



KU LEUVEN CAMPUS BRUSSELS
FACULTY OF LAW
Academic year 2024-2025

**Navigating Post-mortem Genetic Data Protection in the Digital Hereafter:
If DNA Decays, Does Privacy Stay?**

Word Count: 14 987

Promoter: L. DRECHSLER
Co-Promoter: E. KINDT

Master's thesis, submitted by
Thierry TORFS
as part of the final examination for the degree of
MASTER OF INTELLECTUAL PROPERTY AND ICT LAW



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Abstract

This thesis explores the legal landscape surrounding post-mortem genetic data within the European Union (EU), addressing the question of how individuals can maintain control over their genetic data after death. While the General Data Protection Regulation (GDPR) primarily safeguards the rights of living individuals, the relational nature of genetic data – where genetic information about the deceased can also reveal information about biological relatives – creates unique challenges for post-mortem data governance.

The research analyses the fragmented legal landscape throughout EU Member States, underscoring the lack of harmonised legislation and the resulting uncertainty in the protection of post-mortem genetic data. By reviewing national laws, EU guidelines, and relevant case law, the thesis identifies gaps in both legal protection and enforcement.

The research employs a mixed methods approach, combining legal doctrine research, comparative legal analysis, and case studies to provide a comprehensive analysis. Key judicial decision of the Court of Human Rights (ECtHR) and the Court of Justice of the European Union (CJEU) are analysed to understand the continuous evolving principles surrounding post-mortem genetic data protection.

Technological developments, such as advanced consent management systems and privacy-enhancing technologies, are evaluated for their potential to improve post-mortem data control. However, the integration of these tools with existing legal frameworks remains unclear. This thesis concludes by recommending a more coherent European approach, combining legal clarification, technological safeguards, and stakeholder involvement to ensure that genetic privacy is respected post-mortem.

Acknowledgments

I am grateful for the opportunity to contribute to the discussion on post-mortem genetic data protection and to have performed my thesis on this topic.

First, I would like to express my sincere gratitude to my promotor **Prof. Dr. Laura Drechsler** for her guidance and support throughout this research. Her expertise and insights in data protection law have been invaluable, I am honoured to have her as my promotor.

I am also thankful to my co-promotor **Prof. Dr. Els Kindt**, for supervising me during this research and for her insightful feedback and encouragement, as well as her knowledge and expertise.

Furthermore, I would like to express my gratitude to my **family and friends** for their unwavering support and encouragement. Thank you all for being on this journey with me.

Table of Contents

1. Introduction	1
1.1 Background and Context.....	1
1.1.1 Post-Mortem Privacy Concerns and Genetic Data	1
1.1.2 Balancing Rights and Interests	2
1.2 Ethical and Privacy Concerns in Post-Mortem Genetic Data Protection	3
1.2.1 Privacy versus Data Protection.....	3
1.2.2 Informed Consent Challenges	4
1.2.3 Post-mortem Genetic Data Protection and the Legal Landscape	4
1.1. Research Question and Objectives.....	5
1.1.1. Main Research Question.....	5
1.1.2. Sub-Questions	6
1.1.3. Methodology	6
2. Legal Framework and Current Data Protection Laws on Post-Mortem Genetic Data Protection in the EU.....	8
2.1. Introduction.....	8
2.2. Overview of European Data Protection Law	8
2.3. Applicability of the GDPR to Genetic Data and Post-Mortem Data.....	9
2.3.1. Genetic Data as a Special Category.....	9
2.3.2. Applicability of the GDPR to Post-Mortem Genetic Data Protection....	10
2.4. Guidelines and Recommendations on Genetic Data Processing.....	11
2.4.1. EDPB and Council of Europe Guidelines	11
2.5. Legal and Ethical Challenges in Post-Mortem Genetic Data Protection...	13
2.5.1. Consent and Legitimate Interest	13
2.5.2. Impact on Living Relatives	14
2.5.3. Ethical Considerations and Research Guidelines	15
2.6. National legislation	16
2.6.1. Countries with Specific Legislative Provisions	17
2.6.2. Countries with Limited or No Specific Provisions	18
2.7. Conclusion.....	23

3. Case Law on Post-Mortem Genetic Data and Privacy.....	25
3.1. Introduction.....	25
3.2. Proportionality and Necessity in Genetic Data Retention	25
3.3. Proportionality in Data Retention for Minor Offenders	26
3.4. Familial Identification and Genetic Profiling	26
3.5. Posthumous Reproduction and Ethical Considerations.....	27
3.6. Religious Objections to Post-Mortem Examinations.....	27
3.7. Balancing Competing Interests in DNA Testing for Ancestry	28
3.8. Conclusion.....	31
4. Stakeholders.....	33
4.1. Introduction.....	33
4.2. Balancing Competing Interests in Post-Mortem Genetic Data Protection	33
4.3. The Deceased and Their Relatives	34
4.4. Healthcare Professionals	35
4.5. Researchers and Biotech Companies	35
4.6. Public Interest Groups	37
4.7. Conclusion.....	38
5. Interpretation of Findings	39
5.1. Introduction.....	39
5.2. Legal Fragmentation	39
5.3. Legal Precedents on Post-Mortem Genetic Privacy	40
5.4. Stakeholder Perspectives on Post-Mortem Genetic Data	41
5.5. Enforcement and Technological Challenges.....	42
5.6. The “Right to Erasure” and Post-Mortem Data	43
5.7. Conclusion.....	43
6. Technological Tools for Balancing Post-Mortem Genetic Data Protection	44
6.1. Introduction.....	44
6.2. Legal and Ethical Frameworks.....	44
6.2.1. The Data Subject and Their Post-Mortem Genetic Data	44
6.2.2. Rights of Surviving Family Members.....	46
6.2.3. Other Stakeholders in the Context of Post-Mortem Genetic Data	47

6.3.	Technological Measures for Post-Mortem Genetic Data Control.....	49
6.3.1.	Anonymisations and the Limits of Genetic Data De-Identification.....	49
6.3.2.	Feasibility of Anonymisation Techniques.....	50
6.3.3.	Technological Solutions	52
6.3.4.	Advanced Consent Management Systems	53
6.3.5.	Robust Data Storage and Access Control.....	53
6.3.6.	AI and Smart Contract Systems	53
6.3.7.	Access Management and Data Minimisation Techniques.....	54
6.3.8.	Role-Based Access Control.....	54
6.3.9.	Data Degradation and Minimisation Methods	55
6.3.10.	Compliance with GDPR Principles.....	56
6.3.11.	Adaptability to National Laws	57
6.4.	Fostering a Culture of Responsibility and Accountability	59
6.5.	Conclusion.....	61
7.	Recommendations for a Comprehensive Post-Mortem Genetic Data Protection Framework.....	63
7.1.	Introduction.....	63
7.2.	Legal Recommendations	63
7.2.1.	Clarification and Amendment of the GDPR.....	63
7.2.2.	National Legislation and Implementation.....	66
7.2.3.	Strengthening Data Security and Anonymisation Techniques.....	67
7.2.4.	Balancing Stakeholder's Interests	68
7.2.5.	International Cooperation and Harmonisation	69
7.3.	Technological Recommendations.....	71
7.3.1.	Integration with the European Health Data Space (EHDS)	71
7.3.2.	Data Security and Privacy-Enhancing Technologies (PETs)	71
7.3.3.	Consent and Preference Management.....	73
7.3.4.	Interoperability and Harmonisation.....	74
7.4.	Conclusion.....	75
8.	Conclusion.....	77
8.1.	Introduction.....	77

8.2.	Addressing the Main Research Question	77
8.3.	Summary of Findings	77
8.4.	Implications for Future Research and Policy	78
Bibliography		80
Annexes		87
Annex I. Glossary of Terms.....		87
Annex II. Relevant EU Directives and Recommendations		91
Annex III: National Laws		97
Annex IV. Case Summaries.....		105

List of Abbreviations

ABAC	Access-Based Access Control
AI	Artificial Intelligence
CJEU	Court of Justice of the European Union
DNA	Deoxyribonucleic Acid
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
EDPB	European Data Protection Board
EHDS	European Health Data Space
EU	European Union
GDPR	General Data Protection Regulation
LED	Law Enforcement Directive
MFA	Multi-Factor Authentication
PETs	Privacy-Enhancing Technologies
RBAC	Role-Based Access Control
SIEM	Security Information and Event Management

List of Annexes

Annex I. Glossary of Terms.....	87
Annex II. Relevant EU Directives and Recommendations	91
Annex III: National Laws	97
Annex IV. Case Summaries.....	105

1. Introduction

1.1 Background and Context

1.1.1 Post-Mortem Privacy Concerns and Genetic Data

The digital age has caused an exponential increase in the generation, storage, and processing of personal data, including genetic information. While much attention is given to protecting genetic information of living individuals, the fate of this data after death remains largely unexplored. Post-mortem privacy, in the context of personal data, refers to the protection and control of an individual's personal and genetic information after their death ¹.

Genetic data holds a unique position within post-mortem privacy because of its relational nature, as it not only reveals information about the deceased, but also about their living relatives. This poses significant challenges for post-mortem data protection. There is a need to balance the rights of the deceased, the interests of living relatives, and the potential benefits for medical research ².

For instance, consider a scenario where a young adult suddenly passes away from a cardiac arrest. Post-mortem genetic testing reveals a genetic variant linked to Long QT Syndrome, a condition that can cause sudden cardiac death. This information helps understanding the cause of death, but is also important information for living relatives who may share the same genetic predisposition ³.

¹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>

² Ibid., Boers, S. N., van Delden, J. J. M., Knoers, N. V., & Bredenoord, A. L. (2015). Postmortem disclosure of genetic information to family members: active or passive? *Trends in Molecular Medicine*, 21(3), 148-153. <https://doi.org/10.1016/j.molmed.2015.01.002>

³ Ribeiro, S., Coelho, L., Puentes, K., Miltenberger-Miltenyi, G., Faria, B., Calvo, L., Primo, J., Sanfins, V., & Lourenço, A. (2019). Postmortem genetic testing: Clinical diagnosis is not ended by the patient's death [10.1016/j.repce.2019.09.001]. *Revista Portuguesa de Cardiologia (English edition)*, 38(7), 503-509. <https://doi.org/10.1016/j.repce.2019.09.001> , Tester David, J., & Ackerman Michael, J. (2007). Postmortem

Post-mortem genetic data raises two primary issues from a data protection and privacy perspective. First, although the General Data Protection Regulation (GDPR) is designed to protect the personal data of living individuals, post-mortem genetic data may also reveal identifiable information about living relatives, making the GDPR's protection applicable for these living relatives. Second, since the GDPR does not extend to the data of deceased persons, there is considerable uncertainty and variation across Member States concerning the appropriate handling, access, and use of this data after death ⁴.

This thesis will address to what extent a living person can determine what will happen to their genetic information after death, and the rights of stakeholders, such as family members.

1.1.2 Balancing Rights and Interests

Several EU Member States have begun to recognise the importance of post-mortem data protection for genetic data. This increasing recognition underscores the need for a more coherent and harmonised European approach to post-mortem data protection, particularly in the context of genetic identifiability ⁵. The management of genetic data requires a comprehensive framework that respects the wishes of the deceased while enabling legitimate use of data for research, historical preservation, and familial purposes.

Technological measures for post-mortem genetic data control have emerged in recent years, allowing individuals to manage their personal data more effectively and

Long QT Syndrome Genetic Testing for Sudden Unexplained Death in the Young. *JACC*, 49(2), 240-246. <https://doi.org/10.1016/j.jacc.2006.10.010>

⁴ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>

⁵ Malgieri, G. (2019). R.I.P.: Rest in Privacy or Rest in (Quasi-)Property?: The Internet of Bodies. In. <https://doi.org/10.5040/9781509926237.ch-006>

ensuring that their wishes regarding genetic information are respected after their death. However, the interaction between these technological measures and legal frameworks remains elusive, requiring a more integrated approach. For instance, while tools such as blockchain-based systems can securely store and manage post-mortem genetic data, it is not clear how these tools align with existing legal frameworks, such as the GDPR ⁶. This raises questions about who should be able to access or modify such data after death, and whether these systems can address the relational nature of genetic information regarding living relatives.

The effective management of post-mortem genetic data requires a combination of technological solutions and legal regulations to ensure that the rights of the deceased and their families are upheld, particularly in the context of identifiability of genetic data.

1.2 Ethical and Privacy Concerns in Post-Mortem Genetic Data Protection

1.2.1 Privacy versus Data Protection

Privacy refers to an individual's right to control access to their personal information, including genetic data. Even though privacy and data protection are closely linked, they are distinct concepts. Privacy addresses the right to confidentiality, whereas data protection involves the mechanisms and safeguards put in place to prevent unauthorised use or breaches ⁷.

One of the major concerns in post-mortem genetic data protection is the privacy of the deceased and their living relatives. Genetic data can reveal sensitive information about an individual's health, ancestry, and other genetic traits, which may have implications

⁶ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Boers, S. N., van Delden, J. J. M., Knoers, N. V., & Bredenoord, A. L. (2015). Postmortem disclosure of genetic information to family members: active or passive? *Trends in Molecular Medicine*, 21(3), 148-153. <https://doi.org/10.1016/j.molmed.2015.01.002>

⁷ Concurrences., P. a. d. p. (2024). Privacy and data protection - Cuncurrences. In <https://www.concurrences.com/en/dictionary/privacy-and-data-protection>

for their family members. The permanent nature of genetic data increases the risk of future misuse, as technological advancements may enable more detailed analyses and increase risk of unauthorised access ⁸.

1.2.2 Informed Consent Challenges

Informed consent is one of the fundamental principles of ethical research and data use, ensuring respect for autonomy and individual decision-making. This is also a legal requirement in many jurisdictions to comply with the regulations governing the use of personal data and participation in research. However, obtaining consent from deceased individuals is inherently impossible. Even though consent provided while they were alive could still be valid from an ethical research perspective, this depends on the scope and conditions under which it was initially given. Proxy consent from family members may not always be feasible or ethically valid, which raises questions about the legitimacy of using post-mortem genetic data without explicit consent from the deceased individual. The absence of clear guidelines for obtaining proxy consent further complicates the ethical concerns ⁹.

1.2.3 Post-mortem Genetic Data Protection and the Legal Landscape

Post-mortem genetic data protection addresses the ethical, legal, and security challenges associated with an individual's genetic information after their death. Among these challenges, the identifiability and sensitivity of genetic data are particularly significant, as genetic data can reveal sensitive information about individuals and their relatives, bringing them under the GDPR's scope. These aspects

⁸ Bak, M. A. R., & Willems, D. L. (2022). Contextual Exceptionalism After Death: An Information Ethics Approach to Post-Mortem Privacy in Health Data Research. *Sci Eng Ethics*, 28(4), 32. <https://doi.org/10.1007/s11948-022-00387-0>, Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>

⁹ Gibbon, V. E., Thompson, J. C., & Alves, S. (2024). Informed proxy consent for ancient DNA research. *Communications Biology*, 7(1), 815. <https://doi.org/10.1038/s42003-024-06413-0>, Wicclair, M. R. (2002). Informed consent and research involving the newly dead. *Kennedy Inst Ethics J*, 12(4), 351-372. <https://doi.org/10.1353/ken.2002.0028>

are central to this thesis, which focuses on addresses these two specific challenges within the broader context of post-mortem genetic data protection ¹⁰.

This thesis specifically examines post-mortem genetic data protection within the framework of European Union (EU) law, with particular emphasis on the GDPR. This research explores how existing provisions of the GDPR can be interpreted and adapted to address the specific challenges posed by post-mortem genetic data.

The remainder of this thesis is structured as follows:

- Chapter 2: Legal Framework and Current Data Protection Laws on Post-Mortem Genetic Data Protection in the EU
- Chapter 3: Case Law on Post-Mortem Genetic Data and Privacy
- Chapter 4: Stakeholders
- Chapter 5: Interpretation of Findings
- Chapter 6: Technological Tools for Balancing Post-Mortem Genetic Data Protection
- Chapter 7: Recommendations for a Comprehensive Post-Mortem Genetic Data Protection Framework
- Chapter 8: Conclusion

1.1. Research Question and Objectives

1.1.1. Main Research Question

The main research question guiding this thesis is: How can post-mortem genetic data protection be integrated under European data protection law to ensure individuals maintain control over their genetic information after death, thereby upholding

¹⁰ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Noroozi, M., Bahmani, F., Mousavizadeh, K., Saeedi Tehrani, S., Hashemi, A., & Forouzandeh, M. (2022). To use or not to use? an ethical analysis of access to data and samples of a deceased patient for genetic diagnostic and research purposes. *J Med Ethics Hist Med*, 15, 13. <https://doi.org/10.18502/jmehm.v15i13.11569>

fundamental rights to privacy, preventing potential misuse of sensitive genetic information, and fostering public trust in genetic research and data handling practices?

1.1.2. Sub-Questions

To address the main research question, the following sub-questions will be explored.

- (i) To what extent do existing European data protection laws and guidelines apply to post-mortem genetic data, and what are the main legal and ethical challenges that arise?
- (ii) How have key judicial decisions shaped the legal landscape for the protection and use of post-mortem genetic data?
- (iii) How do the interests and concerns of families, healthcare professionals, researchers, biotech companies, and the broader public influence the governance of post-mortem genetic data?
- (iv) What are the main gaps, challenges, and areas of fragmentation in the current legal and practical approaches to post-mortem genetic data, and how do these impact the rights and interests of the deceased and their relatives?
- (v) How can technological measures complement legal frameworks to ensure effective protection and responsible use of post-mortem genetic data?
- (vi) What practical steps can be taken at both the legislative and technical levels to ensure a coherent, effective, and ethically sound framework for the protection and responsible use of genetic data?

1.1.3. Methodology

I will use a mixed-methods approach to answer the different research questions. By combining legal doctrine research, comparative legal analysis, and case studies, I will attempt to address the complex nature of post-mortem genetic data protection within the European legal framework. The methods described below complement each other and will ensure a robust and comprehensive analysis.

Legal doctrine research analyses existing laws and regulations, and their applicability to post-mortem genetic data. This includes the GDPR (2016/679) and guidelines issued by the EDPB. While the Law Enforcement Directive (LED, 2016/680) would be of interest, it is beyond the scope of this thesis ¹¹.

Comparative legal analysis will examine and compare post-mortem data protection laws in different EU Member States, focussing on legal frameworks, regulatory approaches, and implementation challenges ¹².

Case study analysis will investigate the effectiveness of existing legal frameworks and specific cases of post-mortem data protection issues and their legal implications ¹³.

Stakeholder analysis will identify and evaluate the interests of various parties involved in the processing of deceased individuals genetic data – including family members, healthcare professionals, researchers, and public interests – which is essential in developing balanced and practical recommendations.

Technological analysis assesses existing and emerging tools, access management systems, and data minimisation techniques that facilitate post-mortem data control. This will contribute to the development of practical recommendations for implementing a post-mortem data protection framework.

¹¹ The LED specifically regulates the processing of personal data by competent authorities for the purposes of the prevention, investigation, detection, or prosecution of criminal offences and the execution of criminal penalties. In contrast, this thesis focuses on the application of general European data protection laws – primarily the GDPR – and their relevance to post-mortem genetic data in non-law enforcement contexts.

¹² Van Hoecke, M. (2015). Methodology of comparative legal research. *Recht Methode Onderz. Onderwijs*. <https://doi.org/10.5553/rem/.000010>

¹³ Argyrou, A. (2017). Making the case for case studies in empirical legal research. *Utr. Law Rev.*, 13(3), 95. <https://doi.org/10.18352/ulr.409>

2. Legal Framework and Current Data Protection Laws on Post-Mortem Genetic Data Protection in the EU

2.1. Introduction

This chapter examines the legal framework governing the protection of post-mortem genetic data within the EU. It addresses the first sub-question of this thesis: To what extent do existing European data protection laws and guidelines apply to post-mortem genetic data, and what are the main legal and ethical challenges that arise?

This chapter discusses the relevant European data protection instruments, such as the GDPR, and explores their applicability to post-mortem genetic data. Then, it reviews guidelines and recommendations from bodies such as the European Data Protection Board (EDPB) and the Council of Europe, as well as national legislations. Special attention is given to the relational nature of genetic data, which may impact the rights of both the deceased and living relatives.

2.2. Overview of European Data Protection Law

European data protection law has evolved the past decades, aiming to safeguard the personal data and privacy rights of individuals. The main legal instrument is the GDPR (2016/679), which came into effect on May 25, 2018, replacing the earlier Data Protection Directive (96/46/EC). The GDPR aims to harmonise data protection laws across all EU Member States, providing a consistent and high level of protection for individuals personal data. It applies to data controllers and processors, whether they are based in the EU or outside, as long as they process the personal data of individuals located in the EU ¹⁴.

The GDPR applies to the processing of personal data, which includes any information relating to an identified or identifiable natural person. This encompasses a wide range

¹⁴ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), 1-88 119 (2016). <http://data.europa.eu/eli/reg/2016/679/oj>

of data, from basic identification data to sensitive data such as genetic and biometric data. The regulation introduces several rights for data subjects, including the right of access, the right to rectification, the right to erasure, the right to restrict processing, the right to data portability, the right to object and the right not to be subject to a decision based solely on automated processing. These rights allow individuals to have greater control over their personal data ¹⁵.

2.3. Applicability of the GDPR to Genetic Data and Post-Mortem Data

2.3.1. Genetic Data as a Special Category

In the context of genetic data, the GDPR classifies them as a special category of personal data, subject to stricter processing conditions. Article 4(13) of the GDPR defines genetic data as *personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question*. The processing of these data is generally prohibited unless specific conditions are met, such as explicit consent from the data subject or processing being necessary for reasons of substantial public interest ¹⁶.

In addition, Article 9 of the GDPR establishes stringent rules for processing special categories of personal data, including genetic data. The sensitivity of genetic data requires robust protection measures to safeguard individual privacy and rights. Article 9(1) stipulates this general prohibition on processing genetic data, with exceptions outlined in Article 9(2). These exceptions include explicit consent, employment and social security obligations, vital interests, legal claims, public interest, healthcare, public health, archiving, research, and statistical purposes ¹⁷.

¹⁵ Ibid.

¹⁶ Ibid., Shabani, M., & Borry, P. (2018). Rules for processing genetic data for research purposes in view of the new EU General Data Protection Regulation. *European Journal of Human Genetics*, 26(2), 149-156. <https://doi.org/10.1038/s41431-017-0045-7>

¹⁷ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement

The processing of post-mortem genetic data presents unique legal considerations. While the GDPR primarily focuses on living individuals, the genetic data of deceased individuals may impact living relatives, raising concerns about privacy and potential genetic discrimination. Article 9(4) allows Member States to introduce further conditions regarding the processing of genetic data, which may extend to post-mortem genetic data regulations.

2.3.2. Applicability of the GDPR to Post-Mortem Genetic Data Protection

Recital 27 of the GDPR clearly states that it “*does not apply to the personal data of deceased persons.*” As a result, the GDPR’s protections and data subject rights are only enforceable by living individuals. Therefore, clear guidelines need to be established for managing post-mortem personal data ¹⁸. However, genetic data can also reveal sensitive information about living relatives, potentially bringing it back under the GDPR’s scope in certain circumstances.

Recital 34 of the GDPR defines genetic data as personal data relating to the inherited or acquired genetic characteristics of a natural person. This includes information obtained from the analysis of biological samples, such as chromosomal, DNA, or RNA analysis, or any other element that provides equivalent information about an individual’s genetic makeup. As mentioned earlier, genetic data is considered a special category of personal data under the GDPR, requiring additional protection due to its sensitive nature and potential impact on an individual’s privacy and rights ¹⁹.

of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), 1-88 119 (2016). <http://data.europa.eu/eli/reg/2016/679/oj>, Staunton, C., Slokenberga, S., & Mascalzoni, D. (2019). The GDPR and the research exemption: considerations on the necessary safeguards for research biobanks. *European Journal of Human Genetics*, 27(8), 1159-1167. <https://doi.org/10.1038/s41431-019-0386-5>, What are the rules on special category data? (2024). <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/lawful-basis/special-category-data/what-are-the-rules-on-special-category-data/>

¹⁸ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), 1-88 119 (2016). <http://data.europa.eu/eli/reg/2016/679/oj>

¹⁹ Ibid.

The GDPR adopts a contextual, risk-based approach to determine the identifiability of genetic data, as stated in Recital 26, which considers “*all the means reasonably likely to be used*” to identify an individual. The assessment takes into account factors such as costs, time required, and available technology. While the GDPR generally treats genetic data as personal data, it recognises that not all genetic information is necessarily identifiable, and the determination must be made on a case-by-case basis ²⁰.

Article 17 of the GDPR, the right to erasure or often referred to as the right to be forgotten, can only be exercised by living individuals, but may have implications for post-mortem data. In some national laws, such as in Spain, family members may request the erasure of a deceased individual’s genetic data under certain circumstances, such as if the deceased had expressed a wish for their data not to be used for research ²¹.

2.4. Guidelines and Recommendations on Genetic Data Processing

2.4.1. EDPB and Council of Europe Guidelines

The EDPB, established by the GDPR, issues guidelines, recommendations, and best practices to clarify the legal framework resulting from data protection directives and promotes the consistent application of the GDPR across the EU. While the Board advises the European Commission and data protection issues, its main tasks include providing guidance to ensure consistent application of data protection rules, taking

²⁰ Ibid., Shabani, M., & Marelli, L. (2019). Re-identifiability of genomic data and the GDPR: Assessing the re-identifiability of genomic data in light of the EU General Data Protection Regulation. *EMBO Rep*, 20(6). <https://doi.org/10.15252/embr.201948316>

²¹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders’ perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), 1-88 119 (2016). <http://data.europa.eu/eli/reg/2016/679/oj>, Shabani, M., & Marelli, L. (2019). Re-identifiability of genomic data and the GDPR: Assessing the re-identifiability of genomic data in light of the EU General Data Protection Regulation. *EMBO Rep*, 20(6). <https://doi.org/10.15252/embr.201948316>

decisions on cross-border data protection cases, and promotes cooperation among national supervisory authorities. The EDPB has emphasised that genetic data is extremely difficult to fully anonymise, even after death, and recommends treating this data with the same technical and organisational safeguards as for living individuals. This includes pseudonymisation, controlled access, and restricting cross-matching with other registries to protect the privacy of living relatives whose data may be implicated.²²

The Council of Europe's recommendation No. R (97) 5 on the protection of medical data addresses the collection, processing, and use of genetic data. While not legally binding, this recommendation provides guidelines for Member States on handling sensitive medical information, including genetic data. It emphasises the need to appropriate safeguards when using genetic information for forensic purposes, stating that such use should be governed by law. This recommendation underscores the importance of protecting individual privacy rights, even after death, and highlights the need for careful consideration of the ethical implications of using genetic data in criminal investigations²³.

Additionally, the Council of Europe's Recommendation CM/Rec(2016)6 presumes consent for the use of biological samples from deceased persons for research, unless the individual expressed opposition while alive. This presumption is generally extended to data derived from those samples²⁴.

²² European Data Protection Board. (2025). *Role of the EPDB*. https://www.edpb.europa.eu/about-edpb/who-we-are/european-data-protection-board_en

²³ COUNCIL OF EUROPE COMMITTEE OF MINISTERS. (1997). *RECOMMENDATION No. R (97) 5 OF THE COMMITTEE OF MINISTERS TO MEMBER STATES ON THE PROTECTION OF MEDICAL DATA*.: COUNCIL OF EUROPE COMMITTEE OF MINISTERS Retrieved from <https://rm.coe.int/cmrec-97-5-on-the-protection-of-medical-data/1680a43b64>

²⁴ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR?

2.5. Legal and Ethical Challenges in Post-Mortem Genetic Data Protection

2.5.1. Consent and Legitimate Interest

The GDPR requires a lawful basis for processing personal data, such as consent or legitimate interest. According to a study conducted for the EDPD, the GDPR presumes compatibility for secondary processing for scientific research purposes, this presumption is subject to appropriate safeguards and does not exempt researchers from the requirement to identify a valid legal basis for processing, especially for special categories of data such as genetic information ²⁵. In the context of deceased individuals, obtaining consent is not possible, and determining legitimate interest becomes complex, particularly when balancing the rights of the deceased with those of other stakeholders ²⁶. This raises the question of whether an alternative legal basis, such as legitimate interest, can be invoked. Additionally, the GDPR requires explicit consent for processing special categories of data, including genetic data, under Article 9(2)(a), unless other conditions apply. This explicit consent highlights the GDPR's emphasis on individual control over sensitive data ²⁷.

Furthermore, there remains the situation where the deceased had not explicitly provided consent. The absence of clear provisions in legal frameworks raises questions about the rights of stakeholders, including family members, who may have legitimate

https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

²⁵ Study on the secondary use of personal data in the context of scientific research., (2020). https://www.edpb.europa.eu/our-work-tools/our-documents/other/study-secondary-use-personal-data-context-scientific-research_en

²⁶ Gibbon, V. E., Thompson, J. C., & Alves, S. (2024). Informed proxy consent for ancient DNA research. *Communications Biology*, 7(1), 815. <https://doi.org/10.1038/s42003-024-06413-0>, Wicclair, M. R. (2002). Informed consent and research involving the newly dead. *Kennedy Inst Ethics J*, 12(4), 351-372. <https://doi.org/10.1353/ken.2002.0028>

²⁷ Gibbon, V. E., Thompson, J. C., & Alves, S. (2024). Informed proxy consent for ancient DNA research. *Communications Biology*, 7(1), 815. <https://doi.org/10.1038/s42003-024-06413-0>, Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), 1-88 119 (2016). <http://data.europa.eu/eli/reg/2016/679/oj>, Wicclair, M. R. (2002). Informed consent and research involving the newly dead. *Kennedy Inst Ethics J*, 12(4), 351-372. <https://doi.org/10.1353/ken.2002.0028>

interest in the use or restriction of such data. National laws within EU Member States vary in their approach to this issue. Some countries may allow the use of genetic data for certain purposes based on presumed consent or balancing interests, while others impose stricter regulations to protect the privacy of the deceased and their relatives. The legal basis for withdrawing consent or restricting data use typically involves balancing the interests of the deceased, the family, and the broader public interest, taking into account ethical considerations and fundamental rights.

2.5.2. Impact on Living Relatives

The processing of genetic data from deceased individuals presents unique legal and ethical challenges as such data often reveals information about both the deceased and their living relatives. While the GDPR does not directly apply to the data of deceased persons, it does protect the personal data of living individuals. If the data from a deceased person can be used to identify or infer information about living relatives, such as genetic predispositions to certain diseases, familial relationships, or other sensitive attributes, then the GDPR's protection extends to those living relatives²⁸.

This means that if research or data processing involving a deceased person's genetic material also reveals identifiable information about living family members, those relatives become "data subjects" under the GDPR and are entitled to exercise their data protection rights, such as access, rectification, or objection to processing. For example, a genetic analysis that uncovers hereditary conditions or familial links, inherently impacts the privacy of living relatives, even if the original data subject is deceased²⁹.

²⁸ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Office, G. D. P. O. s. (n.d.). *Tietosuojaaltuutetun Toimisto*. . <https://tietosuoja.fi/en/faq-genealogy>

²⁹ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Office, G. D. P. O. s. (n.d.). *Tietosuojaaltuutetun Toimisto*. . <https://tietosuoja.fi/en/faq-genealogy>

Controllers must therefore take precautions to prevent the disclosure of personal data about living relatives when processing genetic information from deceased persons. This may include measures such as pseudonymisation, applying controlled access protocols, conducting legitimate interest assessments, and consulting with ethics committees ³⁰.

2.5.3. Ethical Considerations and Research Guidelines

Second, ethical considerations and research guidelines often require respect for the deceased's ante-mortem wishes regarding their genetic data. In the absence of explicit instructions, some guidelines such as CM/Rec(2016)6 by the Council of Europe, suggest a presumption of non-opposition to the use of deceased individual's biological samples and derived data for research purposes ³¹.

Researchers and practitioners must navigate these challenges by adhering to legal frameworks and ensuring that the processing of post-mortem genetic data respects dignity and the rights of both the deceased and their living relatives. This involves balancing scientific research needs with privacy concerns, even when the GDPR may not directly govern this data.

³⁰ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Office, G. D. P. O. s. (n.d.). *Tietosuojaaltuutetun Toimisto*. . <https://tietosuoja.fi/en/faq-genealogy>

³¹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , McGuire, A. L., Moore, Q., Majumder, M., Walkiewicz, M., Eng, C. M., Belmont, J. W., Nassef, S., Darilek, S., Rutherford, K., Pereira, S., Scherer, S. E., Sutton, V. R., Wolf, D., Gibbs, R. A., Kahn, R., & Sanchez, L. A. (2016). The ethics of conducting molecular autopsies in cases of sudden death in the young. *Genome Res*, 26(9), 1165-1169. <https://doi.org/10.1101/gr.192401.115> , Moore, Q. L., Majumder, M. A., Rutherford, L. K., & McGuire, A. L. (2016). Ethical and legal challenges associated with public molecular autopsies. *J. Law Med. Ethics*, 44(2), 309-318. <https://doi.org/10.1177/1073110516654124>

2.6.National legislation

The regulation of post-mortem genetic data protection within the EU presents a complex landscape of legal and ethical considerations, with important variations among Member States. While GDPR serves as the overarching legal framework for data protection in the EU, it does not address the status of deceased individuals' data. This gap has led to diverse national approaches across Member States, reflecting different cultural and ethical perspectives ³².

While the GDPR does not apply to the data of deceased persons, Member States can adopt national legislation to bridge this gap. This had led to a variety of legislations across the EU, resulting in a lack of harmonisations and legal fragmentation. The absence of a unified approach creates challenges for cross-border research and data sharing, as different countries have varying standards and requirements for post-mortem genetic data protection. For instance, Germany's data protection laws have provisions that can be interpreted to extend certain rights to the deceased, while other Member States such as France offer no explicit legal framework for post-mortem data protection, resulting in a fragmented landscape.

The absence of a harmonized European approach to post-mortem data protection leads to inconsistencies and uncertainties across different jurisdictions. The GDPR's emphasis on explicit consent and individual control over personal data becomes complex in a post-mortem context, as it is unclear how the wishes of the deceased regarding their genetic data can be effectively respected and enforced when the GDPR's concepts are primarily designed for living individuals ³³.

³² Malgieri, G. (2019). R.I.P.: Rest in Privacy or Rest in (Quasi-)Property?: The Internet of Bodies. In. <https://doi.org/10.5040/9781509926237.ch-006>

³³ Beyond the grave: Navigating post-mortem data privacy. (2023, 2025/3/20). <https://www.lexdinamica.com/post/beyond-the-grave-navigating-post-mortem-data-privacy>

Post-mortem genetic data protection is essential for several reasons, including the relational nature of genetic data, respecting the autonomy and dignity of the deceased person, preventing misuse and discriminations, maintaining trust in research, and ethical considerations. These reasons are translated into specific legislative approaches that vary across countries, reflecting cultural, religious, and historical factors that shape societal and legal traditions.

For a visual overview of these variations, see **Figure 1** and **Table 1**.

2.6.1. Countries with Specific Legislative Provisions

Several EU countries have implemented specific legislation to extend data protection to deceased individuals. For instance, Estonia and Denmark allow prospective consent of the data subject for up to 10 years after death, a shift from previously requiring consent from next of kin. This is outlined in Estonia's Personal Data Protections Act (revised 2021) and Denmark's National data protection laws ³⁴.

Similarly, Italy, Spain, Slovakia, and Hungary permit post-mortem control by relatives, including access, rectification, or deletion of data, unless the deceased expressly prohibited this while alive. In Italy, this is governed by the Data Protection Code (Art. 2-ter), and in Spain by Organic Law 3/2018 ³⁵.

Bulgaria extends the right of access to personal data to the deceased's family under the Personal Data Protection Act. While, France extends certain rights to heirs of deceased individuals, allowing them to access, rectify, or delete personal data, as well as object

³⁴ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Beyond the grave: Navigating post-mortem data privacy. (2023, 2025/3/20). <https://www.lexdinamica.com/post/beyond-the-grave-navigating-post-mortem-data-privacy>

³⁵ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Čtvrtník, M. (2023). Personality Rights, Privacy, and Post-mortem Privacy Protection in Archives: International Comparison, Germany and "Protection of Legitimate Interests". In (pp. 19-53). https://doi.org/10.1007/978-3-031-18667-7_2 , International Labour Organization. (2007). *Isikuandmete kaitse seadus*. NATLEX. https://natlex.ilo.org/dyn/natlex2/r/natlex/fe/details?p3_isn=90354

to further processing, as per the Loi Pour Une République Numérique (2016). Poland recognises the concept of “information autonomy”, which extends beyond death, allowing individuals to make decisions about the use of their personal data after death, according to the Civil Code (Art. 23). Austria allows for the continuation of certain data protection rights after death, particularly in cases where the deceased’s memory or reputation may be affected, as stated in the Data Protection Act § 1(2) ³⁶.

2.6.2. Countries with Limited or No Specific Provisions

In contrast, other EU Member States, such as the Netherlands, Belgium, Sweden, Finland, and Germany do not have special provisions for deceased person’s data. In the Netherlands, the current Dutch Data Protection Act (Wet bescherming persoonsgegevens) does not include specific provisions regarding post-mortem data usage. Dutch medical professionals are bound by a duty of professional confidentiality, protected under both civil and criminal law, which extends beyond a patient’s death. While the right to privacy generally ends at death in the Netherlands, medical confidentiality continues to apply post-mortem. The Dutch National Medical Treatment Act allows the use of a deceased person’s data for research purposes if consent was given during lifetime or if consent is no longer possible (i.e., after death). This results in that living relatives have no legal authority to decide on the post-mortem use of already collected data from their deceased relative for research purposes. This approach reflects that Dutch legislation has historically avoided the concept of ownership in biomedical research regulation, instead focussing on privacy as the primary regulatory principle ³⁷.

³⁶ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders’ perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Beyond the grave: Navigating post-mortem data privacy. (2023, 2025/3/20). <https://www.lexdinamica.com/post/beyond-the-grave-navigating-post-mortem-data-privacy>

³⁷ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders’ perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>

In Belgium, the legal framework regarding the disclosure of genetic information to at-risk family members remains unclear. Belgian law stipulates that healthcare professionals owe patients a duty of professional secrecy, which continues after a patient's death, as per the Criminal code (Art. 458). However, Belgian jurisprudence has established that there may be exceptional situations where the duty of professional secrecy is not applicable. These situations require a serious, imminent, and actual threat; a balance of interests where the legal interest to be protected has greater value than the one being overruled; and the breach of professional secrecy must be the only way to prevent harm. Recent Belgian scholarship suggests that in cases where a genetic condition is serious and treatable, and the healthcare professional is aware that the patient has not informed family members, the duty to warn may supersede the obligation of professional secrecy ³⁸.

In Sweden, the Data Protection Act explicitly refers to personal data of living individuals, rather than post-mortem data protection. The Swedish Personal Data Protection Act does cover its protections to deceased individuals; instead matters related to post-mortem data are governed by the Patient Data Act (2008:355). Similarly, Finland's data protection laws do not contain special provisions regarding personal data of deceased persons, as outlined in the Data Protection Act (1050/2018). The Finnish approach to post-mortem data protecting appears to be in line with other Nordic countries, focussing primarily on the data protection rights of living individuals ³⁹.

³⁸ Phillips, A., Bronselaer, T., Borry, P., Van Hoyweghen, I., Vears, D. F., Pasquier, L., & Callens, S. (2022). Informing relatives of their genetic risk: an examination of the Belgian legal context. *Ibid.*, 30(7), 766-771. <https://doi.org/10.1038/s41431-021-01016-3>

³⁹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *Ibid.*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>

In Germany, provisions have been introduced to allow the transfer of digital assets, including personal data, to designated heirs under inheritance law (§ 1922 GB) ⁴⁰. Greece, on the other hand, does not explicitly address the protection of individual's data, leaving it to interpretation on a case-by-case basis. The Irish Data Protection Commission states that the GDPR does not apply to deceased person's data. However, data controllers may choose to provide data to relatives upon request, exercising caution to avoid disclosing third party data, as per the Data Protection Act 2018 (Section 71) ⁴¹.

⁴⁰ Bichat, T. (2021). Digital Estate in Germany: Social Media & Bitcoin / Cryptocurrencies | German Inheritance Law. *Schlun & Elseven Rechtsanwälte*. <https://se-legal.de/digital-estate-in-germany-social-media-bitcoin-cryptocurrencies-german-inheritance-law/?lang=en>, Čtvrtník, M. (2023). Personality Rights, Privacy, and Post-mortem Privacy Protection in Archives: International Comparison, Germany and "Protection of Legitimate Interests". In (pp. 19-53). https://doi.org/10.1007/978-3-031-18667-7_2

⁴¹ Processing of personal data. <https://www.irishstatutebook.ie/eli/2018/act/7/section/71/enacted/en/html>

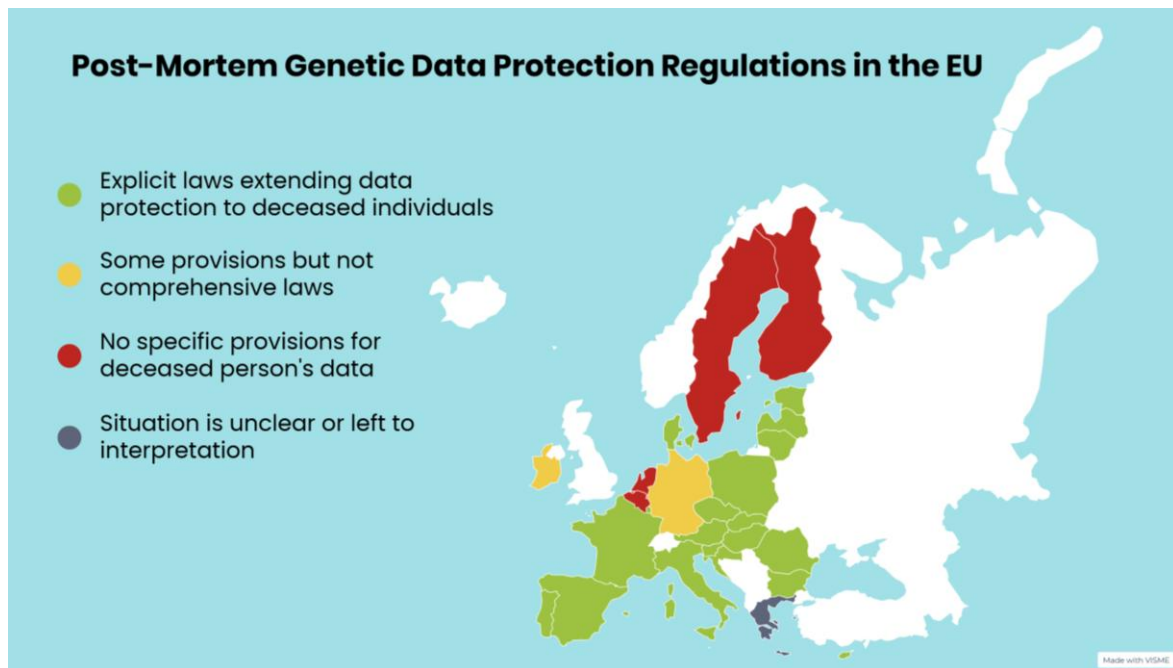


Figure 1. Variations in Post-mortem Genetic Data Protection Legislation Across EU Member States. This map illustrates the diverse legal landscape of post-mortem genetic data protection within the EU. The colour codes underscore the variations in approaches, ranging from explicit legal provisions allowing for extended data protection right to the absence of specific regulations. This visualisation underscores the need for a more coherent and harmonised approach to post-mortem genetic data protection across the EU. Illustration created using Lucid.app and Biorender.com.

Table 1. Comprehensive overview of post-mortem genetic data protection approaches across Europe. The table illustrates the key post-mortem data control mechanisms, the relevant legal basis, and the source of this information for each country. The comparison highlights the variations in national approaches to managing deceased individuals genetic data.

Countries with Specific Legislative Provisions		
Country	Post-mortem Data Control Mechanism	Legal Basis
Austria	Protects deceased's reputation/memory	Data Protection Act § 1(2)
Bulgaria	Family members can request access	Personal Data Protection Act
Denmark	Similar to Estonia's 10-year consent framework	National data protection laws
Estonia	Prospective consent valid for 10 years post-mortem	Personal Data Protections Act (revised 2021)
France	Heirs granted access/rectification/deletion rights	Loi Pour Une République Numérique (2016)
Italy	Relatives exercise rights unless deceased objected	Data Protection Code (Art. 9-ter)
Spain	Relatives control data access/deletions	Organic Law 3/2018
Poland	"Information autonomy" extends post-mortem	Civil Code (Art. 23)
Countries with Limited/No Specific Provisions		
Belgium	Professional secrecy persists post-mortem; exceptions for serious genetic risks	Criminal code (Art. 458)

Finland	No explicit provisions; GDPR default	Data Protection Act (1050/2018)
Germany	Heirs inherit digital assets (incl. data)	Inheritance law (§ 1922 GB)
Ireland	Controllers discretionary disclosure	Data Protection Act 2018 (Section 71)
Netherlands	Research allowed via ante- mortem consent or ethics review	National Medical Treatment Act
Sweden	Relies on GDPR, and medical confidentiality	Patient Data Act (2008:355)

2.7. Conclusion

This chapter set out to answer the research question: To what extent do existing European data protection laws and guidelines apply to post-mortem genetic data, and what are the main legal and ethical challenges that arise?

The analysis shows that the current European data protection framework, most notably the GDPR, does not directly apply to the personal data of deceased individuals, as clarified in Recital 27, GDPR. As a result, the protections and rights designed for living data subjects do not extend automatically to post-mortem genetic data. However, the unique and relational nature of genetic information – where data about the deceased can also reveal sensitive information about living relatives – creates a legal ambiguity. In these cases, if the processing of a deceased person’s genetic data impacts identifiable living persons, the GDPR’s protections may indirectly apply to those relatives, ensuring their privacy and data protection rights are maintained.

Guidelines from the EDPB and recommendations from the Council of Europe emphasise the need for technical and organisational safeguards when handling post-mortem genetic data, especially given the difficulty of fully anonymising such

information. Ethical considerations, such as respecting the wishes of the deceased and safeguarding the interest of living relatives, further complicate the legal landscape.

Further challenges arise from the lack of harmonisation across EU Member States. While some countries, such as Estonia, Denmark, Italy, Spain, Slovakia, and Hungary, have enacted specific provisions granting certain rights to relatives or extending protection to post-mortem data, others have no explicit legal framework, resulting in a fragmented and inconsistent approach across Europe. This complicates cross-border research and data sharing, and raises questions about the enforceability of the deceased's wishes and the rights of their families.

In conclusion, existing European data protection laws only partially address the protection of post-mortem genetic data, primarily through indirect safeguards for living relatives. The main legal and ethical challenges arise from the absence of direct GDPR applicability and national legislative variations. This fragmented legal landscape underscores the need for a clearer, harmonised European legal framework regarding post-mortem genetic data.

3. Case Law on Post-Mortem Genetic Data and Privacy

3.1. Introduction

This chapter analyses how courts at the European and national levels have addressed the challenges and dilemmas associated with post-mortem genetic data. It directly answers to the second sub-question of this thesis: How have key judicial decisions shaped the legal landscape for the protection and use of post-mortem genetic data?

The chapter examines landmark case law from the European Court of Human Rights (ECtHR), the Court of Justice of the European Union (CJEU), and selected national courts. It explores judicial reasoning on issues such as proportionality and necessity in genetic data retention, familial identification, posthumous reproduction, religious and ethical objections, and the balancing of competing interests in requests for genetic testing. While the ECtHR sets minimum human rights standards under the ECHR, the CJEU interprets and applies EU law, including the GDPR and the Charter of Fundamental Rights. Both courts play pivotal roles in shaping the legal landscape of data protection and privacy within Europe. By reviewing these cases, the chapter underscores the evolving standards and principles that influence both national legislation and broader European data protection frameworks. The discussed key cases that have set precedents are detailed in **Table 2**.

3.2. Proportionality and Necessity in Genetic Data Retention

The ECtHR's ruling in *S. and Marper v. UK* (2008) established that indiscriminate retention of DNA profiles and fingerprints from unconvinced individuals violates Article 8 ECHR. The Court emphasised that such practices undermine privacy rights without clear necessity, setting a precedent for proportionality in data retention policies ⁴². This principle was further refined in *Aycaguer v. France* (2017), where the

⁴² Baroness Ludford, S., & Alvaro, A. (2008). *Implications of the S. and Marper v. UK case in relation to the protection of privacy in the fight against terrorism* (Parliamentary question, Issue. https://www.europarl.europa.eu/doceo/document/O-6-2008-0136_EN.html?redirect, S. And marper v. United Kingdom. (2023). <https://www.refworld.org/jurisprudence/caselaw/echr/2008/en/64140>

Court ruled that DNA database storage must differentiate by crime severity, advocating tailored retention periods that could extend to deceased-linked genetic data ⁴³.

The CJEU has also contributed to this matter. In *NG v. Bulgaria* (2024, Case C-118/22), the Court ruled against indefinite biometric and genetic data storage, requiring periodic reviews to justify continued retention ⁴⁴. Similarly, in *V.S. v. Bulgaria* (2023, Case C-205/21), the CJEU prohibited blanket collection of biometric data without strict necessity, reinforcing the need for individualised assessments even in post-mortem contexts ⁴⁵.

3.3. Proportionality in Data Retention for Minor Offenders

The CJEU has addressed proportionality concerns regarding genetic data retention for minor offenders in *JH v. Czech Police* (2023, Case C-57/23). The Court guided time-limited storage practices for deceased-related familial profiles, emphasising that retention periods must be proportional to crime severity and societal interests ⁴⁶.

3.4. Familial Identification and Genetic Profiling

Cases involving familial identification demonstrate how courts balance privacy concerns with societal interests in resolving disputes or investigations. In *Cakicisory and Others v. Cyprus* (ECtHR, 2014), blood sample collection from living relatives for identifying deceased individuals did not violate Article 8 ECtHR. The Court

⁴³ Case of *Aycuaguer v. France*, (2017a). [https://hudoc.echr.coe.int/eng#{%22itemid%22:\[%22001-175007%22\]}](https://hudoc.echr.coe.int/eng#{%22itemid%22:[%22001-175007%22]})

⁴⁴ EUR-Lex - 62022CJ0118 - EN - EUR-Lex. <https://eur-lex.europa.eu/legal-content/NL/ALL/?uri=CELEX:62022CJ0118>

⁴⁵ Wahl, T. CJEU: Systematic collection of biometric and genetic data contrary to EU law. <https://eucrim.eu/news/cjeu-systematic-collection-of-biometric-and-genetic-data-contrary-to-eu-law/>

⁴⁶ *JH v. Czech Police*, (2017b). https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=oj:JOC_2023_173_R_0022

established a precedent for balancing familial identification needs with privacy rights, particularly when the measures are proportionate ⁴⁷.

The *Marianne Vaatstra* case (Netherlands, 2012) illustrates the power of genetic genealogy in forensic investigations. In 1999, sixteen-year-old Marianne Vaatstra was raped and murdered while cycling home in Friesland. Despite the arrest of multiple suspects over the years, the case remained unsolved for over a decade. In 2012, Large-scale Y-chromosomal DNA screening, with over 6,500 local men voluntarily providing samples, led to the resolution of the cold case, demonstrating the potential benefits of genetic identifiability while raising questions about privacy and proportionality ⁴⁸.

3.5. Posthumous Reproduction and Ethical Considerations

In *Baret & Caballero v. France* (2023), the ECtHR addressed France's prohibition on exporting gametes and embryos for posthumous reproduction. The Court upheld France's policy under Article 8 ECHR, emphasising the state's margin of appreciation in regulation sensitive bioethical matters. This case illustrates ethical considerations regarding posthumous reproduction and underscores the state's discretion in balancing individual autonomy with societal values ⁴⁹.

3.6. Religious Objections to Post-Mortem Examinations

The case of *Polat v. Austria* (2021) illustrates how religious objections can intersect with privacy rights under Articles 8 and 9 ECHR. Leyla Polar objected to a post-mortem

⁴⁷ *Cakiciory and Others v. Cyprus* (2014). [https://hudoc.echr.coe.int/eng#{%22itemid%22:\[%22001-147481%22\]}](https://hudoc.echr.coe.int/eng#{%22itemid%22:[%22001-147481%22]})

⁴⁸ Forensic Institute. (2012). Dutch screen DNA of 8,000 men to solve 13-year-old murder. *Forensic Institute*. <https://www.forensicinstitute.nl/news/news/2012/10/02/dutch-screen-dna-of-8000-men-to-solve-13-year-old-murder>, Jong, L., & M'charek, A. (2018). The high-profile case as 'fire object': Following the Marianne Vaatstra murder case through the media. *Crime, Media, Culture*, 14(3), 347-363. <https://doi.org/10.1177/1741659017718036>, Kayser, M. (2017). Forensic use of Y-chromosome DNA: a general overview. In (Vol. 136, pp. 621-635).

⁴⁹ *Baret and Caballero v. France* - 22296/20 and 37138/20, (2023). [https://hudoc.echr.coe.int/tur#{%22itemid%22:\[%22002-14184%22\]}](https://hudoc.echr.coe.int/tur#{%22itemid%22:[%22002-14184%22]}), Observers, S. (2024). *Baret & Caballero v. France: unanimous refusal of access to posthumous reproduction with an uneasy aftermath*. <https://strasbourgobservers.com/2024/01/23/baret-caballero-v-france-unanimous-refusal-of-access-to-posthumous-reproduction-with-an-uneasy-aftermath/>

examination of her child on religious grounds, but Austrian authorities proceeded with the examination citing public health interests. The ECtHR ruled that Austria violated these rights by failing to adequately balance legitimate public health objectives against deeply held religious beliefs ⁵⁰.

3.7. Balancing Competing Interests in DNA Testing for Ancestry

The ECtHR has taken a case-by-case approach to post-mortem genetic identification requests. In *Estate of Jäggi v. Switzerland* (2006), Andreas Jäggi requested DNA testing of his alleged biological father's remains to confirm his ancestry. The Court rules in favour of Jäggi, prioritising his right to know his genetic identity over concerns about disturbing the deceased's rest under Article 8 ECHR ⁵¹.

Conversely, in *Menendez Garcia v. Spain* (2009), the ECtHR denied an exhumation request for grand-paternity verification due to the distant familial relationship between the applicant and the deceased. This decision demonstrates how factors such as familial proximity influence rulings on post-mortem genetic identification ⁵².

⁵⁰ ECHR - European Court of Human Rights. (2021). *Post-mortem examination of baby's body against mother's will led to violations*, Observers, S. (2021). Polat v. Austria: A tale of two missed opportunities. <https://strasbourgobservers.com/2021/12/14/polat-v-austria-a-tale-of-two-missed-opportunities/>

⁵¹ ECHR - European Court of Human Rights. (2006). *Press release issued by the Registrar - CHAMER JUDGEMENT JÄGGI v. SWITZERLAND* [https://bettercarenetwork.org/sites/default/files/2021-06/003-1736071-1820318%20\(1\).pdf](https://bettercarenetwork.org/sites/default/files/2021-06/003-1736071-1820318%20(1).pdf), Mulligan, A. (2022). Anonymous gamete donation and Article 8 of the European Convention on Human Rights: The case for incompatibility. *Med. Law Int.*, 22(2), 119-146. <https://doi.org/10.1177/09685332221096210>

⁵² CASE OF MENÉNDEZ GARCÍA AND ÁLVAREZ GONZÁLEZ v. SPAIN (Applications nos. 73818/11 and 19420/12), (2009).

Table 2. Comparative Analysis of Key European Cases on Post-Mortem Genetic Data Protection. This table presents an overview of important European court cases that have impacted the legal landscape for post-mortem genetic data protection. The cases span from 2008 to 2024, demonstrating the evolution of legal principles in response to advancing genetic technologies and privacy concerns.

Case & Jurisdiction	Scope	Core Legal Principle	Post-Mortem Relevance
<i>Estate of Jäggi v. Switzerland</i> (ECtHR, 2006)	DNA testing of deceased to confirm biological parentage	Rights to know one's ancestry outweighs deceased's right to rest undisturbed under Article 8 ECHR	Sets precedent for prioritising genetic identify over privacy concerns of the deceased
<i>S. and Marper v. UK</i> (ECtHR, 2008)	Retention of DNA profiles and fingerprints of unconvicted individuals	Indiscriminate retention violates Article 8 ECHR	Challenges indefinite post-mortem data retention without clear necessity
<i>Menendez Garcia v. Spain</i> (ECtHR, 2009)	Exhumation request to establish grand-paternity	Distance in familial relationship justifies denial	Demonstrates case-by-case approach to balancing genetic identification with privacy
<i>Marianne Vaatstra</i> (Netherlands, 2012)	Large-scale Y-chromosomal DNA screening	Genetic genealogy in forensic investigations	Demonstrates power of genetic identifiability in post-mortem investigations
<i>Cakicisory and Other v. Cyprus</i> (ECtHR, 2014)	DNA collection from living relatives for identifying deceased	Blood sample collection for genetic profiling did not violate Article 8 ECHR	Establishes precedent for balancing familial identification needs with privacy

<i>Aycaguer v. France</i> (ECtHR, 2017)	DNA database storage for minor offences	Storage must differentiate by crime severity	Supports tailored retention periods for deceased-linked genetic data
<i>Baret & Caballero v. France</i> (ECtHR, 2023)	Prohibition on exporting games and embryos for posthumous reproduction	State margin of appreciation upheld under Article 8 ECHR	Highlights ethical considerations and state discretion in regulating posthumous reproduction
<i>JH v. Czech Police</i> (CJEU, 2023)	Minor offenders' genetic data	Proportionality in retention periods	Guides time-limited storage of deceased- related familial profiles
<i>Polat v. Austria</i> (ECtHR, 2023)	Post-mortem examination conducted against religious objections	Violations of Article 8 and 9 ECHR	Emphasises balancing public health interests with religious and family rights
<i>V.S. v. Bulgaria</i> (CJEU, 2023)	Systematic data collection	Prohibits blanket collection without strict necessity	Applies to post- mortem data acquisition lacking individualised assessment
<i>NG v. Bulgaria</i> (CJEU, 2024)	Indefinite biometric/genetic data storage	Retention requires periodic review	Mandates sunset clauses for post- mortem data in police/research data bases

3.8. Conclusion

This chapter set out to answer the research question: How have key judicial decisions shaped the legal landscape for the protection and use of post-mortem genetic data?

The analysis of European and national case law demonstrates that courts have played a major role in clarifying and evolving the legal standards governing post-mortem genetic data. Landmark decisions from the ECtHR and the CJEU have established core principles of proportionality, necessity, and individual rights that now shape the handling of post-mortem genetic data.

The ECtHR's jurisprudence, has set clear limits on indiscriminate genetic data retention in *S. and Marper v. UK*, emphasising the need for tailored, proportional approaches that respect privacy even after death. Further cases, such as *Aycaguer v. France* and *Jäggi v. Switzerland* further refined these principles, balancing the rights of individuals to know their genetic origins with the privacy and dignity of the deceased. The Court's nuanced, case-by-case approach is evident in its handling of requests for post-mortem genetic testing, where factors such as familial proximity and the purpose of testing are balanced carefully.

The CJEU has reinforced these protections by requiring periodic review of genetic data retention (*NG v. Bulgaria*) and prohibiting blanket data collection without strict necessity (*V.S. v. Bulgaria*). These rulings ensure that even in post-mortem contexts, data processing must be justified and limited in scope and duration.

National courts and specific cases, such as the *Marianne Vaatstra* case in the Netherlands, illustrate how these European standards are implemented in practice, highlighting both the power and risks of genetic identifiability in forensic in familial contexts.

Ethical and religious considerations have also been recognised, with courts acknowledging the importance of balancing individual autonomy, societal interests, and deeply held beliefs, as seen in *Baret & Caballero v. France*, and *Polar v. Austria*.

In conclusion, key judicial decisions have shaped a legal landscape in which the protection and use of post-mortem genetic data are governed by principles of proportionality, necessity, and respect for both the rights of the living and the dignity of the deceased. Courts have established that the handling of post-mortem genetic data demands individualised assessments, continuous monitoring, and careful balancing of competing interests.

4. Stakeholders

4.1. Introduction

This chapter explores the perspectives, interests, and roles of key stakeholders involved in the protection and use of post-mortem genetic data. It addresses the third sub-question of this thesis: How do the interests and concerns of families, healthcare professionals, researchers, biotech companies, and the broader public influence the governance of post-mortem genetic data?

The chapter examines the unique challenges faced by each stakeholder group, including the relational nature of genetic data, the need for access to information, privacy concerns, and the ethical dilemmas that arise when balancing the wishes of the deceased with the interests of living relatives and society. By analysing these perspectives, the chapter highlights the complexity of post-mortem genetic data governance and the necessity of considering diverse viewpoints in developing effective legal and ethical frameworks.

4.2. Balancing Competing Interests in Post-Mortem Genetic Data Protection

Balancing the rights and interests of deceased individuals with those of surviving family members, researchers, and other stakeholders is a delicate task, with current legal frameworks often lacking clear guidelines on how to navigate these competing interests. While technological solutions for post-mortem data control have emerged, their interaction with legal frameworks remains unclear. Effective management of post-mortem genetic data requires a harmonious blend of technological solutions and legal regulations⁵³. The identifiability of genetic data raises unique privacy concerns, as it can reveal sensitive information about both the deceased and their living relatives

⁵³ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Boers, S. N., van Delden, J. J. M., Knoers, N. V., & Bredenoord, A. L. (2015). Postmortem disclosure of genetic information to family members: active or passive? *Trends in Molecular Medicine*, 21(3), 148-153. <https://doi.org/10.1016/j.molmed.2015.01.002>

⁵⁴. Current practices may not adequately address these privacy risks. The complexity of stakeholder interests in this domain is visualised in **Figure 2**.

4.3. The Deceased and Their Relatives

The deceased have an interest in having their previously expressed wishes regarding their genetic data respected. Even after death, considerations of dignity and autonomy require that their preferences should be taken into account where possible. The use of deceased individuals' genetic data for research, historical preservation, and familial purposes raises ethical dilemmas, requiring a balance between the benefits of such uses and the need to respect the deceased's privacy and autonomy. Furthermore, the management of post-mortem genetic data has broader social implications, including potential impacts on familial dynamics, cultural practices, and societal norms, which are often overlooked in current debates and practices ⁵⁵.

Families and relatives of the deceased have a major interest in the handling of post-mortem genetic data due to its relational nature. As described above, many family members care about the privacy and dignity of deceased individuals, as they have emotional and psychological concerns about the potential misuse of genetic information, which could reveal sensitive health or ancestry details. In addition, families may worry about the implications of genetic findings for their own health and well-being, as genetic data can uncover inherited conditions that affect living relatives. They may need access to this information for their own health decisions, to understand potential inherited risks, or for reproductive planning. The right to control or access

⁵⁴ Bak, M. A. R., & Willems, D. L. (2022). Contextual Exceptionalism After Death: An Information Ethics Approach to Post-Mortem Privacy in Health Data Research. *Sci Eng Ethics*, 28(4), 32. <https://doi.org/10.1007/s11948-022-00387-0>, Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>

⁵⁵ Aborode, A. T., Karra-Aly, A., Ogunleye, S. C., Olorunshola, M. M., Folorunso, T. N., Aloba, C. O., & Ogunware, A. E. (2023). Overcoming hurdles: Enhancing post-mortem capabilities for neurological investigations in Africa. *Aging Brain*, 4, 100099. <https://doi.org/10.1016/j.nbas.2023.100099>, Ipsen, D. H., Lykkesfeldt, J., & Tveden-Nyborg, P. (2018). Molecular mechanisms of hepatic lipid accumulation in non-alcoholic fatty liver disease. *Cell Mol Life Sci*, 75(18), 3313-3327. <https://doi.org/10.1007/s00018-018-2860-6>

the deceased individual's genetic data can be a controversial issue, with families claiming control over how this data is used, especially in absence of explicit consent from the deceased individual ⁵⁶.

4.4. Healthcare Professionals

Healthcare professionals are often challenged with the dual nature of genetic data. Genetic information can be used for diagnostic or treatment purposes, including living relatives of the deceased patient. However, healthcare professionals must uphold ethical standards and patient confidentiality, which can extend beyond death, ensuring that genetic data is used responsibly and with the appropriate consent. However, they also have a responsibility to inform at-risk relatives about potential genetic risks, creating a tension between privacy and the duty to warn ⁵⁷.

4.5. Researchers and Biotech Companies

In medical research, genetic information from deceased individuals can provide insights into diseases, inheritable conditions, and population genetics. The data can help contribute to the development of new treatments, guidelines, and insight in human biology. However, ethical and legal considerations are balanced to respect the privacy and dignity of the deceased individual and their families ⁵⁸. Moreover,

⁵⁶ Bak, M. A. R., & Willems, D. L. (2022). Contextual Exceptionalism After Death: An Information Ethics Approach to Post-Mortem Privacy in Health Data Research. *Sci Eng Ethics*, 28(4), 32. <https://doi.org/10.1007/s11948-022-00387-0>, Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>, Hunter, J. E., Schneider, J. L., Firemark, A. J., Davis, J. V., Gille, S., Pawloski, P. A., Liang, S. Y., Schlieder, V., & Rahm, A. K. (2022). Should Health Systems Share Genetic Findings With At-Risk Relatives When the Proband Is Deceased? Interviews With Individuals Diagnosed With Lynch Syndrome. *J Patient Cent Res Rev*, 9(4), 282-289. <https://doi.org/10.17294/2330-0698.1945>, Ormondroyd, E., Moynihan, C., Watson, M., Foster, C., Davolls, S., Ardern-Jones, A., & Eeles, R. (2007). Disclosure of Genetics Research Results after the Death of the Patient Participant: A Qualitative Study of the Impact on Relatives. *Journal of Genetic Counseling*, 16(4), 527-538. <https://doi.org/https://doi.org/10.1007/s10897-007-9088-1>

⁵⁷ Johnson, S. B., Slade, I., Giubilini, A., & Graham, M. (2020). Rethinking the ethical principles of genomic medicine services. *European Journal of Human Genetics*, 28(2), 147-154. <https://doi.org/10.1038/s41431-019-0507-1>

⁵⁸ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. Ibid. Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. (4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C.,

biotechnology companies and data analytics companies have a growing interest in post-mortem genetic data for developing new products and technologies. However, as commercial interests may not always align with the best interest of the deceased or their families, there are ethical concerns raising ⁵⁹.

In addition to medical research, post-mortem genetic data has value for historical research. Genetic analysis in this context can provide insights into migration patterns, genealogy, and the evolution of human societies. DNA from ancient human remains can reveal information about past populations, their movements, and genetic adaptations over time. In cases of historical importance, genetic analysis can help identify remains or verify lineages of historical figures. However, this type of research also raises ethical questions, particularly when dealing with indigenous populations or culturally sensitive remains. Researchers must balance scientific inquiries with respect for cultural beliefs and practices regarding the deceased individual ⁶⁰.

Furthermore, entities that store and process genetic data (e.g., biobanks, genetic testing companies) have a responsibility to implement robust security measures and comply with data protection regulations. This is to avoid that insurance companies and employers could potentially misuse genetic information for discriminatory purposes. Clear regulations are needed to prevent such misuse.

Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

⁵⁹ Koplin, J. J., Skeggs, J., & Gyngell, C. (2022). Ethics of Buying DNA. *J Bioeth Inq*, 19(3), 395-406. <https://doi.org/10.1007/s11673-022-10192-w>

⁶⁰ Alpaslan-Roodenberg, S., Anthony, D., Babiker, H., Bánffy, E., Booth, T., Capone, P., Deshpande-Mukherjee, A., Eisenmann, S., Fehren-Schmitz, L., Frachetti, M., Fujita, R., Frieman, C. J., Fu, Q., Gibbon, V., Haak, W., Hajdinjak, M., Hofmann, K. P., Holguin, B., Inomata, T., . . . Zahir, M. (2021). Ethics of DNA research on human remains: five globally applicable guidelines. *Nature*, 599(7883), 41-46. <https://doi.org/10.1038/s41586-021-04008-x> , D'Alessio, V. (2022). Ancient DNA brings us closer to unlocking secrets of how modern humans evolved. *Horizon The EU Research & Innovation Magazine*. <https://projects.research-and-innovation.ec.europa.eu/en/horizon-magazine/ancient-dna-brings-us-closer-unlocking-secrets-how-modern-humans-evolved>

4.6. Public Interest Groups

Finally, the public has an interest in ensuring that genetic data is used responsibly and ethically, and that the benefits of genetic research are realised while potential risks are minimised.

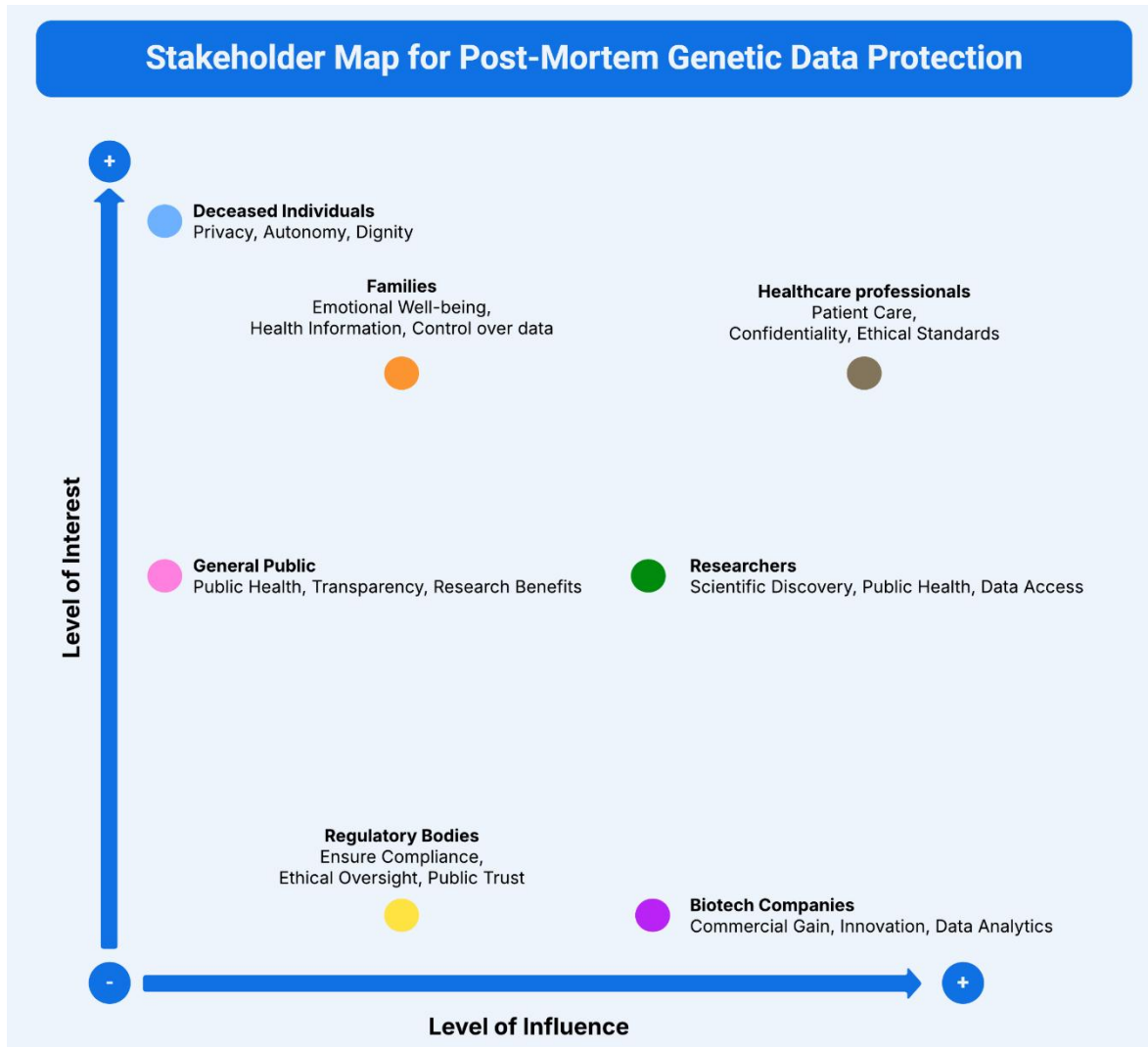


Figure 2. Stakeholder Map for Post-Mortem Genetic Data Protection. The stakeholder map illustrates the various interests and levels of influence among stakeholders involved in the management and protection of post-mortem genetic data. Each stakeholder is positioned based on their level of interest and influence, providing a visual representation of the complex relationships. Illustration created using Lucid.app and Biorender.com.

4.7. Conclusion

This chapter addressed the sub-question: How do the interests and concerns of families, healthcare professionals, researchers, biotech companies, and the broader public influence the governance of post-mortem genetic data?

The analysis demonstrates that the governance of post-mortem genetic data is shaped by diverse interests of multiple stakeholders. Families and relatives are primarily concerned about the deceased's ante-mortem wishes, while accessing information relevant to their own health. Healthcare professionals must balance patient confidentiality with their duty to inform at-risk relatives. Researchers and biotech companies regard post-mortem data as a resource for scientific research and commercial purposes but must respect ethical boundaries and privacy rights. Public interest groups advocate for responsible use that aligns with societal values.

In conclusion, effective governance requires inclusive frameworks that address these diverse perspectives, ensuring that genetic data is used ethically and respectfully, while balancing the benefits of research with the rights and dignity of both the deceased and their families.

5. Interpretation of Findings

5.1. Introduction

This chapter critically analyses the findings from preceding the legal framework, case law, and stakeholder perspectives presented in the preceding chapters. The analysis highlights the relation between European and national regulations, the practical challenges identified in landmark cases, and the concerns raised by key stakeholders in the field of post-mortem genetic data protection. It addresses the fourth sub-question of this thesis: What are the main gaps, challenges, and areas of fragmentation in the current legal and practical approaches to post-mortem genetic data, and how do these impact the rights and interests of the deceased and their relatives?

The chapter begins by examining the fragmented nature of existing legal frameworks and the inconsistencies that arise across different Member States. It then considers the influence of judicial precedents on the interpretation of post-mortem privacy and data protection rights. The perspectives of key stakeholders are integrated to highlight areas where current practices fall short, particularly in terms of enforcement, technological advancement, and the application of rights such as erasure to post-mortem genetic data.

5.2. Legal Fragmentation

The most fundamental limitation is the GDPR's explicit exclusion of deceased individuals from its scope ⁶¹. This creates a legal vacuum, leaving the protection of post-mortem genetic data largely to inconsistent national laws and ethical guidelines. The lack of a unified EU approach results in legal fragmentation and legal uncertainty, making it difficult to establish clear standards for data protection and usage.

⁶¹ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), 1-88 119 (2016). <http://data.europa.eu/eli/reg/2016/679/oj>

While some national laws address post-mortem data, specific guidance on obtaining and interpreting consent for genetic testing and scientific research is often lacking. It remains unclear how to interpret “data wills” or legacy contacts and whether presumed consent mechanisms are ethically acceptable. This can potentially lead to uncertainty and potential misuse of genetic data.

5.3. Legal Precedents on Post-Mortem Genetic Privacy

European case law from the ECtHR and CJEU demonstrates a nuanced and continuous evolving approach to post-mortem genetic data, emphasising the need to balance individual privacy with societal interests.

The ECtHR has established that the collection and retention of genetic data are *prima facie* interferences with privacy under Article 8 ECHR, not only for individuals but also for their relatives. Cases such as *S. and Marper v. UK* set the principle that indiscriminate retention of DNA profiles - especially from those not convicted – violates privacy rights unless justified by strict necessity and proportionality. This principle has been refined in subsequent cases such as *Aycaguer v. France*, which underscored need for tailored retention policies based on crime severity and for robust safeguards even for convicted individuals ⁶².

The CJEU has reflected these concerns, ruling against the indefinite storage of biometric and genetic data and requiring periodic reviews to justify continued retention, as seen in *NG v. Bulgaria* (C-118/22). The CJEU has also prohibited blanket collection of genetic data without individualised assessment, reinforcing the principle of necessity in *V.S. v. Bulgaria* (C-205/21) ⁶³.

⁶² Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>, Tuazon, O. M., Custers, B., & Zwenne, G.-J. (2025). Genometric data privacy within the ECHR regime. *International Data Privacy Law*, ipaf004. <https://doi.org/10.1093/idpl/ipaf004>

⁶³ ECJ ruling on right to erasure of biometric and genetic data. (n.d.). <https://eucrim.eu/news/cjeu-ruling-on-right-to-erasure-of-biometric-and-genetic-data/>

Both courts have recognised the relational nature of genetic data, acknowledging that privacy infringements can extend to relatives and broader genetic groups. Cases involving familial identifications (*Cakicisory and Others v. Cyprus*) and large-scale forensic screenings (*Marianne Vaatstra* case) illustrate the courts' careful balancing of privacy with public interest in solving crimes or establishing identity ⁶⁴.

Additionally, the ECtHR has addressed ethical and cultural concerns, such as religious objections to post-mortem examinations (*Polat v. Australia*) and the right to know one's ancestry (*Estate of Jäggi v. Switzerland*), taking a case-by-case approach to competing interests.

In summary, European courts require that any processing or retention of post-mortem genetic data must be justified by necessity, proportionality, and adequate safeguards, while recognising the broader privacy impacts on families and society.

5.4. Stakeholder Perspectives on Post-Mortem Genetic Data

The management of post-mortem genetic data is determined by multiple stakeholder interests and ethical questions. Stakeholders, including families, healthcare professionals, researchers, biotech companies, and public interest groups, encounter challenges due to the lack of harmonised regulations at European and national levels.

Families and relatives are central in this debate, as genetic data is inherently relational. They often attempt to protect the dignity and privacy of the deceased, while also having legitimate interests in accessing genetic information that may inform their own health decisions. Emotional, psychological, and cultural factors further complicate these decisions.

Healthcare professionals are tasked with balancing patient confidentiality – which may extend beyond death – with their ethical duty to inform at-risk relatives of

⁶⁴ Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>

potential hereditary conditions. This creates a tension between respecting the privacy of the deceased and promoting the health interests of living family members.

Researchers and biotech companies regard post-mortem genetic data as a valuable resource for advancing medical science, developing new therapies, and understanding human biology. However, there are several ethical concerns regarding consent, privacy, and potential misuse as commercial interests may not always align with the values or wishes of the deceased and their families.

Public interest groups and the wider public emphasise the need for responsible and ethical use of genetic data while minimising the risk to individual privacy. They advocate for legal frameworks that optimise the societal benefits of genetic research through clear frameworks, transparency, and the implementation of safeguards.

In conclusion, the current patchwork of legal and ethical standards is inadequate to address the unique challenges posed by post-mortem genetic data. Stakeholders demand a more harmonised approach that combines technological solutions with clear legal guidelines.

5.5. Enforcement and Technological Challenges

Even where national laws exist, enforcement mechanisms are often weak or lacking, making it difficult to ensure compliance and address violations. Rapid advancements in genetic technologies, such as whole-genome sequencing (WGS) and genome editing, further complicate the regulatory landscape. Existing legal frameworks may struggle to keep pace with these developments, requiring ongoing review and adaptation. Stronger enforcement is needed to deter the misuse of post-mortem genetic data and protect the rights of individuals and families. Effective enforcement mechanisms are crucial for maintaining public trust and ensuring the integrity of genetic research.

The use of post-mortem genetic data for commercial purposes, such as developing personalised medicine or genetic testing services, raises ethical concerns about profit

motives and potential exploitation. Clear regulations are needed to ensure that commercial activities are aligned with ethical principles and public interest, preventing the misuse of genetic data for financial gain ⁶⁵.

5.6. The “Right to Erasure” and Post-Mortem Data

The application of the “right to erasure” or “right to be forgotten” to post-mortem data raises complex questions. While some national frameworks allow family members to request erasure of a deceased individual’s data, the legal basis and practical implications of such requests remain unclear, especially when the data has scientific or public health value. Clear guidelines are needed to balance privacy concerns with the potential benefits of retaining genetic data for research purposes.

5.7. Conclusion

This chapter set out to answer the sub-question: What are the main gaps, challenges, and areas of fragmentation in the current legal and practical approaches to post-mortem genetic data, and how do these impact the rights and interests of the deceased and their relatives?

The findings from the legal framework, case law, and stakeholder chapters reveal a fragmented and evolving landscape regarding post-mortem genetic data protection in the EU. Addressing these challenges will require multiple efforts including legal harmonisation, robust enforcement, technological interventions and ongoing dialogues between stakeholders. The currently available technological tools and legal recommendations are discussed in the next chapters.

⁶⁵ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders’ perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>

6. Technological Tools for Balancing Post-Mortem Genetic Data Protection

6.1. Introduction

This chapter explores the role of technological solutions in supporting the legal and ethical management of post-mortem genetic data. It addresses the fifth sub-question of this thesis: How can technological measures complement legal frameworks to ensure effective protection and responsible use of post-mortem genetic data?

The chapter begins by examining how legal and ethical requirements for post-mortem genetic data protection interact with technical solutions, such as anonymisation, advanced consent management systems, and robust data storage and access controls. It then assesses the feasibility and limitations of these technologies in addressing challenges related to identifiability, data minimisation, and the rights of both the deceased and their living relatives. Special attention is given to emerging tools such as AI-drive access management, smart contracts, and privacy enhancing technologies (PETs), as well as the importance of adaptability to national legal variations.

6.2. Legal and Ethical Frameworks

6.2.1. The Data Subject and Their Post-Mortem Genetic Data

The principle of autonomy suggests that individuals should have the right to control their personal data, including genetic information, and to make decisions about their use after their death. This includes the right to provide explicit consent for specific purposes, such as medical research or familial health risk assessment, the duration of the consent, or to prohibit any use of their data ⁶⁶.

The creation of advanced directives or “data wills” that specify the deceased’s wishes regarding the use of their genetic data post-mortem is crucial. These allow to respect

⁶⁶ Ibid., Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

the deceased's autonomy, provide legal and ethical clarity and balance the interests of the deceased, their families, and society in the use of post-mortem genetic data. These directives should be legally binding and respected by all stakeholders. Such directives can include clearly outlining permissions and restrictions for data use, designating data executors to oversee the implementation of wishes, and providing options for time-limited embargoes on data access. In the absence of explicit consent from the deceased, establishing protocols for obtaining consent from family members is necessary ⁶⁷.

Implementing tiered consent models can help balance various interest by allowing individuals to different levels of access and use for their post-mortem genetic data. These models may include consent for medical research but not for commercial use, allowing access to immediate family members but not distant relatives, or specifying which types of studies or institutions can use the data ⁶⁸.

However, the enforceability of such wishes is not always clear-cut, particularly in the absence of specific legal frameworks or testamentary provisions. In some jurisdictions, the wishes of the deceased may be given significant weight while in others, they may be subject to override bases on competing interests or public policy considerations. The applicability of the GDPR to the data of living relatives adds another layer of

⁶⁷ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. Ibid. Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. (4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Noroozi, M., Bahmani, F., Mousavizadeh, K., Saeedi Tehrani, S., Hashemi, A., & Forouzandeh, M. (2022). To use or not to use? an ethical analysis of access to data and samples of a deceased patient for genetic diagnostic and research purposes. *J Med Ethics Hist Med*, 15, 13. <https://doi.org/10.18502/jmehm.v15i13.11569>

⁶⁸ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>

complexity as the processing of such data must comply with the GDPR's principles of lawfulness, fairness and transparency ⁶⁹.

6.2.2. Rights of Surviving Family Members

In cases where a person has not considered the implications of their genetic data, the rights of stakeholders, including family members, become particularly relevant. Family members may have a legitimate interest in accessing or controlling the use of the data, especially if it has implications for their own health ⁷⁰.

National laws may provide mechanisms for withdrawing consent or restricting the use of data in such circumstances. For example, if a family member may be able to demonstrate that of the use of the data would violate their privacy or cause them undue harm. Balancing the rights of the surviving family members with the wishes of the deceased and the broader public is a complex task. This involves considering the ethical, legal, and practical implications of allowing family members to access, control, or erase genetic data. Clear guidelines and legal frameworks are necessary to ensure that these rights are respected while also protecting the privacy and autonomy of the deceased ⁷¹.

⁶⁹ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

⁷⁰ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

⁷¹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. Ibid.Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. (4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

6.2.3. Other Stakeholders in the Context of Post-Mortem Genetic Data

The use of genetic data while maintaining medical secrecy is another major consideration, particularly in the context of research and secondary use of the data. The principle of medical confidentiality requires that healthcare professionals protect the privacy of their patients' medical information, including genetic data. However, this principle may need to be balanced against the potential benefits of using the data for research purposes, such as identifying genetic markers for diseases ⁷².

The establishment of ethics committees to review and approve requests for access to post-mortem genetic data ensures that ethical considerations are upheld. These committees should include representatives from various stakeholder groups, including families, researchers and legal experts. Developing ethical guidelines for researchers and healthcare professionals ensures that genetic data is used responsibly and with consideration for the deceased's privacy and dignity ⁷³.

The EDPB study notes that few Member States provide clear guidance on how to balance the transparency obligation with exemptions for research, especially when data subjects cannot be identified or informed, which is particularly relevant in the context of post-mortem genetic data ⁷⁴. Studies for the EDPB on the use of medical data for research provides insights into the legal and ethical considerations surrounding the secondary use of genetic data, including the need for anonymisation, data

⁷² Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. Ibid. Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. (4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid. ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

⁷³ Methner, D. N., Scherer, S. E., Welch, K., Walkiewicz, M., Eng, C. M., Belmont, J. W., Powell, M. C., Korchina, V., Doddapaneni, H. V., Muzny, D. M., Gibbs, R. A., Wolf, D. A., Sanchez, L. A., & Kahn, R. (2016). Postmortem genetic screening for the identification, verification, and reporting of genetic variants contributing to the sudden death of the young. *Genome Res*, 26(9), 1170-1177. <https://doi.org/10.1101/gr.195800.115>

⁷⁴ Study on the secondary use of personal data in the context of scientific research., (2020). https://www.edpb.europa.eu/our-work-tools/our-documents/other/study-secondary-use-personal-data-context-scientific-research_en

minimisation, and robust access controls. For example, the EDPB's guidelines on consent under the GDPR emphasise the need for specific and informed consent for the processing of sensitive data, including genetic data, and the right to withdraw consent at any time ⁷⁵.

The public interest in genetic research and data use must also be taken into account. Genetic data can provide valuable insights into diseases, heritable conditions, and population genetics. Balancing the public interest with the privacy of the deceased and their family members is essential to ensure that genetic research is conducted ethically, responsibly, and legally ⁷⁶.

Even though this is beyond the scope of this thesis, it is important to acknowledge the use of genetic data for forensic investigations. Genetic data can be used to identify deceased individuals, solve criminal cases, and establish familial relationships. However, the use of genetic data for forensic purposes raises ethical and legal concerns, particularly regarding privacy, discrimination, and the potential for misuse ⁷⁷.

⁷⁵Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

⁷⁶ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. Ibid.Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. (4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

⁷⁷ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. Ibid.Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. (4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

6.3. Technological Measures for Post-Mortem Genetic Data Control

6.3.1. Anonymisations and the Limits of Genetic Data De-Identification

Anonymisation is a widely used technique in data protection, aiming to irreversibly remove personal identifiers from data sets so that individuals can no longer be identified. However, in the context of genetic information, the effectiveness and feasibility of true anonymisation are contested. Unlike other types of personal data, genetic data is inherently unique to each individual. Even after the removal of direct identifiers, such as names or contact details, the DNA sequence itself remains a powerful identifier.

Multiple studies have shown that with sufficient reference databases and computational techniques, such as cross-dataset linkage and AI-driven phenotype-genotype correlation, it is possible to re-identify individuals from anonymised genetic data, especially when combined with other publicly available information. This high risk for re-identification is further amplified by the relational nature of genetic data, which can also reveal information about biological relatives ⁷⁸.

It is essential to distinguish between the different types of materials and data when considering anonymisation. While digital genetic data (such as DNA sequences stored in databases) may be subject to anonymisation techniques, biological tissues and physical samples inherently contain the full genetic code of the donor and cannot be truly anonymised. Even if separated from direct identifiers, the tissue itself remains a persistent source of identifiable genetic information. This contrasts with other types of

⁷⁸ Banda, J., November 15). Inherently identifiable: Is it possible to anonymize health and genetic data? IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>. (2023). *Inherently identifiable: Is it possible to anonymize health and genetic data?* IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>, Erlich, Y., Shor, T., Carmi, S., & Pe'er, I. (2018). Re-identification of genomic data using long range familial searches. *bioRxiv*, 350231. <https://doi.org/10.1101/350231>, Venkatesaramani, R., Malin, B. A., & Vorobeychik, Y. (2021). Re-identification of individuals in genomic datasets using public face images. *Science Advances*, 7(47), eabg3296. <https://doi.org/doi:10.1126/sciadv.abg3296>

health data, such as aggregated statistics or non-genetic laboratory results, which can be often anonymised more effectively ⁷⁹.

Given these challenges, the concept of anonymisation in the context of genetic data must be carefully approached. Regulatory frameworks and technological safeguards should recognise that genetic information, whether digital data or physical tissues, carries a persistent risk of re-identification. As such, reliance on anonymisation alone is insufficient for the protection of post-mortem genetic data. Instead, a combination of robust access controls, data minimisation techniques, ongoing risk assessment, and robust data anonymisation techniques is necessary to safeguard the privacy of both the deceased individuals and living relatives ⁸⁰. This can be complemented by the use of advanced access control mechanisms, such as encryption and secure data storage solutions, to ensure that only authorised personnel can access sensitive data ⁸¹. For a visual representation of these technological measures discusses below, see **Figure 3**.

6.3.2. Feasibility of Anonymisation Techniques

The feasibility of genetic data presents major challenges. While traditional anonymisation methods, such as removing direct identifiers (name, date of birth, address), can reduce the risk of re-identification, these techniques are often insufficient for genetic data due to its inherently unique nature. Even small sets of genetic markers

⁷⁹ Banda, J., November 15). Inherently identifiable: Is it possible to anonymize health and genetic data? IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>. (2023). *Inherently identifiable: Is it possible to anonymize health and genetic data?* IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>, Herbert Smith Freehills | Global law firm. (n.d.-a). Challenges with anonymising genetic data. <https://www.herbertsmithfreehills.com/notes/ip/2021-10/what-does-it-mean-to-anonymise-genetic-data>

⁸⁰ Corrales Compagnucci, M., Meszaros, J., Minssen, T., Arasilango, A., Ous, T., & Rajarajan, M. (2019). Homomorphic Encryption: The 'Holy Grail' for Big Data Analytics and Legal Compliance in the Pharmaceutical and Healthcare Sector? *European Pharmaceutical Law Review*, 3(4). <https://doi.org/10.21552/eplr/2019/4/5>, GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

⁸¹ Moore, Q. L., Majumder, M. A., Rutherford, L. K., & McGuire, A. L. (2016). Ethical and legal challenges associated with public molecular autopsies. *J. Law Med. Ethics*, 44(2), 309-318. <https://doi.org/10.1177/1073110516654124>

can be used to re-identify individuals, particularly when cross-references with other datasets of public resources such as genealogy registers ⁸².

Technological advancements, including AI-driven data analysis and the increasing availability of large-scale genomic and health datasets, have further impacted the effectiveness of re-identification. What is considered anonymous today may become re-identifiable in the future as new methods and reference data emerge. As a result, anonymisation is often described as “increasingly illusory” in the context of genomic data, and there is growing scepticism among data protection experts and regulators that true anonymisation of genetic or biometric data may be impossible ⁸³.

From a regulatory perspective, the GDPR adopts a risk-based approach: data may be considered anonymous if the risk of re-identification is not reasonably likely, taking into account available technology and the context of data processing. However, this threshold is difficult to meet for genetic data, especially for whole genome sequences or rare disease variants, which are highly distinctive. Some types of aggregated or highly generalised genetic data (e.g., population-level variant frequencies) may be considered anonymous, but more individual-level genomic data remains at risk of re-identification ⁸⁴.

⁸² Banda, J., November 15). Inherently identifiable: Is it possible to anonymize health and genetic data? IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>. (2023). *Inherently identifiable: Is it possible to anonymize health and genetic data?* IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>, Herbert Smith Freehills | Global Law Firm. (n.d.-b). *Challenges with anonymising genetic data*. <https://www.herbertsmithfreehills.com/notes/ip/2021-10/what-does-it-mean-to-anonymise-genetic-data>

⁸³ Akyüz, K., Goisauf, M., Chassang, G., Kozera, Ł., Mežinska, S., Tzortzatou-Nanopoulou, O., & Mayrhofer, M. T. (2023). Post-identifiability in changing sociotechnological genomic data environments. *Biosocieties*, 1-28. <https://doi.org/10.1057/s41292-023-00299-7> , Banda, J., November 15). Inherently identifiable: Is it possible to anonymize health and genetic data? IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>. (2023). *Inherently identifiable: Is it possible to anonymize health and genetic data?* IAPP. <https://iapp.org/news/a/inherently-identifiable-is-it-possible-to-anonymize-health-and-genetic-data>

⁸⁴ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Herbert Smith Freehills | Global law firm. (n.d.-a). Challenges with anonymising genetic data.

Moreover, anonymisation comes with trade-offs. It can reduce data utility, limit linkage across datasets, and hinder research collaboration, while not guaranteeing robust privacy protection. In practice, many organisations rely on pseudonymisation and strict access controls, rather than full anonymisation, to balance data utility and privacy risks ⁸⁵.

6.3.3. Technological Solutions

Technological solutions for post-mortem genetic data control must consider the diverse stakeholders, the deceased, their living relatives, and the research community. Security measures should aim to uphold the deceased's autonomy and right to privacy, respect the relatives interests by preventing misuse of genetic information, and ensure the integrity and confidentiality of the data used for research ⁸⁶.

To balance these interests, technological solutions should focus on enhanced anonymisation techniques to pseudonymise genetic data while preserving their utility for research purposes, secure data enclaves to access and analyse sensitive data under strict security protocols, and auditing and monitoring systems to track data access and usage ⁸⁷.

The protection of post-mortem genetic data is a major concern in various fields, including biotechnology and data analytics. Ensuring the privacy and security of genetic information after an individual's death involves the implementation of robust technological measures that safeguard sensitive data from unauthorised access,

<https://www.herbertsmithfreehills.com/notes/ip/2021-10/what-does-it-mean-to-anonymise-genetic-data>

⁸⁵ Dvorin, T. (2024). *Data anonymization techniques: pros and cons*. Duality Technologies. <https://dualitytech.com/blog/data-anonymization-techniques-pros-and-cons/>

⁸⁶ Costello, R. Á. (2022). Genetic Data and the Right to Privacy: Towards a Relational Theory of Privacy? *Human Rights Law Review*, 22(1), ngab031. <https://doi.org/10.1093/hrlr/ngab031>

⁸⁷ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>

misuse, and breaches, while also respecting the deceased's wishes and complying with legal and ethical standards ⁸⁸.

6.3.4. Advanced Consent Management Systems

Advanced consent management systems can be developed to allow individuals to specify their preferences for post-mortem use of their genetic data. These systems enable individuals to set expiration dates for data use, allow granular access control over which types of research can use the data, and specify whether relatives can access or control the data after death. Such systems empower individuals to maintain control over their genetic data even after they have passed away ⁸⁹.

6.3.5. Robust Data Storage and Access Control

Robust data storage and access control mechanisms are crucial for protecting genetic data. Encryption of genetic data at rest and in transit, along with multi-factor authentication (MFA) for accessing deceased individuals' data, ensures that only authorised personnel can view or manipulate the genetic data. Blockchain technology can conduct immutable audit trails of data access, providing a transparent and secure record of all interactions with the data ⁹⁰.

6.3.6. AI and Smart Contract Systems

AI and smart contract systems can be implemented to automatically enforce the deceased's wishes regarding their genetic data. These systems can trigger the deletion or anonymisation of data after a specified time, grant or revoke access to relatives based on pre-set conditions, and apply different levels of data access for various types of

⁸⁸ Ibid., Herbert Smith Freehills | Global law firm. (n.d.-a). Challenges with anonymising genetic data. <https://www.herbertsmithfreehills.com/notes/ip/2021-10/what-does-it-mean-to-anonymise-genetic-data>

⁸⁹ Oliva, A., Kaphle, A., Reguant, R., Sng, L. M. F., Twine, N. A., Malakar, Y., Wickramarachchi, A., Keller, M., Ranbaduge, T., Chan, E. K. F., Breen, J., Buckberry, S., Guennevig, B., Haas, M., Brown, A., Cowley, M. J., Thorne, N., Jain, Y., & Bauer, D. C. (2024). Future-proofing genomic data and consent management: a comprehensive review of technology innovations. *GigaScience*, 13. <https://doi.org/10.1093/gigascience/giae021>

⁹⁰ Ibid.

research. By automating these processes, the risk of human error or misinterpretation is significantly reduced ⁹¹.

Advanced techniques such as advanced pseudonymisation and differential privacy algorithms can protect privacy while still allowing valuable research. Pseudonymisation separates identifying information from genetic data, while differential privacy algorithms enable analysis without exposing individual-level data. These methods ensure that research can continue without compromising the privacy of the deceased ⁹².

Specialised data trusts can be established to manage post-mortem genetic data, acting as independent stewards that enforce ethical guidelines and legal requirements. These trusts mediate requests for data access from researchers and relatives, ensuring that the data is used responsibly and in accordance with the deceased's wishes ⁹³.

6.3.7. Access Management and Data Minimisation Techniques

Access management and data minimisation are essential strategies for protecting post-mortem genetic data, ensuring that sensitive information is handled responsibly and ethically. These techniques help mitigate risks associated with unauthorised access and misuse, while also respecting the privacy and autonomy of the deceased. Implementing robust access management and data minimisation strategies is crucial for maintaining compliance with regulatory frameworks.

6.3.8. Role-Based Access Control

Implementing robust access control measures is required for safeguarding post-mortem genetic data. Researchers and institutions must establish strict protocols to ensure that only authorised individuals can access this sensitive information. For

⁹¹ Ibid.

⁹² Ibid.

⁹³ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

example, researchers may have access to anonymised data, while living relatives could access specific information relevant to their health. This includes implementing role-based access control (RBAC) to limit data access based on job responsibilities and using attribute-bases access control (ABAC) to dynamically adjust access permissions based on contextual factors. Encrypting data both at rest and in transit further prevents unauthorised access, adding an essential layer of security ⁹⁴.

Access management for post-mortem genetic data presents unique challenges, as multiple individuals or family members may have legitimate claims to the data. Institutions must carefully consider these complexities when designing access protocols, ensuring that the deceased's wishes are respected and that the privacy of surviving relatives is protected. Maintaining audit trails of data access and usage helps monitor compliance with access policies and detect any unauthorised activities, further enhancing security ⁹⁵.

6.3.9. Data Degradation and Minimisation Methods

Data minimisation is a key principle in protecting post-mortem genetic data, involving the collection and retention of only the genetic information necessary for specific research purposes. Effective data minimisation techniques include input limitation, which involves collecting only strictly necessary genomic data and demographic

⁹⁴ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , Suhartono, J. Rule-Based Access Control (RuBAC) vs Role-Based Access Control (rbac). <https://sis.binus.ac.id/2024/10/25/rule-based-access-control-rubac-vs-role-based-access-control-rbac/> , Tall, A. M., & Zou, C. C. (2023). A Framework for Attribute-Based Access Control in Processing Big Data with Multiple Sensitivities. *Applied Sciences*, 13(2), 1183. <https://www.mdpi.com/2076-3417/13/2/1183>

⁹⁵ Bak, M. a. R. (2021). Good science at heart: Lessons on ethics from big data research in sudden cardiac arrest. . https://doi.org/https://pure.uva.nl/ws/files/64944311/Chapter_6.pdf , DNAnexus. (2021). *Security, Privacy & Quality for your Genomic Analysis*. https://20779781.fs1.hubspotusercontent-na1.net/hubfs/20779781/White%20Papers/Security-Privacy-Compliance-for-Genomic-Analysis_2021.pdf, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

attributes to reduce data uniqueness. Data degradation methods, such as data aggregation or processing techniques that reduce identifiability while maintaining research value, are crucial. Pseudonymisation, which replaces personally identifiable information with unique aliases or codes, further enhances privacy protection. In some cases, selective removal, such as eliminating specific genotypes from RNA-Sequencing databases, can enhance anonymisation ⁹⁶.

When implementing these techniques, researchers must balance data protection with the need for comprehensive genomic analyses, especially in large-scale studies of rare conditions. Establishing clear data retention policies ensures that genetic data is not stored longer than necessary and specifies the conditions under which it will be securely deleted or anonymised.

6.3.10. Compliance with GDPR Principles

The implementation of technological measures for post-mortem genetic data control must align with and complement existing legal frameworks to ensure comprehensive protection of genetic data while respecting individual rights and societal interests.

The GDPR serves as the cornerstone for data protection in the EU, establishing guidelines for the processing and protection of personal data. While the GDPR merely focusses on the data of living individuals, the principles of data minimisation, purpose limitation, and security are equally relevant to post-mortem data. Technological measures must be designed to uphold these principles, ensuring that genetic data is collected, stored, and processed in a manner that respects the rights and dignity of the deceased. This includes robust security measures, such as encryption and access controls, to protect data from unauthorised access and privacy breaches. Additionally,

⁹⁶ Bonomi, L., Huang, Y., & Ohno-Machado, L. (2020). Privacy challenges and research opportunities for genomic data sharing. *Nat Genet*, 52(7), 646-654. <https://doi.org/10.1038/s41588-020-0651-0> , Gomborg, M. (2024). *Privacy laws, ethics and the conundrum of DNA*. IAPP. <https://iapp.org/news/a/privacy-laws-ethics-and-the-conundrum-of-dna-2>, Herbert Smith Freehills | Global law firm. (n.d.-a). Challenges with anonymising genetic data. <https://www.herbertsmithfreehills.com/notes/ip/2021-10/what-does-it-mean-to-anonymise-genetic-data>

consent management systems must align with the GDPR's requirements for explicit consent and the right to withdraw consent, ensuring that the deceased's wishes are respected even after their death.

While the GDPR highlights the importance of obtaining a valid legal basis for processing genetic data – with explicit consent being one options – it does not require explicit consent in all circumstances. In the context of post-mortem data, obtaining explicit consent from the deceased is often not possible, and the GDPR itself does not apply to deceased individuals data. As a result, alternative bases such as public interest or scientific purposes under GDPR Articles 6(1)e and 9(2)(j) might be used instead. Notably, the Council of Europe advocates for the presumption of ethical consent for research purposes when the deceased's wishes are unknown, as outlined in Recommendation CM/Rec(2016)6. This approach aims to facilitate research while still respecting the dignity and privacy of the deceased and their relatives ⁹⁷.

6.3.11. Adaptability to National Laws

Given the global nature of genetic research, technological measures must be flexible enough to adapt to different legal requirements across jurisdictions. Implementing geolocation-based access controls ensures compliance with national laws, while modular systems can be easily adjusted to meet varying legal standards in different countries. Blockchain technology can create immutable records of consent and data usage across borders, providing a transparent and secure way to manage access and compliance ⁹⁸.

⁹⁷ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

⁹⁸ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

Advanced AI systems can be programmed to incorporate legal and ethical guidelines into their decision-making process, automatically flagging potential legal issues in research proposals involving post-mortem genetic data. These systems can guide researchers through complex legal requirements for data usage and sharing, ensuring that data access requests are evaluated against relevant laws and ethical standards. This support for ethical and legal decision-making helps maintain responsible and compliant practices ⁹⁹.

Technological measures can also facilitate regulatory oversight and auditing processes. For instance, automated reporting systems can generate compliance reports for regulatory bodies and secure portals to access and review data handling practices to enhance transparency and accountability. Another example are AI-powered monitoring systems which can detect and alert authorities to potential legal violations, further strengthening regulatory compliance and enforcement ¹⁰⁰.

⁹⁹ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Legal Q&A: What are the main concerns regarding processing samples and data from deceased persons? (2024). <https://bbmri.at/news-articles/legal-qa-what-are-the-main-concerns-regarding-processing-samples-and-data-from-deceased-persons/>

¹⁰⁰ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Legal Q&A: What are the main concerns regarding processing samples and data from deceased persons? (2024). <https://bbmri.at/news-articles/legal-qa-what-are-the-main-concerns-regarding-processing-samples-and-data-from-deceased-persons/> , McGuire, A. L., Moore, Q., Majumder, M., Walkiewicz, M., Eng, C. M., Belmont, J. W., Nassef, S., Darilek, S., Rutherford, K., Pereira, S., Scherer, S. E., Sutton, V. R., Wolf, D., Gibbs, R. A., Kahn, R., & Sanchez, L. A. (2016). The ethics of conducting molecular autopsies in cases of sudden death in the young. *Genome Res*, 26(9), 1165-1169. <https://doi.org/10.1101/gr.192401.115>

As laws governing genetic data and post-mortem rights continue to evolve, technological solutions must be adaptable. Modular architectures allow for easy updates to align with new legal requirements, while machine learning algorithms can interpret and apply new legal precedents to data management practices. Regular review processes help institutions stay acquainted of changing laws and adapt their systems accordingly ¹⁰¹.

6.4. Fostering a Culture of Responsibility and Accountability

By raising public awareness about the importance of post-mortem genetic data protection and the rights of deceased individuals, a culture of respect and responsibility can be fostered. This could involve educational campaigns on the importance of genetic privacy, resources to help individuals create data wills, and information on the potential benefits and risks of genetic data sharing.

Establishing accountability measures for organisations and individuals handling post-mortem genetic data, including penalties for misuse and mechanisms for reporting and addressing violations, ensures responsible management ¹⁰².

¹⁰¹ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Legal Q&A: What are the main concerns regarding processing samples and data from deceased persons? (2024). <https://bbmri.at/news-articles/legal-qa-what-are-the-main-concerns-regarding-processing-samples-and-data-from-deceased-persons/> , McGuire, A. L., Moore, Q., Majumder, M., Walkiewicz, M., Eng, C. M., Belmont, J. W., Nassef, S., Darilek, S., Rutherford, K., Pereira, S., Scherer, S. E., Sutton, V. R., Wolf, D., Gibbs, R. A., Kahn, R., & Sanchez, L. A. (2016). The ethics of conducting molecular autopsies in cases of sudden death in the young. *Genome Res*, 26(9), 1165-1169. <https://doi.org/10.1101/gr.192401.115>

¹⁰² Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Moore, Q. L., Majumder, M. A., Rutherford, L. K., & McGuire, A. L. (2016). Ethical and legal challenges associated with public molecular autopsies. *J. Law Med. Ethics*, 44(2), 309-318. <https://doi.org/10.1177/1073110516654124>

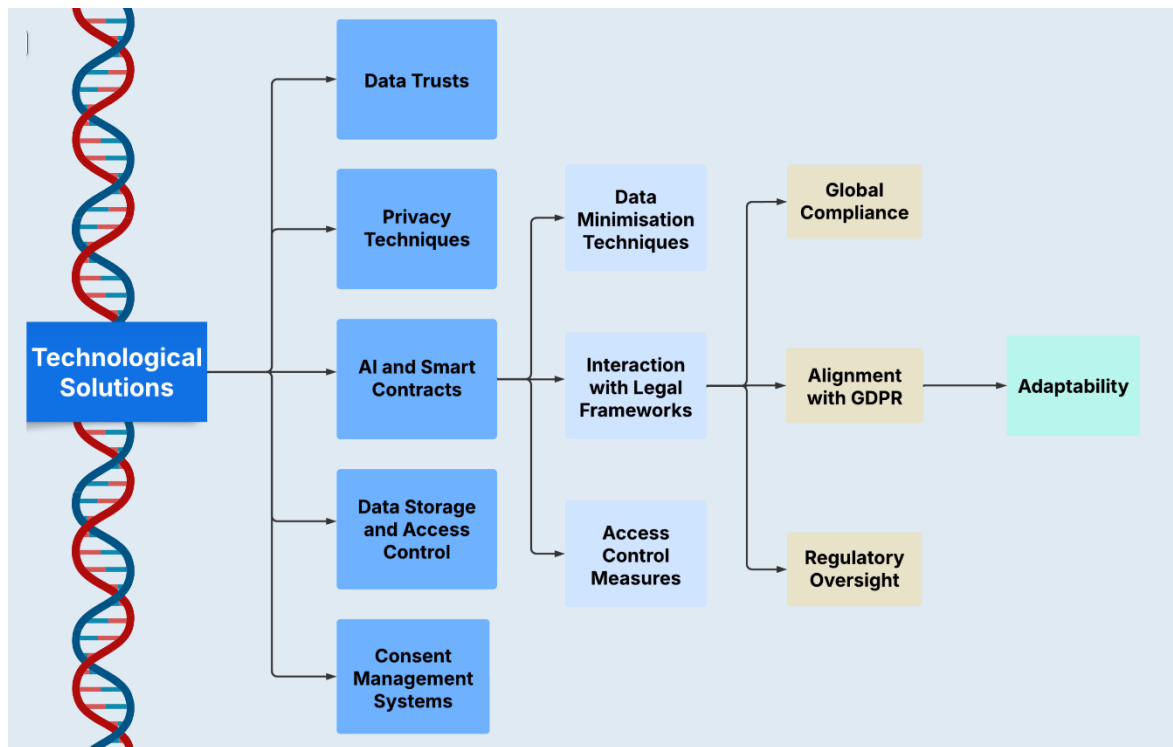


Figure 3. Flowchart illustrating the technological measures for post-mortem genetic data control. The chart outlines the key components and their relationships, starting from technological solutions and leading to adaptability and regulatory oversight. Illustration created using Lucid.app and Biorender.com.

6.5. Conclusion

This chapter set out to answer the sub-question: How can technological measures complement legal frameworks to ensure effective protection and responsible use of post-mortem genetic data?

The analysis demonstrates that technological solutions are a major aspect in addressing the unique challenges posed by genetic information. Traditional approaches, such as anonymisation, while valuable, are often insufficient due to the inherent identifiability and relational nature of genetic data. The persistent risk of re-identification means that reliance on anonymisation alone cannot guarantee privacy for either the deceased or the living relatives.

To address these limitations, a multi-layered approach is essential. Advanced consent management systems allow individuals to specify detailed preferences for the post-mortem use of their genetic data. Robust data storage and access controls, including encryption, MFA, and audit trails, provide strong safeguards against unauthorised access and misuse.

Emerging technologies, such as AI-driven access management and smart contracts, further enhance compliance with the wishes of the deceased and regulatory requirements, by automating data governance processes and reducing the risk of human error. Techniques such as advanced pseudonymisation and differential privacy allow for research to continue without compromising privacy.

However, the effectiveness of these technological tools depends on their integration with clear legal standards and ethical oversight. National legal variations and the absence of harmonised regulations across jurisdictions present challenges, underscoring the need for adaptable technological solutions that can accommodate diverse legal and cultural contexts.

In conclusion, technological measures are essential in bridging the gap between legal principles and practical data protection for post-mortem genetic data. By combining

advanced consent management, security controls, privacy-enhancing technologies, and automated governance systems, it is possible to respect the wishes of the deceased, protect the interest of living relatives, and enable responsible research.

7. Recommendations for a Comprehensive Post-Mortem Genetic Data Protection Framework

7.1. Introduction

This chapter presents concrete legal and technological recommendations to address the gaps, challenges, and inconsistencies identified in the previous chapters regarding post-mortem genetic data protection in the EU. It answers the final sub-question of this thesis: What practical steps can be taken at both the legislative and technical levels to ensure a coherent, effective, and ethically sound framework for the protection and responsible use of genetic data?

The chapter is structured in two main parts. First, it proposes legal reforms and policy measures, including clarifications to the GDPR, the development of more harmonised national laws, and the establishment of clear rules for consent, data access, and the rights of living relatives. It also addresses the need for enhanced enforcement, international cooperation, and the integration of privacy and security by design into all relevant processes. Second, the chapter outlines technological solutions, such as advanced consent management systems, privacy-enhancing technologies, and secure data storage, that can complement legal measures and foster a robust culture of accountability and trust.

7.2. Legal Recommendations

The recommendations listed below attempt to address the gaps identified in the previous sections and to provide a robust framework that respects the rights of the deceased, protects the interests of living relatives, and enable legitimate uses of genetic data for research and other societal beneficial purposes. For a visual representation of these recommendations, see **Figure 4**.

7.2.1. Clarification and Amendment of the GDPR

The GDPR should be clarified, or potentially amended via an interpretative guideline from the EDPB, to explicitly address the processing of genetic data after death. While

Recital 27 acknowledges that Member States can provide rules regarding data of deceased persons, the GDPR itself lacks specific provisions. Clear language should be added to define the scope of post-mortem data protection and the rights applicable to it. This inclusion is necessary to eliminate ambiguity and ensure consistent application across the EU ¹⁰³.

This suggestion is based on insights from case studies, such as *S. and Marper v. UK* (2008) and *Aycaguer v. France* (2017) ¹⁰⁴. Even though these cases do not interpret the GDPR directly, they are relevant because they set important standards for the protection of genetic data under Article 8 ECHR. In *S. and Marper v. UK* the ECtHR recognised the uniquely sensitive and permanent nature of genetic data, emphasising that its retention – even after death – can impact the privacy of both the deceased and their living relatives. *Aycaguer v. France* further emphasised that retention policies for genetic data must be proportionate and accompanied by adequate safeguards.

In line with the recommendations outlined in the study conducted for the EDPB, this thesis advocates for the development of EU-level guidelines to clarify the conditions and safeguards for secondary use of genetic data in research, and for greater harmonisation of national laws to ensure legal certainty for researchers and protection for data subjects ¹⁰⁵.

The GDPR should define who is authorised to act on behalf of the deceased regarding their genetic data. This could include next of kin, designated legal representatives (specified in a “data will” or advanced directive), or a newly established category of

¹⁰³ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>, Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

¹⁰⁴ As discussed in 3. Case Law on Post-Mortem Genetic Data and Privacy

¹⁰⁵ Study on the secondary use of personal data in the context of scientific research., (2020). https://www.edpb.europa.eu/our-work-tools/our-documents/other/study-secondary-use-personal-data-context-scientific-research_en

“data executors”. Clear criteria for determining representation are crucial to avoid disputes and ensure proper data management. Establishing these criteria is essential for respecting the deceased’s autonomy and safeguarding their genetic privacy ¹⁰⁶.

The establishment of harmonised rules across EU Member States for obtaining proxy consent for use of post-mortem genetic data is essential for the ethical and legal use of post-mortem genetic data. This should involve defining the circumstances under which proxy consent is permissible, the information that must be provided to the proxy, and the process for documenting and verifying consent. A tiered approach, considering the sensitivity of the data and the purpose of processing, may be appropriate. This mechanism balances the need for consent with the practical realities of post-mortem data management ¹⁰⁷.

The implementation of clear data retention policies that specify the maximum length of time that post-mortem genetic data can be stored is essential to uphold the GDPR’s principles of storage limitation and data minimisation. These policies should be regularly reviewed and updated to reflect changes in legal requirements and technological capabilities. The employment of technologies restricting data usage to pre-defined, legitimate purposes, which can be enforced through access controls and

¹⁰⁶ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders’ perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>, Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

¹⁰⁷ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders’ perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. Ibid.ESHG PPPC Comments on postmortem use of genetic data for research purposes. (2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>, Principles of consent: Deceased people - Consent and Participant information sheet preparation guidance. <https://www.hra-decisiontools.org.uk/consent/principles-deceased.html>

stringent data usage agreements is required. Furthermore, data minimisation requires collecting and storing only the genetic data strictly necessary for each specified purpose, imposing data aggregation and summarisation techniques to reduce granularity while preserving utility for legitimate research or historical analyses. Such measures ensure that the invasiveness of genetic data retention is proportional to the intended use, reducing risks to both the deceased's dignity and the privacy of living relatives ¹⁰⁸.

7.2.2. National Legislation and Implementation

EU Member States enact national laws that complement the GDPR by providing specific rules for post-mortem genetic data protection. These laws should address issues such as data retention periods, access protocols, and mechanisms for enforcing the rights of the deceased. This ensures that the specific challenges associated with post-mortem data are addressed comprehensively at the national level ¹⁰⁹.

National data protection authorities (DPAs) should be empowered and equipped with the resources to oversee the processing of post-mortem genetic data. This includes the authority to investigate complaints, conduct audits, and impose sanctions for non-compliance. Independent oversight is a major aspect for ensuring accountability and maintaining public trust ¹¹⁰.

¹⁰⁸ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z> , GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Madej, M., Karpiński, P., Akopyan, H., Witt, M., & Sasiadek, M. M. (2023). Genetic data protection as an indispensable element of genomic medicine development. *Pol Arch Intern Med*, 133(2). <https://doi.org/10.20452/pamw.16425>

¹⁰⁹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

¹¹⁰ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a

National legislation should address the rights of stakeholders, including family members, in cases where the deceased had not explicitly considered the implications of their post-mortem genetic data. Clear legal mechanisms should be established for withdrawing consent or restricting the use of data, subject to appropriate safeguards and judicial oversight.

Furthermore, Member States should launch public awareness campaigns to educate citizens about their rights regarding post-mortem genetic data and the mechanisms available to exercise these rights. This includes providing information on how to create “data wills” or advanced directives and how to designate legal representatives. Public awareness helps to foster a culture of respect and responsibility regarding genetic data

¹¹¹.

7.2.3. Strengthening Data Security and Anonymisation Techniques

The implementation of data security standards for all organisations processing post-mortem genetic data is crucial for complying with GDPR’s principles, even in the absence of explicit post-mortem guidelines. This includes the use of encryption, access controls, and regular security audits to prevent unauthorised access and data breaches. Strong security measures are required to protect sensitive genetic information and maintain public trust ¹¹².

systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

¹¹¹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders’ perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

¹¹² Fekete, Á. (2022, 2025/3/21). What are privacy enhancing technologies? The 5 best PETs for the modern tech stack. <https://mostly.ai/blog/what-are-privacy-enhancing-technologies>, GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

Encouraging the development and adoption of privacy-enhancing technologies, such as differential privacy and homomorphic encryption, to enable the analysis of genetic data while minimising the risk of re-identification. These technologies are essential for balancing the benefits of research with the need for privacy protection ¹¹³.

By developing clear guidelines on how to anonymise or pseudonymise post-mortem genetic data effectively, it is possible to mitigate the specific risks associated with genetic identifiability while facilitating legitimate data use. These guidelines should be regularly reviewed and updated to reflect advancements in re-identification techniques. Stricter anonymisation standards should be imposed when genetic data is used for historical purposes, and familial data is not relevant. Effective anonymisation is crucial for protecting the privacy of both the deceased and their living relatives ¹¹⁴.

7.2.4. Balancing Stakeholder's Interests

To ensure responsible post-mortem genetic data governance, it is essential to legally define the legitimate interests that may justify the processing of post-mortem genetic data without consent. This should include scientific research, public health initiatives, and historical preservations. However, these interests should be carefully balanced against the rights of the deceased and their families. This balance is essential for ensuring that the benefits of genetic research are realised without compromising individual rights ¹¹⁵. The ethical considerations highlighted in cases such as *Polat v.*

¹¹³ Fekete, Á. (2022, 2025/3/21). What are privacy enhancing technologies? The 5 best PETs for the modern tech stack. <https://mostly.ai/blog/what-are-privacy-enhancing-technologies>

¹¹⁴ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Fekete, Á. (2022, 2025/3/21). What are privacy enhancing technologies? The 5 best PETs for the modern tech stack. <https://mostly.ai/blog/what-are-privacy-enhancing-technologies>, GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

¹¹⁵ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5>, Belgian Advisory Committee on Bioethics. (2006). *Opinion no 38 of November 13th, 2006 on genetic testing to determine descent after death*. Retrieved from

Austria (2021) and *Estate of Jäggi v. Switzerland* (2006) demonstrate the need for a nuanced approach that respects both individual autonomy and societal values ¹¹⁶.

To safeguard the rights and interest of all stakeholders, ethical review boards should be mandated to examine research proposals using post-mortem genetic data. These boards should assess the ethical implications of research proposals and ensure that appropriate safeguards are in place to protect the rights and interests of all stakeholders. Ethical oversight is crucial for maintaining the integrity of genetic research .

In order to recognise the potential for unexpected discoveries, standardised procedures should be developed to guide the handling of incidental findings identified during the analysis of post-mortem genetic data. This includes providing guidance on how to communicate such findings to relatives and how to offer appropriate support and counselling. Addressing incidental findings in a responsible manner is essential for minimising potential harm and respecting the rights of affected individuals ¹¹⁷.

7.2.5. International Cooperation and Harmonisation

To encourage an internationally consistent approach, collaborative efforts should be directed towards establishing international standards for the protection of post-mortem genetic data. This is essential because genetic data often crosses borders in

https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/opinion_38_web.pdf, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

¹¹⁶ As discussed in 3. Case Law on Post-Mortem Genetic Data and Privacy

¹¹⁷ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Belgian Advisory Committee on Bioethics. (2006). *Opinion no 38 of November 13th, 2006 on genetic testing to determine descent after death*. Retrieved from https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/opinion_38_web.pdf, Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

research collaborations, public health initiatives, and historical preservation efforts. Without harmonised laws, legal uncertainties can hinder international research and compromise privacy. An international consistent approach includes collaborating with international organisations, such as the Council of Europe and the United Nations, to promote best practices and harmonise legal frameworks ¹¹⁸. International cooperation is emphasised by cross-border implications of cases, such as *Cakicisory and Others v. Cyprus* (2014) ¹¹⁹.

The protection of sensitive genetic information, particularly across international boundaries, requires the development and implementation of rules regulating cross-border transfers of post-mortem genetic data. Facilitating secure data transfers is crucial for enabling international research collaborations ¹²⁰.

Finally, promoting the sharing of best practices and lessons learned among EU Member States and other countries is essential for continuous improvement and effective implementation of protections measures. This includes organising conferences, workshops, and training programs to encourage collaboration and knowledge exchange ¹²¹.

¹¹⁸ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. Ibid. Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. (4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

¹¹⁹ As discussed in 3. Case Law on Post-Mortem Genetic Data and Privacy

¹²⁰ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

¹²¹ Bak, M. A. R., Ploem, M. C., Ateşyürek, H., Blom, M. T., Tan, H. L., & Willems, D. L. (2020). Stakeholders' perspectives on the post-mortem use of genetic and health-related data for research: a systematic review. *European Journal of Human Genetics*, 28(4), 403-416. <https://doi.org/10.1038/s41431-019-0503-5> , Harbinja, E. (2013). Does the EU Data Protection Regime Protect Post-Mortem Privacy and What Could Be The Potential Alternatives? *SCRIPTed*, 10. <https://doi.org/10.2966/scrip.100113.19>

7.3. Technological Recommendations

To support and enhance a comprehensive post-mortem genetic data protection framework, several technical measures are recommended. These measures complement the legal recommendations and address the technological challenges associated with post-mortem genetic data protection. For a visual representation of these recommendations, see **Figure 4**.

7.3.1. Integration with the European Health Data Space (EHDS)

The European Health Data Space is intended to serve as a central EU infrastructure for the secure exchange, access, and secondary use of health data, including genetic information, according to the plans set out by the European Commission and the EU legislator. Technological frameworks for post-mortem genetic data protection should therefore be designed to ensure compatibility and interoperability with the EHDS and similar digital health data platforms. They are designed to facilitate secure, pseudonymised, or anonymised data sharing for research and clinical purposes as the EHDS is gradually implemented across the EU ¹²². The EHDS Regulation, published in March 2025, establishes the main principles and objectives, but its full implementation will depend on the adoption of additional implementing acts and a phased rollout over the coming years ¹²³.

7.3.2. Data Security and Privacy-Enhancing Technologies (PETs)

To mitigate the risks of unauthorised access, robust encryption strategies must be implemented to secure post-mortem genetic data, irrespective of whether it is in transit or at rest. This can be achieved by using industry-standard encryption algorithms and

¹²² Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

¹²³ Arnold & Porter. (n.d.). *European Health Data Space Regulation published in the EU Official Journal | Advisories*. <https://www.arnoldporter.com/en/perspectives/advisories/2025/03/european-health-data-space-regulation-published>

regularly updated encryption keys¹²⁴. Data at rest encryption protects the data when stored on physical media, while data in transit protects the data as it moves from one location to another. By enforcing MFA for all users accessing post-mortem genetic data an additional layer of security is added beyond usernames and passwords, reducing the risk of unauthorised access¹²⁵. Furthermore, the implementation of role-based access control (RBAC) ensures that users only have access to the data and functionalities necessary for their specific roles. Access permissions should be reviewed and updated regularly to reflect changes in user responsibilities. Finally, maintaining comprehensive audit trails of all access to and modifications of post-mortem genetic data, including timestamps, user IDs, and details of the actions performed is crucial¹²⁶.

Platforms, such as the EHDS should incorporate advanced privacy-enhancing technologies (e.g., strong encryption, pseudonymisation, and differential privacy techniques) to protect the identities of both the deceased and their living relatives, given the relational nature of genetic data. The employment of differential privacy techniques can add statistical noise to genetic data, allowing for aggregate analyses while protecting individual privacy. This allows to balance post-mortem privacy protection with research utility¹²⁷. Furthermore, the use of homomorphic encryption enables computations on encrypted genetic data without decrypting it first, allowing researchers to analyse data without accessing the raw information first. This can be

¹²⁴ Crypt4GH: a secure method for sharing human genetic data. https://www.ga4gh.org/news_item/crypt4gh-a-secure-method-for-sharing-human-genetic-data/

¹²⁵ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/, Madej, M., Karpiński, P., Akopyan, H., Witt, M., & Sasiadek, M. M. (2023). Genetic data protection as an indispensable element of genomic medicine development. *Pol Arch Intern Med*, 133(2). <https://doi.org/10.20452/pamw.16425>

¹²⁶ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/

¹²⁷ APPLYING DIFFERENTIAL PRIVACY TECHNIQUES TO PROTECT INDIVIDUAL PRIVACY IN GENOMIC DATA SHARING. (2024). *International Journal of Engineering & Scientific Research*, 12(02). https://doi.org/https://www.ijmra.us/project%20doc/2024/IJESR_FEBRUARY2024/IJESR1Feb24_77689.pdf

archived, by applying k -anonymity and l -diversity techniques to ensure that each record in a dataset is indistinguishable from at least $k-1$ other records and that each sensitive attribute has at least l well-represented values. Additionally, the replacement of sensitive genetic data with non-sensitive tokens, allows for data processing without exposing the underlying information. This data masking should be applied consistently and in a manner that preserves the utility of the data ¹²⁸.

7.3.3. Consent and Preference Management

To translate the principles of autonomy and consent, it is essential to develop secure platforms that enable individuals to specify their preferences for the management of their genetic data after death. These platforms should integrate with legal frameworks for wills and advance directives. The use of blockchain technology can be explored to create fixed records of individuals' consent and preferences regarding their genetic data, while smart contracts could automate compliance with these preferences, reducing reliance on proxy decision-makers. However, these solutions must implement decentralised data storage solutions to distribute genetic data across multiple locations, reducing the risk of a single point of failure or unauthorised access. Distributing genetic information across secure nodes while employing hardware-based secure enclaves for processing genomic datasets. These enclaves should provide hardware-based security features that protect data from unauthorised access and modification ¹²⁹.

¹²⁸ GDPR Brief: processing the data of the deceased for scientific research purposes — looking beyond the GDPR? https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-processing-the-data-of-the-deceased-for-scientific-research-purposes-looking-beyond-the-gdpr/ , Madej, M., Karpiński, P., Akopyan, H., Witt, M., & Sasiadek, M. M. (2023). Genetic data protection as an indispensable element of genomic medicine development. *Pol Arch Intern Med*, 133(2). <https://doi.org/10.20452/pamw.16425>

¹²⁹ Albalwy, F., Brass, A., & Davies, A. (2021). A Blockchain-Based Dynamic Consent Architecture to Support Clinical Genomic Data Sharing (ConsentChain): Proof-of-Concept Study. *JMIR Med Inform*, 9(11), e27816. <https://doi.org/10.2196/27816> , Zarchi, G., Sherman, M., Gady, O., Herzig, T., Idan, Z., & Greenbaum, D. (2022). Blockchains as a means to promote privacy protecting, access availing, incentive increasing, ELSI lessening DNA databases. *Front Digit Health*, 4, 1028249. <https://doi.org/10.3389/fdgth.2022.1028249>

The technological infrastructure should support the recording and enforcement of the deceased's ante-mortem wishes regarding the use of their genetic data. If no explicit consent exists, default technical safeguards should reflect a presumption of non-opposition, subject to ethical review and national legal requirements. Mechanisms for managing and updating consent preferences, including the ability for relatives to intervene with their interests are affected, should be built into these platforms.

7.3.4. Interoperability and Harmonisation

Given the diversity of national post-mortem data protection laws within the EU, technological solutions should be adaptable to Member State-specific requirements, while striving for harmonisation through common standards promoted by the EHDS.

In addition, real-time monitoring systems can be used to detect and respond to security incidents involving post-mortem genetic data. For example, intrusion detection systems and security information and event management (SIEM) tools can identify suspicious activities, complying with the purpose limitation principle of the GDPR. Regular security audits allow for assessment of technical safeguards and identification of vulnerabilities in storage architecture. As a part of a comprehensive security strategy, proactive penetration testing can be performed by independent auditors to detect vulnerabilities in architecture storage. Finally, comprehensive data breach response plans that outline the steps in the event of a security incident involving post-mortem data must be developed and implemented. These plans must also be tested on a regular basis and be updated to ensure their effectiveness ¹³⁰.

However, overly restrictive access controls or blanket prohibitions on data sharing could limit valuable research. Therefore, a balanced approach is essential,

¹³⁰ Fellmann, F., Rial-Sebbag, E., Patch, C., Hentze, S., Stefandottir, V., Mendes, Á., van El, C. G., Cornel, M. C., Forzano, F., on behalf of the, P., & Professional Committee of the European Society of Human, G. (2020). ESHG PPPC Comments on postmortem use of genetic data for research purposes. *European Journal of Human Genetics*, 28(2), 144-146. <https://doi.org/10.1038/s41431-019-0525-z>

incorporating data minimisation, secure data enclaves, and tiered access systems to enable responsible research while respecting privacy, ethical and legal considerations.

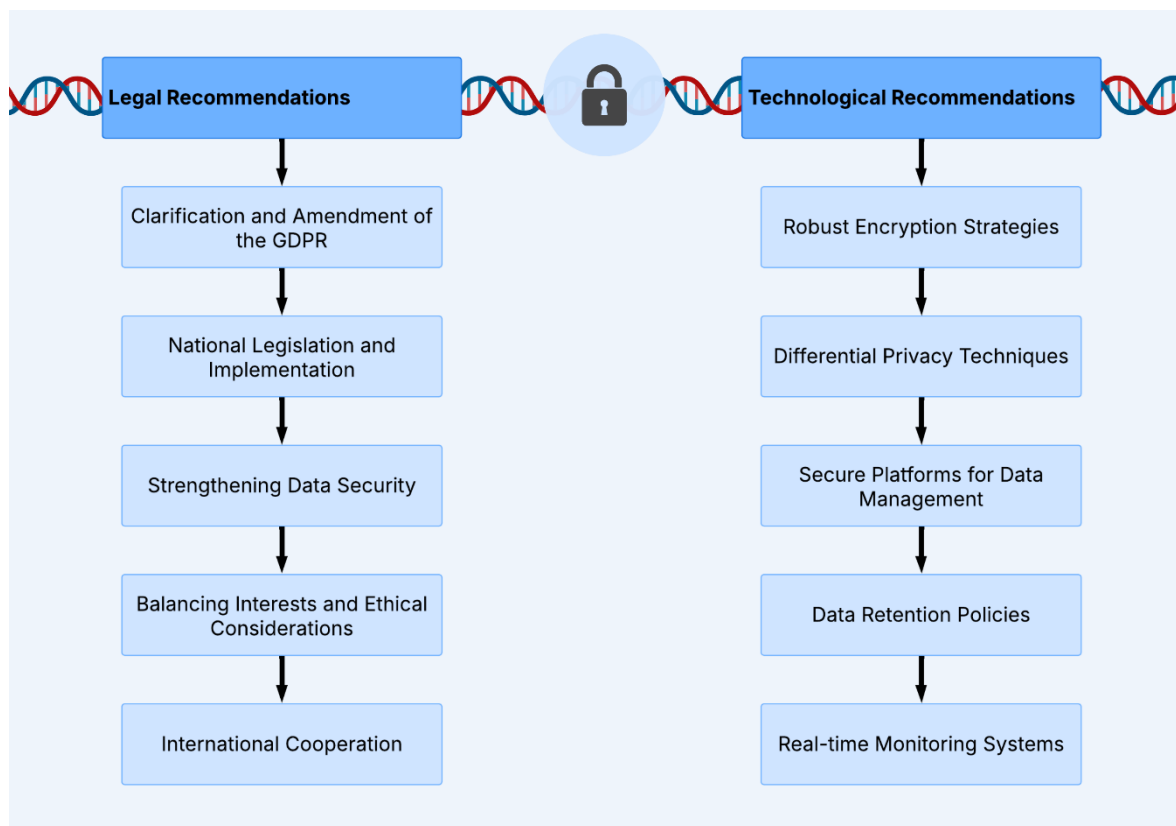


Figure 4. Flowchart of Recommendations for a Comprehensive Post-Mortem Genetic Data Protection Framework. The flowchart illustrates a structured framework of recommendations to enhance post-mortem genetic data protections. The flowchart describes legal recommendations and technological recommendations, each targeting distinct aspects of data governance and security. Illustration created using Lucid.app and Biorender.com.

7.4. Conclusion

This chapter addressed the final sub-question: What practical steps can be taken at both the legislative and technical levels to ensure a coherent, effective, and ethically sound framework for the protection and responsible use of post-mortem genetic data?

The analysis shows that a comprehensive framework requires both legal and technological innovation. Legally, the GDPR should be clarified to explicitly address

post-mortem genetic data, with harmonised national laws, clear regulations for consent, representation, and data retention, and a oversight by data protection authorities. Technologically, robust data security, privacy-enhancing technologies, and integration with platforms such as the EHDS are important aspects. Secure consent and preference management systems will allow individuals to control the use of their post-mortem genetic data, while advances anonymisation and access controls protect privacy and allow research.

In conclusion, by combining harmonised legal standards with state-of-the-art technological safeguards the EU can ensure respectful, secure and beneficial use of post-mortem genetic data, thereby balancing the rights of the deceased and the interests of other stakeholders.

8. Conclusion

8.1. Introduction

This final chapter synthesises the main findings of the thesis, and addresses the main research question: How can post-mortem genetic data protection be integrated under European data protection law to ensure individuals maintain control over their genetic information after death, thereby upholding fundamental rights to privacy, preventing potential misuse of sensitive genetic information, and fostering public trust in genetic research and data handling practices? The chapter first summarises the key insights from the legal, judicial, stakeholder, and technological analyses. It then reflects on the challenges and opportunities identified, and concludes with recommendations for future research and policy development.

8.2. Addressing the Main Research Question

This thesis demonstrates that current European data protection law, particularly the GDPR, does not provide explicit or harmonised protection for post-mortem genetic data. As a result, individuals have limited ability to determine the fate of their genetic information after death. The lack of clear provisions leads to fragmentation across Member States and uncertainty for all stakeholders involved. This regulatory gap complicates the upholding of privacy rights, increases the risk of misuse of sensitive genetic information, and can undermine public trust in genetic research and data handling practices.

8.3. Summary of Findings

The GDPR and other legal frameworks regarding data protection focus primarily on protecting the data of living individuals, leaving uncertainty about the management of post-mortem genetic data. This gap underscores the need to explicit guidelines and harmonised regulations across EU Member States.

The ethical considerations associated with post-mortem genetic data protection are multifaceted, involving the balancing of the deceased's privacy rights with the

interests of the living relatives and the broader societal benefits of genetic research. The relational nature of genetic data adds an extra layer of complexity, as it can reveal sensitive information about both the deceased and their living relatives.

Advances in technology offer promising opportunities for enhancing post-mortem genetic data protection. Techniques such as encryption, access controls, and data anonymisation can mitigate risks associated with unauthorised access and misuse. However, these solutions must be integrated with legal frameworks to ensure comprehensive protection.

The management of post-mortem genetic data involves various stakeholders, including families, researchers, healthcare professionals, and biotechnology companies. Balancing these interests requires robust ethical guidelines and transparent decision-making processes.

Analysis of key legal cases highlights the evolving legal principles surrounding post-mortem genetic data protection. These cases underscore the importance of respecting the deceased's wishes while considering the potential benefits of genetic research for public health and scientific advancement.

8.4. Implications for Future Research and Policy

Future policies should aim to develop comprehensive legal frameworks that explicitly address post-mortem genetic data protection. This includes clarifying the scope of data protection rights, defining who can act on behalf of the deceased, and establishing harmonised rules for obtaining proxy consent.

Specific ethical guidelines should be developed in consultation with various stakeholders to ensure these guidelines are practical and respect all interests. These guidelines should balance the rights of the deceased with the interests of living relatives and broader societal benefits of genetic research.

Future policies should focus on integrating technological solutions with legal frameworks to ensure protection of post-mortem genetic data. This includes

developing secure platforms for managing consent, implementing advanced data anonymisation techniques, and ensuring compliance with data protection principles.

Furthermore, public awareness should be raised about the importance of post-mortem genetic data protection. Educational campaigns should inform individuals about their rights and the mechanisms available to exercise these rights, creating a culture of respect and responsibility regarding genetic data.

Collaborative efforts are required to establish international standards for post-mortem genetic data protection. This includes working with international organisations to promote best practices and harmonise international legal frameworks regarding post-mortem genetic data protection.

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Annexes

Annex I. Glossary of Terms

This annex provides a glossary of terms relevant to the discussion on data protection, particularly in the context of genetic data and post-mortem data.

- **Access-Based Access Control (ABAC):** An authorisation model that grants access to resources based on attributes associated with the user, the resource, and the current environment.
- **Access Control:** Mechanisms that regulate who or what can view or use resources in a computing environment. This includes Role-Based Access Control (RBAC) and Attribute-Based Access Control (ABAC).
- **Anonymisation:** The process of removing personally identifiable information from data sets, so that the individuals to whom the data refers cannot be identified.
- **Artificial Intelligence (AI):** The simulation of human intelligence processes by computer systems, including learning, reasoning, and problem-solving.
- **Biobanks:** Repositories that store biological samples (such as blood, tissue, or DNA) for research purposes.
- **Blockchain:** A decentralised, distributed ledger technology that records transactions on multiple computers. It is known for its use in cryptocurrencies but also has applications in secure data storage and management.
- **Consent:** Permission granted by an individual for a specific action, such as the collection, use, or disclosure of their personal data. In the context of genetic data, consent is often required for research and medical purposes.
- **Court of Justice of the European Union (CJEU):** The highest court in the European Union, ensuring the uniform application and interpretation of EU law.
- **Data Controller:** An entity that determines the purposes, conditions, and means of the processing of personal data.

- **Data Minimisation:** A principle of data protection that requires data to be adequate, relevant, and limited to what is necessary for the purposes for which they are processed.
- **Data Processor:** An entity that processes personal data on behalf of the data controller.
- **Data Protection:** The safeguarding of the privacy rights of individuals in relation to the processing of personal data.
- **Data Subject:** An individual whose personal data are being collected, held or processed.
- **Differential Privacy:** A system for publicly sharing information about a dataset by describing the patterns of groups within the dataset while withholding information about individuals in the dataset.
- **Deoxyribonucleic Acid (DNA):** A molecule that carries the genetic instructions used in the growth, development, and reproduction of all known living organisms and many viruses.
- **Encryption:** The process of converting data into a code to prevent unauthorised access.
- **Ethics Committees:** Bodies responsible for reviewing the ethical aspects of research proposals and ensuring that they comply with ethical standards and guidelines.
- **European Convention on Human Rights (ECHR):** An international treaty safeguarding human rights and fundamental freedoms in Europe.
- **European Court of Human Rights (ECtHR):** A court established by the European Convention on Human Rights to rule on allegations of violations of the convention.
- **European Data Protection Board (EDPB):** An independent European body ensuring the consistent application of data protection rules throughout the European Union.
- **European Union (EU):** A political and economic alliance of 27 Member States located primarily in Europe.

- **General Data Protection Regulation (GDPR):** A regulation in EU law on data protection and privacy in the European Union and the European Economic Area. It also addresses the transfer of personal data outside the EI and EEA areas.
- **Genetic Data:** Personal data relating to the inherited or acquired genetic characteristics of an individual, which give unique information about the physiology or health of that individual.
- **Genomic Sequencing:** The process of determining the complete DNA sequence of an organism's genome at a single time.
- **Homomorphic Encryption:** A form of encryption that allows computations to be carried out in ciphertext, thus generating an encrypted result which, when decrypted, matches the result of operations performed on the plaintext.
- **Informed Consent:** Consent given by an individual who has received and understood all relevant information about a procedure or research study.
- **Law Enforcement Directive (LED):** An EU directive concerning the processing of personal data by competent authorities for the purposes of the prevention, investigation, detection, or prosecution of criminal offenses or the execution of criminal penalties.
- **Multi-Factor Authentication (MFA):** An authentication method that requires the user to provide two or more verification factors to gain access to a resource.
- **Personal Data:** Any information relating to an identified or identifiable natural person.
- **Post-Mortem Data:** Data relating to an individual after their death.
- **Post-Mortem Genetic Data Protection:** The protection of genetic data of deceased individuals, ensuring that their privacy and the interests of their living relatives are respected.
- **Privacy-Enhancing Technologies (PETs):** Technologies that help protect personal data and privacy by minimising data processing, maximising data security, and empowering individuals with control over their data.

- **Proxy Consent:** Consent given by a representative on behalf of an individual who is unable to provide consent themselves, such as a deceased person.
- **Pseudonymisation:** The process of replacing private identifiers with fake identifiers or pseudonyms.
- **Right to Erasure:** Also known as the “right to be forgotten”, it is the right of an individual to request the deletion of their personal data.
- **Role-Based Access Control (RBAC):** An approach to restricting system access to authorised users based on their roles within an organisation.
- **Security Information and Event Management (SIEM):** A software solution that collects and analyses security logs and event data to detect and respond to security threats.
- **Smart Contracts:** Self-executing contracts with the terms of the agreement directly written into lines of code. They automatically enforce and execute an agreement as soon as predefined conditions are met.
- **Stakeholders:** Individuals, groups, or organisation that have an interest or concern in a particular issue or project.
- **Technological Measures:** Tools and systems used to protect and manage data, including encryption, access controls, and anonymisation techniques.

Annex II. Relevant EU Directives and Recommendations

This annex provides an overview of the relevant provisions from the General Data Protection Regulation (GDPR), the Council of Europe Recommendation No. R (97) 5, and the Council of Europe Recommendation CM/Rec(2016)6 that pertain to the processing of personal data, including genetic data and the data of deceased persons.

“General Data Protection Regulation (GDPR)”

Recital 27

- (1) *This Regulation does not apply to the personal data of deceased person.*
- (2) *Member States may provide for rules regarding the processing of personal data of deceased persons.*

Article 1

- (1) *This Regulation lays down rules relating to the protection of natural persons with regard to the processing of personal data and rules relating to the free movement of personal data.*

Article 4

- (1) *‘personal data’ means any information relating to an identified or identifiable natural person (‘data subject’); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;*
- (2) *‘processing’ means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction;*

- (11) 'consent' of the data subject means any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her;
- (13) 'genetic data' means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question;
- (14) 'biometric data' means personal data resulting from specific technical processing relating to the physical, physiological or behavioural characteristics of a natural person, which allow or confirm the unique identification of that natural person, such as facial images or dactyloscopic data;
- (15) 'data concerning health' means personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status;

Article 5

- (1) Personal data shall be:
 - (b) collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes ('purpose limitation');
 - (d) accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay ('accuracy');
 - (e) kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods insofar as the personal data will be processed solely for

archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) subject to implementation of the appropriate technical and organisational measures required by this Regulation in order to safeguard the rights and freedoms of the data subject ('storage limitation');

Article 6

- (1) Processing shall be lawful only if and to the extent that at least one of the following applies:
 - (a) *the data subject has given consent to the processing of his or her personal data for one or more specific purposes;*
 - (d) *processing is necessary in order to protect the vital interests of the data subject or of another natural person;*
 - (e) *processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;*
 - (f) *processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child.*
- (4) *Where the processing for a purpose other than that for which the personal data have been collected is not based on the data subject's consent or on a Union or Member State law which constitutes a necessary and proportionate measure in a democratic society to safeguard the objectives referred to in Article 23(1), the controller shall, in order to ascertain whether processing for another purpose is compatible with the purpose for which the personal data are initially collected, take into account, inter alia:*
 - (a) *any link between the purposes for which the personal data have been collected and the purposes of the intended further processing;*
 - (c) *the nature of the personal data, in particular whether special categories of personal data are processed, pursuant to Article 9, or whether personal data related to criminal convictions and offences are processed, pursuant to Article 10;*

(e) the existence of appropriate safeguards, which may include encryption or pseudonymisation.

Article 9

- *(1) Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited.*
- *(2) Paragraph 1 shall not apply if one of the following applies:*
 - (a) the data subject has given explicit consent to the processing of those personal data for one or more specified purposes, except where Union or Member State law provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject;*
 - (c) processing is necessary to protect the vital interests of the data subject or of another natural person where the data subject is physically or legally incapable of giving consent;*
- *(4) Member States may maintain or introduce further conditions, including limitations, with regard to the processing of genetic data, biometric data or data concerning health.*

Article 17

- *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;"*¹³¹

"Council of Europe Recommendation No. R (97) 5

Principles for Processing Medical Data

- *Medical data shall be collected and processed fairly and lawfully, and only for specific purposes directly relevant to the health of the data subject or for medical research, public health, or hospital management.*
- *Appropriate safeguards must be provided by domestic law when processing medical data automatically, including confidentiality, security, and the rights of individuals.*

Conservation of Medical Data

- *In general, medical data shall be kept no longer than necessary to achieve the purpose for which they were collected.*

Access Control

- *To guarantee the possibility of checking and ascertaining to which persons or bodies personal data can be communicated by data transmission equipment (control of communication)."*¹³²

¹³¹ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), 1-88 119 (2016). <http://data.europa.eu/eli/reg/2016/679/oj>

¹³² COUNCIL OF EUROPE COMMITTEE OF MINISTERS. (1997). *RECOMMENDATION No. R (97) 5 OF THE COMMITTEE OF MINISTERS TO MEMBER STATES ON THE PROTECTION OF MEDICAL DATA.*: COUNCIL OF EUROPE COMMITTEE OF MINISTERS Retrieved from <https://rm.coe.int/cmrec-97-5-on-the-protection-of-medical-data/1680a43b64>

“Council of Europe Recommendation CM/Rec(2016)6

Respect for Dignity and Rights

- *Member States should protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity, the right to private life, and other rights and fundamental freedoms with regard to any activities related to biological materials of human origin*

Consent Principles

- *The use of biological materials of human origin for research purposes should be based on free, informed, and explicit consent obtained from the individual concerned before their death, unless otherwise provided by law”* ¹³³

¹³³

CM/REC(2016)6, (n.d.).
[https://search.coe.int/cm/#{%22CoEIdentifier%22:\[%22090000168064e8ff%22\],%22sort%22:\[%22CoEValidationDate%20Descending%22\]}](https://search.coe.int/cm/#{%22CoEIdentifier%22:[%22090000168064e8ff%22],%22sort%22:[%22CoEValidationDate%20Descending%22]})

Annex III: National Laws

This annex provides an overview of the national data protection laws in various European countries regarding the processing of personal data of deceased persons. The information is collected from the relevant legal provisions of each country.

Austria

“National Data Protection Act

Processing of personal data in case of emergency (§ 10)

- (1) In case of emergency, public-sector controllers and relief organisations shall be authorised to jointly process data to the extent that this is necessary to assist persons directly affected by a disaster, to locate and identify missing or deceased persons and to provide information to their relatives.*
- (2) Anybody who lawfully possesses personal data shall be permitted to transfer these data to public-sector controllers and relief organisations if these controllers and organisations need this personal data to manage a disaster for the purposes specified in para. 1.*
- (3) The transfer abroad of personal data is permitted insofar as this is absolutely necessary to fulfil the purposes mentioned in para. 1. Data that by themselves would make the data subject liable to criminal prosecution shall not be transferred unless they are absolutely necessary for identification in a particular case. The Data Protection Authority shall be informed immediately about the data transfers performed and about the circumstances of the motivating incident. The Data Protection Authority shall prohibit further data transfers if the interference with the fundamental right to data protection resulting from the data transfer is not justified by the special circumstances caused by a disaster.”¹³⁴*

Belgium

¹³⁴ Datenschutzbehörde, Ö. Data protection laws. <https://data-protection-authority.gv.at/data-protection-laws/relevant-data-protection-laws>

Criminal Code

“Article 458

Doctors, surgeons, health officers, pharmacists, midwives, and all other persons who, by reason of their status or profession, are the custodians of secrets confided to them, who, except in cases where they are called to testify in court or where the law obliges them to disclose such secrets, reveal them, shall be punished by imprisonment of eight days to six months and a fine of one hundred to five hundred francs.”¹³⁵

Bulgaria

“Personal Data Protection Act

Article 25f

(1) A data controller or processor may process personal data of deceased persons only if there is a legal basis for this. In such cases, the data controller or processor shall take the appropriate measures so that the rights and freedoms of others or a public interest would not be adversely affected.”¹³⁶

Denmark

“Data Protection Act

Chapter 1: General Provisions – Part 1: Material scope of the Act

This Act and the General Data Protection Regulation shall apply to the data of deceased persons for a period of 10 years following the death of the deceased.”¹³⁷

Estonia

¹³⁵ STRAFWETBOEK. In JUSTEL - Geconsolideerde Wetgeving (pp. 1–144) [Book]. Belgisch Staatsblad. , (1867). https://www.ejustice.just.fgov.be/img_1/pdf/1867/06/08/1867060850_N.pdf

¹³⁶ Personal Data Protection Act. (n.d.). CPDP. <https://cpdp.bg/en/legislation/personal-data-protection-act/>

¹³⁷ Act on supplementary provisions to the regulation on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (the Data Protection Act), (208). <https://www.datatilsynet.dk/media/7753/danish-data-protection-act.pdf>

“Personal Data Protection Act

Chapter 3: OTHER CASES OF PROCESSING PERSONAL DATA

§ 9. Processing of personal data after death of data subject

- (1) *The consent of a data subject shall remain valid during the lifetime of the data subject and for 10 years after the death of the data subject, unless the data subject decided otherwise. If the data subject died as a minor, his or her consent shall be valid for the term of 20 years after the death of the data subject.*
- (2) *After the death of the data subject, processing of his or her personal data is permitted only with the consent of the successors of the data subject, except in the case:*
- a. 10 years have passed since the death of the data subject;*
 - b. 20 years have passed since the death of a data subject who was a minor;*
 - c. personal data are processed under any other legal bases.”* ¹³⁸

Finland

“Data Protection Act (1050/2018)

Section 2 Scope of application

This Act applies within the scope of application of Article 2 of the Data Protection Regulation. This Act and the Data Protection Regulation also apply, with the exception of Article 56 and Chapter VII of the Regulation, to the processing of personal data in the course of activities referred to in points (a) and (b) of Article 2(2), unless otherwise provided elsewhere by law.” ¹³⁹

France

LOI n° 2016-1321 du 7 octobre 2016 pour une République numérique

¹³⁸ Personal Data Protection Act–Riigi teataja, (n.d.).
<https://www.riigiteataja.ee/en/eli/523012019001/consolide>

¹³⁹ Data Protection Act (1050/2018), (2018).
https://legislationline.org/sites/default/files/documents/65/FINN_data%20protection.pdf

“Article 63:

(1) Law No. 78-17 of 6 January 1978 on data processing, files and freedoms is amended as follows:

- a. “When the data subject is deceased, these rights are exercised by his heirs.*
- b. The first paragraph shall not apply where the deceased has expressed his opposition during his lifetime.*
- c. In the absence of any expression of will by the deceased, the heirs may exercise these rights only to the extent that they are necessary:*
 - i. either to allow the ascertainment of the death,*
 - ii. or to defend the memory of the deceased,*
 - iii. or to allow the heirs to assert their rights.*

(2) After Article 40, the following articles are inserted:

- a. General guidelines shall be registered with a trusted digital third party certified by the Commission nationale de l’informatique et des libertés.*
- b. Specific guidelines shall be registered with the data controller.*
- c. Specific guidelines may designate a person responsible for their execution; this person shall be deemed to be the executor. Failing designation or, unless otherwise stipulated, in the event of the death of the designated person, his heirs shall be entitled to do so.*
- d. In the absence of any guidelines or mention to the contrary, the heirs may exercise the rights referred to in that same article.*
- e. When the data subject wishes to register his guidelines with the data controller, the latter shall inform him of the possibility of registering them with a trusted digital third party certified by the Commission nationale de l’informatique et des libertés.” 140*

Germany

¹⁴⁰ LOI n° 2016-1321 du 7 octobre 2016 pour une République numérique (1) - Légifrance, (n.d.). <https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000033202746>

“Book 5 – Law of Succession

Section 1922 – Universal succession

- (1) *Upon the death of a person (devolution of an inheritance), that person’s property (inheritance) passes as a whole to one or more than one other persons (heirs).*
- (2) *(2) The share of a co-heir (share of the inheritance) is governed by the provisions relating to inheritance.”* ¹⁴¹

Ireland

“Data Protection Act 2018 - Part 5

“personal data” means information relating to—

- 1.1. *an identified living individual, or*
- 1.2. *a living individual who can be identified from the data, directly or indirectly, in particular by reference to—*
- 1.2.1. *an identifier such as a name, an identification number, location data or an online identifier, or*
- 1.2.2. *one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of the individual;”* ¹⁴²

Italy

“Italian personal data protection code – Legislative Decree no. 196 of 30 June 2003

Mechanisms to Exercise Rights

The rights as per Section 7, where related to the personal data concerning a deceased, may be exercised by any entity that is interested therein or else acts to protect a data subject or for family-related reasons deserving protection.” ¹⁴³

¹⁴¹ Book 5. Law of Succession (Section 1922 – 2063) – LawEuro. (n.d.). <https://laweuro.com/?p=15608>

¹⁴² Revised Acts. , (n.d.). <https://revisedacts.lawreform.ie/eli/2018/act/7/revised/en/html>

¹⁴³ Italian Personal Data Protection Code - Legislative Decree no. 196 of 30 June 2003. . (n.d.). <https://www.privacy.it/archivio/privacycode-en.html>

Netherlands

“National Medical Treatment Act

Article 7:457 – Obligation of Secrecy

1. *The care provider is obliged to maintain secrecy regarding everything that becomes known to him in connection with the treatment agreement, except insofar as any provision of law obliges him to communicate or results from his task.*

Article 7:458 – Data for Scientific Research

1. *If data from the medical file are to be used for scientific research or statistics in the field of public health without the consent of the patient, this is only permissible if:*
 - *asking for consent is impossible or would require a disproportionate effort,*
 - *the research serves a public interest,*
 - *the research cannot be carried out without the data in question in identifiable form,*
 - *the privacy of the person concerned is sufficiently safeguarded, for example by pseudonymisation, and*
 - *the patient has not objected to the provision of the data.*
2. *The care provider shall ensure that the data are only provided in this way after the research protocol has been approved by an ethics committee.*
3. *The provision of data for scientific research or statistics as referred to in the first paragraph is recorded in the medical file.”* ¹⁴⁴

Spain

¹⁴⁴ Wetten.nl - Regeling - Burgerlijk Wetboek Boek 7 - BWBR0005290., (2019). <https://wetten.overheid.nl/BWBR0005290/2019-11-15/0/Boek7/Titeldeel7/Afdeling5/afdrukken>

“Organic Law 3/2018, of December 5, on Personal Data Protection and guarantee of digital rights

Article 3. Data of deceased persons.

- 1. Persons related to the deceased for family or de facto reasons, as well as their heirs, may contact the data controller or data processor to request access to their personal data and, where appropriate, their rectification or erasure. As an exception, the persons referred to in the preceding paragraph may not access the data of the deceased, nor request its rectification or deletion, when the deceased had expressly forbidden it or it is so established by law. Said prohibition shall not affect the right of the heirs to access the data of the deceased’s estate.*
- 2. The persons or institutions that the deceased had expressly designated for this purpose may also request, in accordance with the instructions received, access to the deceased’s personal data and, where appropriate, its rectification or deletion. A Royal Decree will establish the requirements and conditions for accrediting the validity and validity of these mandates and instructions and, if applicable, their registration.*
- 3. In the event of the death of minors, these powers may also be exercised by their legal representatives or, within the framework of its competencies, by the Public Prosecutor’s Office, which may act ex officio or at the request of any interested individual or legal entity. In the event of death of persons with disabilities, these powers may also be exercised, in addition to those mentioned in the preceding paragraph, by those who have been designated for the exercise of support functions, if such powers are understood to be included in the support measures provided by the designated person.” ¹⁴⁵*

Sweden

“Patient Data Act (2008:355 Section 3)

¹⁴⁵ Organic Law 3/2018, of December 5, on Personal Data Protection and guarantee of digital rights., (2018). <https://www.uspceu.com/Portals/0/docs/transparencia/normativa/legislacion-general/EN%20-%20Organic%20Law%203-2018,%20of%20December%205,%20on%20Personal%20Data%20Protection%20and%20guarantee%20of%20digital%20rights..pdf>

In this Act the following terms are used with the meaning stated below

Personal data: All kinds of information that directly or indirectly may be referable to a natural person who is alive.”¹⁴⁶

Poland

“The Civil Code – Tytyl V. SUCCESSION

Art. 922.

- (1) Property rights and obligations of the deceased pass, upon his death, to one or several persons in accordance with the provisions of this book.*
- (2) Succession does not include the deceased’s rights and obligations that are strictly and personally related to him or rights which, on his death, pass to specified persons irrespective of whether they are heirs.*
- (3) Succession debts include the costs of the deceased’s funeral to the extent to which the funeral is customary in the given milieu, costs of the succession proceedings, the obligation to satisfy claims for legitim (forced share) and the obligation to carry out legacies, bequests, devises and instructions, and other obligations provided for in this book.” ¹⁴⁷*

¹⁴⁶ Personal Data Act. (1998). *Personal Data Act.*
<https://freedominfo.org/documents/sweden%20personal%20data%20act-eng.pdf>

¹⁴⁷ The Civil Code, (1964). <https://supertrans2014.wordpress.com/wp-content/uploads/2014/06/the-civil-code.pdf>

Annex IV. Case Summaries

This annex provides summaries of key cases discussed in the thesis, highlighting their scope, core legal principles, and relevance to post-mortem data and genetic information.

Estate of Jäggi v. Switzerland (ECtHR, 2006)

Scope: DNA testing of a deceased to confirm biological parentage.

Summary: The applicant sought a DNA test on the remains of a deceased man to establish paternity. Swiss courts denied the request, prioritising the deceased right to rest undisturbed. The ECtHR held that, under Article 8 ECHR, the right to know one's ancestry forms part of private life and can outweigh the deceased's interests.

Core Legal Principle: The rights to know one's ancestry outweigh the deceased's right to rest undisturbed under Article 8 of the ECHR.

Post-Mortem Relevance: Sets a precedent for prioritising genetic identity over the privacy concerns of the deceased.

S. and Marper v. United Kingdom (ECtHR, 2008)

Scope: Retention of DNA profiles and fingerprints of unconvicted individuals.

Summary: Two applicants, whose DNA and fingerprints were retained by police despite acquittal or dropped charges, challenged the indefinite retention policy. The ECtHR found that blanket, indiscriminate retention violated Article 8 ECHR, as it failed to strike a fair balance between public and private interests.

Core legal Principle: Indiscriminate retention violates Article 8 ECHR.

Post-Mortem Relevance: Challenges the indefinite post-mortem data retention without clear necessity.

Menendez Garcia v. Spain (ECtHR, 2009)

Scope: Exhumation request to establish grand-paternity.

Summary: The applicant request exhumation of his alleged grandfather to establish paternity. The ECtHR upheld the Spanish court's refusal, noting the

distant familial relationship and the need to balance the applicant's interest with the deceased's and family rights.

Core Legal Principle: The distance in familial relationship justifies the denial of the request.

Post-Mortem Relevance: Demonstrates a case-by-case approach to balancing genetic identification with privacy.

Marianne Vaatstra Case (Netherlands, 2012)

Scope: Large-scale Y-chromosomal DNA screening.

Summary: Dutch authorities conducted mass DNA screening of over 6,500 men so solve a 1999 murder. Familial DNA searching led to the identification and arrest of the perpetrator.

Core Legal Principle: Genetic genealogy in forensic investigations.

Post-Mortem Relevance: Demonstrates the power of genetic identifiability in post-mortem investigations.

Cakicisory and Other v. Cyprys (ECtHR, 2014)

Scope: DNA collecting from living relatives for identifying the deceased.

Summary: Applicants objected to the collection of blood samples for identifying missing relatives. The ECtHR found no violation of Article 8, holding that the collection was proportionate and justified by the need to identify the deceased.

Core Legal Principle: Blood sample collection for genetic profiling did not violate Article 8 ECHR.

Post-Mortem Relevance: Establishes a precedent for balancing familial identification needs with privacy.

Ayacaguer v. France (ECtHR, 2017)

Scope: DNA database storage for minor offences.

Summary: The applicant challenged the retention of his DNA following a minor offence. The ECtHR held that storage must be proportionate and differentiated by crime severity, supporting the need for tailored retention periods for genetic data, including data related to deceased individuals.

Core Legal Principle: Storage must differentiate by crime severity.

Post-Mortem Relevance: Supports tailored retention periods for post-mortem genetic data.

Baret & Caballero v. France (ECtHR, 2023)

Scope: Prohibition on exporting gametes and embryos for posthumous reproduction.

Summary: The applicant challenged France's prohibition on exporting gametes and embryos for posthumous reproduction. The ECtHR upheld the state's margin of appreciation under Article 8 ECHR, underscoring the complexity and state discretion in regulating posthumous reproduction.

Core Legal Principle: State margin of appreciation upheld under Article 8 ECHR.

Post-Mortem Relevance: Underscores ethical considerations and state discretion in regulating posthumous reproduction.

JH v. Czech Police (CJEU, 2023)

Scope: Minor offenders' genetic data.

Summary: The CJEU addressed the proportionality of retention periods for genetic data of minor offenders, guiding that time-limited storage is required.

Core Legal Principle: Proportionality in retention periods.

Post-Mortem Relevance: Guides time-limited storage of deceased-related familial profiles.

Polat v. Austria (ECtHR, 2023)

Scope: Post-mortem examination conducted against religious objections.

Summary: The applicant's family objected to a post-mortem examination on religious grounds. The ECtHR found violations of Articles 8 and 9 ECHR, emphasising the need to balance public health interests with religious and familial rights in post-mortem contexts.

Core Legal Principle: Violations of Articles 8 and 9 ECHR.

Post-Mortem Relevance: Emphasising balancing public health interests with religious and family rights.

***V.S. v. Bulgaria* (CJEU, 2023)**

Scope: Systematic data collection.

Summary: The CJEU ruled that blanket, systematic data collection without strict necessity is prohibited, a principle applicable to post-mortem data acquisition lacking individualised assessment.

Core Legal Principle: Prohibits blanket collection without strict necessity.

Post-Mortem Relevance: Applies to post-mortem data acquisition lacking individualised assessment.

***NG v. Bulgaria* (CJEU, 2024)**

Scope: Indefinite biometric/genetic data storage.

Summary: The CJEU held that indefinite retention of biometric and genetic data requires periodic review, mandating sunset clauses for post-mortem data in police and research data bases to ensure compliance with data protection principles.

Core Legal Principle: Retention requires periodic review.

Post-Mortem Relevance: Mandates sunset clauses for post-mortem data in police/research databases.