Repositório ISCTE-IUL

Deposited in *Repositório ISCTE-IUL*:
2025-04-02

Deposited version:
Publisher Version

Peer-review status of attached file:
Peer-reviewed

Citation for published item:
Maia, T., Silva, S. & Freitas, C. (2019). Solidarity and reciprocity in data governance: Information sharing among gamete donors and recipients. In Yves Charpak, Denis Zmirou-Navier, Dineke Zeegers Paget (Ed.), European Journal of Public Health. (pp. 239-239).: Oxford University Press (OUP).

Further information on publisher's website:
10.1093/eurpub/ckz185.648

Publisher's copyright statement:
This is the peer reviewed version of the following article: Maia, T., Silva, S. & Freitas, C. (2019). Solidarity and reciprocity in data governance: Information sharing among gamete donors and recipients. In Yves Charpak, Denis Zmirou-Navier, Dineke Zeegers Paget (Ed.), European Journal of Public Health. (pp. 239-239).: Oxford University Press (OUP)., which has been published in final form at https://dx.doi.org/10.1093/eurpub/ckz185.648. This article may be used for non-commercial purposes in accordance with the Publisher's Terms and Conditions for self-archiving.

Use policy

Creative Commons CC BY 4.0
The full-text may be used and/or reproduced, and given to third parties in any format or medium, without prior permission or charge, for personal research or study, educational, or not-for-profit purposes provided that:

- a full bibliographic reference is made to the original source
- a link is made to the metadata record in the Repository
- the full-text is not changed in any way

The full-text must not be sold in any format or medium without the formal permission of the copyright holders.

Serviços de Informação e Documentação, Instituto Universitário de Lisboa (ISCTE-IUL)
Av. das Forças Armadas, Edifício II, 1649-026 Lisboa Portugal
Phone: +(351) 217 903 024 | e-mail: administrador.repositorio@iscte-iul.pt
https://repositorio.iscte-iul.pt

Solidarity and reciprocity in data governance: information sharing among gamete donors and recipients

Cláudia De Freitas

T Maia[1]*, S Silva*[1,2]*, C De Freitas*[1,2,3]
[1]EPIUnit, Instituto de Saúde Pública da Universidade do Porto, Porto, Portugal
[2]Departamento de Ciências da Saúde Pública e Forenses e Educa, Faculdade de Medicina, Universidade do Porto, Porto, Portugal
[3]CIES-IUL, Instituto Universitário de Lisboa, Lisbon, Portugal
Contact: claudia_defreitas@yahoo.com

Background:

Decreasing fertility rates have spiralled a growth in demand for assisted reproduction technologies, including reproduction through donated gametes. Gamete donation is grounded on solidaristic practices traditionally focused on the gift of gametes. However, solidarity and reciprocity between donors and recipients may also be enacted through the sharing of other types of information (e.g. donation outcomes, medical and identifying information). Little is known, however, about these stakeholders' preferences regarding information sharing, which is crucial to promoting people-centred policy for data governance in gamete donation.

Methods:

A self-report structured questionnaire was completed by 69 donors and 161 recipients (participation rate: 77.4%) between July 2017 and April 2018 at the Portuguese Public Bank of Gametes. Opinions about access to donation outcomes and medical, extended profile and identifying information about recipients, donors and children were analysed using descriptive statistics.

Results:

Most participants considered that recipients should not have access to donors' identifying (92%) and extended profile (79%) information, but that they should access donors' medical information (58%). Donors stated more frequently that they should receive information about the outcomes of donation (e.g. pregnancies and births) than recipients (32% vs. 12%). Participants also disagreed with donors' access to recipients' medical (83%) and extended profile information (92%) and children's identifying information (98%).

Conclusions:

People-centred policy on data governance in gamete donation should be informed by donor and recipients' preferences. Sharing donation outcomes with donors and medical information from donors with recipients can foster solidarity and reciprocity between them. This requires the development of a matching mechanism (via consent) to accommodate their preferences.

Key messages:

- Policy on data governance should be informed by gamete donors and recipients' preferences.
- Sharing desired information with donors and recipients can foster solidarity and reciprocity between them.