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# *Protecting Genetic Privacy in Biobanking through Data Protection Law* by Dara Hallinan

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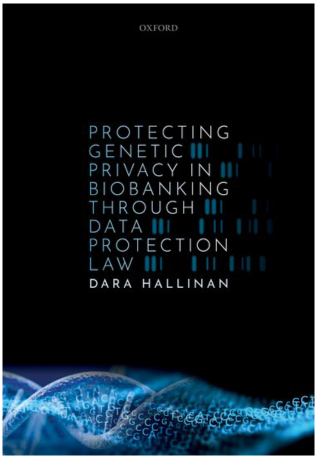

*Protecting Genetic Privacy in Biobanking through Data Protection Law* by Dara Hallinan (Oxford University Press 2021) 304pp; hardback £110

With biobanking becoming the cornerstone of medical research and personalised healthcare, protecting genetic privacy has emerged as a critical issue. DNA, which carries sensitive personal information, is uniquely individual and functions as an ultimate identifier. Moreover, if compromised, it cannot be replaced. Collecting, storing and using genetic data in biobanks for scientific research, therefore, requires robust safeguards that protect individuals' rights and prevent misuse. In an era where biobanks serve as essential infrastructure for medical research that increasingly relies on genetic data, Dara Hallinan's *Protecting Genetic Privacy in Biobanking through Data Protection Law* is a timely and insightful exploration of how genetic privacy in biobanks is protected across Europe. The book comprehensively analyses the European Union (EU) General Data Protection Regulation (GDPR), arguing that 'the substantive

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framework presented by the GDPR already offers an admirable baseline level of protection for genetic privacy' (at 3). Although the book identifies numerous issues – specifically, 'twenty-three different problems, of eight distinct types' (at 258) – with the GDPR, Hallinan also argues that the GDPR provides the flexibility to enable solutions and procedural mechanisms to address those challenges (at 259).

Hallinan's book is divided into 11 chapters, including the introduction (chapter 1) and conclusion (chapter 11).

Chapters 2 and 3 provide background information about the concept of genetic data and the European biobanking landscape, respectively. Chapter 2 explains what information genetic analyses can reveal and situates such analyses within their social context. Chapter 3 offers an overview of the origins of European biobanking, as well as the approaches and operations shaping it.

Chapter 4 details the theoretical foundation for the types of genetic privacy rights research subjects, genetic relatives and genetic groups have in biobanking. An essential, though not standalone, component of the book's overall narrative, this chapter depicts the conflict between different rightsholders. Notably, the chapter addresses the conflicts and confluences between genetic privacy rights and the legitimate interests of researchers, society and other stakeholders, including those without research interests, such as insurers.

Chapters 5 and 6 explore the protection of genetic privacy in biobanking at the international and European level, respectively. In examining international law, the book highlights its shortcomings, demonstrating that international protection provides a mere baseline rather than a definitive standard. It maps common and emerging international principles using tables. In my view, such mapping proves especially useful in highlighting that, unlike the rights of research subjects, the rights of genetic relatives and groups are not afforded international protection (at 85–88). Chapter 6 presents an engaging 'thought experiment' (at 91) and examines genetic privacy in biobanking in Europe by focusing on three chosen countries – Estonia, Germany and the United Kingdom (UK) – while excluding their respective data protection laws. It examines the Estonian Human Genes Research Act 2000, the German Civil Code and the Human Tissue Act 2004 of the UK. By comparing these three countries' approaches in tables, it also highlights gaps in the protection offered by national laws and demonstrates that the GDPR's broad, directly applicable and robust data protection framework serves as a viable alternative to national regulations (at 126–127). This analysis underscores the need for comprehensive data protection in biobanking, setting the stage for the book's subsequent chapters, which evaluate the effectiveness of the GDPR's protection.

Accordingly, the next three chapters (7, 8 and 9) examine the GDPR provisions in the context of biobanking. Chapter 7 addresses the subject matter, including whether biological samples qualify as personal data. Chapter 8 focuses on the GDPR's classification of biobanking, specifically the categorisation of both actors and personal data. Chapter 9 provides a compact exploration of key legal aspects of the GDPR's provisions, including the data protection impact assessment required before processing genetic data, consent requirements, data subject rights, data protection principles and cross-border transfers. Hallinan's concise summary of the GDPR in chapter 9 effectively identifies the relevant issues and laws related to genetic privacy. I find this chapter particularly engaging and highly referenceable, as it encapsulates all the key points about genetic data protection under the GDPR and can be read on its own.

Chapter 10 critically assesses the adequacy of the GDPR as an overarching framework for data protection in depth. This detailed chapter, more than double the length of others, identifies eight categories of issues within the GDPR system: its structural design; the level of protection it offers to research subjects, genetic relatives, and groups; the substantive protection it ensures; its technical applicability; its disproportionate impact on research; its practical application to biobanking; and the degree of harmonisation across Europe. I think two aspects of this analysis make this chapter unique. First, the chapter not only identifies the problems but also ranks the severity of their negative consequences for biobanking. Moreover, it proposes potential solutions for them. Second, Hallinan schematises 'the gaps in member states' approaches without data protection' and the degree of necessity for a solution for each gap (necessary, strictly necessary, or not necessary) in a table (at 252–253). The table indicates whether the GDPR's internal mechanisms can address the problems or if parallel national legislation is required to facilitate solutions. This unique schematisation effectively makes a technical topic more accessible and comprehensible. Hallinan concludes the overall analysis by asserting that none of the problems he identifies in the GDPR's approach fundamentally undermine its utility as a framework for protecting genetic privacy in biobanking, as most issues are 'amenable to resolution' (at 254).

*Protecting Genetic Privacy in Biobanking through Data Protection Law* offers a well-structured exploration of a critically important topic, identifies challenges and provides strategies and policy recommendations for mitigating those challenges. In my view, the book's thorough examination of the GDPR's provisions makes it an essential reference for understanding genetic privacy in biobanking and European data protection law, especially for policy-makers and stakeholders in the biobanking field.

Researchers' growing reliance on biobanks makes addressing privacy concerns unquestionably urgent, but the extent to which the book's proposed solutions will be embraced, particularly given genomic technologies' rapid pace of change, remains uncertain. Hallinan acknowledges that uncertainty and, in the conclusion, writes of biobanking's future outlook (at 259):

> The biobanking community have choices as to how they perceive, and operationalise, the GDPR. They may choose to embrace the GDPR, and establish a healthy culture of compliance in which the potential of the law may best be realised, or they may choose to oppose the GDPR, and establish a culture of resistance in which realisation of potential is impossible. Time will tell.