; Van den Broeck et al., 2013). The reasons to donate in this study were very similar to the reasons found in the study of 2012 (Bay et al., 2014). The percentage that would continue to donate without financial compensation ($\pm 20\%$) was very similar to that in other studies (Mahieu et al., 2019). No statistically different results were found between donor type and reasons to donate. This is remarkable considering that the donor type influenced almost all other positions and attitudes of donors. A possible explanation could be the extra compensation Danish donors received when opting for ID-release donation.

There are few studies looking at the social setting of sperm donation. Many donors in this study shared their donor status with others, although most only with a selected few. This position has not changed much over time. In the

Bay study of 2012, 27% of the donors were completely open about it, 52% shared the information with only a selected group, and 22% did not discuss the matter with anyone (Bay et al., 2014). In a recent Belgian study, 29% of candidate sperm donors planned to keep it a secret from everyone (Thijssen et al., 2017). An earlier study found that 91% of donors had told their partner about their donation and the majority of the partners were highly supportive (Daniels et al., 2012). However, this may be an overestimation as it is likely that candidate donors who suspect that their partner will not agree with the donation either do not make the step or refrain from telling them. Provoost and colleagues (Provoost et al., 2017) showed that male students were reluctant to donate spermatozoa because they did not want to talk about the issue with their partner and/or because they feared a negative reaction by their future partner. In addition, Jadva and co-workers (Jadva et al., 2011) reported that 20.6% of the donors had concerns about how a current or future spouse/partner might feel if they knew. Most studies indicate that only a minority of the donors involved their partner in the decision (Van den Broeck et al., 2013).

Only a few studies contain information on how many donors intend to inform their own children, let alone on those who have informed their children. Qualitative research has shown that donors are concerned about how their own children would react when they were told that their father was a donor (Wheatley, 2019). The current study showed that almost half of the donors intended to tell but studies on disclosure show that intentions are not always put into practice (Nuffield Council on Bioethics, 2013).

There is a lack of empirical studies on the experiences of and attitudes of donors towards expanded carrier screening (Amor et al., 2018). Oocyte donors in a Spanish clinic were surprised by the information on testing and the possibility of being carriers (Abuli et al., 2016). After adequate genetic counselling before and after the test, the results of testing did not seem to have a meaningful emotional or psychological impact on the donors. Studies have shown that one of the motives of sperm donors is to find out about the quality of their spermatozoa (Thijssen et al., 2017). This was confirmed

in the current study, where 40% of donors gave this as a reason to donate. It was not asked whether genetic testing also served as an incentive (free access to information that might be useful for their own reproduction or health).

This study showed that the overwhelming majority of donors were very positive towards genetic testing in general. They were also very positive about the extended carrier screening as applied in this sperm bank. The present policy is to screen for only 46 recessive disorders. It is difficult to speculate whether the donors' attitude would change if the screening panel were extended with dominant diseases and predispositions to diseases such as cancer. At present, sperm banks and clinics use very different panels, some containing hundreds of diseases including diseases whose detection may have a direct impact on the donors' future health and/or reproduction (Pennings, 2020). The attitude of the donors in this study differs considerably from that of Australian donors who were much more concerned about increased genetic testing and who, if tested, did not want to know the results (Amor et al., 2018). Only around 20% in the current study seemed to want some degree of control over the information flow of the results of the testing. It is likely that the donors were not aware of the possible impact that genetic testing for some diseases (such as cancer predispositions) could have for their personal life. In addition, there is the possibility that their confidence in and acceptance of genetic testing may have been biased by the fact that they all tested negative for all the variants included in the panel.

This is a cross-sectional study that does not allow a causal inference between donor type and attitude statements to be made. It is also a snapshot in time, which holds the possibility that attitudes may change with new developments in the coming years. Moreover, in this study tests for statistically significant differences between ID-release and non-ID-release donors were performed for all items on the questionnaire, thus increasing the risks of false-positive results. However, no adjustment of the *P*-value was made as such adjustment in this type of explorative research would increase the risk of making type II errors (not rejecting the null hypothesis). The main element that makes the study unique (i.e. the

choice between ID-release and non-ID-release) also renders the generalization of the findings more difficult. The groups of ID-release versus non-ID-release donors in the current sample will in a way be 'purer' than in other studies in which candidate donors had no choice regarding this position.

CONCLUSIONS

The systematic comparison of donor types showed that there are two groups of donors with very different attitudes towards several aspects of the donation. The results indicated that non-ID-release donors are unlikely to become ID-release donors. The possibility to choose either ID-release or non-ID-release allows the recruitment of more donors than if only one donor type were accepted. The general attitude of donors towards genetic testing and extended genetic screening is very positive but further studies on the attitude of candidate donors and in particular their understanding of implications of genetic screening results are needed.

ACKNOWLEDGEMENT

The authors wish to thank Anita Bech Borup for the assistance with the statistical analysis.

REFERENCES

- Abuli, A., Boada, M., Rodriguez-Santiago, B., Coroleu, B., Veiga, A., Armengol, L., Barri, P.N., Perez-Jurado, L.A., Estivill, X. **NGS-based array for the identification of individuals carrying recessive genetic mutations in reproductive medicine.** *Hum. Mutat.* 2016; 37: 516–523
- Amor, D.J., Kerr, A., Somanathan, N., McEwen, A., Tome, M., Hodgson, J., Lewis, S. **Attitudes of sperm, egg and embryo donors and recipients towards genetic information and screening of donors.** *Reprod. Health* 2018; 15: 26
- Bay, B., Larsen, P.B., Kesmodel, U.S., Ingerslev, H.J. **Danish sperm donors across three decades: motivations and attitudes.** *Fertil. Steril.* 2014; 101: 252–257
- Bos, H., van Rijn-van Gelderen, L., Gartrell, N. **Self-esteem and problem behavior in Dutch adolescents conceived through sperm donation in planned lesbian parent families.** *J. Lesbian Studies* 2020; 24: 41–55
- Carone, N., Gartrell, N.K., Rothblum, E.D., Koh, A.S., Bos, H.M.W. **The stability of psychological adjustment among donor-conceived offspring in the U.S. National Longitudinal Lesbian Family Study from childhood to adulthood: Differences by donor type.** *Fertil. Steril.* 2021; 115: 1302–1311
- Daniels, K.R., Kramer, W., Perez-y-Perez, M.V. **Semen donors who are open to contact with their offspring: issues and implications for them and their families.** *Reprod. Biomed. Online* 2012; 25: 670–677
- Emon, A. **A donor by no name is just another number? The management of anonymity in US cryobanks.** *BioSocieties* 2016; 12: 1–22
- Harper, J.C., Kennett, D., Reisel, D. **The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business.** *Hum. Reprod.* 2016; 31: 1135–1140
- Jadva, V., Freeman, T., Kramer, W., Golombok, S. **Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring.** *Hum. Reprod.* 2011; 26: 638–645
- Mahieu, F., Decler, W., Osmanagaoglu, K., Provoost, V. **Anonymous sperm donors' attitude towards donation and the release of identifying information.** *J. Assist. Reprod. Genet.* 2019; 36: 2007–2016
- Mertes, H., Lindheim, S., Pennings, G. **Ethical quandaries around expanded carrier screening in third party reproduction.** *Fertil. Steril.* 2018; 109: 190–194
- Nikou, B.S., Won, J., Choi, H., Pan, S., Lee, J.A., Antonelli, C., Bar-Chama, N., Shamonki, J.M., Copperman, A.B. **Motivations of sperm donors.** *Fertil. Steril.* 2020; 114: e268–e269
- Nuffield Council on Bioethics. 2013 **Donor conception: ethical aspects of information sharing.** Nuffield Council on Bioethics/London
- Ombelet, W., Van Robays, J. **History of human artificial insemination.** *Facts Views Vis. ObGyn.* 2010; monograph: 1–5
- Payne, MR, Skytte, A-B, Harper, JC. **The use of expanded carrier screening of gamete donors.** *Hum. Reprod.* 2021; 36: 1702–1710
- Pennings, G. **The 'double track' policy for donor anonymity.** *Hum Reprod* 1997; 12: 2839–2844
- Pennings, G. **Genetic databases and the future of donor anonymity.** *Hum. Reprod.* 2019; 34: 786–790
- Pennings, G. **Expanded carrier screening should not be mandatory for gamete donors.** *Hum. Reprod.* 2020; 35: 1256–1261
- Provoost, V, Van Rompuy, F, Pennings, G. **Non-donors' attitudes towards sperm donation and their willingness to donate.** *J. Assist. Reprod. Genet.* 2017; 35: 107–118
- Sociedad Espanol de Fertilidad. 2017 **Registro nacional de actividad 2017 - Registro SEF.** Informe estadístico de tecnicas de reproduccion asistida
- Thijssen, A, Dhont, N, Vandormael, E, Cox, A, Klerkx, E, Creemers, E, Ombelet, W. **Artificial insemination with donor sperm (AID): heterogeneity in sperm banking facilities on a single country (Belgium).** *Facts Views Vis. ObGyn.* 2014; 6: 57–67
- Thijssen, A, Provoost, V, Vandormael, E, Dhont, N, Pennings, G, Ombelet, W. **Motivations and attitudes of candidate sperm donors in Belgium.** *Fertil. Steril.* 2017; 108: 539–547
- Van den Broeck, U, Vandermeeren, M, Vanderschueren, D, Enzlin, P, Demyttenaere, K, D'Hooghe, T **A systematic review of sperm donors: demographic characteristics, attitudes, motives and experiences of the process of sperm donation.** *Hum. Reprod. Update* 2013; 19: 37–51
- Wheatley, A. **We're not related in any way, only by blood": Danish sperm donors and (imagined) relationships.** *Fam. Relatsh. Soc.* 2019; 8: 137–152

Received 17 March 2021; received in revised form 7 June 2021; accepted 21 June 2021.