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Your genetic data is my genetic data: Unveiling another enforcement issue of the GDPR

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ABSTRACT

The General Data Protection Regulation aims to protect data subjects by granting them control over their data. The shared nature of genetic data causes significant challenges in this framework by posing the question of whether the donor's biological family members can also be considered data subjects or not. In this respect, we have examined both scenarios and concluded that biological family members could indeed be considered in the scope of the data protection framework. However, we highlighted certain shortcomings attached to this interpretation, especially when biological family members exercise their data subject rights. Hence, we explored potential conflicts that might arise when biological family members exercise their right to information, right to access, right to erasure and right to restriction of processing. As a practical solution to this pressing problem, we called on the European Data Protection Board to revisit the 2004 Working Document on Genetic Data in order to develop principles to be applied when solving such conflicts and thus provide certainty and clarity to genetic data processing.

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1. Introduction

Over the last two decades, we have witnessed a significant improvement in our technical ability to sequence genetic information at scale.¹ Nowadays, researchers use this ever-growing available genetic information for various purposes, such as understanding what makes us prone to certain diseases and

coming up with more precise treatment methods. In order to capitalize on this development, the European Union kick-started the “1+ Million Genomes” initiative, amongst others, aiming at sequencing more than one million genomes by the end of 2022.² In addition, several infrastructures are planned for storing, using, and sharing genomics data by several stakeholders in Europe to unlock the full potential of genomics.³

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¹ Rachel H. Horton and Anneke M. Lucassen, ‘Recent developments in genetic/genomic medicine’ (2019) 133(5) *Clinical Science* 697, 697.

² ‘European ‘1+ Million Genomes’ Initiative’ (European Commission, 9 September 2021) <<https://digital-strategy.ec.europa.eu/en/policies/1-million-genomes>> accessed 31 January 2022.

³ See, for example, ‘European Health Data Space’ (European Commission) <https://ec.europa.eu/health/ehealth-digital-health-and-care/european-health-data-space_en> accessed 15 January

However, along with its promises, some contested uses of genetic data have also occurred in recent years. For instance, law enforcement officers used genetic information on genealogy websites to solve cold cases.⁴ Likewise, border agencies benefited from such resources to establish the nationalities of failed refugee claimants in an attempt to deport these individuals.⁵ Furthermore, direct-to-customer genetic testing kits revealed hidden family secrets.⁶ These are excellent examples of how processing genetic data can lead to infringements of the rights and freedoms of individuals. Moreover, the growing incorporation of new technologies such as artificial intelligence into this field might soon create infringements that cannot be foreseen with our current capabilities. Therefore, it is crucially important to effectively regulate the processing of genetic data.

For this purpose, the General Data Protection Regulation⁷ (GDPR) constitutes an essential safeguard, at least at the EU level. Since its enactment in 2016, the GDPR has become a normative frame of reference for data protection, serving as an optimal tool to preserve natural persons' fundamental rights and freedoms. Hence, the European legislator considers the GDPR an overall success that could meet several expectations.⁸ However, various actors have stated the opposite, especially underlining the difficulties in enforcing the GDPR.⁹ Besides these shortcomings, some problems also arose in the European data protection framework due to either the wording of the GDPR itself or the authoritative interpretations of its provisions. The unresolved issue regarding the definition of genetic data is one of the most obvious examples of this problem.

2022; 'Federated European infrastructure for genomics data' (European Commission, 17 November 2021) <<https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/digital-2021-cloud-ai-01-fei-ds-genomics>> accessed 20 December 2021.

⁴ Tim Arango, Adam Goldman and Thomas Fuller, 'To Catch a Killer: A Fake Profile on a DNA Site and a Pristine Sample' (*The New York Times*, 27 April 2018) <<https://www.nytimes.com/2018/04/27/us/golden-state-killer-case-joseph-deangelo.html>> accessed 25 November 2021.

⁵ Tamara Khandaker, 'Canada is using ancestry DNA websites to help it deport people' (VICE, 26 July 2018) <<https://www.vice.com/en/article/wjxmy/canada-is-using-ancestry-dna-websites-to-help-it-deport-people>> accessed 26 November 2021.

⁶ Dani Shapiro, 'How a DNA Testing Kit Revealed a Family Secret Hidden for 54 Years' (*TIME*, 3 January 2019) <<https://time.com/5492642/dna-test-results-family-secret-biological-father/>> accessed 26 November 2021.

⁷ 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) [2016] OJ L 119/1.

⁸ 'Two years of the GDPR: Questions and answers' (European Commission, 24 June 2020) <https://ec.europa.eu/commission/presscorner/detail/en/qanda_20_1166> accessed 12 December 2021.

⁹ See, for example, Estelle Massé, 'Three Years Under the EU GDPR, An Implementation Progress Report' (AccessNow, May 2021) <<https://www.accessnow.org/cms/assets/uploads/2021/05/Three-Years-Under-GDPR-report.pdf>> accessed 15 November 2021.

Indeed, the fundamental structure of the GDPR, that is, the idea that data is linked to a concrete data subject,¹⁰ does not work so well with genetic data. This is due to a simple reason: contrary to many other types of personal data, genetic data is not exclusively linked to one data subject but to several people who share some part of their biological architecture with that data subject.¹¹ In other words, since we share a significant percentage of our DNA with our genetic relatives, once our genetic data is processed, it does not only reveal information about ourselves but also about our biological family members.¹² Unfortunately, this feature does not work well with the assumptions made by the GDPR.¹³

Under such a scenario, two main options can be considered. On the one hand, one can assign the data subject status only to the donor of the genetic data in question. Alternatively, one can consider biological family members of the donor as data subjects too, as already been suggested by some authors.¹⁴ Indeed, such an approach might be beneficial to mitigate the risks attached to genetic data processing, as any infringement on such data will also affect these individuals along with the donor.¹⁵ Nevertheless, it might be argued that accepting such ideas might create challenges that are impossible to tackle from the GDPR's perspective.

However, this is not a clear-cut matter. As a matter of fact, one must consider that both alternatives would have different consequences in practice, and none of them is easy to deal with. This paper aims to find out the strengths and weaknesses of each of them, so as to clarify this complex issue. For this purpose, we will first analyse whether genetic data could be considered personal data of biological family members on a conceptual basis. Afterwards, we will explore the issues that this approach might bring. Finally, we will present some tentative ideas about the most promising ways to resolve the issues uncovered.

¹⁰ GDPR, art 4(1).

¹¹ See also, Graeme Laurie, 'Genetic privacy: A challenge to medico-legal norms' (Cambridge University Press 2002), 1-3.

¹² In some cases, genetic data may reveal information about other individuals who are not biological family members of donors. Some examples of these type of situations could be given as carrying the same genes as the donor that are associated with predispositions to certain diseases or behaviour. However, unless very exceptional case-specific circumstances occur, these individuals cannot be considered as rightsholders within the European data protection framework for several reasons, as already explored by some authors. See here, for example, Dara Hallinan and Paul de Hert, 'Genetic Classes and Genetic Categories: Protecting Genetic Groups Through Data Protection Law' in Linnet Taylor, Luciano Floridi and Bart Van der Sloot (eds), *Group Privacy: New Challenges of Data Technologies* (Springer 2017) 175, 186. Therefore, biological family members of donors are the focal point of our analysis and individuals who form the "genetic categories", as defined by Hallinan and de Hert, of the donor do not fall under the analysis scope of this paper unless relevant.

¹³ See also, Adam Panagiotopoulos, 'Genetic Information and Communities' (2018) 4(4) *European Data Protection Law Review* 459, 460.

¹⁴ Hallinan and de Hert (n 12) 179.

¹⁵ See also, Fatos Selita, 'Genetic Data Misuse: Risk to Fundamental Human Rights in Developed Economies' (2019) 7(1) *Legal Issues Journal* 53, 62.

2. The conceptual analysis: can my genetic data also be personal data of my biological family members?

Are my genetic data also my biological family members' personal data? There are some good reasons to think that this is not the case at all. When defining genetic data, Article 4 of the GDPR directly refers to the natural person from whom the biological sample had been collected. Indeed, it specifically mentions "personal data (...) which result, in particular, from an analysis of a biological sample from the natural person in question". Thus, considering this last part of the definition, one can argue that genetic data can only be considered the personal data of the sample donor.¹⁶ This interpretation is well sustained on the basis that the definition provides particular relevance to the biological sample that was obtained from a concrete donor, the data subject.

Of course, such an approach would inevitably exclude the biological family members of donors from the protective scope of the data protection framework.¹⁷ However, this could lead to biological family members being put in a vulnerable position when their common genetic data is processed, as the processing also has certain impacts on them. Amongst many other examples, as a result of this processing, biological family members of donors might suffer severe inconveniences regarding their insurance policies, be subjected to discriminatory outcomes in the labour market, find their family secrets to be revealed, and be confronted with information about a hereditary disease they would otherwise not wish to know about. Therefore, leaving these individuals outside of the protective scope of the GDPR might not be the best scenario regarding a processing activity that inevitably has certain consequences for them.

Last but not least, an emerging practice in genetic and healthcare research might also constitute a valid reason to oppose leaving the biological family members outside the scope of the GDPR. Thanks to advancements in biobanking and data sharing abilities, researchers are shifting their practices from collecting samples for a specific project to using already collected samples.¹⁸ As a result of this practice, we might soon expect that the genetic material collected from people who are now deceased will become more accessible or even more valuable than the ones collected from the living. The latter could be the case, especially considering that the GDPR does not apply to the personal data of deceased people.¹⁹ Infringements in such cases could occur in traditional ways, such as when researchers use the collected data for purposes other than the ones the sample was initially collected for or even

in contemporary ways such as unveiling family secrets of royals²⁰ or simply for "genetic paparazzi"²¹ purposes. As it is clear from these examples, adverse effects of processing the common genetic data may occur on biological family members even after the donor's death. However, by being outside the protection scope of the GDPR, these individuals might be left unarmed against these infringements. Indeed, such an outcome would be clearly against the aims of the GDPR, particularly the aim of safeguarding every person's right to protection of their personal data.²² Thus, an alternative approach capable of avoiding such an inconvenient conclusion that would fit much better with the GDPR as a whole would be to consider processing common genetic data as the personal data of the biological family members of the donor.

In fact, such an approach could have its basis within the GDPR itself. First, while defining the genetic data under Article 4(13), the GDPR refers "in particular" to the samples collected directly from the donors. This means that genetic data obtained directly from the donors are indeed their personal data, while genetic data related to the data subjects obtained by other means could also be considered as such. The European legislator's emphasis on the "in particular" seems to reinforce this positioning. As such, if the European legislator had wanted to produce such an exclusion, it would not have included "in particular" in the provision in the first place.

Moreover, the GDPR defines "data concerning health" as: "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".²³ Since genetic data provide information about the donor's physical or mental health, amongst other aspects, this provision may also be considered in the genetic data processing context. Notably, the European legislator does not make any reference in this provision to how the data concerning health is obtained. Therefore, through deductive logic, it can be argued that the definition of genetic data is independent of whether it is obtained from the individual concerned or not. This means that genetic data, or at least the type of genetic data which reveals information related to the physical or mental health of the individual concerned, can be considered personal data of individuals other than the original donor.

Some other arguments offer additional support for considering the biological family members of the donor as data subjects, and one of them stems from the definition of the personal data itself enshrined in the GDPR. Article 4 GDPR states

¹⁶ Petro Sukhorolskyi and Valeriia Hutsaliuk, 'Processing of Genetic Data under GDPR: Unresolved Conflict of Interests' (2020) 14(2) Masaryk University Journal of Law and Technology 151, 157; See also, Taner Kuru, 'Genetic Data: The Achilles' Heel of the GDPR?' (2021) 7(1) European Data Protection Law Review 45, 53-54.
¹⁷ *ibid*

¹⁸ See, for instance, Rasmus Bjerregaard Mikkelsen, Mickey Gjeris, Gunhild Waldemar and Peter Sandøe, 'Broad consent for biobanks is best – provided it is also deep' (2019) 20(71) BMC Medical Ethics 1, 3.

¹⁹ GDPR, art 1(1) and recital 27.

²⁰ Grace Browne, 'Scientists Settled a Century-Old Family Drama Using DNA From Postcards' (WIRED, 3 January 2022) <https://www.wired.com/story/dna-artifact-testing/?_hscenc=p2ANqtz_-72qbAlthY7x9one-S2QUBR1Eeqik1Jjfuj7UZ_gCQvbxqu1rIz7GKB-sh2zcNA0EkbZdaM-juwP8J090Qd3H5sgrL7w&_hsmi=199883257&utm_campaign=Clips&utm_content=199883257&utm_medium=email&utm_source=hs_email> accessed 8 May 2022.

²¹ Yaniv Heled and Liza Vertinsky, 'Genetic Paparazzi: Beyond Genetic Privacy' (2021) 82(3) Ohio State Law Journal 409.

²² See Case C-319/20, Meta Platforms Ireland Limited v Bundesverband der Verbraucherzentralen und Verbraucherverbände – Verbraucherzentrale Bundesverband e.V. [2022] ECLI:EU:C:2022:322, para 73.

²³ GDPR, art 4(15).

that “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”. As it can be understood from this definition, the concept of personal data is rather broad and covers all types of information.²⁴ Hence, the Court of Justice of the European Union decided on the boundaries of this rather broad definition in several cases. According to the most recent and relevant test that the Court developed, in order to determine whether the information is personal data of an individual, it should be checked whether it is linked to that particular person because of its content, purpose or effect.²⁵ In other words, if it is possible to connect a piece of information with a natural person by the content, purpose or effect of its processing, that information is considered the personal data of that natural person. Since this is precisely what happens in the case of the genetic information linked to the biological family members, then, these data should be considered their personal data.²⁶

Indeed, such an approach has already been followed and justified for differing reasons by various stakeholders. For example, when delivering its opinion on genetic data processing, already in 2004, the Article 29 Data Protection Working Party²⁷ (WP29) envisaged that family members could be considered data subjects.²⁸ In its opinion on the concept of personal data, the WP29 again stated that, in some cases, the information about deceased individuals might also refer to living ones, especially regarding the genetic information that they had shared.²⁹ Considering this, the WP29 concluded that, as long as the shared information is linked at the same time to the living, any personal data of the deceased may indirectly fall under the scope of the data protection framework.³⁰ The World Health Organization Regional Office for Europe recently followed the same approach while examining the word “relating” and concluded that family members could be considered data subjects.³¹ In the same vein, the data protection watchdog of the United Kingdom, the Information Commissioner’s Office, stated that medical records of a deceased individual could include genetic information that may also be used to identify their living relatives; thus, these medical records can

also be considered as the relatives’ personal data with regard to the Data Protection Act.³² Considering that the Data Protection Act defines personal data as “any information relating to an identified or an identifiable living individual”,³³ it seems that the considerations made by the Information Commissioner’s Office can be perfectly extended to the GDPR framework as well. Taking this further, some scholars even argue that, in certain cases, unborn children’s biological parents can be considered data subjects regarding the genetic data obtained from the child.³⁴

If this is true for the deceased people and unborn children, the same argumentation should also be true for the genetic data of the living since the nature of the information and the consequences derived from processing it are exactly the same. Such an approach would indeed align with the *ubi eadem ratio, ibi idem jus* principle. In fact, by following a similar approach, in the case of *S. and Marper*, the European Court of Human Rights stated that the cellular samples “contain a unique genetic code of great relevance to both the individual concerned and his or her relatives”.³⁵ The Court, therefore, concludes that the retention of these samples should be regarded as “interfering with the right to respect for private lives of the individuals concerned”.³⁶ With this judgement, the European Court of Human Rights notably extends the scope of the right to privacy far beyond the donor who provides the sample and also includes their biological family members.

Even if the donor’s biological family members could be linked to the common genetic data, one other criterion should be considered to determine their data subject status under the European data protection framework. Deriving from the definition of personal data enshrined under Article 4(1), the biological family members should be either identified or identifiable from the donor’s processed genetic material. In fact, this criterion makes it impossible, apart from exceptional circumstances, for people who are not the donor’s biological family members but possess the same genetic architecture as the donor, for example by carrying the same genes that are associated with certain diseases, to be considered as data subjects when the donor’s genetic data is processed since the kinship and identification thereof could not be achieved for these individuals even with the auxiliary information. Therefore, those individuals are not entitled to be considered as data subjects under the scope of the GDPR unless case-specific exceptional circumstances occur. Although it might be considered a shortcoming, in fact, this feature guarantees the proper functioning of the GDPR since otherwise everyone could have been considered data subject when anyone’s genetic data is processed as all human beings share certain genetic makeup with others in a way.

²⁴ Case C-553/07, *College van burgemeester en wethouders van Rotterdam v M.E.E. Rijkeboer* [2009] ECLI:EU:C:2009:293, para. 59; Case C-434/16 *Peter Nowak v Data Protection Commissioner* [2017] ECLI:EU:C:2017:994, para 33.

²⁵ C-434/16 *Nowak* (n 24) para 35.

²⁶ See, *Kuru* (n 16) 47-48.

²⁷ Replaced by the European Data Protection Board in accordance with Article 68 GDPR since May 2018.

²⁸ Article 29 Data Protection Working Party, ‘Working Document on Genetic Data’ (2004) WP 91, 8.

²⁹ Article 29 Data Protection Working Party, ‘Opinion 4/2007 on the Concept of Personal Data’ (2007) WP 136, 22.

³⁰ *ibid*

³¹ World Health Organization Regional Office for Europe, ‘The protection of personal data in health information systems – principles and processes for public health’ (2021), 3.

³² Information Commissioner’s Office, ‘Information about the deceased’ (2013), 4.

³³ Data Protection Act 2018 (UK), pt 1, s 3(2).

³⁴ Kart Pormeister and Lukasz Drozdowski, ‘Protecting the Genetic Data of Unborn Children: A Critical Analysis’ (2018) 4(1) European Data Protection Law Review 53, 61.

³⁵ *S. and Marper v the United Kingdom*, App nos 30562/04 and 30566/04 (ECtHR, 4 December 2008) para 72.

³⁶ *ibid* para 73.

After excluding this group, we have biological family members of the donor, who can be identified or identifiable from the processed genetic data of the donor. Even though the genetic data does not reveal the identity of biological family members as a stand-alone, with auxiliary information, these people become indeed identifiable. The most prominent examples that could be given in this regard are the familial DNA searches done by law enforcement officers, as well as the establishment of parentage in paternity/maternity cases. This feature, in fact, opens the door for the question of which biological family members should be considered data subjects, especially considering the broad understanding of the Court of Justice of the European Union on identifiability.³⁷ For example, in the infamous Golden State Killer case, law enforcement officers reached profiles equivalent to the third cousins of the crime scene DNA they had at hand.³⁸ Should we then conclude that even the third cousins of the donors are considered data subjects? To prevent uncertainties and broaden the scope of the GDPR to the extent that it is not practically or logically enforceable anymore, we believe that the precise assignment of this status should be context-dependant and dealt with on a case-by-case basis, while in theory, any biological family member can still be considered a data subject, given the broad understanding of the identifiable criterion. For example, if a hospital receives a court order regarding a paternity case, there will be only one member from the donor's biological family who could be identified or identifiable regarding this process. However, if paternity is questioned within royal families, then identification of even the third cousins could be the case. Hence, in our conclusion, determining who should be considered data subject should depend on each case's circumstances, while in theory, all biological family members could be considered as such. Lastly, we believe that such an approach would also help us to reduce the complexities of recognising biological family members as data subjects under the European data protection framework.

Considering all the above, it can be concluded that, when their common genetic data is being processed, the sample donor's biological family members should be considered data subjects, provided that the processing is related to them and they are identifiable, regardless of whether the sample donor is still alive or not. However, if this is the case, they would have to be provided with all the rights and freedoms that the GDPR includes for data subjects unless we grant them rights of a different character, as the WP29 suggested.³⁹ Nevertheless, as the next chapters will show, this approach might have consequences that are hard, if not impossible, to resolve within the data protection framework as it stands.

³⁷ See Case C-582/14 Patrick Breyer v Bundesrepublik Deutschland [2016] ECLI:EU:C:2016:779 and T-384/20 OC v Commission [2022] ECLI:EU:T:2022:273.

³⁸ Jocelyn Kaiser, 'We will find you: DNA search used to nab Golden State Killer can home in on about 60% of white Americans' (Science, 11 October 2018) <<https://www.science.org/content/article/we-will-find-you-dna-search-used-nab-golden-state-killer-can-home-about-60-white>> accessed 8 May 2022.

³⁹ WP29 (n 28) 8.

3. The practical hardship of enforcing data subject rights by the donor's biological family members

Having strong conceptual reasons to consider the processed common genetic data as personal data of the donor's biological family members does not necessarily mean that this interpretation should prevail. Indeed, the interpretation of a rule cannot be regarded as valid if it does not align well with the legislator's main objectives. The European legislator crafted the GDPR to ensure legal certainty for economic operators and provide data subjects with the same level of enforceable rights, as well as obligations and responsibilities for controllers.⁴⁰ Therefore, if considering the processed common genetic data as personal data of biological family members renders the application of the GDPR too complex or even impossible in practice, it is clear that a broad understanding of the notion of personal data and data subject should not be applied.

However, even in such cases, the GDPR might still protect biological family members through certain provisions, such as those concerning data protection principles and obligations of data controllers when processing personal data. For example, it has been argued that biological family members should be considered in the data protection impact assessment (DPIA) process if they have a legitimate interest in the processing.⁴¹ However, while the same authors identified that the lack of clear *rationae personae* would affect the proper functioning of this obligation,⁴² other authors argued that the GDPR actually considers only the data subjects as the primary point of reference in the context of DPIA.⁴³ Furthermore, there is always the risk of the biological family members' rights and interests not being appropriately handled or disregarded altogether in the DPIA process as they are not actively participating in such processes. The same concerns come into play for similar obligations imposed on data controllers by the data protection framework, such as data protection by design and by default. Data controllers might neglect to consider the biological family members' rights and interests or simply ignore them when complying with these obligations.

Therefore, the only way to provide full and effective protection to biological family members within the data protection framework appears to be to assign them data subject status, so that they can actively challenge any infringements by exercising their data subject rights. However, it is hard to know whether this interpretation incorporates such enormous complexities into the current framework and if there are any solutions to overcome such complexities. These possible difficulties will probably come into play, especially when biological family members would like to exercise their data subject rights, since, in such cases, different stakeholders' conflicting rights and interests will be at stake, namely the donor, the biological family members, the data controllers, and society

⁴⁰ GDPR, recital 13.

⁴¹ Hallinan and de Hert (n 12) 184.

⁴² *ibid* 188-189.

⁴³ Kuru (n 16) 54-56.

in general.⁴⁴ The conflicts between these stakeholders' interests can come into play in different contexts. In the healthcare context, for example, the donors and their biological family members might have a conflict regarding their right (not) to know, and the controller might be confronted with the obligation of secrecy towards the donor and disclosure obligation towards the biological family members; while the society would have an interest in processing this genetic data regardless of all these rights and interests attached as it would advance the state-of-the-art of scientific progress. Although this is a well-known dilemma, an answer for it has not been adequately put forward in bioethical or biomedical regulations so far. Nevertheless, thanks to the advancements in genetic sequencing technologies, this and many other dilemmas attached to genetics are now also being discussed under the data protection framework. On the one hand, this could become a nightmare for practitioners if we try to balance all these interests by accepting them as equal under the data protection framework. Here, a solution could be to prioritize the already established rights and obligations under the GDPR over the novel ones. For example, genetic data processing in the healthcare context will inevitably involve a professional secrecy obligation for the controllers. Hence, in such cases, a *priori* solution might appear as prevailing the interests of the donor and controller over the ones of biological family members. On the other hand, if we solve any possible complexity by rendering the biological family members' rights inapplicable, we will somehow produce a scenario that does not work well with the aims that the GDPR is supposed to achieve, the protection of data subject's fundamental rights and freedoms. Unfortunately, the answer to this dilemma cannot be found in the existing regulatory environment.

In our opinion, there is no general rule, nor can there be one, to solve such conflicts, as the solution will be dependant on specific facts of each case. Therefore, an analysis that primarily focuses on the question of how a fair balance can be struck between the competing interests when biological family members exercise their data subject rights without rendering the whole GDPR impractical is needed. Hence, we dedicate the following sections to conducting this analysis by focusing on four rights: the right to information, the right to access, the right to erasure, and the right to restriction of processing. We have decided to focus on these rights for two main reasons. The right to information and right to access were chosen because they appeared as the ones which are predominantly exercised by data subjects in practice, and existing case law from the member states regarding genetic data processing somehow gravitates around them, as explained in the following sections. On the other hand, the right to erasure and the right to restriction of processing were chosen because they illustrate the novel complexities that might occur in the future due to the contemporary cases related to genetic data processing, such as the implementation of artificial intelligence in genetic research and establishment of European Health Data Space.

Lastly, the following structure is followed while examining the consequences of biological family members exercising these rights. We first briefly introduced information about the right in question and then illustrated the potential consequences of biological family members exercising this right. Afterwards, we presented potential solutions to prevent the adverse consequences that might arise and finalised the chapters by identifying further complexities these solutions might bring.

3.1. Right to information

One of the most significant issues posed by considering genetic data as personal data of biological family members comes from the right to information.⁴⁵ The GDPR requires data subjects to be made aware of the risks related to the processing of their personal data and how to enforce their rights defined under the data protection legislation.⁴⁶ In this regard, data controllers are obliged to fulfil several responsibilities, including providing information to data subjects.⁴⁷ This obligation derives from the fairness and transparency principles defined under Article 5(1)(a) GDPR,⁴⁸ which requires data subjects to be informed about the processing's existence and purposes,⁴⁹ and are regulated under Articles 13 and 14 GDPR.

If we consider genetic data as personal data of biological family members, at first glance, it becomes compulsory for data controllers to inform all the biological family members when their common genetic data is being processed. Indeed, they should be informed about the existence of the processing so that they can enforce the rights attached to their data subject status. For example, in this case, when processing a donor's genetic data, a hospital could be obliged to provide information, at least to immediate family members, about the existence and purpose of the processing. If this is the case, the whole framework of genetic data processing could become a nightmare since controllers would then have to continuously share a lot of information and face contradictory instructions from different family members. In this context, problems could arise, for example, regarding access to the biological family members' contact information: How could the hospital make sure that the information provided is complete and accurate? Who should be responsible if the information is not complete and accurate, the donor or the hospital? Besides, what should be the content of the information provided? Let us assume the test took place regarding the identification of Huntington's Disease. Should the hospital let the immediate family members know about this purpose in detail or just

⁴⁵ See also, Mark Taylor, *Genetic Data and the Law: A Critical Perspective on Privacy Protection* (Cambridge University Press 2012) 103-130.

⁴⁶ GDPR, recital 39: 'Natural persons should be made aware of risks, rules, safeguards and rights in relation to the processing of personal data and how to exercise their rights in relation to such processing.'

⁴⁷ GDPR, art 13 and 14.

⁴⁸ GDPR, art 5(1)(a): 'Personal data shall be processed lawfully, fairly and in a transparent manner in relation to the data subject.'

⁴⁹ GDPR, recital 60: 'The principles of fair and transparent processing require that the data subject to be informed of the existence of the processing operation and its purposes.'

⁴⁴ See also Dara Hallinan, *Protecting Genetic Privacy in Biobanking through Data Protection Law* (Oxford University Press 2021), 63.

mention that a genetic examination took place regarding a hereditary disease so that it would not infringe the biological family members' right (not) to know?

Nevertheless, there is a promising way to avoid such scenarios. An earlier article by Kuru explored how data controllers may easily benefit from the exceptions to the obligation to provide information in the genetic data processing context.⁵⁰ Indeed, in the case of genetic data, these exceptions are particularly relevant since the GDPR foresees that the Member States may adopt, by law, specific rules in order to safeguard the professional or other equivalent secrecy obligations in so far as is necessary to reconcile the right to the protection of personal data with an obligation of professional secrecy.⁵¹ Furthermore, Article 14(5)(d) states that the controller shall not provide the data subject with information about the processing where the personal data must remain confidential, subject to an obligation of professional secrecy regulated by Union or Member State law, including a statutory obligation of secrecy.

In practice, all Member States include rules that impose professional secrecy on practitioners in their regulations. Thus, one might perfectly argue that the GDPR has opted to advocate the confidentiality obligation of data controllers over that of the biological family members' potential interest in knowing the existence and consequences of genetic data processing, at least when genetic data are also health data. Consequently, the controllers shall refuse to reveal any information about the processing unless the donor allows them to proceed. In such a case, Article 14(5)(d) might be used as the legal ground for this refusal.⁵² Therefore, the right to information does not seem to lead to a significant complexity in terms of coherence and applicability of the GDPR when biological family members are also considered data subjects since genetic data and health data are protected by secrecy obligations.

However, as underlined by the WP29, given the sensitive nature of genetic data processing, potentially serious implications and consequences of the disclosure and use of the information retrieved thereof in the biological family members' lives should be carefully considered, which eventually may lead to a possible obligation to disclose such information to these individuals in order for them to safeguard their health and exercise their right (not) to know.⁵³ Therefore, a general remark inferring that data controllers are not obliged to inform the biological family members in any case due to, for instance, a confidentiality obligation would not be accurate. Because, in such a case, biological family members may find themselves in a vulnerable position against infringements since they would not be aware of the processing in the first place. Nevertheless, research has revealed that there is a certain fragmentation between the healthcare practitioners' role in the disclosure of genetic information to family members with regards to the conditions and the degree of the disclo-

sure.⁵⁴ Thus, it is still unknown in which conditions and to which degree this information should be provided to biological family members.

Besides, what happens if genetic data are not health data? What if they are, for instance, data about ancestry?⁵⁵ Quite curiously, the issue becomes even more problematic when we remove the sensitivity of the genetic data from the equation since the need for secrecy does not apply any longer. Thus, it cannot be used to solve the issue, which is not a minor one. Today, millions of people worldwide send their genetic material to companies in order to learn about their ancestry. In such cases, if biological family members are considered data subjects, controllers would have a *prima facie* obligation to inform them about the processing pursuant to Article 14. While the GDPR still allows some exemptions for this obligation,⁵⁶ it is unclear who should fulfil this obligation in practice and how to identify the concerned biological family members. Since data controllers do not precisely know who the biological family members of the donors are, how can they properly fulfil this obligation? Can they ask donors to provide them with the identity of their biological family members? Wouldn't such a measure be intrusive and contrary to the GDPR itself?⁵⁷ Would it not be better to consider such practices as a kind of "disproportionate effort" as per Article 14(5)(b)? These questions can hardly be answered at this precise moment.

3.2. Right to access

The GDPR allows data subjects to obtain confirmation from the controllers about whether personal data concerning them is being processed and, if this is the case, gain access to their personal data.⁵⁸ Based on this request, controllers should provide data subjects with a copy of their processed data.⁵⁹ Since the right to access aims at empowering data subjects to have control over their personal data, the European Data Protection Board states that the "controllers should not assess 'why' the data subject is requesting the access, but only 'what' the data subject is requesting and whether they hold personal data relating to that individual".⁶⁰ Due to the importance of the right to access for data subjects, the European legislator provides a broad understanding of which information should be provided to data subjects when they exercise their right to access. An example of this is the provisions in the GDPR concerning access to health data. In such cases, according to Recital 63, data subjects may access the data in their medical records containing information such as diagnoses, examination results, assessments by

⁵⁰ Kuru (n 16) 49-51.

⁵¹ GDPR, recital 164.

⁵² GDPR, art 14(5)(d): 'Paragraphs 1 to 4 shall not apply where and insofar as where the personal data must remain confidential subject to an obligation of professional secrecy regulated by Union or Member State law, including a statutory obligation of secrecy.'

⁵³ WP29 (n 28) 8.

⁵⁴ Amicia Phillips, Pascal Borry, Ine Van Hoyweghen and Danya F. Vears, 'Disclosure of genetic information to family members: a systematic review of normative documents' (2021) 23(11) *Genetics in Medicine* 2038.

⁵⁵ Iñigo De Miguel Beriain and Daniel Jove, 'Is it possible to place limits on the self-determination of your own genetic data? Certainly, and there is an urgent need for it!' (2021) (15) *BioLaw Journal-Rivista di BioDiritto* 209.

⁵⁶ See, for instance, GDPR, art 14(5).

⁵⁷ GDPR, art 11.

⁵⁸ GDPR, art 15(1).

⁵⁹ GDPR, art 15(3).

⁶⁰ European Data Protection Board, 'Guidelines 01/2022 on data subject rights - Right of access' (18 January 2022) Version 1.0, 9.

treating physicians and any treatment or interventions provided.

However, such an approach may lead to complexities and certain infringements in the genetic data processing context. The first one could be identified as providing excessive information to biological family members about their shared genetic makeup or that of the donor. This is because, upon exercising their right to access, biological family members will have access not only to their common genetic data but also to all the interpretations concerning it, e.g. disease susceptibility, conditions that might be inherited and passed onto offspring, personality traits, dietary suggestions, ancestry and genealogy examination results. Of course, this may lead to dramatic consequences in terms of confidentiality and privacy breaches.

In such cases, the first solution could be depriving biological family members of enjoying their right to access since disclosing the common genetic data and other information related to its processing would be against the confidentiality obligation of the controller. This seems particularly accurate if we also remember that the European legislator introduced a specific provision to avoid the inappropriate use of the right to access. Indeed, the GDPR states that the right to access should not adversely affect the rights and freedoms of “others”.⁶¹ Although it does not clarify who should be classified as “others” in such cases, Recital 63 can be used to understand how to interpret this provision. While reiterating that the right to access should not adversely affect the rights or freedoms of “others”, the European legislator in Recital 63 refers to trade secrets, intellectual property and the copyright protection of software as examples of such rights and freedom of “others”.⁶² Clearly, these are the rights or freedoms that the data controllers or processors can enjoy. Therefore, an inference can be made to the parties who are involved in the processing and referred to by the European legislator via the word “others”. Consequently, without a doubt, donors should be considered under the scope of “others” when their biological family members wish to exercise their right to access.⁶³

In practice, such interpretation could allow data controllers to refuse access requests made by biological family members. For instance, a direct-to-customer genetic testing company may refuse it since disclosing the requested information might cause privacy infringements for their user and/or breach of their contractual obligations towards the user. Likewise, researchers or medical practitioners may also refuse them since the disclosure might reveal sensitive information of their patients, donors, and/or participants and compromise their confidentiality obligation. In fact, similar cases have already been taken to courts in some Member States. For example, when a woman asked the Erasmus University Medical Centre Rotterdam to provide her with the genetic material of a deceased research participant who claimed that he was her father, the Rotterdam Court of First Instance tried to strike a

balance between the right to the personality of the requesting party, the right to privacy of the deceased participant and the duty of confidentiality by the data controller. The Court eventually decided that the request should be denied since the duty of confidentiality should prevail over the requesting party's interests in this case.⁶⁴

However, the lack of a proper balancing test prior to the decision of denial to comply with the access request from biological family members could eventually put these individuals in a vulnerable position. This is because data controllers might focus on “the rights and freedoms of others” more than the “adverse effect” while interpreting Article 15(4). Considering the sensitive nature of genetic information and the possible effects of this information on one's life, in certain cases, the interests of biological family members could prevail over that of the donor and the controller. Therefore, such an interpretation may lead to undesired consequences, which would be against the aims of the GDPR itself. Yet, as it stands, neither the GDPR nor the case law provides any guidance on how to carry out such a balancing test between the competing interests of several data subjects and the controller over the same personal data. Although the European Data Protection Board (EDPB), the successor of WP29, suggests that in cases related to Article 15(4), data controllers should try to reconcile the conflicting rights since, according to Recital 63, such a clash of interests should not *prima facie* result in refusal to provide all information to the requested parties, it also states that an access request may only concern the data of the person making the request while access to other's personal data can only be requested with appropriate authorisation.⁶⁵ When applied in genetic data processing context, this interpretation causes a dichotomy. On the one hand, biological family members can exercise their access request since the processed common genetic data is considered their personal data too, and their interest in having access to the processed genetic data may prevail over the rights and interests of others in certain cases. On the other hand, since the same data is also the donor's personal data, they may be deprived of exercising their right to access altogether. Thus, considering the lack of proper practical guidance on this matter, it is still unknown whether and how the adverse effects of the right to access requests of biological family members on the fundamental rights and freedom of others should be handled by data controllers.

Quite curiously, complying with the access request by biological family members might become even more complicated when the donor is deceased. Considering the rapid advancements in sequencing technologies, an individual's genome may reveal more (sensitive) information ten years in the future than it does now; thus, it might have even more adverse effects on the individual's rights and freedoms in the future than it does at present.⁶⁶ Indeed, researchers, in princi-

⁶¹ GDPR, art 15(4).

⁶² GDPR, recital 63: “That right should not adversely affect the rights or freedoms of others, including trade secrets or intellectual property and in particular the copyright protecting the software.”

⁶³ The EDPB also follows the same interpretation by stating “‘Others’ means any other person or entity apart from the data subject who is exercising their right of access.”. See EDPB (n 60) 50.

⁶⁴ Case C/10/583910/KG ZA 19-1062, X v Erasmus Universitair Medisch Centrum Rotterdam [2019] ECLI:NL:RBROT:2019:9757, retrieved from <https://gdprhub.eu/index.php?title=Rb_Rotterdam_-_C/10/583910/KG_ZA_19-1062> accessed 31 January 2022.

⁶⁵ EDPB (n 60) 19-51.

⁶⁶ Miriam C. Buiten, “Your DNA is One Click Away”: The GDPR and Direct-to-Consumer Genetic Testing” in Klaus Mathis and

ple, keep processing participants' genetic data regardless of whether they are still alive or not. While the progressively more common practice in genetic research is to store the samples and data for potential research instead of collecting samples and data for a specific project,⁶⁷ there is a great possibility that the genetic material of the deceased soon becomes more accessible or even more valuable than the living. Besides, there is always the chance for genetic data to be further processed for purposes other than the one it was originally collected for.⁶⁸ Hence, adverse effects may occur for biological family members even after the donor's death. In fact, examples of such situations have already started to arise. For instance, researchers in the US published the genome of Ms. Henrietta Lacks, who was diagnosed with cervical cancer and died in 1951, five decades later, without asking consent from her (living) family members.⁶⁹ After her family members learnt about this publication, they claimed that the published sequence also contained information about themselves, which eventually led researchers to take down Ms. Lacks' genome from the public databases.⁷⁰

Nevertheless, the GDPR, as it stands, falls short of answering how access requests regarding the personal data of the deceased should be handled. This is because the GDPR clearly states that the deceased person's personal data is outside of the scope of its protection.⁷¹ Therefore, *prima facie* conclusion for data controllers in responding to the access request by biological family members regarding the genetic data shared by a deceased donor would be to refuse such requests. However, as explained in the previous section, the deceased person's genetic data can be considered their (living) biological family members' personal data. Hence, there is a great possibility for their personal data to be considered within the scope of data protection legislation even after their death. Such dichotomy would inevitably create significant uncertainties for data controllers when complying with, or rejecting, the access request of deceased data subjects' biological family members, and there has been no guidance made by the European legislator or any competent authority on how to balance the interests of the involved parties in such cases. Should the interest of the living prevail at all costs? Should we respect the privacy of the deceased instead?

Since the data protection legislation does not provide any answer or guidance on how to deal with such cases, a fragmented approach exists amongst the Member States. Unlike the Dutch decision mentioned above, in which the confiden-

tiality obligation prevailed,⁷² the Italian DPA granted a woman access to her father's genetic data, even though the donor had denied his consent, on the grounds that the privacy of the dead should not override the living's right to health.⁷³ The Icelandic Supreme Court also took a similar approach and acknowledged the descendants' personal privacy by underlining that the deceased's hereditary characteristics can apply to themselves too.⁷⁴ As seen from these examples, there is an inevitable fragmentation in practices and interpretations regarding the management of the deceased's family members' genetic data. Considering that ensuring a high level of protection of every person's right to the protection of their personal data and having a consistent and homogenous application of the data protection rules in the EU are amongst the aims of the GDPR, such fragmentation is indeed creating an obstacle for the GDPR to fulfil its promises in the context of genetic data processing.

Further complexities in the context of the right to access occur when the requesting party's identification is in question. Since, in principle, processing the common genetic data does not reveal the identity of the donor's biological family members as a stand-alone, data controllers need to verify the requiring parties' identity by other means. However, the GDPR prevents data controllers from acquiring or processing additional information to identify the data subject for the sole purpose of complying with their obligations.⁷⁵ Therefore, as per Article 11(2) GDPR, the primary conclusion that can be drawn is that by solely relying on this identification problem, data controllers may deny the requests made by the biological family members.⁷⁶ Yet, as stated above, a default inference that deprives biological family members of exercising their right to access may lead to undesired consequences, given the sensitive nature of genetic information and its effects on one's life. In fact, the GDPR states that data subjects might provide data controllers with additional information enabling their identification in order to exercise their rights, including the right to access, and data controllers cannot refuse to consider this information.⁷⁷ Furthermore, the European legislator asks data controllers to use all reasonable measures to verify the identity of the data subjects requesting access to their data.⁷⁸ In that regard, data controllers themselves may also request the requesting party to provide additional information to confirm their identity if they have reasonable doubts concerning the requesting party's identity.⁷⁹ Considering all these provisions, one can argue that either biological family members can actively prove the link between themselves and the processed genetic data or, when in doubt, data controllers might seek

Avishalom Tor (eds), *Consumer Law and Economics* (Springer 2021) 205, 206; Pormeister and Droidowski (n 34) 53; Selita (n 15) 62-63.

⁶⁷ Rasmus Bjerregaard Mikkelsen, Mickey Gjerris, Gunhild Walde- mar and Peter Sandøe, 'Broad consent for biobanks is best – provided it is also deep' (2019) 20(71) *BMC Medical Ethics* 1, 3.

⁶⁸ WP29 (n 28) 5; See also Mark J. Taylor and David Townend, 'Issues in Protecting Privacy in Medical Research Using Genetic Information and Biobanking: The Privileged Project' (2010) 10(4) *Medical Law International* 253, 255; Panagiotopoulos (n 13) 464.

⁶⁹ Muhammad Naveed et al, 'Privacy in the Genomic Era' (2015) 48(1) *ACM Computing Surveys* 1, 8.

⁷⁰ *ibid*

⁷¹ GDPR, recital 27.

⁷² *X v Erasmus Universitair Medisch Centrum Rotterdam* (n 64)

⁷³ *Cittadini e società dell'informazione* 1999, no. 8, p. 13-15, retrieved from WP29 (n 28) 9.

⁷⁴ Michelle N. Meyer, 'Comparative Law-Genetic Privacy-Icelandic Supreme Court Holds that Inclusion of an Individual's Genetic Information in a National Database Infringes on the Privacy Interests of His Child' (2004) 118 *Harvard Law Review* 810, 811-812.

⁷⁵ GDPR, art 11(1).

⁷⁶ GDPR, art 11(2).

⁷⁷ GDPR, art 11(2) and recital 57.

⁷⁸ GDPR, recital 64.

⁷⁹ GDPR, art 12(6).

auxiliary information to ensure such a link exists. However, both scenarios could result in quite problematic outcomes.

Firstly, since the controllers cannot be sure whether the requesting party is indeed a biological family member of the donor in question, one can easily infer that there will always be doubts concerning the requesting party's identity. In principle, biological family members can only prove their identity and their kinship with the donor in this context by undergoing a genetic test. Considering the possible adverse effects of undergoing a genetic test on a person, however, it is quite questionable whether this identification can be considered a reasonable measure as defined in the GDPR. This is a tricky situation for data controllers, as something as simple as asking for signatures, let alone genetic testing, for the purpose of identification can potentially cause infringements.⁸⁰ Besides, even if asking for a genetic test is considered valid, what if the requesting party opposes undergoing a genetic test but is indeed a donor's biological family member? Wouldn't this prevent him/her from exercising his/her rights without any valid ground? Unfortunately, the GDPR, again, falls short of answering these questions in its current form, and competent authorities have produced no practical guidance on how to deal with such issues.

3.3. Right to erasure

Also known as the "right to be forgotten" and being maybe the most "famous" data subject right defined under the GDPR thanks to the Costeja judgement,⁸¹ the right to erasure allows data subjects to ask data controllers to erase their personal data. Of course, the possibility of having their personal data erased constitutes significant empowerment for data subjects in our digitalised world, as their personal data could be subjected to processing that is no longer desirable for them. Therefore, the European legislator granted data subjects the right to erasure.⁸² According to Article 17(1), data subjects may ask for their data to be erased if, amongst others, the personal data is no longer necessary for the purposes it was initially collected, or it has been unlawfully processed. If one of such conditions is met, data controllers are obliged to erase the data without undue delay. However, the right to erasure is not an absolute right, and in some instances, the others' rights and interests might prevail against the data subject's right to erasure. According to the European legislator, such cases might arise, for example, if the personal data is processed in order to exercise the right to freedom of expression and information or to comply with a legal obligation.⁸³ Consequently, each request for erasure needs to be evaluated individually considering its facts, since various rights and interests of different stakeholders have to be balanced.

⁸⁰ See, for instance, Case 90.20.77:0245, Hessische Beauftragte für Datenschutz und Informationsfreiheit [2020], retrieved from <[https://gdprhub.eu/index.php?title=HBDI_\(Hesse\)_-_90.20.77:0245](https://gdprhub.eu/index.php?title=HBDI_(Hesse)_-_90.20.77:0245)> accessed 31 January 2022.

⁸¹ Case C-131/12, Google Spain SL and Google Inc. v Agencia Española de Protección de Datos (AEPD) and Mario Costeja González [2014] ECLI:EU:C:2014:317

⁸² GDPR, art 17.

⁸³ GDPR, art 17(3).

If we consider biological family members as data subjects, then they should also be able to exercise this right against data controllers if, for instance, their personal data have been unlawfully processed. It is undoubtedly true that pursuant to Article 9(1), the processing of genetic data is prohibited unless certain conditions are met, such as obtaining the data subject's explicit consent. Accordingly, direct-to-customer genetic test service providers ask for explicit consent from donors before processing their genetic data and only proceed with the processing once it has been gathered. However, if biological family members are considered data subjects, we would have to deal with a scenario in which some data subjects would not have provided their explicit consent to this processing since they would be unaware of the processing. Therefore, the exception that allows for processing data of special categories would not apply.⁸⁴ Thus, there would be good reasons to think that biological family members could exercise a right to erasure in such cases due to unlawful processing. However, in practice, this could create a scenario that would be difficult to manage. Imagine, for example, that a donor's parent or child wants to delete certain data from the donor's medical record. Or that a son would like to erase the genetic data provided by his father in a clinical trial. Could they do so by appealing to the right of erasure? Would their status as data subjects enable them to benefit from that right?

As explained above, the right to erasure is not absolute, and data controllers need to handle each case by conducting a balancing test between the competing rights and interests of the involved parties. Therefore, the question of whether a biological family member can "delete" a donor's personal data might find a convincing answer through the exceptions provided for the right to erasure. For instance, according to Article 17(3)(d), when processing is necessary for, inter alia, scientific research purposes and the use of the right to erasure is likely to render impossible or seriously impair the achievement of the objectives of the processing, this right cannot be exercised. Besides, controllers may refuse the requests if the processing is necessary to comply with a legal obligation requiring it, as defined under Article 17(3)(b). Thus, one can argue that a donor's genetic data cannot be erased from the clinical records, at least for some time, due to a right to erasure request by a biological family member since laws oblige data controllers to keep them.

However, with the advancements in genetic sequencing technologies and developments in genomics, we might soon be confronted with challenging cases in which complying with the right to erasure would be practically impossible. Imagine, for instance, a biological family member exercising his/her right to erasure regarding the genetic data that has been used to train artificial intelligence. Although such a scenario could be seen as futuristic at first glance, given the increasing number of biobanks storing genetic data, the ongoing efforts in the European Union to create a "European Health Data Space" and "Federated European infrastructure for genomics data" and the intersection of artificial intelligence and genomics in general, it might not be that far for such cases to occur. In this scenario, however, providing a right to erasure

⁸⁴ Kuru (n 16) 51-53.

to biological family members might cause dramatic consequences because 1) erasure is an obligation that is very tricky to comply with within the context of artificial intelligence; and 2) erasure of the retrospective use of genetic data by itself is very problematic. Villaronga and others comprehensively explored the first one, and they highlighted the disconnection between the language and requirements by law and the technical reality that makes it impossible for artificial intelligence to truly “forget”, as required by the European legislator.⁸⁵ Cabral further explored this disconnection and stressed that the results of the right to erasure could be quite problematic. By providing examples to his argumentation, he suggested that the right to erasure can cause the training data to be diminished, leading the algorithm to underperform, thus discriminating against certain groups. Hence, complying with the right to erasure requests by the biological family members regarding genetic data that has been used for training algorithms may lead to adverse effects for other individuals or even for those same individuals. Although such outcomes could be prevented by simply finding new datasets, this would be a costly procedure and may interrupt the algorithmic development process.⁸⁶ Because of this, data controllers may continuously rely on the exception provided under Article 17(3)(d) if, for example, they process the contested genetic data for scientific research. However, as explained in the earlier sections, there have been some cases in which the donor’s biological family members contested the processing of the donor’s genetic data for scientific purposes and managed to take action against such processing since it would have adversely affecting their rights and interests. If biological family members are empowered with such tools in the conventional genetic research setting, why should they then be deprived of such tools in advanced settings just because technical difficulties arise when attempting to comply with such requests for erasure?

On the other hand, further problems may arise regarding the erasure of the retrospective erasure of genetic data. This is because different stakeholders can use the same genetic data in several domains. For instance, in practice, the same genetic sample taken from a biobank might be used by different researchers for various research purposes. Therefore, while it is already hard, if not impossible, to track and undo the past uses of genetic samples and data in biobanking and genetic research,⁸⁷ it would be even harder to track the models that have been trained by this data.⁸⁸ Hence, it would be an extremely difficult task to deal with the erasure requests made by biolog-

ical family members in the age of artificial intelligence-driven genetic research. The GDPR, as it stands, is not ready to respond to these novel challenges.

3.4. Right to restriction of processing

The European legislator introduced the right to restriction of processing via Article 18 GDPR. Based on this right, under certain conditions, e.g. when the processing is unlawful, data subjects may ask data controllers to restrict the processing.⁸⁹ Consequently, data controllers cannot further process the personal data in question, with the exception of storage, unless the data subject consents to it or it is to protect the rights of other natural or legal persons or an important public interest.⁹⁰ Hence, simply stated, restriction of processing could be understood as limiting the controllers’ abilities without having the personal data deleted. Because of this feature, exercising the right to restriction of the processing could be considered by data subjects more favourable than the right to erasure since they may benefit from keeping the information alive for various reasons, e.g. using the personal data in question for legal claims.

Indeed, the right to restriction of processing could be considered a useful and efficient data subject right that can be exercised by biological family members as well, since they can restrict the processing of their common genetic data but still can have access to or use such information for various purposes. Furthermore, considering that the right to restriction of processing could also prevent the practical complexities that the right to erasure creates within the genetic data processing context, it might be the most desirable solution for all parties involved when there is a dispute. However, certain shortcomings will still appear if biological family members exercise their right to restriction of processing.

First of all, the dichotomy of having two different instructions, from the biological family members and the donor, over the processed common genetic data implies a problem. As explained before, upon receiving the restriction request, data controllers cannot process the personal data further unless obtaining the data subject’s consent. What then happens if a controller receives a restriction request from a biological family member but the original donor provides his/her consent for such processing – whose rights or interests should prevail in such cases? What if the biological family members ask for a restriction of processing in order to protect their right not to know? Should their interest outweigh the rest in such cases even though Article 18(2) allows further processing in order to protect the rights of another natural person – in this case, the donor’s right to know, for example? While this dilemma is still not solved in the bioethical context and different jurisdictions provide different answers to it, unfortunately, here too the GDPR, as it stands, falls short of answering such questions.

In fact, the right to restriction of processing could be the elephant in the room in the genetic data processing context, given that thousands of individuals around the world are posting their genetic testing results on social media without ob-

⁸⁵ Eduard Fosch Villaronga, Peter Kieseberg and Tiffany Li, ‘Humans forget, machines remember: Artificial intelligence and the right to be forgotten’ (2018) 34(2) *Computer Law & Security Review* 304, 313.

⁸⁶ Tiago Sergio Cabral, ‘Forgetful AI: AI and the Right to Erasure under the GDPR’ (2020) 6(3) *European Data Protection Law Review* 378, 388.

⁸⁷ Ciara Staunton, ‘Individual Rights in Biobank Research Under the GDPR’ in Santa Slokenberga, Olga Tzortzatou and Jane Reichel (eds), *GDPR and Biobanking Individual Rights, Public Interest and Research Regulation across Europe* (Springer 2021) 91, 97.

⁸⁸ See also, Mélanie Bourassa Forcier, Hortense Gallois, Siobhan Mullan and Yann Joly, ‘Integrating artificial intelligence into health care through data access: can the GDPR act as a beacon for policy-makers?’ (2019) 6(1) *Journal of Law and the Biosciences* 317, 331.

⁸⁹ GDPR, art 18(1).

⁹⁰ GDPR, art 18(2).

taining consent from their biological family members. In such cases, sensitive information, such as health, from the donor and/or their biological family members thereof, is published on social media often without any restrictions. In fact, researchers revealed that people find it “fun” to take genetic tests and share them with others.⁹¹ Such an attitude might cause harm to their biological family members, especially when the shared information reveals sensitive information because it might lead them to be vulnerable in various contexts, such as employment or insurance.⁹² Since recital 67 GDPR mentions the possibility of making the personal data unavailable to users or temporarily removing published data from a website as means of restriction, in such cases, biological family members might exercise this right instead of the right to erasure, given that they may still have an interest in accessing the genetic information in question.

At this point, one might consider that if donors upload their genetic test results to a website, it will constitute a purely personal activity and, therefore, it would fall outside the scope of the GDPR.⁹³ Hence, the solution could be clear-cut: biological family members cannot exercise their right to restriction of processing because the data protection framework does not protect such activity in the first place. However, this might not be the case. The Court of Justice of the European Union consistently interpreted this exception, also known as the “household exemption”, narrowly. Particularly in the *Lindqvist* case, the Court stated that Internet publications accessible to an indefinite number of people could not be exempt from the scope of the data protection framework.⁹⁴ At present, the courts and DPAs in Europe follow this narrow interpretation and apply data protection rules strictly to cases in which social media posts uploaded on public profiles are disputed. For example, the Court of First Instance of Gelderland recently decided that a grandmother should take down photos of her grandchild from her social media accounts as she had failed to obtain consent from the child’s legal representatives.⁹⁵ In another recent case, the Icelandic DPA found that the household exemption cannot be applied when the subjected photographs are accessible to all Facebook users without any restrictions.⁹⁶ Taken together, it is without a doubt that people who share their genetic test results on social media with an indefinite number of people can be confronted with data

protection rights by their biological family members. Thus, in such cases, biological family members can indeed ask the controller to stop the public exposure of their genetic information by claiming that the processing is unlawful by stating, for example, that their consent has not been obtained for such processing.

Unsurprisingly, this would also create some further legal and ethical dilemmas. First of all, although biological family members can base their request on the unlawfulness of the processing due to the lack of their consent, the mere fact that the results have been manifestly made public by the donor him/herself, who is also a data subject for this processing, can be considered as the valid legal ground pursuant to Article 9(2)(e). How should controllers decide whether this processing is lawful or not in the first place? Moreover, let us imagine a case in which a donor uploads his/her genetic testing results on social media in an attempt to find support groups, advice or treatment for a hereditary disease. It seems compatible with this purpose to make the results available to an indefinite number of people, and the donor can be considered to pursue a legitimate aim in doing so. In such cases, data controllers might have the option to refuse the restriction request based on Article 18(2) in an attempt to protect the donor’s rights and interests. Yet, biological family members might still be concerned that such information may leave them in a vulnerable position, for instance, regarding their employment. Whose rights and interests should prevail in such cases? How should the controller solve such a dispute? Unfortunately, the GDPR does not answer such questions as it currently stands, and there is no guidance issued from any competent authorities on how to solve such conflicts.

4. Rights that exist in theory but are not enforceable in practice?

The GDPR was built on a fundamental belief: that data subjects are autonomous and self-sufficient agents able to exercise control over their personal data. On this basis, the GDPR introduced a very individual-centric framework where the rights to data protection are related to only a particular data subject.⁹⁷ Suppose we break this individual-centric framework by considering biological family members as data subjects, either as a group or individually. In that case, we will have to face some practical consequences that lead to several complexities within the data protection framework that the GDPR clearly falls short of answering. Keeping this in mind, as stated in the previous sections, if we want to ensure legal certainty for all the parties involved in genetic data processing and maintain the data protection framework as a functioning one, we should probably restrain some of the data subject rights of the biological family members.

This is, of course, perfectly doable. Indeed, the GDPR provides Member States with such flexibility via many provisions. Leaving aside what has already been mentioned about some concrete rights, some articles in the GDPR allow further restrictions on the data subject rights. For instance, Article 23 allows the Union or Member State law to restrict data subject

⁹¹ Effy Vayena, Elli Gourna, Jürg Streuli, Ernst Hafen and Barbara Prainsack, ‘Experiences of early users of direct-to-consumer genomics in Switzerland: An exploratory study’ (2012) 15(6) *Public Health Genomics* 352, 360.

⁹² See also Buiten (n 66) 211.

⁹³ GDPR, art 2(2)(c).

⁹⁴ Case C-101/01, *Bodil Lindqvist* [2003] ECLI:EU:C:2003:596, para 47. The same approach also followed in following cases. See, Case C-73/07, *Tietosuojavaltuutettu v Satakunnan Markkinapörssi Oy and Satamedia Oy*, [2008] ECLI:EU:C:2008:727, para 44; Case C-345/17, *Sergejs Buivids* [2019] ECLI:EU:C:2019:122, para 43.

⁹⁵ Case C/05/368427 / KG ZA 20-106, *X v Y* [2020] ECLI:NL:RBGEL:2020:2521, retrieved from <https://gdprhub.eu/index.php?title=Rb._Gelderland_-_C/05/368427> accessed 31 January 2022.

⁹⁶ Case 2020010552, *Persónuvernd* [2021], retrieved from <[https://gdprhub.eu/index.php?title=Pers%C3%B3nuvernd_\(Iceland\)_-_no_2020010552](https://gdprhub.eu/index.php?title=Pers%C3%B3nuvernd_(Iceland)_-_no_2020010552)> accessed 31 January 2022.

⁹⁷ Panagiotopoulos (n 13) 465.

rights in order to ensure, inter alia, the protection of the data subject or rights and freedoms of others.⁹⁸ Furthermore, under certain conditions, Article 89(2) permits the Union or Member State law to provide derogations for some data subject rights when personal data is processed for scientific research purposes.⁹⁹ Lastly, Article 9(4) and Recital 53 allow Member States to introduce further limitations on processing genetic data.¹⁰⁰ Thus, certain derogations and limitations to data subject rights of biological family members can be introduced by the Union or Member State law in order to prevent these complexities from occurring when genetic data is processed.

However, if we try to avoid the issues created by considering genetic relatives as data subjects by restricting the rights involved, we might be acting against the fundamental aims of the GDPR, including ensuring a high level of protection of every person's right to the protection of their personal data.¹⁰¹ At this point, it must be recalled that, in order to ensure effective protection of the right to data protection, as well as the functioning of the internal market in the European Union, the data subjects' rights and the obligations of those who process personal data should be strengthened and set in detail.¹⁰² If we proceed the other way around, this normative approach would have some undesirable consequences. First, such derogations and limitations would leave biological family members in a vulnerable position against infringements. Furthermore, this might also create an illusion of protection for those individuals, which in practice does not exist. This would not be an optimal scenario. As Edwards and Veale stated, "*rights become dangerous things if they are unreasonably hard to exercise or ineffective in results, because they give the illusion that something has been done while in fact things are no better*".¹⁰³

To overcome these complexities, some authors have also suggested creating a separate group of data subjects equipped with different kinds of data subject rights than those of the 'primary data subjects'.¹⁰⁴ However, such a binary structured approach would bring enormous theoretical and practical complexities to the data protection framework. Theoretically, it would be difficult, if not impossible, to justify and conceptualise a 'new type' of data subject within the GDPR, as it lacks the flexibility to accommodate this new dynamic.¹⁰⁵ Practically, we might create a disadvantaged status by default for bi-

ological family members by assigning them a 'secondary' status, even though the processing in question might have as severe adverse effects on them compared to the 'primary' ones – the donors.

Thus, we need to find a way to avoid default derogations and limitations of data subject rights for biological family members and create further complexities that would cause a dramatic failure of the GDPR. In short, a reasonable solution must be found by using the existing tools in the framework we have at hand. To this end, we will devote our next section.

5. Isn't there a way forward?

Although a hard one, solving the complexities associated with recognising biological family members as data subjects is not an impossible task. First of all, one must remember that the right to protection of personal data is not an absolute one; hence, even though biological family members are entitled to be data subjects, it does not mean that their rights and interests should prevail at all costs. In other words, their rights and interests should be balanced against the fundamental rights of others in accordance with the principle of proportionality. In fact, this approach was already suggested by the WP29 back in 2004.¹⁰⁶

However, conducting this balancing test is particularly challenging even for the data protection authorities themselves considering the fact that infringements related to genetic data processing can be subjected to other legal frameworks too, such as family law. Yet, when other legal frameworks are involved in the dispute at hand, we often see that data protection authorities tend to declare themselves incompetent and refer to the relevant courts. For instance, the Icelandic DPA recently stated that it had no power to render a binding decision on the limits of freedom of expression so that such disputes should be subjected to judicial review.¹⁰⁷ In another dispute, the Icelandic DPA considered that the question of whether an employer should have been more diligent in informing the data subject of the processing at hand was a matter of labour law rather than data protection law and again declared itself incompetent to solve such a dispute.¹⁰⁸ The Danish DPA also declared itself incompetent to solve a dispute regarding provisions that are *lex specialis* to the GDPR.¹⁰⁹ Considering that another dispute was a matter of administrative law, the Danish DPA again declared itself incompetent.¹¹⁰ Based on these decisions, we believe that if similar complaints came before them regarding genetic data processing, it is quite possible that the DPAs would declare themselves incompetent to avoid solving a dispute that is indeed a matter of data

⁹⁸ GDPR, art 23(1)(i) and recital 73.

⁹⁹ GDPR, art 89(2): 'Where personal data are processed for scientific or historical research purposes or statistical purposes, Union or Member State law may provide for derogations from the rights referred to in Articles 15, 16, 18 and 21 subject to the conditions and safeguards referred to in paragraph 1 of this Article in so far as such rights are likely to render impossible or seriously impair the achievement of the specific purposes, and such derogations are necessary for the fulfilment of those purposes.'

¹⁰⁰ GDPR, recital 53: 'Member States should be allowed to maintain or introduce further conditions, including limitations, with regard to the processing of genetic data, biometric data or data concerning health.'

¹⁰¹ See, C-319/20 Meta (n 22) para 73.

¹⁰² GDPR, recital 11.

¹⁰³ Lillian Edwards and Michael Veale, 'Enslaving the algorithm: From a "Right to an Explanation" to a "Right to Better Decisions"?' (2018) 16(3) IEEE Security & Privacy 46, 50.

¹⁰⁴ Taylor (n 45) 105-106.

¹⁰⁵ See also, Hallinan (n 44) 190.

¹⁰⁶ WP29 (n 28) 9.

¹⁰⁷ Persónuvernd (n 96)

¹⁰⁸ Case 2020123070, Persónuvernd [2021], retrieved from <[https://gdprhub.eu/index.php?title=Pers%C3%B3nuvernd_\(Iceland\)_-_nr._2020123070](https://gdprhub.eu/index.php?title=Pers%C3%B3nuvernd_(Iceland)_-_nr._2020123070)> accessed 31 January 2022.

¹⁰⁹ Case 2019-31-1713, Datatilsynet [2020], retrieved from <https://gdprhub.eu/index.php?title=Datatilsynet_-_2019-31-1713> accessed 31 January 2022.

¹¹⁰ Case 2019-812-0035, Datatilsynet [2020], retrieved from <https://gdprhub.eu/index.php?title=Datatilsynet_-_2019-812-0035> accessed 31 January 2022.

protection law too. Even if they do try to solve it, given the existing fragmentation regarding their decisions on genetic data processing mentioned in earlier chapters, the outcomes will be inconsistent. Such outcomes would indeed go against the GDPR since one of its primary aims is to ensure legal certainty, as well as have consistent and homogenous application of the data protection rules throughout the Union.¹¹¹ Thus, we urgently need an alternative solution to the current general avoidance of solving such issues. In our opinion, the EDPB could provide valuable input to face this challenge.

According to Article 70(1), the EDPB is responsible for the consistent application of the GDPR in the Union. In order to fulfil this obligation, the EDPB, by its own initiative as well, can examine any question covering the application of the GDPR and issue guidelines, recommendations and best practices to encourage the consistent application of the data protection legislation or review the practical application of the guidelines, recommendations and best practices.¹¹² Therefore, the EDPB can come up with principles to be considered while dealing with the disputes that arise due to genetic data processing in order to ensure the consistent application of the data protection rules in the Union. In fact, the need to define a common approach to establish appropriate safeguards for the processing of genetic data was already identified by the WP29 back in 2004, considering the developments in the field of genetics at that time.¹¹³ In this working document, the WP29 also expressed its intention to revisit the document and focus later in detail on specific aspects, taking into account the experience of DPAs on the related matter and technological developments concerning genetic data.¹¹⁴ It has been 18 years since this one and only working document on genetic data was published and the EDPB has yet to revisit this document despite the ground-breaking advancements in genetic sequencing technologies that have occurred in the meantime. Even though the GDPR has replaced the Directive 95/46/EC in the meantime, it falls short of answering many questions regarding genetic data processing, as illustrated in the previous chapters.¹¹⁵ Therefore, the EDPB should be encouraged to revisit this document by examining the recent developments in genetics and their impacts on the data protection framework and come up with guidelines, recommendations, and best practices regarding genetic data processing.

Although we do not believe that it is very likely for EDPB to take on such a task immediately, we think that it is crucial for the EDPB to address this issue, especially considering that the EU itself is leading certain genomics initiatives, such as 1+ Million Genomes, European Health Data Space and the Federated European infrastructure for genomics data, and investing in the intersection of artificial intelligence and genomics. Moreover, as explained in earlier sections, thanks to the advancements in biobanking, the practice in biomedical research is shifting from collecting samples for each research to using collected samples for further research. Such practices may soon lead to discussions about the status of genetic data

of the deceased, an issue which we do not currently think about. Furthermore, impacts of novel concepts such as data altruism are yet to be seen in the genetic data processing context. While these novel developments will inevitably bring further challenges to the data protection framework from the genetic data processing context, we are still missing the answers to some of the very fundamental questions arising when genetic data is processed. Thus, we believe that EDPB should revisit the 2004 working document on genetic data.

In doing so, the EDPB should primarily focus on deciding whether genetic data should be considered as personal data of the biological family members of donors (or, indeed, of which relatives). Furthermore, if the EDPB proceeds in that way, it should develop certain principles to apply that can be used by the DPAs while solving disputes regarding genetic data processing on a case-by-case basis. In specific, these principles should primarily address:

1. Whether and which biological family members should be considered data subjects?
2. If so, what should be the scope of the data subject rights of biological family members?
3. How should competing interests of the donors, biological family members, data controllers and processors, and society in general be conciliated while processing genetic data?

Acknowledging that genetic data processing might trigger various other frameworks depending on the context of processing, such as family law, criminal law, or health law, we urge the EDPB to develop principles that have a rather holistic nature since they should be applied in various contexts. In fact, the EDPB should even consider circumstances when it is better for data protection to be faded from the scene by taking into account that other frameworks, such as bioethics, are better equipped to solve the problem at hand. In such an attempt, we believe that EDPB should actively engage with other relevant stakeholders, such as bioethics committees, lawyers, human/patient rights organisations, researchers, and developers, in order to understand better the emerging risks attached to genetic data processing and how to mitigate risks attached to genetic data processing in the best manner without hindering the progress of genetic research.¹¹⁶ Furthermore, identifying best practices from different Member States might also help EDPB provide more practical and future-proof principles.

6. Conclusion

Especially after the boom of direct-to-customer genetic testing services, millions of people worldwide have been sharing their genetic material to learn about their ancestry, get lifestyle advice or discover what might be waiting for them in the future regarding their health. This ever-growing amount of available genetic data and the interpretations made from it can be a powerful tool to improve the quality of our lives. However, processing genetic data can also cause significant infringements of the fundamental rights and freedoms of in-

¹¹¹ GDPR, recital 7 and 10.

¹¹² GDPR, art 70(1)(e) and 70(1)(l).

¹¹³ WP29 (n 28) 13.

¹¹⁴ *ibid* 14.

¹¹⁵ See also, Pormeister and Drozdowski (n 34) 54.

¹¹⁶ See also, Panagiotopoulos (n 13) 469.

dividuals.¹¹⁷ Due to its very nature, the risks and benefits of processing genetic data therefore affect not only the donors but also their biological family members. This creates significant challenges for the European data protection framework when regulating genetic data processing. Although, due to the broad scope of the GDPR, biological family members can be considered data subjects along with the original donor when their common genetic data is processed, such interpretation leads to severe legal and practical uncertainties for all parties involved in the genetic data processing. Therefore, such complexities should be addressed to ensure legal and practical certainty for all the parties involved and consistent application of data protection rules in the Union. In this regard, the EDPB should revisit the 2004 Working Document on Genetic Data by considering recent developments in genetics and their implications on fundamental rights, particularly the right to data protection.

¹¹⁷ See also Selita (n 15) 75; Robert I. Field, Ethan Dombroski, Mary Kate McDevitt and Whitney A. Petrie, 'Genetic Databases and the Future of Medicine: Can Law and Ethics Keep up? Perspectives and Analysis of a Conference' (2021) 13(2) *Drexel Law Review* 321, 326.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

No data was used for the research described in the article.

CRediT authorship contribution statement

Taner Kuru: Writing – original draft, Writing – review & editing. **Iñigo de Miguel Beriain:** Writing – original draft, Writing – review & editing.

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