PHD PROGRAM IN HEALTH DATA SCIENCE - HEADS

Bioethics and Legislation

October 25th 2023

Mónica Correia

Affiliate Professor Center of Bioethics





Summary

The Right to Be Forgotten **Regarding Health Data**

- 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



Minimisation



(5)



Consent



Individual access

The Right to Be Forgotten – The Problem

New paradigm

Health data holder

Patient

Is the right to be forgotten ethically admissible regarding health data?

How to fulfil the right to be forgotten? Should it be done?



The Problem

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.

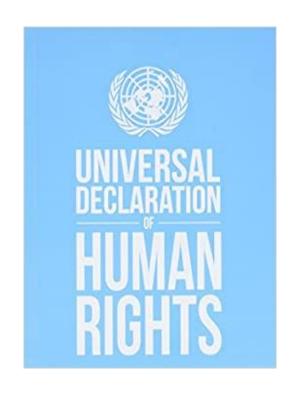








Fundamental right Pillar of democratic societies





Privacy

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

1948 – Universal Declaration of Human Rights (United Nations)

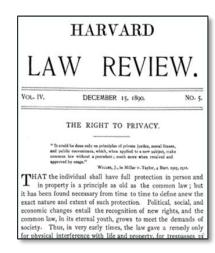




No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

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"



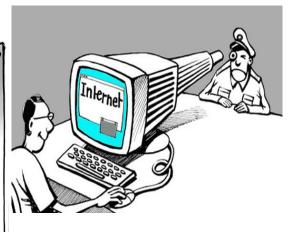
Life dominated by "Big Data"





"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

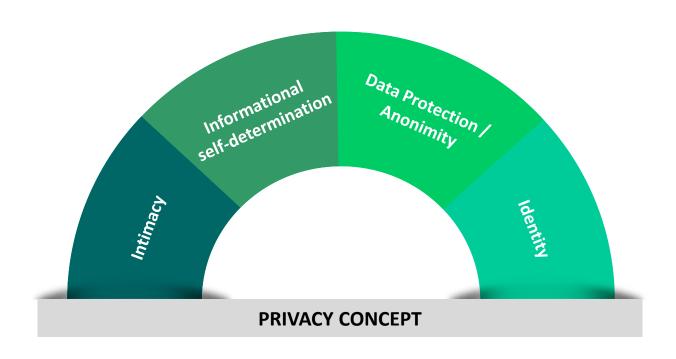


Privacy vs. Data Protection

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 developing coaming the coaming of 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.







The Right to Be Forgotten

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;
- 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;
- 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).







The Right to Be Forgotten (cont.)

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.

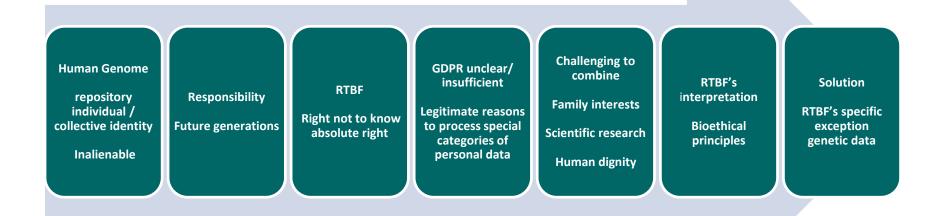






Perspective I

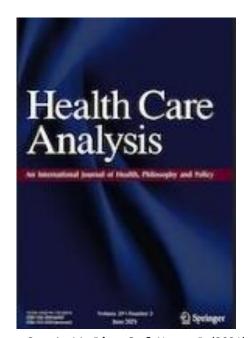
The GDPR's Right to Be Forgotten Regarding Genetic Data: A Legal and Ethical Analysis





Perspective II

Gender Transition: Is There a Right to Be Forgotten?



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





information are presented.

"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



Perpective II

Marginalisation transgender people Unequal

healthcare

Repentance Selfdetermination Unlikely to screen genetic diseases

Relevant biological descents Medical records important some types of research

How certain health issues manifest differently based on biological sex at birth Other ethical struggles

Marriage

Adoption

Inability to trace previous identity

Gender identity

Fundamental human right related to personality

Not absolute

Solution

International regulation

Principles: liberty /proportionality

Inalienable rights human person Future generations

Solution

Technology protect necessary information

Right to selfdetermination individual/others present / future



Perspective III

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



ALE Bundaics 2021; 27 (1): 69-78. DOI: https://doi.org/10.406/CS1726-500720210001000000
THE RIGHT TO BE FORGOTTEN VERSUS THE RIGHT TO
DISCLOSURE OF GAMETE DONORS' ID: ETHICAL AND LEGAL
CONSIDERATIONS

Mónica Correia¹, Guilhermina Rego², Rui Nunes³

Means: The amounts of games down in the current of models primated production relations (ART) and the decident flow flowing the sound being senter of beinging largest self-study is a current and while shaden point is not a few flowing the sound with the primate and the sound of the sound

Keywords: anonymity, disclosure, ethics, gamete donation, privacy, 'right to be forgotten'

El derecho al olvido frente al derecho a revelar la identificación de los donantes de gametos: consideraciones éticas y

Formore II amonima de los denamos de generos en el commo de la tristaca de reproducción molicamente anistis. Un el reducto de de contractorio cameros de lacular desigio en una municipa especialmente debuche en la contractorio de la contractorio del contractorio de la contractorio del contrac

Palabras clave: anonimaro, divulgación, ética, donación de gameros, privacidad, 'derecho al obrido'

O Direito ao Esquecimento sersus o Direito à Divulgação da Identificação de Dadores de Gâmetas: Considerações Éstica e Legais

Research O sensitions for defending digitients as contraved due their the granding medication and middle of the defending and desired as confidenced in the confidence of the

Palavras-chave: anonimato, divulgação, ética, doação de gâmetas, privatidade, 'direito ao esqueciment

*Faculty of Medicine of the University of Perm, Peers, Permgd. ORCID: https://www.doi.org/0000-0002/934-7029 Communitation.com/orciditation/orce/

Faculty of Medicine of the University of Purss, Purss, Purssyl, OBCID: http://orcid.org/0000-0002-8590-9832 Generaposelence: golfministeraggicaled as pre Faculty of Medicine of the University of Purss, Purss, Purssyl, OBCID: http://orcid.org/0000-0002-1377-9899

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



Perspective III

RTBF / purpose limitation principle / data minimisation

Difficulties to enforce the right to disclosure of donor identification

RTBF

Influence international trend towards nonanonymity

Right to anonymity **Absolute right**

Important Broad discussion

21

Legal protection individual rights

> **Biological** descendants

> > **Donors**

Legal and emotional family

Ethical and legal approach

Improving concepts personal identity personality



Perspective IV

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



THE RIGHT TO BE FORGOTTEN AND COVID-19: PRIVACY VERSUS PUBLIC INTEREST Mónica Correia¹, Guilhermina Rego², Rui Nunes³ Abstract: Recent studies highlight the importance of digital surveillance to gather individual health information due to the global pundemic caused by the new COVID-19 disease. This paper analyses in legal and orbical implications at the interface between the individual right no privacy and the collective interests of public health. We framed the discussion in law, domentolog and rellizationism. The lasted theories and human rights, especially privacy, are crucial in our argument. Health-derived differentiate and efforts to solve them, especially by information technologies, bloothics and law, exist at these perspectives interface. In periodical, we analysed the intersection between automost, the right to spiricey, and the so-called rights to be forgetted in the particular, we analyzed the immercions between autonomy, the right to privacy, and the so called "right to be longormic in the public helds rounts, in roth woods, we entitled the right to whethin much secondormic resums of health that a radical mean of control over general data enabled in britch 87 of the General Data Protection Regulations (OPPR). Govern the of specific production of the results of the resu Keywords: COVID-19, ethics, privacy, public health, 'right to be forgotten' El derecho al olvido y el COVID-19: privacidad frente a interés público Resumen: Estudios recientes destacin la importancia de la vigilancia digital para recoger información sanitaria individual debido a la trandemia mundial causada por la morva enfermedad COVID-19. Este articulo stadita sus implicaciones lesales y écicas en la interfaz entre el derecho individual a la priscaldad y los intereses cultervos de la salud pública. Emmacamos la discussión en el derecho, la destrología y el utilizatione. Estas últimas tereixa y los derechos humanos, especialmente la priscaldad, son concisio en masson argamento. Los difinans descondos con la salud y los enferansos por ensolverlos, especialmente a través. cración on mestros argamento. Los dienas séricionados con la saled y los enhamas por mediverso, especialmente a trede-de la translegad de información, ha historia, y ol derecho, ser consumar en la intertada de na perspectiva. En particular, a anátumos la innescedio entre la aumonesta, d'elecndo a la persociada y el farama de función al devidor en el contexto de la sulta pública. Escán condustante el derecho a beserven del responsable del transmento la pueda de función de solad, un medio racical de control sobre los datas persociados con afrecidos en el miscola y Fales. del transmentos la pueda pública. Escán del (GCFP). Dela la final de especial del control sobre los datas persociados en afrecido y Fales pueda del pueda del (GCFP). Dela la final del especial del control sobre los delas persociados de destro dame por el dela pueda por la control del pueda final del servicio del destro dame por el delas persociados del control del pueda final delas del control del pueda final del servicio del dello dame por el del pueda d de las garantias legales, sugiriendo la aplicación del "derecho al obido" según una interpretación ética. Palabras clave: COVID-19, érica, privacidad, salud pública, "derecho al olvido" O Direito ao Esquecimento e COVID-19: Privacidade sersas Interesse Público Resumor: Estudios recentes utilentam a importância da vigilância digital para recolher informações individuais de sainde devido à pandemis global causada pela nova desença CVMID-19. Esta artigio analism as usas implicações legais e feitica na interface entete e direitos individual à princidade e os interesses coloritos. Enqualemnos a discussión os direitos, na dornotelogia. eno utilitarismo. As úlcimas teorias e os direitos humanos, especialmente a privacidade, são cruciais na nosta argumentação Exlemas derivados da saúde e esforços para os resolver, especialmente através das tecnologias da informação, da bioética e d direito, existem na interface destra pempetroa. Em puricular, analisimos a interseção cura autonomia, dicieo à princidade, con claumo d'inferio no su oqueriremos mon commo da sudie pública. For oura pulavas, amulianos o derivado de bode en responsive pelo tratamento o appagamento dos dados de salde, um maio radicial de controlo dos dados pessasio embelecida e no aragio 17-0 de Regulamento Gord dados de salde, um maio radicial de controlo dos dados pessasio embelecida e no aragio 17-0 de Regulamento Gord de Proteçais de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Controlo dos dados pessasios em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de especificados em relação a Foresta de Dados (RFTP). Dada a faita de RFTP (RFTP).

Acta Bioethica 2021; 27 (1): 59-67. DOI: http://dx.doi.org/10.4067/S1726-569X2021000100059

Palasma-chave: COVID-19, ética, privacidade, suide pública, 'direito ao esquecimento

Faculty of Medicine of the University of Porto, Porto, Phrougal, ORCID: https://orcid.org/0000-0002-9034-7029

de acordo com uma interrortação ética.

*Paculary or Medicine of the University of Prens, Paris, Portugat. CML, LEP, Empirical angustro-tomic 20034-0225 Correspondence: microsis@mod.up.pt *Paculary of Medicine of the University of Paris, Paris, Paris, Deragal. ORCID: http://orcid.org/0000-0002-8590-9632

reutilização de tais dados no âmbito aliagado dos objetivos de saide pública, o consentimento implicito não aborda a questa da proporcionalidade. Destacamos a insuficiência de salvaguandas juridicas, superindo a aplicação do "direito ao esquecimento"

Excelly of Medicine of the University of Pures, Pures, Puresgal. OBCID: http://occid.org/0000-0002-8590-5832
 Correspondence: guilbernisaspojiened.org.pt
 Excelly of Medicine of the University of Pures, Purus, Purusgal. OBCID: http://occid.org/0000-0002-1577-5899



Perspective IV

Discussion

Deontology

Utilitarianism

Human rights

Imperative public health reasons

No basis for exercising the 'right to be forgotten'

Conflicting human rights

Proportionality critical factor

Burden of proof of health authorities

Demonstrate compelling reasons

Moral duty to preserve patients' health data Strict utilitarian perspective

Marginalisation / Social stigma

Vulnerability increase

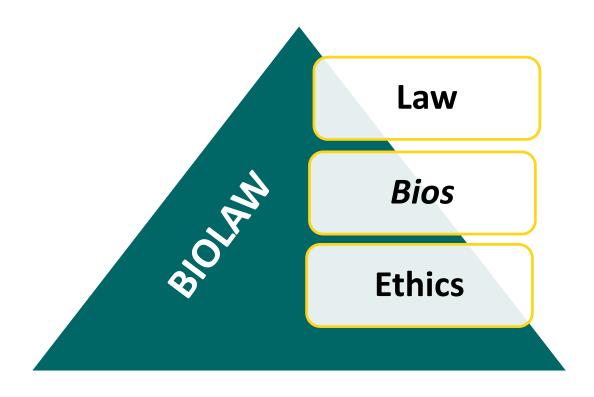


General Conclusions

- 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



General Conclusions





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-intenet-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!

Mónica Correia

mcorreia@med.up.pt





FACULDADE DE MEDICINA UNIVERSIDADE DO PORTO

Alameda Prof. Hernâni Monteiro 4200-319 Porto

WWW.MED.UP.PT