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People-centred policy for data governance in gamete donation: access to information by gamete donors and recipients

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LIST OF ABBREVIATIONS

ART – Assisted Reproductive Technologies

EC – European Commission

ELSI – Ethical, legal and social issues

EU – European Union

ICSI – Intracytoplasmatic sperm injection

IVF – In Vitro fertilisation

NCB – Nuffield Council on Bioethics

PCO – Portuguese Classification of Occupations

WHO – World Health Organization

RESUMO

A governação de dados na área da doação de gâmetas tem-se debruçado sobre questões prementes como a definição das condições necessárias para a partilha de informação (básica, médica, fenotípica, sobre perfis e dados de identificação) entre dadores, beneficiários e crianças. Na última década, um número crescente de países transitou de uma cultura de sigilo e não-divulgação de informação para um regime aberto de doação de gâmetas. Também em Portugal a remoção do anonimato dos dadores foi recentemente mandatada pelo Tribunal Constitucional com um efeito retrospectivo, sem que houvesse uma consulta prévia dos atores diretamente envolvidos na doação de gâmetas, causando grande controvérsia. Conhecer as perspetivas de dadores e beneficiários de gâmetas quanto à revelação de informação é crucial para incorporar nas políticas as opiniões, preferências e valores das pessoas. No entanto, os estudos empíricos sobre este tema são escassos em Portugal. Este estudo tem como objetivo produzir evidência para informar o desenvolvimento de políticas centradas nas pessoas no âmbito da governação de dados na procriação medicamente assistida com doação heteróloga, através da análise da predisposição de dadores e beneficiários para partilhar e aceder a informação relacionada com a doação de gâmetas.

Entre Julho de 2017 e Abril de 2018, 69 dadores e 161 beneficiários preencheram um questionário no Banco Público de Gâmetas (taxa de participação: 77.4%). Recolheram-se dados sociodemográficos e características reprodutivas, bem como as opiniões quanto ao acesso dos beneficiários a informação sobre os dadores, e o acesso dos dadores a informação sobre os beneficiários, as crianças e os resultados da doação. Os dados são apresentados em contagens e proporções e as associações foram quantificadas através do teste do Qui-Quadrado ou teste exato de Fisher, quando apropriado.

A maioria dos participantes considerou que os beneficiários não devem ter acesso a informação detalhada de perfil e a informação identificável dos dadores, mas concordaram com o acesso à informação médica. Os dadores mostraram-se mais favoráveis do que os beneficiários quanto à partilha de informações médicas ou de informação detalhada do perfil de dadores. Dadores e beneficiários partilharam opiniões semelhantes em relação à possibilidade dos dadores terem acesso a informação médica e a informação detalhada de perfil sobre os beneficiários, assim como a informação identificável das crianças nascidas através de doação de gâmetas, com mais de 80% dos participantes a manifestarem discordância. Contudo, encontraram-se diferenças estatisticamente significativas entre os dois grupos quanto a um possível acesso por parte de dadores a informação básica sobre os

resultados da doação, com os dadores a referir mais frequentemente que deveriam ser informados sobre se a doação resultou numa gravidez ou no nascimento de crianças.

Esta dissertação gera evidência capaz de sustentar recomendações para o desenvolvimento de políticas centradas nas pessoas no âmbito da governação de dados na doação de gâmetas, apresentando três propostas que contemplam questões éticas, legais e sociais e promovem o respeito pelas necessidades e interesses dos atores envolvidos na procriação medicamente assistida com doação heteróloga. Em primeiro lugar, propõe que o acesso a informação básica seja reconhecido como um veículo capaz de permitir a reciprocidade entre beneficiários e dadores de gâmetas. Em segundo lugar, apela à criação de um mecanismo de correspondência (via consentimento) para acomodar, em simultâneo, os interesses e preferências de ambos os grupos envolvidos. Por último, salienta a necessidade de melhorar o acesso de dadores e beneficiários a profissionais especificamente treinados no aconselhamento sobre questões ligadas à procriação medicamente assistida com recurso a doação de gâmetas, incluindo a remoção do anonimato e o acesso a outros tipos de informação. A inclusão destes tópicos na tomada de decisão é fundamental para uma boa governação da informação relacionada com a doação de gâmetas e poderá possibilitar mudanças políticas transformadoras, num momento marcado pela falta de consenso em torno da transição para um regime de não anonimato e em que se observa uma maior consideração pelas preferências dos atores envolvidos na doação de gâmetas.

ABSTRACT

In the field of gamete donation, data governance is concerned with the conditions set for sharing basic, medical, phenotypic, extended profile and identifying information among gamete recipients, gamete donors and donor-conceived children. In the last decade, transition from a culture of secrecy and non-disclosure of information related to gamete donation to an open-identity donation regime has been observed in a growing number of countries. The removal of anonymity in the donation of gametes has also been mandated by the Constitutional Court in Portugal. This happened without previous consultation with the stakeholders directly involved in gamete donation and undertook a retrospective effect, causing large controversy. Learning about how gamete donors and recipients feel about information disclosure is crucial to imbue policy with people's views, preferences and values. However, in Portugal, there is a shortage of empirical studies on this subject. This study aims to produce evidence to inform the development of people-centred policy for data governance in gamete donation for reproductive purposes by assessing gamete donors and recipients' willingness to access and share information related to gamete donation.

Between July 2017 and April 2018, 69 donors and 161 recipients (participation rate: 77.4%) completed a self-report structured questionnaire at the Portuguese Public Bank of Gametes. Data on sociodemographic and reproductive characteristics were collected, as well as opinions about recipients' access to information about donors and donors' access to information about recipients, children and donation outcomes. Data are presented as counts and proportions and the associations were quantified through the Chi-squared test or Fisher's exact test when appropriate.

Most participants considered that recipients should not have access to extended profile information and identifying information about donors, in contrast with the tendency to agree with their access to medical information. Donors were more likely to be favorable to recipients' access to medical and extended profile information about themselves than gamete recipients. Donors and recipients shared similar opinions regarding donors' access to medical and extended profile information about recipients and identifying information about children born through gamete donation, with more than 80% showing disagreement with its disclosure. However, statistically significant differences were found between both groups regarding donors' access to basic information about the outcomes of gamete donation, with donors stating more frequently that they should be informed about whether their donations have resulted in any pregnancies or the birth of any children.

This dissertation presents evidence on which to ground recommendations for people-centred policy for data governance in gamete donation. It makes three proposals that acknowledge the ethical, legal and social issues framing the discussion on this topic and promote respect for the needs and interests of the stakeholders involved in donor-assisted reproduction. First, it proposes that basic information be recognised as a vehicle for enabling reciprocity between gamete recipients and donors. Second, it establishes that a matching mechanism (via consent) is necessary to accommodate the interests and preferences of both stakeholder groups. Third, it points to the need to further stakeholders' access to counsellors specifically trained to advise on issues linked to information associated with donor-assisted reproduction, including the removal of anonymity and access to other types of information. Bringing these issues into the decision-making table will likely contribute to enabling transformative policy change at a time in which there is little consensus regarding the transition into an open-identity regime and greater consideration for stakeholders preferences is needed for the good governance of information related to gamete donation.

INTRODUCTION

1. Data governance in gamete donation

The ever-faster ability to digitally collect and process electronic medical records data, genetic and genomic data, and wellness, fitness and lifestyle data from applications and wearable devices has magnified the potential uses and expected advancements that were once reserved to the exploitation of more conventional forms of health data such as laboratory test results, diagnostic images, individual medical records and public health registry data [1]. This exponential expansion of health data availability, uses and outcomes has brought considerable attention to the potential benefits and risks associated with data production, collection, storage, use and sharing, as well as the need to rethink its governance [2,3].

Health-related research can further basic science, enhance the discovery of new treatments and drugs, advance the development of personalized medicine, improve the quality of health care service delivery and promote the design of better public health interventions [2]. However, without due safeguards, it can also lead to undue identification, results commercialisation and unforeseen surveillance [4,5]. Such misuses of health information can undermine the right to privacy, autonomy and security not just of the individuals who donate the data but also of “secondary data subjects”, i.e. people who are not data’s primary sources but who can be associated with or identified by data provided by another party (e.g. family members) [6]. As Barbara Prainsack argues, health information is *social*. Not only “can [it] be used to make probabilistic inferences about (one’s) biological relatives (...)” (p.32) but its interpretation requires connection and collaboration with others. This understanding of health information has several implications for data governance. First, the needs, values and preferences of both primary and secondary data subjects must be accounted for. Second, safeguards are needed to ensure a more balanced power relationship between those who donate data and those who are most likely to use it (e.g. researchers, research consortia, corporations), including instruments to enable accountability and mitigate harm caused by, for example, inadvertent data leakages [6,7]. Third, innovative governance frameworks and mechanisms are required to enable the involvement of all stakeholders in decision-making concerned with the uses of data that do reflect the public interest and maximize scientific progress [2,3,7].

In the field of gamete donation, data governance is concerned among other things with the conditions of access to information by the various stakeholders involved in the conception of children using donated gametes, namely gamete recipients, gamete donors and donor-conceived children. Information related to gamete donation entails: a) basic information, which includes the outcomes of donation namely the number of pregnancies and births and the sex

of the offspring; b) medical information, which includes clinical and genetic data; c) phenotypic information, which includes general body characteristics such as eye and hair colour, length, weight; d) extended profile information, which includes information about personal characteristics such as personality, interests, hobbies, educational level; and, e) identifying information, which includes the name [8,9]. The conditions set for information sharing among gamete donors, recipients and donor-conceived children vary between countries and they are largely determined by the socio-cultural and political frameworks that influence people's understandings of and experiences with Assisted Reproductive Technologies (ART).

Considering that gametes carry the very specific potential to generate a new life, they are a unique form of biological material whose donation and use raises many ethical, legal and social issues (ELSI). We argue that the ELSI linked to donor-assisted reproduction are context-bound and value-laden [5,10,11] and that policy concerned with information sharing among gamete donors and recipients must take this into account.

1.1 Ethical, legal and social issues

1.1.1. Ethical and social issues

Reproductive donation comprises a variety of materials that include gametes (spermatozoa and oocytes), embryos, blastomeres, uteri (in cases of surrogacy pregnancy) and embryonic stem cells [12]. Gametes are peculiar cells in that they enable the creation of new human beings. They may also give rise to more intimate social relationships between donors and recipients than other types of donation (e.g. blood) [13], which influence people's predisposition to donate them. Indeed, gametes have been found to be amongst the human biological materials people are least willing to donate for research [14]. While other human tissues, cells or organs can only be used for research purposes, or to perpetuate or enhance the quality of life of a person, gametes can also be used for reproductive purposes, and it is the fear that they may be used for the latter end without one's consent that drives many people to refrain from donating [14].

Critical approaches to gamete donation for reproductive purposes may be partly explained by the premise of the genetic filiation of the family, which is central in many Western societies. This premise has been reinforced by "genetic essentialism" that affirms the primacy of bio-genetic bonds as the source of socio-legal relationships between parents and their offspring [15], and of individual's identity. Genealogy and genetic inheritance are also pillars of most religions, which historically have not supported the donation of biological materials, including gametes [16,17]. These socio-cultural frameworks are based on assumptions about

motherhood and fatherhood that view the former as an expected outcome of women's biology and the latter as a demonstration of strength, virility, responsibility and ability to ensure genetic continuity on the part of men [18,19]. Inability to achieve genetic parenthood within these contexts is often considered a failure [20].

Where gamete donation presents itself as a solution to overcome infertility and enable couples or single women to conceive children, donor-assisted reproduction has been mainly characterized by a culture of secrecy and non-disclosure [21]. Even if the socio-cultural frameworks described above do not extend to whole populations, they are nevertheless ingrained in contemporary societies. A diagnosis of infertility can have negative psychosocial impact on both males and females: men may begin to question their masculinity and women may struggle with the inability of fulfilling the desire to be mothers naturally [22,23]. It can also lead to fear of stigmatisation, causing people to hide their infertility from their social networks [21]. Stigmatisation can be imposed by others by means of a judgment, label or stereotype, or self-enacted when the infertile person loses self-esteem and confidence and develops a negative perception about itself [23]. To a large extent, the stigma attached to infertility appears to be grounded on the continued emphasis given to biological parenthood, whose unfulfillment is often understood as deviance and failure [23]. This not only causes emotional pain and doubt about the ability to fulfil one's role in society [23], it also has social implications, namely the reinforcement of secrecy around infertility management through assisted reproduction and the isolation of those engaged at the receiving end of this process [18,24,25].

Data governance in gamete donation has also raised several social and ethical issues more specifically connected to sperm and oocyte donors. Debates on egg donation ethics and social impacts have evolved from essentialist arguments questioning the morality of donation based on religion to consequentialist arguments that focus on the practical issues linked to egg donation such as the acceptability of financial compensation for the donation act, the possibility of postmenopausal pregnancies its risks and the validity of the arguments that women may have to justify this practice and concerns regarding commodification and exploitation in egg-sharing models which propose that women in need of ovarian hyperstimulation can themselves donate a proportion of harvested eggs collected during the procedure in exchange for a discount on treatment's fees [26]. Discussions on ethical and social issues concerning sperm donors, on the other hand, have focused on the establishment of age requirements for sperm donors, both by setting a starting age upon which donation becomes ethically acceptable and a limit age of donation to safeguard sperm quality and on imposing limits to the number of conceptions using a single donor's sperm to prevent the possibility of consanguinity, namely by conducting an analysis of the density and mobility of the local population [27]. This last measure may not suffice to control the number of single donor conceptions due to cross border

care, a practice based on the autonomy and freedom of movement, where patients travel to another country to receive treatment due to legal restrictions in their home countries, to avoid waiting-lists, to avoid high costs of treatment or to be treated in a regime more suitable to their preference (e.g. anonymous donation regimes) [28,29].

Just like patients, gametes also circulate, usually from countries with a gamete surplus to gamete-deprived countries. In the absence of a global epidemiological surveillance mechanism, it is unclear how many cross-border donations sperm and egg donors are able to do while still engaged in donating for local programmes. The implementation of a harmonized Single European Code for tissues and cells such as the one enacted by European Commission's Directive 2006/86/EC [30] could be interpreted as a step further to regulate gamete circulation, namely by ensuring the "traceability of human tissues and cells from the donor to the recipient and vice-versa". However, reproductive cells are exempt from the scope of this Directive. This is a missed opportunity to enable the creation of a mechanism that can offer safeguards in regard to both the number of gametes circulating across borders and their quality.

There are other issues expressed by sperm donors that influence willingness to donate and that can become barriers to sperm donors recruitment, namely fears that their partner would not agree with the donation, feelings of responsibility towards the potential offspring and possible discomfort while donating [31]. While some of the issues described above are social, others are clearly grounded on individual values that shape one's understanding of the ethics of gamete donation [32].

1.1.2. Legal issues

In the absence of a common legislation for ART in the European Union (EU), each Member State has enacted its own policies concerning the treatment of involuntary childless [33]. This has led to major differences in the way EU countries have legislated on gamete donation. While some countries provide a fixed amount of money to compensate donors, as it is the case of Portugal, others provide compensation only for proved expenses that donors might have had [34]. Restrictions on who can donate gametes can also be found. Germany and Norway do not allow egg donation, contrasting with the rest of EU countries [29]. In Austria, Finland, the Netherlands, Sweden and the UK, gamete donation is done under an open-identity regime, which means that donors' identification are recorded and shared with their potential offspring at a later time [33,34]. In the remaining EU countries, a regime of anonymous donation prevails. Some of those countries, however, are transitioning into an open-identity regime, as is the case of Portugal, though not always without dispute [35].

The debate around anonymity has attempted to find consensus between the rights of three key stakeholders that are difficult to combine: the rights of gamete recipients and parents-to-be to autonomy and privacy; the rights of gamete donors to autonomy and confidentiality; and the rights of donor-conceived children to know their genetic origin [17]. Calls for open-identity donation are mostly based on donor-conceived children's "right to know" their genetic identity and to access information about their conception [36,37]. The rights and interest of gamete recipients and donors in information exchange related with donor-assisted reproduction (e.g. donors extended profiles, donation outcomes) have received much less attention from both policy-makers and academics [8], causing legislation on open-identity donation to be devoid of these parties' preferences.

In Portugal, the use of ART was first regulated in July 2006 (Law 32/2006) [38]. Under this law, the donation of gametes is allowed only when the following four requirements are fulfilled: 1) the donation benefits a heterosexual couple joined by marriage or living together for at least two years as if they were husband and wife; 2) the couple is unable to reach pregnancy through the use of their own gametes under the current medical and scientific knowledge; 3) the quality of the gametes used needs is assured; and 4) the anonymity and confidentiality of the donors is protected and they cannot ever be considered the parents of the potential offspring, under any circumstance. In June 2016, in the aftermath of austerity measures that weighed on the health care system [39], the law was revised [40] extending access to ART to all women irrespective of the existence of a diagnosis of infertility, their marital status and sexual orientation, and turning ART into a complementary method of procreation. In May 2018, donor anonymity was removed [35]. Transition into an open-identity regime was justified on the grounds of establishing a sociocultural and ethical framework for access to ART based on equity, autonomy and individuality, which also brings the well-being of donor-conceived children to the fore by safeguarding their right to know their genetic ancestry and their right to access information about the donation, in accordance with the principles established by the Portuguese Constitution [10,21,35,41]. This reflects a hierarchical shift in the portfolio of risks [42] associated with the ethical, social and legal implications of gamete donation, in which the emphasis previously given to the medical and technical specificities of gamete donation procedures has made way for socio-ethical concerns such as respect for autonomy (of gamete donors and recipients) and non-maleficence (by enabling donor-conceived children's access to potentially relevant genetic information) [10,11].

The shift towards an open-identity regime has raised concerns about a possible decrease in gametes supply as a result of changes in donors' willingness to donate in the absence of previously guaranteed anonymity [21,43]. Although there is still limited evidence on this issue, the impact of transition from anonymous to open-identity donation on gametes availability

appears to be context-bound and dependent on people's values. Data from the UK, where such change was introduced in 2005, shows that after an initial decrease in the number of donors in the first few years after the change, the number of donations has stabilised [44,45]. In Australia, where a similar regulatory change happened in 2005, the number of donors remained consistent [46,47]. Moreover, the removal of anonymity led to a shift in sperm donors demographics from young men (quite often students) to older men [48].

In Portugal, the 2018 legislative change led to the removal of anonymity with a retroactive effect, i.e. all donations done before the law was introduced with potential to result in a pregnancy or the birth of a child were subject to the open-identity regime, unless donors refused to have their identities revealed. Disagreement with this aspect of the law caused the interruption of ongoing treatments and the retractions of many donations. The majority of refusals to have one's anonymity removed came from male donors. Comparatively, female donors were less opposed to having their identities disclosed [49–52]. The sudden removal of anonymity has caused such large controversy, particularly regarding its retroactive effect, that some political parties and patient associations called for the implementation of a transitional period in which donors who had finished the donation process before the legislative change could still have their anonymous status protected [53]. In the wake of the transition toward an open-identity regime, some couples transferred frozen embryos to Spain, where anonymity is protected by law, in order to complete their treatment there [54]. The impact of this political change has been deeply felt by all stakeholders involved, launching a debate not only about anonymity in gamete donation but also about the conduct of the Portuguese Constitutional Court, which is responsible for bringing legislation into effect, with reports and testimonies claiming that the decision was “totalitarian” and that it “did not take donors into account” [55,56].

The present situation attests to the importance of understanding stakeholders' perspectives in order to develop policy and enact change that are able to account for people's values, needs and interests. Promoting transformative change in policy [57] thus requires the creation of opportunities for stakeholder participation in decision-making and the use of the best evidence available when developing regulations and guidelines [10,58]. Public participation in health policy creates an interface for state-citizen dialogue and decision-making that can be used to improve the quality of care and interventions [59], ultimately contributing to people-centeredness by incorporating stakeholders' values and preferences into policy and care. The promotion of people-centred care is a major goal of the WHO global strategy for integrated care that aims to put people and communities at the centre of the health system through the creation of enabling and empowering environments able to encourage participation and improve health governance [60]. To apply these insights into the field of data governance in gamete donation, it is crucial to understand how the discussion around rights of ownership of

donated material is framed and how stakeholders involved in gamete donation view the sharing of and access to information associated with donor-assisted reproduction.

1.2. Policy on information sharing in gamete donation

Ownership in donor-assisted reproduction may be understood as an individual entitlement to deciding the destination and use of one's biological material [61]. The ways in which the various stakeholders engaged in this process conceive of gametes ownership determine their perceptions about, on the one hand, the moment in which ownership should be relinquished by donors and claimed by recipients (e.g. immediately after donation; after the birth of donor-conceived child; after the donor-conceived child reaches adulthood) and, on the other hand, the type of compensation that should be offered in exchange for the gift of gametes, if any.

Compensation for gamete donation is a highly debated issue. However, many agree that some form of compensation is necessary to acknowledge both the gift and the time, effort and energy dispensed by donors in connection to the donation [62]. Donors can be compensated financially, in kind (e.g. expenses reimbursement) or with information associated with the process of donor-assisted reproduction (e.g. outcomes of donation, clinical and genetic information). Information can offer an additional form of compensation for donation or an alternative where other types of compensation are undesirable, unlawful or unfeasible [8,63]. Understanding whether this is a viable alternative for the stakeholders involved in donor-assisted reproduction requires an analysis of how they position themselves in regard to information sharing. Such positionings are mediated by policy on information ownership, which sets forth the terms in which it can be legally claimed and accessed. But they also call upon subjective perceptions of ownership of data that depend on individuals' socio-cultural and ethical referents and which may be more or less in conformity with policy.

1.2.1. Ownership: theories, meanings and practices

Ownership is a key issue on current discussions about gamete donation over which there are no consensual guidelines. The notion of ownership builds on concepts of property that serve as the basis for the establishment of appropriate "bundles of rights" [64]. Two major theories emerge when discussing "property rights": 1) the *natural rights theory*, which defends that ownership arises from a mix of our "labour" with an "object" that grants it value. This theory interprets property as something that is independent of social conventions and that is centred on a relationship between the person and the object; and, 2) the *social constructivist theory*, which defends that ownership is the result of the choices and the events that best promote

values such as justice and economic productivity. According to this theory, it is the responsibility of the government to issue laws capable of enabling such a system [64].

The application of “property rights” to gamete donation has called attention to the potential commodification of gametes [65,66]. The concept of ownership is closely tied to the occurrence of economic transactions [64], which, in turn, are deeply intertwined with the commodification of goods. Although business ethics instills that markets should revolve around systems of trust and social responsibility, the commodity market is a morally and ethically challenging space that implicates constantly shifting values, depending on opportunities to turn profits [66]. The donation of human tissues and cells is highly permeable to social inequalities, where those at the bottom of the social ladder can feel forced to donate body parts in exchange for needed financial retribution that can set them at even greater disadvantage on the long-run (e.g. due to health complications). For this reason, avoiding commercialisation and commodification of the human body and promoting altruistic donations have been advocated by some to be paramount to prevent exploitation [64].

Prainsack [6] argues that human relations are simultaneously self-interested and other-oriented and that donations of biological material must not be understood a matter of pure altruism but as a gift. Gifts are offered voluntarily and its value cannot be quantified financially [67]. However, as Prainsack goes on to assert, even if the person offering the gift may not expect direct financial compensation, there is a “web of indebtedness and future reciprocity” (p.37) [68] that is established once the gift is presented [6]. As donors and recipients of biological materials often do not know each other nor do they necessarily share the same community or values, reciprocity needs to be defined in terms of treating the gift giver “according to the same standards that she herself accords the recipients” (p.37) [6]. In the context of gamete donation, this would mean that gamete donors are informed of what the goals and purposes of the recipients of their gift are, namely if the gametes are donated for research or for reproduction purposes and what results were achieved (e.g. new treatment; birth of a child). In such circumstances, the threshold of altruism may need to be adapted through the implementation of a mixed-model that lays out several possible strategies for reciprocity or compensation [62].

The Nuffield Council of Bioethics (NCB) in Britain developed an ethical framework [63] to inform policy decision-making on the donation of biological materials for medical and research purposes. The NCB framework for donation is sensitive to many of the aforementioned issues including the protection of donors’ welfare, the avoidance of exploitation and harm and the establishment of a system that values trust and respect. It also emphasizes the role of the state in promoting and implementing measures that facilitate donation with the aim of improving general health. Furthermore, it raises the argument that payment may not be a direct

contradiction to the primary focus on altruism that donors may have, as interventions need to be contextually adapted. It nonetheless adverts that a deep commitment to maintaining altruism is crucial and that some “incentives” can be perceived as “ethically dubious” as they can alter individuals’ perceptions about the potential risks of donation.

A major contribution of the NCB framework for donation is an intervention ladder (Figure 1) that sets out several strategies for encouraging donation of biological materials that may find more or less acceptance on the part of the stakeholders involved in the process and that should be considered when implementing donation policies [63,69].

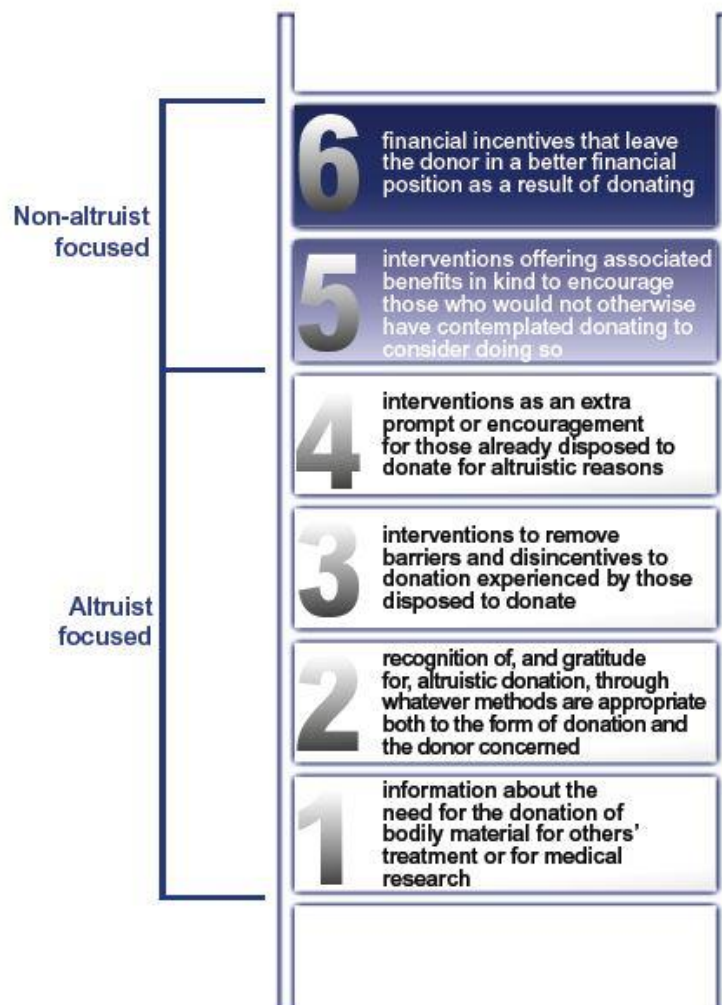


Figure 1. Intervention Ladder for promoting donation of biological materials, Nuffield Council on Bioethics [63]

The first four rungs are described as “altruist focused” and establish: 1) the need to inform people of the impact that their donation may have; 2) the expression of appreciation for what has been donated; 3) the effort that should be made to remove potential barriers obstructing

willing donors from donation (e.g. providing compensation for expenses they may have); and, 4) the encouragement of people primarily motivated by altruism to donate by providing incentives, such as tokens or money. The last two rungs are non-altruist focused and encompass the offering of incentives to benefit a donor who would not have an altruistic motive to donate or who would donate only to obtain monetary or financial gain [63,69]. As it can be observed, the higher one goes on the rungs of the ladder the more the proposals impose on individuals' rights. According to the Nuffield Council of Bioethics, the option to turn into policy either of the strategies suggested in the latter two rungs should not be done without the presence of strong ethical arguments and the involvement of the different stakeholders in final decision-making [63].

As attested by discussions arising in connection to Court cases held in the UK in which individuals sought reprisal for property damages after the institutions responsible for storing their gametes inadvertently destroyed them, financial compensation associated with donated gametes continues to raise concerns with the commodification of biological materials [70,71]. Sharing information with donors can be an alternative expression of appreciation for the gametes donated, that has not deserved sufficient attention in the literature. In the next section, we review the evidence available on the perspectives of donors and recipients access to information associated with donor-assisted reproduction. Understanding these stakeholders' perspectives concerning information exchange is key to making proposals for policy that are centred on people's values and interests.

1.2.2. Access to information: public views and attitudes

Studies on public views and attitudes about access to information associated with gamete donation focus mostly on the views of the stakeholders directly involved in this process, i.e. donors, recipients and, to a much less extent, donor-conceived children. There are a few exceptions in which the views of other members of the public (e.g. non-donors) were also explored [31,72,73]. Furthermore, most studies address the views and attitudes of donors [44,74] while only a few compare between donors and recipients' views about sharing information related to donor-assisted reproduction [75–78].

Considering stakeholders' views about the different types of information, the literature available is consensual in regard to donors' preference for having access to basic information that is whether donations result in a pregnancy or in the birth of a child [44,75,76,79,80]. A study comparing between donors and recipients' views about access to basic information in Sweden showed that while oocyte and sperm donors agreed that they should be informed if the donation led to a successful birth (89% and 73%, respectively), only 39% of sperm recipients

would agree to sharing this information with donors [75]. Another study carried out in the USA found that recipients were open to disclose basic information with donors, introducing conflicting evidence on this topic. A study focusing only sperm donors in Belgium concluded that about half of the participants would like to receive information about the number of children born from their donated gametes [80]. Similar results were found in an USA study focusing on sperm and oocyte donors that concluded that most donors considered important to be able to access basic information [79].

Where medical information is concerned, an Australian study shows that donors are open to disclosing their genetic records with recipients [81]. Another study from the USA also concluded that the large majority of donors are willing to share their medical information [82] with recipients. Regarding recipients' opinions about access to donor medical information, a study from the UK shows that most sperm recipients agree with receiving non-identifying medical information from donors [78].

Concerning stakeholders' views on sharing extended profile information, a study from Western Australia shows that donors are open to disclosing this data, although their willingness to share this information decreases when their anonymity is not safeguarded. However, a study conducted in Sweden shows that both donors and recipients would not want to have access to or disclose information about their education and interests [75]. A survey of sperm donors' attitudes in the UK also shows that most donors would agree with giving recipients access to information on their physical characteristics, attitudes and interests, although most of them also stated that they did not want contact with the recipients and would not want the offspring to have access to this data [83].

Studies addressing donors' views regarding access to extended profile information about donor-conceived children were scarce. A study from the USA shows that close to 30% of donors would like to have access to offspring's non-identifying information, although it is not stated if this information relates to medical records or extended profile information [79]. A study conducted in Belgium showed that around one quarter of donors would like to have access to information about the children conceived through the use of their sperm, although, once again, it is not stated if this is medical information or extended profile information [80]. The lack of differentiation between non-identifying medical information and non-identifying extended profile information appears to be common place in the empirical studies assessing stakeholders' views about sharing of non-identifying data.

The disclosure of identifying information appears to raise the least consensual opinions among stakeholders. In part, this is explained by the different policy regimes regulating data protection in gamete donation (i.e. anonymous vs. open-identity donation regimes). A systematic review

on sperm donors' attitudes points that public views and attitudes about anonymity have changed over time with donors showing greater willingness to donate without the guarantee of anonymity in more recent times [74]. Another review shows that oocyte donors are more open to the disclosure of identifying information [44] than sperm donors, though there is another study conducted in the USA in which no differences were found between female and male donors [77] regarding donor anonymity. Concerning recipients' opinions about receiving identifying information about donors, a study from the UK showed that most sperm recipients would like to have access to this data [78], but few information was found on this topic. Similarly, few information was found regarding donors' views about access to identifying information about children. A study from the USA shows that around half of donors would like to have access to identifying information about the offspring [79]. A study from Belgium conducted with non-donors found that most of the participants would not want to have access to identifying information such as the name of the child born from gamete donation [31]. Regarding recipients opinions about access to donors' identifying information, an Australian study shows that recipients consider access to the donor's name one of the most important pieces of information they should receive [84]. The same Australian study also included a group of donor-conceived children. The findings from this group show that donor-conceived children believe that having access to the donor's name is the most important information they could receive [84].

The views expressed by the gamete donation stakeholders in the evidence collected from the literature have to be contextually adapted to the regime of donation in practice in the country where the study was conducted. Stakeholders' views are likely to be influenced by the culture of the system, which means that the evidence collected may only reflect the views of the respondents in that particular setting [46]. This means that different studies in different countries are likely to have different results, depending on the regime of donation in place.

To our knowledge, no studies have been done on the views of donors and recipients about access to and sharing of information associated with donor-assisted reproduction in Portugal.

2. OBJECTIVES

Donor-assisted reproduction has been characterised by a culture of secrecy and non-disclosure [18,21,24], which is at the basis of the anonymity regime regulating the donation of gametes in many Western countries. In the last decade, the rights of donor-conceived children to knowing their genetic identity have taken centre stage in the socio-ethical debates associated with donor-assisted reproduction [8,21,36,37]. This has influenced the transition to an open-identity donation regime in a growing number of countries. Portugal is one of the countries undergoing this regulatory transition. The legislative changes leading to the removal of donor anonymity were mandated by the Portuguese Constitutional Court without previous consultation with the stakeholders directly involved in that process and undertook a retroactive effect. Although these changes still have to be regulated by the Portuguese Parliament, this generated considerable controversy and led to a reduction of donations, the interruption of treatments and to an increase in recipients seeking cross-border treatments in countries where anonymity is protected by the law [35,51,53,54].

Future policy regulation may benefit from a process of transformative policy change [57] in which stakeholders views, preferences and values are taken into account. Setting such a process in motion would require the creation of spaces for dialogue [85] between decision-makers and representatives of gamete donors, recipients and health professionals in which the implications and content of a new law on open-identity donation regime could be addressed. It would also require the availability of evidence about stakeholders' views on the exchange of information associated with gamete donation, including the identification of donors. Learning about how stakeholders feel regarding information disclosure is crucial to imbue policy with people's values and preferences. However, in Portugal, there is a shortage of empirical studies on this subject. This study aims to produce evidence to inform the development of people-centred policy for data governance in gamete donation for reproductive purposes. To achieve this purpose two specific objectives will be undertaken:

1. To assess gamete donors and recipients' willingness to access and share information related to gamete donation;
2. To analyse the factors associated with gamete donors and recipients' willingness to access and share information related with gamete donation, when there are differences between these two stakeholder groups.

3. METHODS

3.1. Design, participants and data collection

This is an observational cross-sectional study based on a hospital-based questionnaire at a public ART center performing IVF/ICSI heterologous and homologous cycles.

Gamete donors and recipients with medical appointments at the Portuguese Public Bank of Gametes were invited to participate in the study between July 2017 and April 2018. Those who attended at least one medical appointment were considered eligible. At the end of the medical appointment, donors and recipients received an informative leaflet (Appendix 1) from a health professional. After, one member of the research team (four, in total) invited them to participate in the study and responded to all of their questions and doubts.

Of the 297 people invited, 69 donors and 161 recipients agreed to participate in the questionnaire (participation rate: 77.4%). Those who refused to participate invoked lack of time (14 donors and 20 recipients), unwillingness to participate (9 donors and 10 recipients) and psychological unavailability (3 recipients). One donor and ten recipients did not specify the reason for refusing participation. Those who decided to participate were accompanied to a private setting at the health care service, where they read and signed the informed consent (Appendix 2).

The participants completed a self-report structured questionnaire, which comprised four main sections of questions covering the following areas:

- Opinions about access to and governance of gamete donation: sources of information, awareness of communication campaigns, perception of donors' compensation and anonymity, criteria for selecting donors and recipients, assessment of allocation of the existing healthcare services, opinions about recipients' access to information about donors and donors' access to information about recipients, children and donation outcomes, and views about recruitment strategies;
- The individual's willingness to donate gametes for family, friends and research purposes and the reasons for their answer, as well as their willingness to receive gametes from family, friends or strangers;
- The individual's willingness to donate embryos for reproductive and research purposes, and opinion on who should be involved in consenting the donation of embryos created by gamete donation for research;
- Sociodemographic and reproductive characteristics: sex, age, country of origin, place of residence, marital status, educational level, working status, occupation, perceived

income adequacy, subjective social class, parental status, diagnosis of infertility, and previous treatments/donations.

This study focuses on the results obtained for the topic relating to opinions about recipients' access to information about donors and donors' access to information about recipients, children and donation outcomes, according to experience with gamete donation (donors vs recipients) and sociodemographic and reproductive characteristics (sex, age, educational level, marital status, working status, occupation, subjective social class, perceived income adequacy, parental status, and previous treatment/donation). The types of information were categorized based on the systematization of literature presented in the introductory section of this dissertation: a) basic information, which includes the outcomes of donation (i.e. diagnosis of pregnancy and births); b) medical information, which includes clinical and genetic data such as blood type; c) extended profile information, which includes information about personal characteristics such as educational level; and, d) identifying information, which includes the name.

Concerning opinions on recipients' access to information about donors, participants were asked to report their position (categorized as no, yes, or maybe) regarding recipients' access to the following information: "medical information about donors (e.g. blood type)", "non-medical information about donors, excluding identification (e.g. educational level), and "personal data about donors, including identification".

A similar approach was used to assess participants' opinions on donors' access to information about recipients, children and donation outcomes. Participants were asked to report their position (categorized as no, yes, or maybe) regarding donors' access to the following data: "whether any pregnancy have resulted from their donation", "whether any children have resulted from their donation", "medical information about recipients (e.g. blood type)", "non-medical information about recipients, excluding identification (e.g. educational level)", "personal data about recipients, including identification", "medical information about children born through their donation", and "personal data about children born through their donation, including identification". Participants' occupations were classified by major professional groups, according to the Portuguese Classification of Occupations (PCO) 2010 [86] and then grouped in three categories: (1) upper white collar, including individuals classified in the upper three major groups of the PCO 2010 - executive civil servants, industrial directors and executives, professionals and scientists, middle management and technicians; (2) lower white collar, comprising individuals classified in the fourth and fifth major group of the PCO 2010 - administrative and related workers, and service and sales workers; and (3) blue collar, including individuals classified in the sixth to ninth major groups of the PCO 2010 - farmers

and skilled agricultural, fisheries workers, skilled workers, craftsmen and similar, machine operators and assembly workers, and unskilled workers. Students (n=28) and armed forces occupations (n=2) were excluded from this classification. Unemployed (n=15) or retired participants (n=1) were classified considering their previous main occupation, when mentioned.

Perceived income adequacy was assessed through the question: "Thinking of your household income, would you say that your household is able to make ends meet?" and the four answer categories consisted in: insufficient, caution with expenses, enough to make ends meet and comfortable. For this study, the answers were recoded into a dichotomous variable: 1) insufficient, including respondents who reported subjective economic hardship, that is, difficulty in making ends meet (insufficient or caution with expenses); 2) sufficient, including respondents who reported considering their household income enough to make ends meet or comfortable.

Participants were considered to have previous treatments or donations if they had at least one previous ART treatment, regardless of using donated or their own gametes (in the case of recipients), or if they had donated gametes at least once before the current donation (in the case of donors).

3.2. Data analysis

Opinions on recipients' access to information about donors and on donors' access to information about recipients, children and donation outcomes according to experience with gamete donation are presented as counts and proportions and the associations were quantified through the Chi-squared test or Fisher's exact test when appropriate. Not all participants answered every question. Therefore, the total in each variable may not add 69 donors and 161 recipients due to missing values. Statistical significance was set at a value of $P < 0.05$.

When statistically significant differences were found between the opinions of donors and recipients, the independent association between the sociodemographic characteristics of participants and the outcome was assessed through the Chi-squared test or Fisher's exact test when appropriate, stratified by the experience with gamete donation, and data is presented as counts and proportions. Differences of proportions higher than 10% were considered relevant to show tendencies when there were at least 10 participants in each category [87].

Statistical analysis was performed with the IBM Statistical Package for the Social Sciences (SPSS) Statistics for Windows, version 23.0, Armonk, NY, USA.

3.3. Ethical approval

Ethical approval was granted by the Portuguese Data Protection Authority and the Ethics Committee for Health from the Centro Hospitalar do Porto on 11 January 2017. All participants formalized their collaboration through a written informed consent according to the World Medical Association Declaration of Helsinki and the Oviedo Convention.

4. RESULTS

4.1. Characteristics of the study participants

The characteristics of the study participants according to experience with gamete donation are summarized in Table 1. Most participants were female (63.0%) and employed (80.6%), had no children (87.8%) and no previous experience with gamete donation (72.6%), and perceived their social class as low/middle-low (70.7%) and their income as sufficient (69.7%). Almost half had an upper white-collar occupation (46.7%). Donors were younger (≤ 30 years) than recipients (79.7% vs. 11.3%) and more educated (> 12 years of education) (58.0% vs. 38.9%). Most donors were single or divorced (81.2%), while over 90% of the recipients were married or lived with a partner.

Table 1. Characterization of study participants, according to experience with gamete donation

	TOTAL (N=230)	Donors (n=69)	Recipients (n=161)
	n (%)	n (%)	n (%)
Sex			
Female	145 (63.0)	46 (66.7)	99 (61.5)
Male	85 (37.0)	23 (33.3)	62 (38.5)
Age (years)			
≤ 30	73 (32.0)	55 (79.7)	18 (11.3)
31-35	64 (28.1)	10 (14.5)	54 (34.0)
> 35	91 (39.9)	4 (5.8)	87 (54.7)
Educational level (years)			
≤ 12	125 (55.3)	29 (42.0)	96 (61.1)
> 12	101 (44.7)	40 (58.0)	61 (38.9)
Marital status			
Married/Living with partner	160 (69.6)	13 (18.8)	147 (91.3)
Single/Divorced	70 (30.4)	56 (81.2)	14 (8.7)
Working status			
Employed	183 (80.6)	38 (55.9)	145 (91.2)
Other ^a	44 (19.4)	30 (44.1)	14 (8.8)
Occupation^b			
Upper white collar	86 (46.7)	19 (45.2)	67 (47.2)
Lower white collar	64 (34.8)	18 (42.9)	46 (32.4)
Blue collar	34 (18.5)	5 (11.9)	29 (20.4)
Subjective social class			
Low/Middle-low	133 (70.7)	43 (71.7)	90 (70.3)
Middle-high/High	55 (29.3)	17 (28.3)	38 (29.7)
Perceived income adequacy			
Insufficient	69 (30.3)	22 (31.9)	47 (29.6)
Sufficient	159 (69.7)	47 (68.1)	112 (70.4)
Parental status			
No children	201 (87.8)	56 (81.2)	145 (90.6)
Children	28 (12.2)	13 (18.8)	15 (9.4)
Previous treatment/donation			
No	167 (72.6)	63 (91.3)	104 (64.6)
Yes	63 (27.4)	6 (8.7)	57 (35.4)

^aUnemployed (4 donors and 11 recipients), students (26 donors and 2 recipients) and retired (1 recipient); ^bStudents, housewives and armed forces occupations were excluded.

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding.

4.2. Recipients' access to information about donors

Most participants considered that recipients should not have access to extended profile information and identifying information about donors, in contrast with the tendency to agree with their access to medical information (Table 2). It is noteworthy that about 20% neither agreed nor disagreed with the latter. Donors were more likely to be favorable to recipients' access to medical and extended profile information about themselves ($p=0.015$ and $p=0.003$, respectively), perhaps expressing more openness to information disclosure than recipients.

Table 2. Opinions on recipients' access to information about donors, according to experience with gamete donation

	Donors (n=69)	Recipients (n=161)
Recipients should have access to:	n (%)	n (%)
Medical information about donors (e.g. blood type)		
Yes	47 (68.1)*	86 (53.8)*
Maybe	15 (21.7)*	30 (18.8)*
No	7 (10.1)*	44 (27.5)*
Non-medical information about donors, excluding identification (e.g. educational level)		
Yes	13 (19.1)*	10 (6.5)*
Maybe	8 (11.8)*	8 (5.2)*
No	47 (69.1)*	135 (88.2)*
Personal data about donors, including identification		
Yes	1 (1.5)	4 (2.6)
Maybe	4 (5.9)	9 (5.9)
No	63 (92.6)	139 (91.4)

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding; * $p < 0.05$ for the comparison between donors and recipients.

Among donors, those who had children and who perceived their social class as low/middle-low and their income as insufficient tended to more frequently agree with recipients' access to medical information about donors (Table 3). Among recipients, a similar position was primarily expressed by the youngest and single/divorced participants, who had no children, who were non-employed and who perceived their social class as low/middle-low.

Table 3. Opinions on recipients' access to medical information about donors according to sociodemographic characteristics, stratified by experience with gamete donation

	Donors (n=69)			Recipients (n=161)		
	Yes n (%)	Maybe n (%)	No n (%)	Yes n (%)	Maybe n (%)	No n (%)
Sex						
Female	31 (67.4)	9 (19.6)	6 (13.0)	55 (55.6)	15 (15.2)	29 (29.3)
Male	16 (69.6)	6 (26.1)	1 (4.3)	31 (50.8)	15 (24.6)	15 (24.6)
Age						
≤30	37 (67.3)	12 (21.8)	6 (10.9)	13 (72.2)	3 (16.7)	2 (11.1)
31-35	7 (70.0)	2 (20.0)	1 (10.0)	28 (51.9)	9 (16.7)	17 (31.5)
>35	3 (75.0)	1 (25.0)	0 (0)	44 (51.2)	18 (20.9)	24 (27.9)
Educational level						
≤12	21 (72.4)	4 (13.8)	4 (13.8)	52 (54.2)	16 (16.7)	28 (29.2)
>12	26 (65.0)	11 (27.5)	3 (7.5)	32 (53.3)	12 (20.0)	16 (26.7)
Marital status						
Married/Living with partner	8 (61.5)	2 (15.4)	3 (23.1)	73 (50.0)	30 (20.5)	43 (29.5)
Single/Divorced	39 (69.6)	13 (23.2)	4 (7.1)	13 (92.9)	0 (0)	1 (7.1)
Working status						
Employed	25 (65.8)	8 (21.1)	5 (13.2)	73 (50.7)	29 (20.1)	42 (29.2)
Other ^a	21 (70.0)	7 (23.3)	2 (6.7)	11 (78.6)	1 (7.1)	2 (14.3)
Occupation^b						
Upper-white collar	12 (63.2)	5 (26.3)	2 (10.5)	32 (48.5)	14 (21.2)	20 (30.3)
Lower-white collar	11 (61.1)	3 (16.7)	4 (22.2)	26 (56.5)	8 (17.4)	12 (26.1)
Blue collar	3 (60.0)	2 (40.0)	0 (0)	18 (62.2)	6 (20.7)	5 (17.2)
Subjective social class						
Low/Middle-low	33 (76.7)*	5 (11.6)*	5 (11.6)*	51 (56.7)	18 (20.0)	21 (23.3)
Middle-high/High	8 (47.1)*	8 (47.1)*	1 (5.9)*	17 (45.9)	7 (18.9)	13 (35.1)
Perceived income adequacy						
Insufficient	18 (81.8)	4 (18.2)	0 (0)	26 (55.3)	10 (21.3)	11 (23.4)
Sufficient	29 (61.7)	11 (23.4)	7 (14.9)	58 (52.3)	20 (18.0)	33 (29.7)
Parental status						
No children	37 (66.1)	14 (25.0)	5 (8.9)	80 (55.6)	30 (18.9)	44 (27.7)
Children	10 (76.9)	1 (7.7)	2 (15.4)	5 (33.3)	2 (13.3)	8 (53.3)
Previous treatment/donation						
No	43 (68.3)	13 (20.6)	7 (11.1)	54 (52.4)	19 (18.4)	30 (29.1)
Yes	4 (66.7)	2 (33.3)	0 (0)	32 (56.1)	11 (19.3)	14 (24.6)

^a Unemployed (4 donors and 11 recipients), students (26 donors and 2 recipients) and retired (1 recipient); ^b Students and armed forces occupations were excluded.

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding; * $p < 0.05$ for the comparison within each group.

Both female donors and recipients and those who were married or lived with the partner were more likely to consider that recipients should not have access to extended profile information about donors, excluding identification (Table 4). This opinion was also more frequently expressed by older and less educated donors, who were employed and who perceived their income as sufficient.

Table 4. Opinions on recipients' access to extended profile information about donors, excluding identification, according to sociodemographic characteristics, stratified by experience with gamete donation

	Donors (n=69)			Recipients (n=161)		
	Yes n (%)	Maybe n (%)	No n (%)	Yes n (%)	Maybe n (%)	No n (%)
Sex						
Female	8 (17.8)	4 (8.9)	33 (73.3)	5 (5.3)	2 (2.1)	88 (92.6)
Male	5 (21.7)	4 (17.4)	14 (60.9)	5 (8.6)	6 (10.3)	47 (81.0)
Age						
≤30	12 (21.8)	8 (14.5)	35 (63.6)	0 (0)	0 (0)	17 (100)
31-35	0 (0)	0 (0)	9 (100)	4 (7.8)	3 (5.9)	44 (86.3)
>35	1 (25.0)	0 (0)	3 (75.0)	6 (7.2)	5 (6.0)	72 (86.7)
Education level						
≤12	5 (17.9)	0 (0)	23 (82.1)	4 (4.4)	4 (4.4)	82 (91.1)
>12	8 (20.0)	8 (20.0)	24 (60.0)	6 (10.2)	4 (6.8)	49 (83.1)
Marital status						
Married/Living with partner	1 (8.3)	1 (8.3)	10 (83.3)	6 (4.2)	8 (5.6)	128 (90.1)
Single/Divorced	12 (21.4)	7 (12.5)	37 (66.1)	4 (36.4)	0 (0)	7 (63.6)
Working status						
Employed	6 (16.2)	3 (8.1)	28 (75.7)	9 (6.5)	8 (5.8)	122 (87.8)
Other ^a	6 (20.0)	5 (16.7)	19 (63.3)	0 (0)	0 (0)	12 (100)
Occupation^b						
Upper-white collar	2 (10.5)	3 (15.8)	14 (73.7)	4 (6.2)	4 (6.2)	57 (87.7)
Lower-white collar	3 (17.6)	1 (5.9)	13 (76.5)	3 (7.1)	4 (9.5)	35 (83.3)
Blue collar	1 (20.0)	0 (0)	4 (80.0)	2 (7.1)	0 (0)	26 (92.9)
Subjective social class						
Low/Middle-low	9 (21.4)	2 (4.8)	31 (73.8)	5 (5.9)	4 (4.7)	76 (89.3)
Middle-high/High	1 (5.9)	3 (17.6)	13 (76.5)	3 (8.3)	3 (8.3)	30 (83.3)
Perceived income adequacy						
Insufficient	5 (23.8)	4 (19.0)	12 (57.1)	1 (2.3)	2 (4.5)	41 (93.2)
Sufficient	8 (17.0)	4 (8.5)	35 (74.5)	9 (8.4)	6 (5.6)	92 (86.0)
Parental status						
No children	11 (19.6)	7 (12.5)	38 (67.9)	7 (5.1)	7 (5.1)	124 (89.9)
Children	2 (16.7)	1 (8.3)	9 (75.0)	3 (21.4)	1 (7.1)	10 (71.4)
Previous treatment/donation						
No	12 (19.4)	8 (12.9)	42 (67.7)	7 (7.0)	6 (6.0)	87 (87.0)
Yes	1 (16.7)	0 (0)	5 (83.3)	3 (5.7)	2 (3.8)	48 (90.6)

^a Unemployed (4 donors and 9 recipients), students (26 donors and 2 recipients) and retired (1 recipient); ^b Students and armed forces occupations were excluded; * $p < 0.05$ for the comparison within each group.

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding.

4.3. Donors' access to information about recipients, children and donation outcomes

Donors and recipients shared similar opinions regarding donors' access to medical and extended profile information about recipients and identifying information about children born through their donation, with more than 80% showing disagreement with its disclosure (Table 5). However, statistically significant differences were found between both groups regarding donors' access to basic information about the outcomes of gamete donation. Donors were more likely to consider that they should be informed about whether their donations have resulted in any pregnancies or the birth of any children ($p < 0.001$). The results revealed that almost two thirds of donors may have an interest in learning the outcome of their donation. Although recipients stated more frequently that donors should not have access to medical information about children born through their donation, the proportion of donors sharing such position was also very high (93.0% vs 81.2%, respectively).

Table 5. Opinions on donors' access to information about recipients, children and donation outcomes, according to experience with gamete donation

	Donors (n=69)	Recipients (n=161)
Donors should have access to:	n (%)	n (%)
Information on whether any pregnancy have resulted from their donation		
Yes	22 (31.9)*	20 (12.4)*
Maybe	22 (31.9)*	21 (13.0)*
No	25 (36.2)*	120 (74.5)*
Information on whether any children have resulted from their donation		
Yes	21 (30.4)*	17 (10.6)*
Maybe	22 (31.9)*	25 (15.6)*
No	26 (37.7)*	118 (73.8)*
Medical information about recipients (e.g. blood type)		
Yes	3 (4.3)	12 (7.8)
Maybe	8 (11.6)	8 (5.2)
No	58 (84.1)	134 (87.0)
Non-medical information about recipients, excluding identification (e.g. educational level)		
Yes	3 (4.3)	3 (1.9)
Maybe	3 (4.3)	2 (1.3)
No	63 (91.3)	149 (96.8)
Personal data about recipients, including identification		
Yes	2 (2.9)	1 (0.6)
Maybe	2 (2.9)	2 (1.3)
No	65 (94.2)	156 (98.1)
Medical information about children born through their donation		
Yes	4 (5.8)*	2 (1.3)*
Maybe	9 (13.0)*	9 (5.7)*
No	56 (81.2)*	146 (93.0)*
Personal data about children born through their donation, including identification		
Yes	1 (1.4)	0 (0)
Maybe	4 (5.8)	3 (1.9)
No	64 (92.8)	155 (98.1)

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding; * $p < 0.05$ for the comparison between donors and recipients.

Donors who perceived their social class as low/middle-low and their income as insufficient were more likely to consider that they should be informed about whether their donations resulted in any pregnancies, whereas male donors tended to be indecisive (Table 6). By contrast, the youngest recipients and those who were single/divorced or non-employed were more likely to disagree with such possibility.

Table 6. Opinions on donors' access to basic information on whether their donations resulted in any pregnancies according to sociodemographic characteristics, stratified by experience with gamete donation

	Donors (n=69)			Recipients (n=161)		
	Yes n (%)	Maybe n (%)	No n (%)	Yes n (%)	Maybe n (%)	No n (%)
Sex						
Female	17 (37.0)*	10 (21.7)*	19 (41.3)*	12 (12.1)	14 (14.1)	73 (73.7)
Male	5 (21.7)*	12 (52.2)*	6 (26.1)*	8 (12.9)	7 (11.3)	47 (75.8)
Age						
≤30	17 (30.9)	19 (34.5)	19 (34.5)	1 (5.6)	2 (11.1)	15 (83.3)
31-35	3 (30.0)	2 (20.0)	5 (50.0)	9 (16.7)	7 (13.0)	38 (70.4)
>35	2 (50.0)	1 (25.0)	1 (25.0)	9 (10.3)	12 (13.8)	66 (75.9)
Education level						
≤12	8 (27.6)	11 (37.9)	10 (34.5)	11 (11.5)	11 (11.5)	74 (77.1)
>12	14 (35.0)	11 (27.5)	15 (37.5)	7 (11.5)	10 (16.4)	44 (72.1)
Marital status						
Married/Living with partner	4 (30.8)	3 (23.1)	6 (46.2)	20 (13.6)	21 (14.3)	106 (72.1)
Single/Divorced	18 (32.1)	19 (33.9)	19 (33.9)	0 (0)	0 (0)	14 (100)
Working status						
Employed	11 (28.9)	12 (31.6)	15 (39.5)	18 (12.4)	21 (14.5)	106 (73.1)
Other ^a	10 (33.3)	10 (33.3)	10 (33.3)	2 (14.3)	0 (0)	12 (85.7)
Occupation^b						
Upper-white collar	6 (31.6)	5 (26.3)	8 (42.1)	10 (14.9)	7 (10.4)	50 (74.6)
Lower-white collar	6 (33.3)	4 (22.2)	8 (44.4)	2 (4.3)	7 (15.2)	37 (80.4)
Blue collar	2 (40.0)	1 (20.0)	2 (40.0)	3 (10.3)	6 (20.7)	20 (69.0)
Subjective social class						
Low/Middle-low	16 (37.2)	14 (32.6)	13 (30.2)	13 (14.4)	12 (13.3)	65 (72.2)
Middle-high/High	3 (17.6)	5 (29.4)	9 (52.9)	5 (13.2)	7 (18.4)	26 (68.4)
Perceived income adequacy						
Insufficient	10 (45.5)	6 (27.3)	6 (27.3)	3 (6.4)	6 (12.8)	38 (80.9)
Sufficient	12 (25.5)	16 (34.0)	19 (40.4)	17 (15.2)	15 (13.4)	80 (71.4)
Parental status						
No children	18 (32.1)	18 (32.1)	20 (35.7)	17 (11.7)	20 (13.8)	108 (74.5)
Children	4 (30.8)	4 (30.8)	5 (38.5)	3 (20.0)	1 (6.7)	11 (73.3)
Previous treatment/donation						
No	20 (31.7)	20 (31.7)	23 (36.5)	13 (12.5)	12 (11.5)	79 (76.0)
Yes	2 (33.3)	2 (33.3)	2 (33.3)	7 (12.3)	9 (15.8)	41 (71.9)

^a Unemployed (4 donors and 11 recipients), students (26 donors and 2 recipients) and retired (1 recipient); ^b Students and armed forces occupations were excluded; * $p < 0.05$ for the comparison within each group.

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding.

When asked about if donors should have access to basic information on whether their donation resulted on the birth of any children, male donors were significantly more indecisive, whereas those more educated, married or living with a partner or those who perceived their social class as high/middle-high tended to disagree with the disclosure of that information more frequently (Table 7). A similar position of disagreement was mainly expressed by the youngest recipients or those who were non-employed or who perceived their social class as low/middle-low.

Table 7. Opinions on donors' access to basic information on whether their donation resulted in the birth of any children according to sociodemographic characteristics, stratified by experience with gamete donation

	Donors (n=69)			Recipients (n=161)		
	Yes n (%)	Maybe n (%)	No n (%)	Yes n (%)	Maybe n (%)	No n (%)
Sex						
Female	16 (34.8)*	9 (19.6)*	21 (45.7)*	12 (12.2)	15 (15.3)	71 (72.4)
Male	5 (21.7)*	13 (56.5)*	5 (21.7)*	5 (8.1)	10 (16.1)	47 (75.8)
Age						
≤30	16 (29.1)	18 (32.7)	21 (38.2)	1 (5.6)	1 (5.6)	16 (88.9)
31-35	3 (30.0)	2 (20.0)	5 (50.0)	8 (14.8)	12 (22.2)	34 (63.0)
>35	2 (50.0)	2 (50.0)	0 (0)	8 (9.3)	12 (14.0)	66 (76.7)
Education level						
≤12	8 (27.6)	12 (41.4)	9 (31.0)	7 (7.4)	13 (13.7)	75 (78.9)
>12	13 (32.5)	10 (25.0)	17 (42.5)	9 (14.8)	11 (18.0)	41 (67.2)
Marital status						
Married/Living with partner	4 (30.8)	2 (15.4)	7 (53.8)	16 (10.9)	24 (16.3)	107 (72.8)
Single/Divorced	17 (30.4)	20 (35.7)	19 (33.9)	1 (7.7)	1 (7.7)	11 (84.6)
Working status						
Employed	11 (28.9)	12 (31.6)	15 (39.5)	15 (10.4)	25 (17.4)	104 (72.2)
Other ^a	9 (30.0)	10 (33.3)	11 (36.7)	2 (14.3)	0 (0)	12 (85.7)
Occupation^b						
Upper-white collar	6 (31.6)	5 (26.3)	8 (42.1)	8 (11.9)	11 (16.4)	48 (71.6)
Lower-white collar	6 (33.3)	3 (16.7)	9 (50.0)	3 (6.5)	8 (17.4)	35 (76.1)
Blue collar	2 (40.0)	1 (20.0)	2 (40.0)	2 (6.9)	6 (20.7)	21 (72.4)
Subjective social class						
Low/Middle-low	16 (37.2)	15 (34.9)	12 (27.9)	9 (10.0)	14 (15.6)	67 (74.7)
Middle-high/High	3 (17.6)	5 (29.4)	9 (52.9)	6 (15.8)	8 (21.1)	24 (63.2)
Perceived income adequacy						
Insufficient	10 (45.5)	7 (31.8)	5 (22.7)	3 (6.4)	7 (14.9)	37 (78.7)
Sufficient	11 (23.4)	15 (31.9)	21 (44.7)	14 (12.6)	18 (16.2)	79 (71.2)
Parental status						
No children	17 (30.4)	17 (30.4)	22 (39.3)	14 (9.7)	24 (16.7)	106 (73.6)
Children	4 (30.8)	5 (38.5)	4 (30.8)	3 (20.0)	1 (6.7)	11 (73.3)
Previous treatment/donation						
No	19 (30.2)	20 (31.7)	24 (38.1)	12 (11.7)	14 (13.6)	77 (74.8)
Yes	2 (33.3)	2 (33.3)	2 (33.3)	5 (8.8)	11 (19.3)	41 (71.9)

^a Unemployed (4 donors and 11 recipients), students (26 donors and 2 recipients) and retired (1 recipient); ^bStudents and armed forces occupations were excluded; * $p < 0.05$ for the comparison within each group.

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding.

Female donors and those with children stated more frequently that donors should not have access to information on medical data from children born through their donation, whereas the youngest ones hesitated more frequently (Table 8).

Table 8. Opinions on donors' access to medical information about children born through their donation according to sociodemographic characteristics, stratified by experience with gamete donation

	Donors (n=69)			Recipients (n=161)		
	Yes n (%)	Maybe n (%)	No n (%)	Yes n (%)	Maybe n (%)	No n (%)
Sex						
Female	1 (2.2)*	4 (8.7)*	41 (89.1)*	1 (1.0)	5 (5.1)	92 (93.9)
Male	3 (13.0)*	5 (21.7)*	15 (65.2)*	1 (1.7)	4 (6.8)	54 (91.5)
Age						
≤30	3 (5.5)	9 (16.4)	43 (78.2)	0 (0)	1 (5.6)	17 (94.4)
31-35	0 (0)	0 (0)	10 (100)	1 (1.9)	3 (5.7)	49 (92.5)
>35	1 (25.0)	0 (0)	3 (75.0)	1 (1.2)	5 (6.0)	78 (92.9)
Education level						
≤12	3 (10.3)	1 (3.4)	25 (86.2)	1 (1.1)	5 (5.4)	86 (93.5)
>12	1 (2.5)	8 (20.0)	31 (77.5)	1 (1.6)	3 (4.9)	57 (93.4)
Marital status						
Married/Living with partner	1 (7.7)	1 (7.7)	11 (84.6)	2 (1.4)	8 (5.5)	135 (93.1)
Single/Divorced	3 (5.4)	8 (14.3)	45 (80.4)	0 (0)	1 (8.3)	11 (91.7)
Working status						
Employed	2 (5.3)	4 (10.5)	32 (84.2)	2 (1.4)	9 (6.4)	130 (92.2)
Other ^a	2 (6.7)	4 (13.3)	24 (80.0)	0 (0)	0 (0)	14 (100)
Occupation^b						
Upper-white collar	0 (0)	2 (10.5)	17 (89.5)	0 (0)	3 (4.5)	63 (95.5)
Lower white collar	1 (5.6)	1 (5.6)	16 (88.9)	1 (2.2)	5 (11.1)	39 (86.7)
Blue collar	1 (20.0)	1 (20.0)	3 (60.0)	0 (0)	1 (3.6)	27 (96.4)
Subjective social class						
Low/Middle-low	3 (7.0)	5 (11.6)	35 (81.4)	2 (2.3)	5 (5.7)	81 (92.0)
Middle-high/High	0 (0)	3 (17.6)	14 (82.4)	0 (0)	3 (8.1)	34 (91.9)
Perceived income adequacy						
Insufficient	2 (9.1)	3 (13.6)	17 (77.3)	1 (2.2)	3 (6.7)	41 (91.1)
Sufficient	2 (4.3)	6 (12.8)	39 (83.0)	1 (0.9)	6 (5.5)	103 (93.6)
Parental status						
No children	3 (5.4)	9 (16.1)	44 (78.6)	2 (1.4)	9 (6.3)	131 (92.3)
Children	1 (7.7)	0 (0)	12 (92.3)	0 (0)	0 (0)	14 (100)
Previous treatment/donation						
No	3 (4.8)	9 (14.3)	51 (81.0)	1 (1.0)	3 (3.0)	97 (96.0)
Yes	1 (16.7)	0 (0)	5 (83.3)	1 (1.8)	6 (10.7)	49 (87.5)

^a Unemployed (4 donors and 11 recipients), students (26 donors and 2 recipients) and retired (1 recipient); ^bStudents and armed forces occupations were excluded; * $p < 0.05$ for the comparison within each group.

Notes: In each variable, the total may not add 69 donors and 161 recipients due to missing values; The proportions may not add 100 due to rounding.

5. DISCUSSION AND CONCLUSION

This is the first study in Portugal to assess the views of gamete donors and recipients about access to and the sharing of information associated with donor-assisted reproduction. Although there is international literature on this topic, most studies examine the views of donors and recipients separately [44,74,79,80,82,83,88]. As such, this study contributes a comparative perspective that is key to consider proposals for data governance whose impact extends to multiple stakeholders. In light of the ongoing transition into an open-identity donation regime observed in Portugal, this study also contributes timely evidence that can be used to develop people-centred recommendations for policy that are sensitive to the complexity and context-bound nature of the ethical and social issues linked to gamete donation and take into account the views and preferences of those directly involved and affected by donor-assisted reproduction.

Gamete donors and recipients expressed similar views about recipients' access to information about donors. Here, a gradation of preferences was observed with both stakeholder groups showing more openness toward the reveal of donors' medical information to recipients, followed by lower willingness to make donors' extended profile information accessible and unwillingness to disclose donors' identifying information. Most gamete donors and recipients also agreed that donors should not be granted access to recipients' medical, extended profile and identifying information, nor should medical and identifying information about their donor-conceived children be disclosed to them. Significantly different views were observed between gamete donors and recipients in regard to donors' access to basic information. While recipients were mostly unwilling to reveal this information, one third of donors showed interest accessing it and another third was indecisive.

Participants' unfavourable position regarding the disclosure of donors' identifying information deserves particular attention as it appears to be at odds with the Portuguese Constitutional Court recent decision to remove donor anonymity [35]. Such decision was driven, to a great extent, by the application of the principle of non-maleficence to donor-conceived children, and its enactment through the granting of access to potentially relevant genetic information [10,11], which requires the identification of donors. As Pennings [89] adverts, when transition into an open-identity donation system is grounded on the right of donor-conceived-children to know their genetic identity without further regard to other stakeholders' needs and preferences, there is a risk that their interests and rights may be ignored, ultimately leading to a general distrust in the system. This is particularly worrying if a retrospective law – one that removes anonymity from donors who completed the process before the passing of legislative change – is

introduced [90] and, if that results in a decrease in the number of donations and a subsequent shortage of gametes [44,46], which will most likely cause recipients to seek cross-border treatment in countries where anonymity is guaranteed [89]. If this happens, donor-conceived children will be deprived from access to genetic information, defeating the original purpose of the law.

Evidence from countries where donor anonymity was removed, including the UK, the Netherlands and Sweden, points to a decrease in the number of donations and treatments, changes in the demographics of gamete donation and an increase in cross-border treatments, immediately following the application of the law [46]. These impacts may not have a long-lasting effect. In the UK, for example, although the number of donations reduced after the open-identity system was introduced in 2005 it has stabilised over time [44]. This may be explained by the introduction of marketing and public awareness campaigns that may have contributed to the changing of public views [45,47,80]. Nevertheless, given the chances that gamete donation may decrease or even be brought to a halt, even if temporarily, there is a need to account for these potential impacts and consider alternative solutions to ensure the replenishment of the Public Bank of Gametes, namely by importing gametes from countries with a similar legislation.

Another relevant finding to respond to this dissertation's main objective concerns participants' views about basic information, in regard to which the most noteworthy differences between gamete donors and recipients were found. Approximately one third of the donors expressed interest in knowing whether their donation resulted in a pregnancy and the birth of children, while another third was indecisive. This means that almost two thirds of donors would consider having access to information about the outcomes of donation, which is consistent with the literature [75,76,79,80]. However, the majority of recipients (75%) disagreed that donors should have access to this information. Underlying reasons for recipients' unwillingness to share basic information with donors may include the wish to protect themselves, and their children, from the possibility of future contact by the donor. Although the sharing of basic information would not allow for the identification of donor-conceived children, recipients may fear that it becomes a stepping stone for donors' to pursue access to that type of information in the future (e.g. through databases with information about donor-conceived children [76]). In Portugal, there is still considerable stigma attached to donor-assisted reproduction, which may lead those who engage in this process to feel that they must protect their privacy at all costs [18]. Yet, the vast majority of the donors who participated in our study expressed no interest in accessing identifying information from either gamete recipients (94%) or the children conceived with their gametes (93%). As suggested by Daniels [91], the act of gamete donation

involves donors giving a part of themselves that has the potential of generating a human life and they believe they should be informed of whether or not such purpose was fulfilled.

In our view, current policy on data governance associated with gamete donation in Portugal is the least accommodating of donors and recipients' interests, favouring the interests of donor-conceived children instead. One way by which donors could be compensated for their gift is by providing them the information they are keen to receive. As argued by Prainsack [6], reciprocity towards donors of biological material can be realised by making clear the purposes of the gift receivers. In the case of gamete donation, that would be the outcomes of donation. Yet a basic premise of health data information sharing is that it should cause no harm to any of the parties involved [8]. As noted above, most recipients in our study disagree that donors be granted access to basic information. To accommodate the needs and preferences of both stakeholders we propose a consent system in which donors and recipients express their positioning in regard to the disclosure of basic information and are matched to each other by taking similar preferences into account. This proposal should be supplemented by the availability of counselling services for both donors and recipients which, among other things, are fundamental to clarify any doubts or fears they may have regarding information safeguards, anonymity, the possibility of contact between donors and offspring, etc. Combining these proposals can foster a more people-centred data governance system in which the needs, interests and preferences of donors and recipients are taken into account.

One last finding that may deserve attention in future policy concerned with gamete donation is the access to medical information about donors and donor-conceived children. Although the majority of donors and recipients agreed that donors' medical information should be accessible to recipients, both stakeholder groups showed strong disagreement with having donor-conceived children's medical information being disclosed. Medical information, and genetic information in particular, can be important for the wellbeing of the donor, the wellbeing of the donor's own children and to the donor's own reproductive decisions if genetic problems are found in the child born through gamete donation [8]. Perhaps the preference of donors' in our study for not wanting to access medical information of donor-conceived children can be explained by the "right not to know", according to which individuals should be able to control whether or not they receive genetic information. Knowledge of certain genetic diseases may "blur the boundaries between health and illness" (p.838) [92], leading to the establishment of a phase previous to the appearance of the disease that can be characterised by the donors' having to deal with the "burden of knowledge" (p.435) [93]. This can lead to psychological dilemmas for the donors regarding if and how they should reveal that information to relatives and whether they should make new life-planning choices and reconsider reproductive options. In our view, the reveal of medical information, and its consequences, has implications for all

the stakeholders, which claims for an in-depth debate around the governance of the disclosure of medical information. In the meanwhile, the availability of regular support from counsellors specialized in the provision of medical information is crucial to help donors to deal with that information [44,74,92,94].

This study, however, does have some limitations. Participants were recruited from only one public reproductive medicine center. Although it was the main national storage bank of donated gametes, the recruitment of gamete donors and recipients in private clinics, as well as those involved in the two remaining public centers (located in Coimbra and Lisbon), would be enriching. The possibility of selection bias from health professionals recruiting patients cannot be excluded. The sample size and the response rate could limit the power to detect small but potentially important differences, but they are quite similar to those observed in other studies with comparable populations [75,76]. Nevertheless, future research would benefit from a prospective analysis with national representative samples. Furthermore, an understanding of the views, values and preferences of other stakeholders, namely donor-conceived children and health professionals involved in gamete donation, could be obtained through further research. More studies are also needed to assess the views of donors and recipients about access to phenotypic information. Hypothesis generated from the findings of this study can be used in subsequent quantitative or qualitative studies in other countries and health settings, contributing to relevant literature in the field of people-centered policy for data governance in gamete donation.

To conclude, this dissertation presents evidence on which to ground recommendations for people-centred policy for data governance in gamete donation. It makes three proposals that acknowledge the legal and ethical issues framing the discussion on this topic and promote respect for the needs and interests of the stakeholders involved in donor-assisted reproduction. First, it proposes that basic information be recognised as a vehicle for enabling reciprocity between gamete recipients and donors. Second, it establishes that a matching mechanism (via consent) is necessary to accommodate the interests and preferences of both stakeholder groups. Third, it points to the need to further stakeholders' access to counsellors specifically trained to advise on issues linked to information associated with donor-assisted reproduction, including the removal of anonymity and access to other types of information. Bringing these issues into the decision-making table will likely contribute to enabling transformative policy change at a time in which there is little consensus regarding the transition into an open-identity regime and greater consideration for stakeholders preferences is needed for the good governance of information related to gamete donation.

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APPENDIX

Appendix 1 – Informative leaflet about the questionnaire

Quem coordena o estudo?

A coordenação é da responsabilidade do Instituto de Saúde Pública da Universidade do Porto (ISPUP), sendo a investigadora principal Susana Silva.

Este estudo é financiado pela **Fundação para a Ciência e a Tecnologia**.

Como será usada a informação?

Os resultados deste estudo serão divulgados de diversas formas (relatórios, artigos científicos e comunicações orais), junto de pessoas que podem tomar decisões em relação aos serviços prestados e às políticas que regulam a doação de gâmetas.

Referimo-nos, por exemplo, a membros do Conselho Nacional de Procriação Medicamente Assistida e da Sociedade Portuguesa de Medicina da Reprodução.

A sua participação será muito valiosa!

A aplicação do questionário só acontecerá depois de esclarecidas todas as suas questões e após assinatura do consentimento informado. Ser-lhe-á dado este folheto informativo e uma cópia do consentimento informado.

Para qualquer dúvida, sugestão ou comentário, por favor entre em contacto connosco:

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FOLHETO DE INFORMAÇÃO AO PARTICIPANTE

**Doação de gâmetas:
Envolvimento público e
cuidados centrados nas
pessoas**

Informação sobre o estudo

Bom dia,

Estamos a desenvolver um estudo sobre as opiniões e experiências de dadores, beneficiários e profissionais de saúde envolvidos na doação de gâmetas.

Gostaríamos de contar com a sua colaboração!

Antes de decidir, é importante que saiba mais acerca deste estudo e do que lhe é pedido se aceitar participar.

Por favor leia atentamente este folheto informativo e coloque todas as perguntas que achar necessário.

Obrigado pelo tempo concedido à leitura desta informação!

Porque queremos falar consigo?

A finalidade deste estudo é conhecer as opiniões de dadores e dadoras de gâmetas, beneficiários e profissionais de saúde sobre os cuidados de saúde e as políticas que regulam a doação de gâmetas.

Serão convidados a participar neste estudo mulheres e homens que pretendem doar ovócitos e espermatozoides a um banco de gâmetas, beneficiários e profissionais de saúde.

Quais serão os benefícios da minha participação?

Será participante de um estudo inovador que procura conhecer as opiniões dos/as dadores/as de gâmetas, beneficiários e profissionais de saúde, contribuindo para:

- Promover sistemas de saúde centrados nas pessoas, que tenham em conta as suas necessidades e preferências;
- Conhecer as opiniões de todas as pessoas envolvidas na doação de gâmetas sobre as políticas que regulam esta prática;
- Incentivar o debate público em torno das respostas aos desafios que enfrenta a doação de gâmetas em Portugal.

Em que consiste a sua participação?

Gostaríamos que respondesse a um questionário, com uma duração prevista de 15 minutos.

Durante a aplicação do questionário, pode colocar todas as suas dúvidas e questões aos investigadores. Como participante não terá que falar sobre assuntos que prefira não abordar.

A informação é confidencial?

Sim, nos termos exigidos pela lei. Este estudo foi aprovado pela Comissão Nacional de Proteção de Dados.

A informação será armazenada de forma segura. Sempre que as informações recolhidas forem utilizadas, nunca será usado o seu verdadeiro nome.

Sou obrigado/a a participar?

Não. Caso decida não participar, esta decisão não terá quaisquer desvantagens nem influenciará os cuidados de saúde. Mesmo depois de aceitar, poderá desistir em qualquer altura e sem justificação.

Appendix 2 – Questionnaire



ID

QUESTIONÁRIO

Doação de gâmetas: Envolvimento público e cuidados centrados nas pessoas

Este estudo pretende conhecer as opiniões de dadores, beneficiários e profissionais de saúde quanto às políticas e aos cuidados de saúde que enquadram a doação de gâmetas.

Não há respostas certas nem erradas, o que nos interessa é conhecer a sua opinião sincera. Desde já agradecemos a sua colaboração e o tempo que irá disponibilizar a responder a este questionário.

Data de preenchimento: / /
(dia) (mês) (ano)

GRUPO I. OPINIÕES SOBRE ACESSO E GOVERNAÇÃO

1. Indique, por favor, quais são as **duas** principais **fontes** onde procura informação sobre doação de gâmetas?

- | | | | | | |
|-------------------------------|--------------------------|---|---|--------------------------|---|
| Profissionais de saúde | <input type="checkbox"/> | 1 | Jornais | <input type="checkbox"/> | 6 |
| Artigos científicos | <input type="checkbox"/> | 2 | Rádio | <input type="checkbox"/> | 7 |
| Internet | <input type="checkbox"/> | 3 | Formação académica (licenciatura, mestrado, etc.) | <input type="checkbox"/> | 8 |
| Familiares, amigos ou colegas | <input type="checkbox"/> | 4 | Outra. | <input type="checkbox"/> | 9 |
| Televisão | <input type="checkbox"/> | 5 | Qual? _____ | | |

1.1. Como se sente em relação à informação que tem sobre doação de gâmetas?

- Nada informado 0 1 2 3 4 Muito informado

2. Recorda-se de ter visto alguma campanha ou anúncio sobre doação de gâmetas?

- Sim 1 Não 0 (p.f. passe para a pergunta 3)

2.1. Diga-nos, por favor, do que se recorda sobre essa campanha ou anúncio. (por ex.: onde viu e o conteúdo)

3. Já teve alguma experiência anterior como dador/a de gâmetas?

- Não _0
- Sim, uma vez _1
- Sim, várias vezes _2

4. Já teve alguma experiência anterior como beneficiário/a de gâmetas (ou seja, já beneficiou de um tratamento com doação de gâmetas)?

- Não _0
- Sim, uma vez _1
- Sim, várias vezes _2

5. Neste momento, qual a sua relação com a doação de gâmetas?

- Sou dador/a _1
- Sou membro de um casal recetor/beneficiário de:
 - Ovócitos doados _2
 - EspERMatozoides doados _3
 - Embriões doados _4
- Sou recetora/beneficiária, mas não pertença a um casal _5
- Sou profissional de saúde:
 - Médico/a _6
 - Enfermeiro/a _7
 - Embriologista _8
 - Biólogo/a _9
 - Psicólogo/a _10
- Outra. _11
Qual? _____
- Não tenho qualquer relação com a doação de gâmetas, neste momento _12

6. Onde ocorreu/ocorreram essa/s experiência/s?

6.1. Localização do centro de fertilidade (pode assinalar mais do que uma opção):

Portugal _1 Fora de Portugal _2

6.2. Tipo de centro de fertilidade (pode assinalar mais do que uma opção):

Público _1 Privado _2

6.3. Número de centros:

Um _1 Dois _2 Três ou mais _3

7. Existem várias formas de compensar financeiramente as pessoas que doam óvulos e espermatozoides. Na sua opinião, qual das seguintes propostas de compensação é a mais adequada? (assinale apenas uma opção)

- Valor monetário igual para dadores de espermatozoides e dadoras de óvulos _1
- Valor monetário variável de acordo com o tipo de doação (óvulos/espermatozoides) _2
- Valor monetário variável de acordo com as despesas efetuadas ou prejuízos resultantes da dádiva _3
- Valor monetário variável de acordo com as características do/a dador/a _4

7.1. É importante, para nós, compreender melhor a sua resposta. Explique-nos, por favor, a sua opinião sobre o valor da compensação financeira atribuída a dadores.

8. Existem diferenças no número de doações que homens e mulheres podem fazer ao longo da vida.

8.1. Na sua opinião, qual o número máximo de doações que cada mulher deve poder fazer? _____

8.2. Na sua opinião, qual o número máximo de doações que cada homem deve poder fazer? _____

9. Em Portugal, a doação é feita em regime de anonimato, mas há países em que isso não acontece. **Qual é a sua opinião sobre o anonimato dos dadores?**

10. Quando os recursos são escassos, podem ser utilizados critérios para indicar as pessoas que têm acesso prioritário a tratamentos. **Em que medida concorda com as seguintes afirmações sobre o acesso prioritário a tratamentos com doação de gâmetas no Serviço Nacional de Saúde?**

Deverão ter prioridade de acesso a tratamentos com doação de gâmetas...	Discordo totalmente	Discordo um pouco	Não concordo nem discordo	Concordo um pouco	Concordo totalmente
Os casais heterossexuais, por comparação com os homossexuais	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
As mulheres casadas, por comparação com as solteiras	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
As pessoas com um peso "normal", por comparação com as que têm excesso de peso/obesidade	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

11. Considera que o/a dador/a deve ter a possibilidade de escolher características das pessoas que vão receber os seus gâmetas?

Sim ₁ Não ₀ (pf. passe para a pergunta 12)

11.1. Que características poderiam escolher? (pode seleccionar mais do que uma opção)

- Idade ₁
- Estado civil ₂
- Orientação sexual ₃
- Nível de escolaridade ₄
- Altura e peso ₅
- Outra: ₆

Qual? _____

12. Considera que os beneficiários devem ter a possibilidade de escolher características dos dadores de gâmetas?

Sim ₁ Não ₀ (pf. passe para a pergunta 13)

12.1. Que características poderiam escolher? (pode seleccionar mais do que uma opção)

- Idade ₁
- Estado civil ₂
- Orientação sexual ₃
- Nível de escolaridade ₄
- Altura e peso ₅
- Outra: ₆

Qual? _____

13. Na sua opinião, as **peessoas que beneficiam de tratamentos com doação de gâmetas** devem ter acesso a:

	Não	Sim	Talvez
- Informação médica sobre dadores (por exemplo, grupo sanguíneo)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Informação não médica sobre dadores (por exemplo, nível de escolaridade), mas não a sua identificação	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Dados pessoais sobre os dadores, incluindo a sua identificação	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Outra: Qual? _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2

14. Na sua opinião, as **peessoas que doam gâmetas** devem ser informadas sobre:

	Não	Sim	Talvez
- Se a doação resultou, ou não, numa gravidez	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Se a doação resultou no nascimento de crianças	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Dados médicos dos beneficiários (por exemplo, grupo sanguíneo)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Dados não médicos dos beneficiários (por exemplo, nível de escolaridade), mas não a sua identificação	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Dados pessoais sobre os beneficiários, incluindo a sua identificação	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Dados médicos das crianças concebidas através da doação de gâmetas	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Dados pessoais das crianças concebidas através da doação de gâmetas, incluindo a sua identificação	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Outra: Qual? _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2

15. Existem diversas estratégias para recrutar dadores de gâmetas. **Por favor, assinale as duas estratégias que, na sua opinião, seriam mais adequadas para Portugal:**

	1. ^a	2. ^a
- Desenvolver campanhas junto de estudantes universitários	<input type="checkbox"/> 1	<input type="checkbox"/> 1
- Promover campanhas para a população em geral	<input type="checkbox"/> 2	<input type="checkbox"/> 2
- Aumentar o valor da compensação financeira de dadores	<input type="checkbox"/> 3	<input type="checkbox"/> 3
- Promover a doação por parte de familiares/amigos de beneficiários	<input type="checkbox"/> 4	<input type="checkbox"/> 4
- Promover a doação por parte de pessoas envolvidas em tratamentos de fertilidade	<input type="checkbox"/> 5	<input type="checkbox"/> 5
- Alterar a legislação para que os dadores possam ser identificados	<input type="checkbox"/> 6	<input type="checkbox"/> 6

15.1. É importante, para nós, compreender melhor a sua resposta. **Explique-nos, por favor, a sua opinião.**

16. Neste momento, Portugal tem um Banco Público de Gâmetas no Porto e recolhem-se óvulos e espermatozoides em centros públicos situados em Coimbra e em Lisboa. **Em que medida concorda com esta localização dos centros públicos?**

Discordo totalmente	Discordo um pouco	Não concordo nem discordo	Concordo um pouco	Concordo totalmente
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

16.1. É importante, para nós, compreender melhor a sua resposta. **Explique-nos, por favor, a sua opinião.**

GRUPO II. PREDISPOSIÇÃO PARA DOAR E RECEBER GÂMETAS

17. Se tivesse todas as condições para poder doar gâmetas, em que medida estaria disponível para:

	Não disponível				Sempre disponível
- Doar gâmetas a familiares	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Doar gâmetas a amigos	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Doar gâmetas a desconhecidos	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Doar gâmetas para projetos de investigação científica	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

17.1. É importante, para nós, compreender melhor a sua resposta. **Explique-nos, por favor, as razões que justificam a sua posição.**

17.2. Em que medida estaria disponível para doar gâmetas para projetos de investigação científica:

	Não disponível				Sempre disponível
- Sem fins lucrativos	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
- Com fins lucrativos	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

17.3. Se os seus gâmetas fossem utilizados em projetos de investigação, gostaria de ser informado sobre isso?

- Sim, gostaria de ser sempre informado sobre o uso dos meus gâmetas	<input type="checkbox"/> 1
- Sim, gostaria de ser informado algumas vezes sobre o uso dos meus gâmetas	<input type="checkbox"/> 2
- Não gostaria de ser informado de cada vez que os meus gâmetas fossem utilizados	<input type="checkbox"/> 3
- Não sei	<input type="checkbox"/> 4

18. Aconselharia um familiar ou amigo próximo a fazer um tratamento com espermatozoides doados:

	Não	Sim	Talvez
- Por um irmão	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Por outro familiar próximo	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Por um amigo	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Por um desconhecido	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2

19. Aconselharia uma familiar ou amiga próxima a fazer um tratamento com óvulos doados:

	Não	Sim	Talvez
- Por uma irmã	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Por outra familiar próxima	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Por uma amiga	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- Por uma desconhecida	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2

GRUPO III. PREDISPOSIÇÃO PARA DOAR EMBRIÕES

20. Imagine que seria beneficiário/a da doação de gâmetas e desse tratamento resultariam vários embriões "excedentários". **Em que medida estaria disponível para:**

- | | | | |
|--|---------------------------------------|---|-------------------|
| | Não disponível | | Sempre disponível |
| - Doar embriões para outros casais | <input type="checkbox"/> ₀ | <input type="checkbox"/> ₁ <input type="checkbox"/> ₂ <input type="checkbox"/> ₃ <input type="checkbox"/> ₄ | |
| - Doar embriões para projetos de investigação científica | <input type="checkbox"/> ₀ | <input type="checkbox"/> ₁ <input type="checkbox"/> ₂ <input type="checkbox"/> ₃ <input type="checkbox"/> ₄ | |

21. Os embriões "excedentários" que resultam de tratamentos com doação de gâmetas podem ser doados para investigação científica. **Na sua opinião, quem deve autorizar ou recusar a doação destes embriões para projetos de investigação?**

- As pessoas que beneficiam do tratamento de fertilidade ₁
- As pessoas que doaram os gâmetas ₂
- Ambos (beneficiários e dadores) ₃

22. Numa escala de 1 a 5, em que 1 é "Discordo totalmente" e 5 "Concordo totalmente", **em que medida concorda com as seguintes afirmações acerca da investigação na área da saúde?**

	Discordo totalmente	Discordo um pouco	Não concordo nem discordo	Concordo um pouco	Concordo totalmente
1. Tenho uma visão positiva sobre a investigação médica, em geral	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
2. A principal motivação dos investigadores na área da medicina é o benefício pessoal	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
3. Pode-se confiar nos investigadores para proteger os interesses das pessoas que participam nos seus estudos	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
4. Todos temos alguma responsabilidade em ajudar os outros ao voluntariamo-nos para participar na investigação médica	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
5. A ciência moderna gera mais danos do que benefícios	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
6. A sociedade precisa de dedicar mais recursos à investigação médica	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
7. A investigação médica precisa de ser rigorosamente regulamentada de forma a prevenir danos nos participantes	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
8. Participar na investigação médica é, em geral, seguro	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
9. Se eu me voluntariar para a investigação médica, sei que a minha informação pessoal será mantida privada e confidencial	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10. Dar muita ênfase à investigação médica e ao progresso científico pode prejudicar quem se voluntaria para a investigação	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11. A investigação médica vai encontrar cura para muitas doenças importantes durante a minha vida	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

GRUPO IV. CARACTERÍSTICAS SOCIODEMOGRÁFICAS

23. Sexo:

- Feminino ₁
Masculino ₂

24. Ano de nascimento: |__|_|_|_|_|

25. De onde é natural?

- Portugal ₁
Outro país ₂

Qual? _____

26. Onde reside atualmente? Distrito: _____

27. Qual é o seu estatuto marital?

- | | | | |
|----------------|---------------------------------------|---|---------------------------------------|
| Solteiro/a | <input type="checkbox"/> ₁ | Viúvo/a | <input type="checkbox"/> ₄ |
| Casado/a | <input type="checkbox"/> ₂ | Divorciado/a | <input type="checkbox"/> ₅ |
| União de facto | <input type="checkbox"/> ₃ | Separado/a (casado/a, mas não vive com o cônjuge) | <input type="checkbox"/> ₆ |

28. Qual o grau de escolaridade mais elevado que completou?

- | | | | |
|--------------------------------------|---------------------------------------|------------------------------|--|
| Nenhum, e não sabe ler nem escrever | <input type="checkbox"/> ₁ | Ensino secundário (12.º ano) | <input type="checkbox"/> ₆ |
| Nenhum, mas sabe ler e escrever | <input type="checkbox"/> ₂ | Bacharelato | <input type="checkbox"/> ₇ |
| 1.º Ciclo do ensino básico (4.º ano) | <input type="checkbox"/> ₃ | Licenciatura | <input type="checkbox"/> ₈ |
| 2.º Ciclo do ensino básico (6.º ano) | <input type="checkbox"/> ₄ | Mestrado/Mestrado Integrado | <input type="checkbox"/> ₉ |
| 3.º Ciclo do ensino básico (9.º ano) | <input type="checkbox"/> ₅ | Doutoramento | <input type="checkbox"/> ₁₀ |

29. Neste momento, qual é a sua principal situação profissional? (assinale apenas uma opção)

- | | | | |
|--|---------------------------------------|--|---------------------------------------|
| Empregado/a a tempo inteiro | <input type="checkbox"/> ₁ | Reformado/a e pré-reformado/a | <input type="checkbox"/> ₅ |
| Empregado/a a tempo parcial | <input type="checkbox"/> ₂ | Doméstico/a /ocupa-se das tarefas do lar | <input type="checkbox"/> ₆ |
| Desempregado/a | <input type="checkbox"/> ₃ | Outra: | <input type="checkbox"/> ₇ |
| Estudante/ na escola/ em formação profissional | <input type="checkbox"/> ₄ | Qual? _____ | |

30. Qual é a sua profissão atual? (se na questão anterior assinalou desempregado/a, doméstico/a ou outra, p.f., considere a última profissão)

31. Considera que os rendimentos do seu agregado familiar são:

- Insuficientes ₁
Tem de ter cuidado com os gastos ₂
Chega para as suas necessidades ₃
Confortáveis ₄

32. Algumas pessoas consideram que a sociedade portuguesa está dividida em classes sociais. Das seguintes classes, em qual delas se incluiria?

- | | | |
|--------------------|--------------------------|---|
| Classe baixa | <input type="checkbox"/> | 1 |
| Classe média baixa | <input type="checkbox"/> | 2 |
| Classe média alta | <input type="checkbox"/> | 3 |
| Classe alta | <input type="checkbox"/> | 4 |
| Em nenhuma destas | <input type="checkbox"/> | 5 |
| Prefere não dizer | <input type="checkbox"/> | 6 |

33. Tem filhos?

- | | | | |
|-----|--------------------------|---|---------------------------------|
| Não | <input type="checkbox"/> | 0 | (p.f. passe para a pergunta 34) |
| Sim | <input type="checkbox"/> | 1 | |

33.1. Quantos filhos tem? _____

34. Alguma vez lhe foi diagnosticada infertilidade?

- | | | |
|-----|--------------------------|---|
| Não | <input type="checkbox"/> | 0 |
| Sim | <input type="checkbox"/> | 1 |

Muito obrigada pela sua colaboração!