

# PHD PROGRAM IN HEALTH DATA SCIENCE – HEADS

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## Bioethics and Legislation

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October 25th 2023

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Center of Bioethics

# The Right to Be Forgotten Regarding Health Data

## Summary

1. Introduction
2. The Problem
3. Privacy
4. Privacy vs. Data Protection
6. Perspectives I-IV
7. General Conclusions

# The Right to Be Forgotten Regarding Health Data



(1)

# Introduction

- Big data
- Robotics
- Artificial intelligence
- Quantum computing



(2)

# Introduction

## Self-determination

(3)



## Minimisation

(4)



(5)

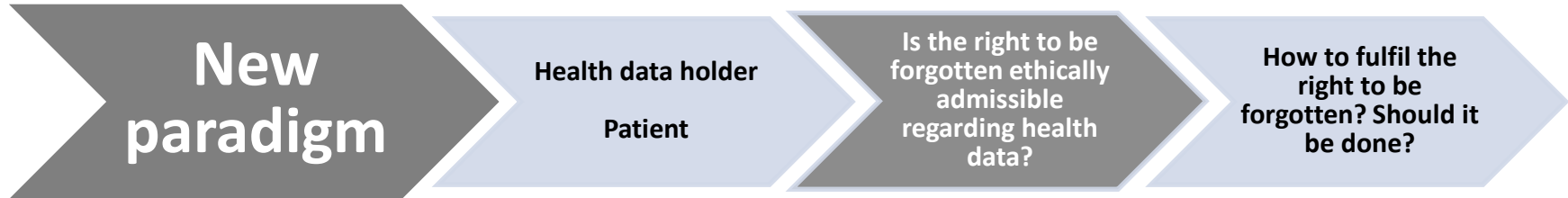


## Consent

(6)



## Individual access



### The ethical admissibility of the right to be forgotten (RTBF) regarding health data, exploring:

- Principles of autonomy, privacy and human dignity / right to delete genetic data.
- Relationship of health data, privacy, data protection and identity projection / gender transition.
- Ethical dilemma right to disclosure of gamete donors' identity in medically-assisted reproduction techniques.
- Interface individual right to privacy and collective interests of public health.

Perspective  
I

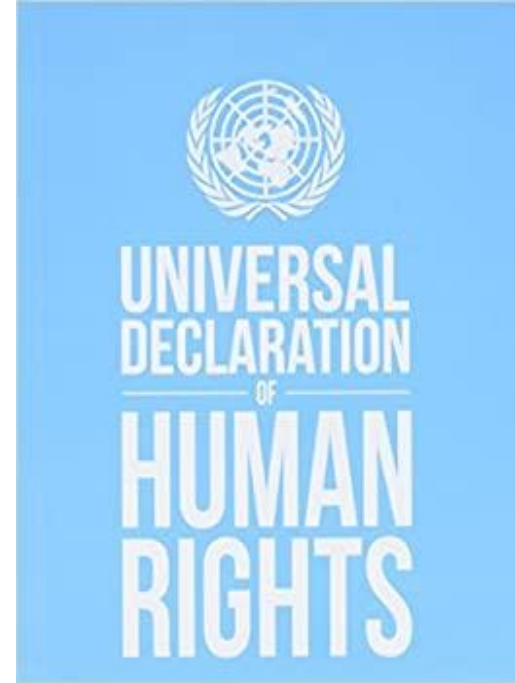
Perspective  
II

Perspective  
III

Perspective  
IV

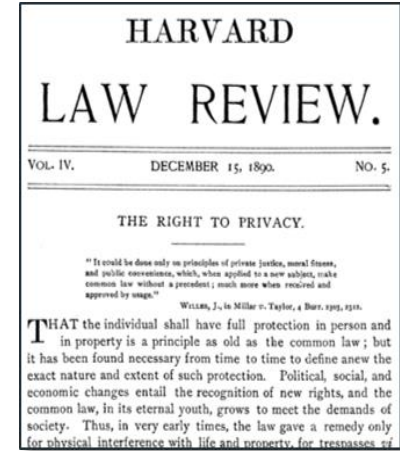
# Fundamental right

Pillar of  
democratic  
societies





1890 – “The Right to Privacy”: Law Review article published by American jurist Louis Brandeis;



1948 – Universal Declaration of Human Rights (United Nations)



## Article 12

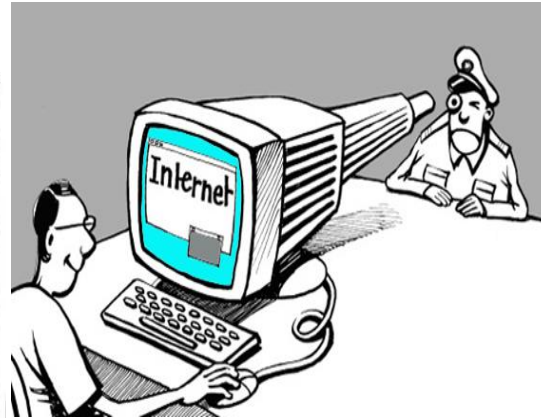
No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

1967 – Privacy and Freedom, by Alan Westin;

“the claim of individuals ... to determine for themselves when, how and to what extent information about them is communicated”

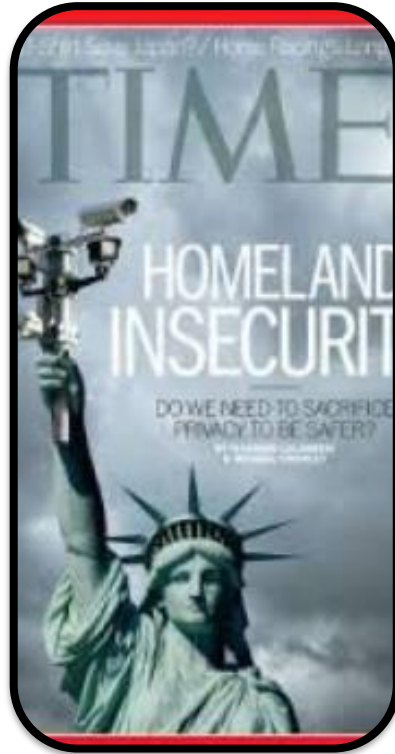


*“Any collection and processing of personal data, whether identifiable or not, for the purposes of influencing or managing those whose data have been garnered.”*



**Lyon (2001)**

# *Surveillance*



New forms of  
intervention

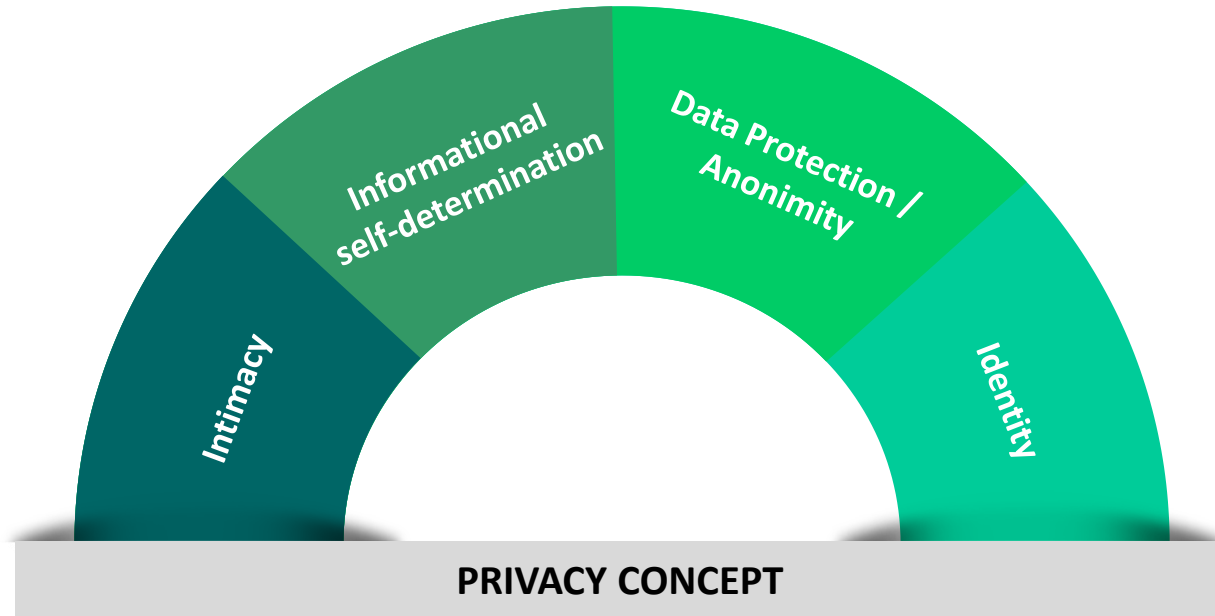
Decisive factor in law  
enforcement

Additional security

Political agenda of  
the democratic  
countries

In the 1990s, the personal data concept was known by a restricted group of people and sectors that worked directly on this matter.

Technological development, social networks - personal data is a concept most people in Europe and developed countries are familiar with. A new global dimension an investigation by The New York Times and Observer newspapers, made public that fifty million Facebook user profiles would have been used without the consent of the holders to identify personality and behavioural patterns and political propaganda, concluding that they were used in the 2016 United States of America (USA) presidential campaign, to influence voters in favour of candidate Donald Trump; social network Facebook would have known of this same misuse did nothing to prevent it: <https://www.nytimes.com/2018/03/17/us/politics/cambridge-analytica-trump-campaign.html> accessed on 24/4/2019.



## Article 17

### Right to erasure ('right to be forgotten')

1. The data subject shall have the right to obtain from the controller the erasure of personal data concerning him or her without undue delay and the controller shall have the obligation to erase personal data without undue delay where one of the following grounds applies:

- (a) the personal data are no longer necessary in relation to the purposes for which they were collected or otherwise processed;
- (b) the data subject withdraws consent on which the processing is based according to point (a) of Article 6(1), or point (a) of Article 9(2), and where there is no other legal ground for the processing;
- (c) the data subject objects to the processing pursuant to Article 21(1) and there are no overriding legitimate grounds for the processing, or the data subject objects to the processing pursuant to Article 21(2);
- (d) the personal data have been unlawfully processed;
- (e) the personal data have to be erased for compliance with a legal obligation in Union or Member State law to which the controller is subject;
- (f) the personal data have been collected in relation to the offer of information society services referred to in Article 8(1).



(7)

### Article 17

#### Right to erasure ('right to be forgotten')

(...)

3.Paragraphs 1 and 2 shall not apply to the extent that processing is necessary:

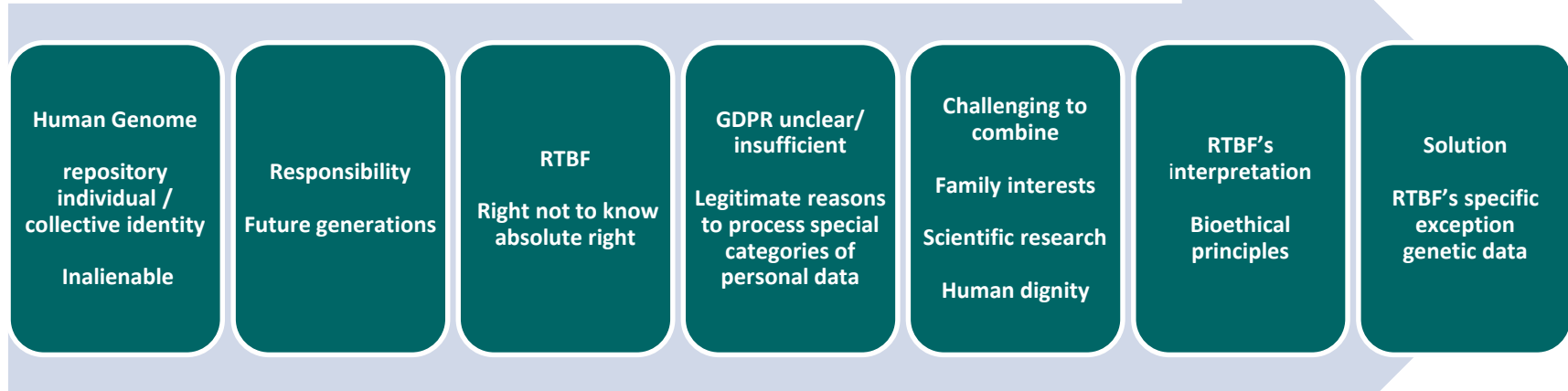
- (a) for exercising the right of freedom of expression and information;
- (b) for compliance with a legal obligation which requires processing by Union or Member State law to which the controller is subject or for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;
- (c) for reasons of public interest in the area of public health in accordance with points (h) and (i) of Article 9(2) as well as Article 9(3);
- (d) for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) in so far as the right referred to in paragraph 1 is likely to render impossible or seriously impair the achievement of the objectives of that processing; or
- (e) for the establishment, exercise or defence of legal claims.



(7)



### The GDPR's Right to Be Forgotten Regarding Genetic Data: A Legal and Ethical Analysis



Correia, M., Rêgo, G., & Nunes, R. (2022)

# Gender Transition: Is There a Right to Be Forgotten?



Correia, M., Rêgo, G., & Nunes, R. (2021)

Health Care Analysis  
<https://doi.org/10.1007/s10728-021-00433-1>

ORIGINAL ARTICLE



Gender Transition: Is There a Right to Be Forgotten?

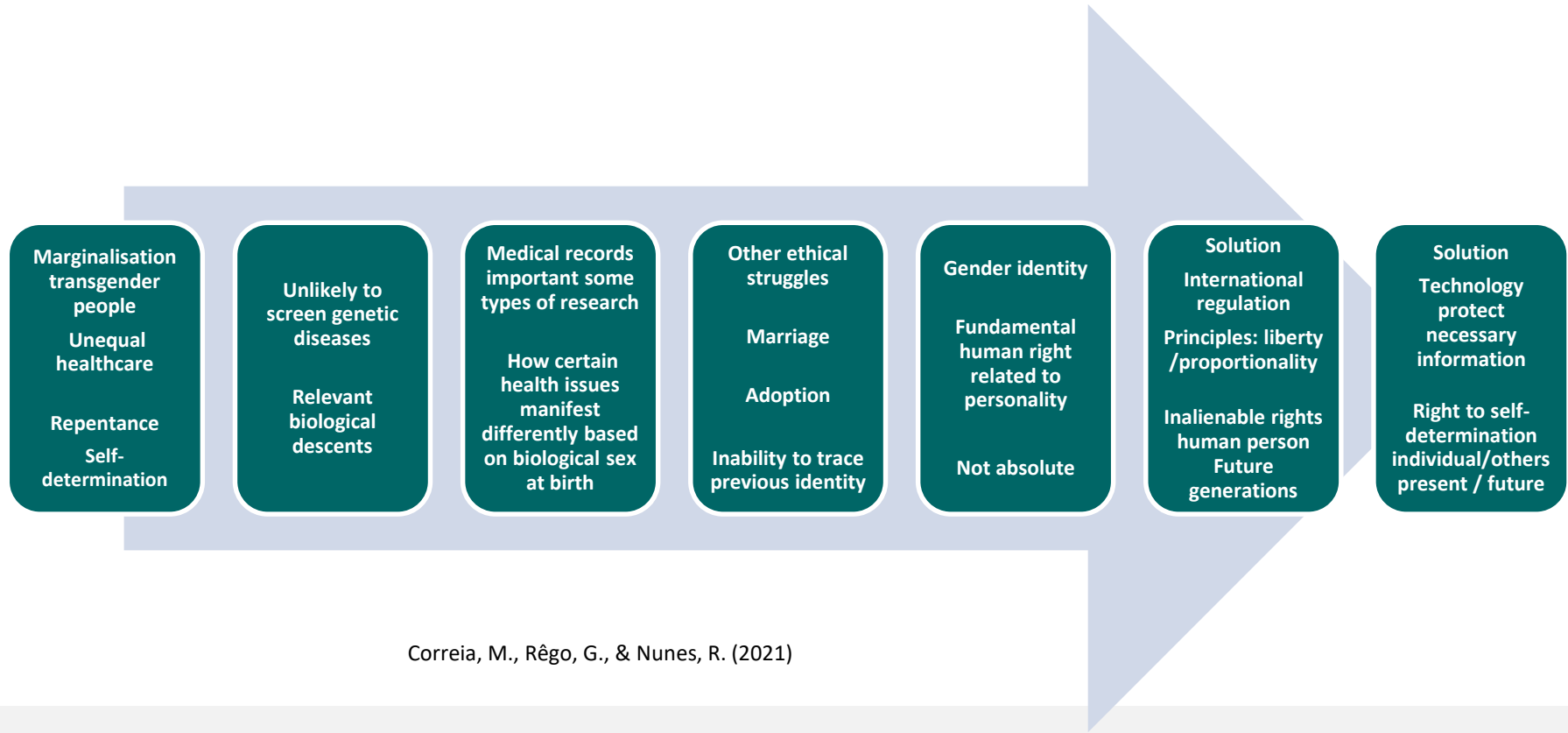
Mónica Correia<sup>1</sup> · Guilhermina Rêgo<sup>1</sup> · Rui Nunes<sup>1</sup>

Accepted: 8 April 2021  
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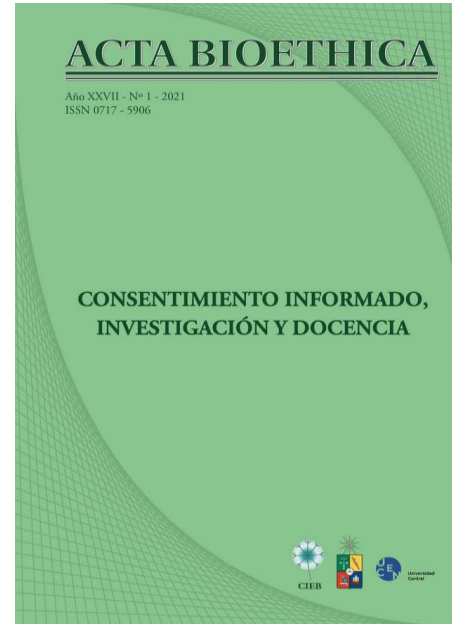
### Abstract

The European Union (EU) faced high risks from personal data proliferation to individuals' privacy. Legislation has emerged that seeks to articulate all interests at stake, balancing the need for data flow from EU countries with protecting personal data: the *General Data Protection Regulation*. One of the mechanisms established by this new law to strengthen the individual's control over their data is the so-called "right to be forgotten", the right to obtain from the controller the erasure of records. In gender transition, this right represents a powerful form of control over personal data, especially health data that may reveal a gender with which they do not identify and reject. Therefore, it is pertinent to discern whether the right to have personal data deleted—in particular, health data—is ethically acceptable in gender transition. Towards addressing the ethical dimensions of the right to be forgotten in this case, this study presents relevant concepts, briefly outlines history, ethics and law of records considering the evolution from paper to electronic format, the main aspects of identity construction and gender identity, and explores the relationship between privacy, data protection/information control and identity projection. Also, it discusses in gender transition the relation between "the right to self-determination", "the right to delete", and "the right to identity and individuality". Conclusions on the ethical admissibility of the 'right to be forgotten' to control gender-affirming information are presented.

**Keywords** Ethics · 'Right to be forgotten' · Gender transition · Health data

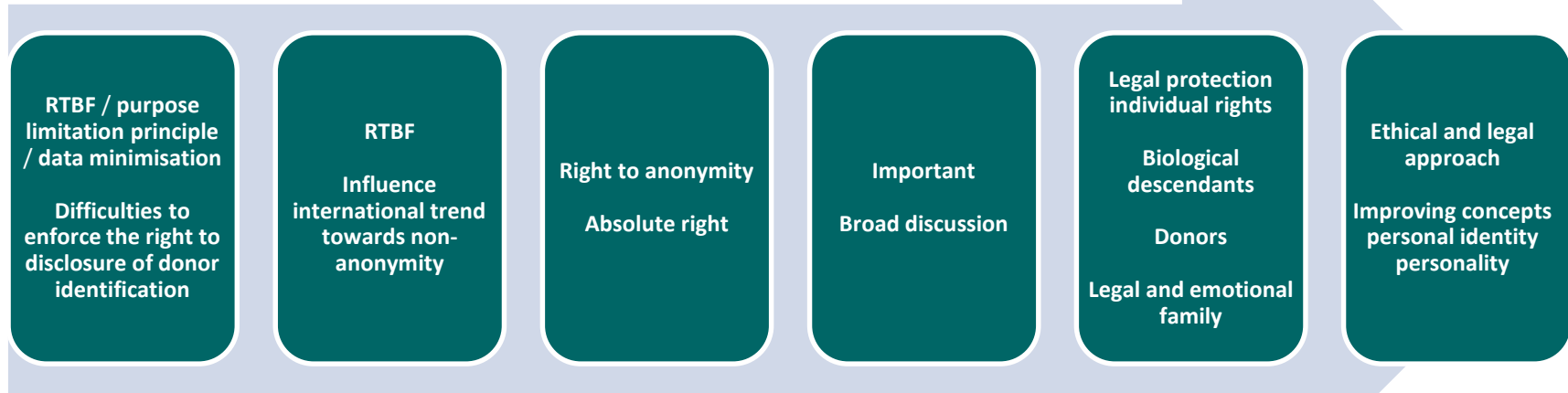


## The Right to Be Forgotten *versus* the Right to Disclosure of Gamete Donors' ID: Ethical and Legal Considerations



Correia, M., Rêgo, G., & Nunes, R. (2021)

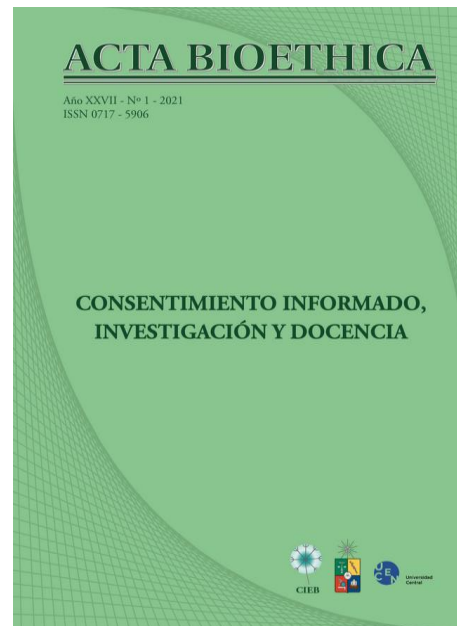




Correia, M., Rêgo, G., & Nunes, R. (2021)

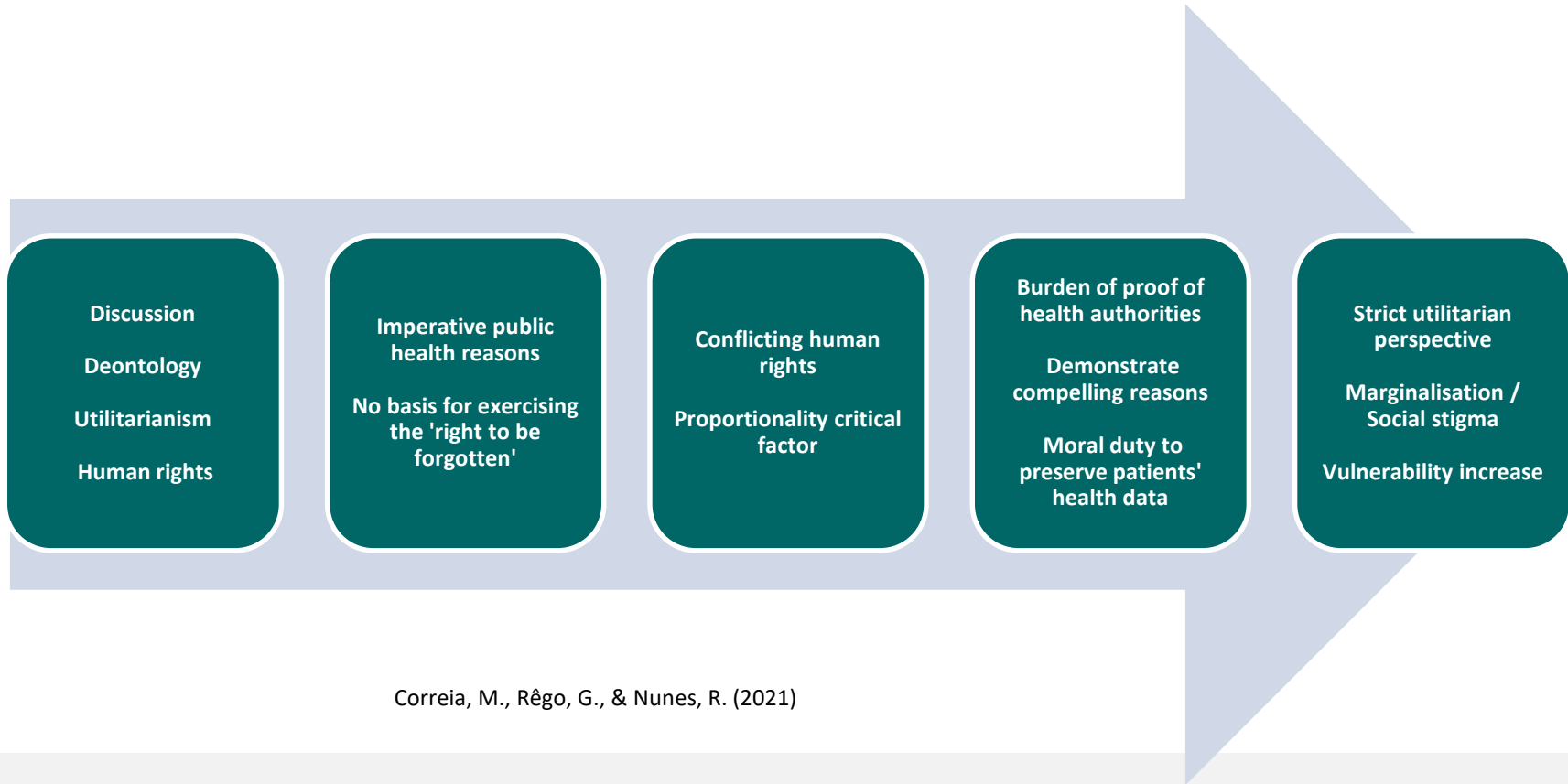
# The Right to Be Forgotten and COVID-19: Privacy versus Public Interest

## Perspective IV



Correia, M., Rêgo, G., & Nunes, R. (2021)



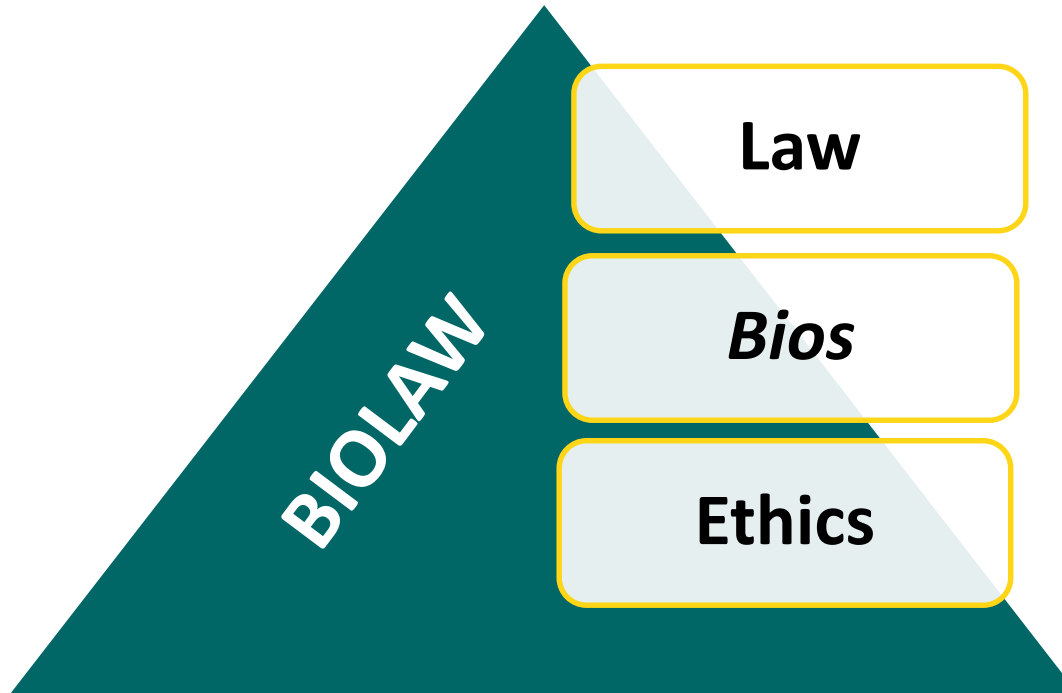


Correia, M., Rêgo, G., & Nunes, R. (2021)

## General Conclusions

1. Different considerations as to what underlies the right to be forgotten — autonomy (informational self-determination), privacy, identity — individual conditions of freedom and essential in promoting human dignity
2. The RTBF is fundamental to rebalance individual fundamental rights in the face of technological development
3. It guarantees the maintenance of great civilisational conquests in the subject of fundamental rights, especially that of informational self-determination
4. Because it is not an absolute right, the IV perspectives resulting from the research reflect the concerns and aspects to be considered in ethically and legally more problematic cases
5. International regulatory measures mitigated with technological solutions based on ethics, where privacy should be reinvented together with the background of transparency in procedures that restrict fundamental rights.
6. Proportionality in its triple strands – necessity, adequacy and prohibition of excess – is a critical factor regarding the solutions proposed





## References

1. <https://sergiopontes.jusbrasil.com.br/artigos/620566588/sobre-o-direito-ao-esquecimento>
2. <https://petrurbanksu.wordpress.com/>
3. <https://aulazen.com/historia/autodeterminacao-dos-povos-e-novos-estados/>
4. <https://www.machertecnologia.com.br/o-que-e-data-minimization-ou-minimizacao-de-dados-lgpd/>
5. <https://cenie.eu/pt/blog/o-consentimento-informado>
6. <https://www.meuportoseguro.com.br/minha-vida/tecnologia/seguranca-na-internet-saiba-como-proteger-seus-dados-pessoais/>
7. <https://www.bettercloud.com/monitor/gdprs-right-to-be-forgotten/>
8. Correia, M., Rêgo, G., & Nunes, R. (2022). The GDPR's Right to Be Forgotten Regarding Genetic Data: A Legal and Ethical Analysis. *Health Care Analysis*, submitted
9. Correia, M., Rêgo, G., & Nunes, R. (2021). Gender Transition: Is There a Right to Be Forgotten? *Health Care Analysis*, doi:10.1007/s10728-021-00433-1
10. Correia, M., Rêgo, G., & Nunes, R. (2021). The Right to Be Forgotten versus the Right to Disclosure of Gamete Donors' ID: Ethical and Legal Considerations. *Acta Bioethica*, 27(1), 69-78, 10.4067/S1726-569X2021000100069
11. Correia, M., Rêgo, G., & Nunes, R. (2021). The Right to Be Forgotten and COVID-19: Privacy versus Public Interest. *Acta Bioethica*, 27(1), 59-67, 10.4067/S1726-569X2021000100059

# Thank you!

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