

EXCEPTIONALISM AND THE DEVELOPMENT OF GENOMICS LAW AND POLICY IN AUSTRALIA

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In this article we examine the concept of genetic exceptionalism and its role in the development of genomics law and policy in Australia over the past two decades. We examine exceptionalism in a context where there is renewed debate within bioethics about its relevance for genomics, where the landscape of genetic and genomic science has undergone considerable change over the past 20 years, and where ethical, legal, and social issues continue to arise as governments seek to implement genomics into health care to achieve health benefits. We conclude that Australia has and can continue to take a sophisticated view of questions raised in the exceptionalist debate, and that recent calls for a contextual rather than exceptionalist approach offer a way forward that coheres with over 20 years of genetic and genomic law and policy in Australia.

I INTRODUCTION

Our understanding of the human genetic code has developed considerably over the past 20 years.¹ A first draft of the human genome with preliminary analysis was published in 2001.² As genetic and genomic science has developed, and new health

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1 See, eg, International Human Genome Sequencing Consortium, 'Initial Sequencing and Analysis of the Human Genome' (2001) 409(6822) *Nature* 860; International Human Genome Sequencing Consortium, 'Finishing the Euchromatic Sequence of the Human Genome' (2004) 431(7011) *Nature* 931.

2 'Initial Sequencing and Analysis of the Human Genome' (n 1).

applications have been identified, Australian law and policy makers have weighed the best approach to these evolving technologies. Just over 20 years ago, the Commonwealth Parliament considered genetic privacy and discrimination legislation in the form of the Genetic Privacy and Non-Discrimination Bill 1998.³ Shortly afterwards, the Australian Law Reform Commission ('ALRC') and Australian Health Ethics Committee ('AHEC') of the National Health and Medical Research Committee ('NHMRC') undertook their landmark inquiry on the protection of human genetic information, starting with the release of an Issues Paper in 2001, and a Discussion Paper in 2002, and culminating in the 2003 report *Essentially Yours: The Protection of Human Genetic Information in Australia* ('*Essentially Yours*').⁴ In 2006, the *Privacy Act 1988* (Cth) ('*Privacy Act*') was amended, and national guidelines issued in 2009, to allow clinicians, in some circumstances, to disclose genetic information about an individual to that person's genetic relatives who may be at risk of genetic diseases.⁵

The widespread implementation of genomics in health care is now a national priority, as indicated by development of the National Health Genomics Policy Framework ('*Framework*').⁶ The purpose of the Framework is to coordinate a national approach and to 'harness the health benefits of genomic knowledge and technology into the Australian health system in an efficient, effective, ethical and equitable way to improve individual and population health'.⁷ Accompanying the Framework is an *Implementation Plan*, which aims to provide 'a blueprint for coordinated action by governments, health professionals, non-government organisations and industry to work in partnership to embed genomics in the Australian health system'.⁸ The *Implementation Plan* includes a commitment to revisit key recommendations from the *Essentially Yours* report, in light of 'the

3 Senate Legal and Constitutional Legislation Committee, Parliament of Australia, *Provisions of the Genetic Privacy and Non-Discrimination Bill 1998 (as Introduced in the 38th Parliament)* (Report, March 1999) ('*Provisions of the Genetic Privacy and Non-Discrimination Bill 1998*').

4 Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information* (Issues Paper No 26, November 2001) <<https://www.alrc.gov.au/wp-content/uploads/2019/08/IP26.pdf>>; Australian Law Reform Commission and Australian Health Ethics Committee, *Protection of Human Genetic Information* (Discussion Paper No 66, August 2002); Australian Law Reform Commission and Australian Health Ethics Committee, *Essentially Yours: The Protection of Human Genetic Information in Australia* (Report No 96, March 2003) ('*Essentially Yours*').

5 *Privacy Act 1988* (Cth) ss 16B(4), 95AA ('*Privacy Act*'). See also National Health and Medical Research Council, *Use and Disclosure of Genetic Information to a Patient's Genetic Relatives under Section 95AA of the Privacy Act 1988 (Cth): Guidelines for Health Practitioners in the Private Sector* (Guideline No PR3, March 2014) 4–5 <<https://www.nhmrc.gov.au/about-us/publications/guidelines-approved-under-section-95aa-privacy-act-1988-cth>> ('*Section 95AA Guidelines*').

6 Australian Health Ministers' Advisory Council, *National Health Genomics Policy Framework 2018–2021* (2017) i ('*National Health Genomics Policy Framework*').

7 Ibid 5.

8 Department of Health (Cth), *Implementation Plan: National Health Genomics Policy Framework 2018–2021* (2018) 2 ('*Implementation Plan*').

changing context since 2003', particularly in relation to privacy legislation and genetic discrimination in insurance.⁹

Woven throughout these regulatory debates has been consideration, both explicitly and implicitly, of genetic exceptionalism. Genetic exceptionalism is 'the idea that genetic information is special or unique'.¹⁰ This article aims to provide timely reflections on the Australian approach to genetic and genomic law and policy, including the role of exceptionalism in Australian debates on privacy. A historical view illuminates the distinction, which has sometimes been obscured, between the question of whether genetic information is in fact unique, and the pragmatic assessment of whether it is best regulated under a specialised regime. Genetic exceptionalist approaches to law and policy are often motivated by concerns about risks to genetic privacy and the prospect of genetic discrimination. These concerns were outlined by Annas, Glantz, and Roche in 1995: 'Genetic information ... can predict an individual's likely medical future for a variety of conditions; it divulges personal information about one's parents, siblings, and children; and it has historically been used to stigmatize and victimize individuals'.¹¹ For others, exceptionalism is justified not by the inherent risks of genetic information, but by misunderstandings and preconceptions about the power of genetics.¹² Sabatello and Juengst have argued that beliefs such as genetic essentialism (that our genes represent 'hard wired' traits), genetic determinism (that our genes determine our behaviour), and genetic reductionism (the discounting of all other factors that influence behaviour and health) form the basis of stigma and the discriminatory use of genetic information.¹³ They conclude that the ethical, legal, and social implications of these beliefs, even if not well-founded, must be addressed alongside the development of genomic medicine.¹⁴

The exceptionalist position has been criticised as weighting too heavily concerns about the misuse of an individual's genetic and genomic information over the potential public benefits to human health of its appropriate use, and relying on an artificial distinction between genetic information and other forms of health information.¹⁵ More recently, Garrison et al have proposed genetic contextualism, 'the concept that genomic information can both be similar to and maintain distinct

9 Ibid 11.

10 Nanibaa' A Garrison et al, 'Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism' (2019) 19(1) *American Journal of Bioethics* 51, 51.

11 George J Annas, Leonard H Glantz and Patricia A Roche, 'Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations' (1995) 23(4) *Journal of Law, Medicine and Ethics* 360, 360.

12 Ellen Wright Clayton et al, 'The Law of Genetic Privacy: Applications, Implications, and Limitations' (2019) 6(1) *Journal of Law and the Biosciences* 1, 7–8; Maya Sabatello and Eric Juengst, 'Genomic Essentialism: Its Provenance and Trajectory as an Anticipatory Ethical Concern' (2019) 49(S1) *Hastings Center Report* S10.

13 Sabatello and Juengst (n 12).

14 Ibid S16.

15 See, eg, Lawrence O Gostin and James G Hodge Jr, 'Genetic Privacy and the Law: An End to Genetics Exceptionalism' (1999) 40(1) *Jurimetrics* 21.

qualities from other areas of medicine’, as an alternative to the more starkly dichotomous framing of the exceptionalist debate.¹⁶ As will be seen below in Parts III and IV, a contextual approach to genetic and genomic information is not novel in Australia.

This article traces the exceptionalist position through the past two decades of Australian law and policy, as exemplified by the introduction of the Genetic Privacy and Non-Discrimination Bill 1998 (Cth) (‘the 1998 Bill’), the subsequent *Essentially Yours* report published in March 2003, amendments to the *Privacy Act* to permit the disclosure of genetic information to relatives in some circumstances, and most recently the development of the National Health Genomics Policy Framework. In Part II we discuss the exceptionalist arguments for specialised Commonwealth legislation addressing genetic privacy and discrimination, and the report from the Commonwealth Senate Legal and Constitutional Legislation Committee. In Part III we analyse the approach adopted in *Essentially Yours*, which identified specific features of genetic information that, it argued, should be considered in the context where that information was to be used. In Part IV we discuss the introduction of s 95AA of the *Privacy Act* which permits the disclosure of genetic information to relatives in some circumstances and consider whether this can be regarded as an example of genetic exceptionalism. In Part V, we discuss the development of the National Health Genomics Policy Framework, including its call to revisit the recommendations of *Essentially Yours* in terms that harken back to the 1998 Bill, and we reflect on recent calls for genomic contextualism. Finally, in Part VI, we conclude that Australia has and can continue to take a sophisticated view of questions raised in the exceptionalist debate, and that recent calls for a contextual rather than exceptionalist approach offer a way forward that coheres with over 20 years of genetic and genomic law and policy in Australia.

II THE GENETIC PRIVACY AND NON-DISCRIMINATION BILL 1998

In 1998, Australia had the opportunity to adopt genetic-specific legislation when the Genetic Privacy and Non-Discrimination Bill 1998 (Cth) was introduced in the Australian Senate. The 1998 Bill proposed a single, comprehensive piece of legislation at the Commonwealth level to govern the handling of both genetic information and DNA samples, to define rights and responsibilities with respect to genetic information, and to make genetic discrimination unlawful in Australia. The main objects of the proposed legislation were to govern the collection, storage, and use of genetic information and DNA samples; to create enforceable rights and responsibilities with respect to genetic information; and to provide protection against genetic discrimination and for genetic privacy.¹⁷ Additional provisions placed limits on the use of DNA samples in research.¹⁸ The Bill provided for

16 Garrison et al (n 10) 57.

17 Genetic Privacy and Non-Discrimination Bill 1998 (Cth) cl 6.

18 Ibid pt 5.

recourse to the Privacy Commissioner in cases of interference with an individual's privacy, and to the Human Rights and Equal Opportunity Commission in cases of genetic discrimination.¹⁹ It also provided for a right to recover damages or equitable relief where a person's DNA sample had been negligently or wilfully collected, stored, or analysed contrary to the proposed Act.²⁰ In her second reading speech, Senator Natasha Stott Despoja argued that the Commonwealth should lead the development of genetic privacy regulation to ensure a harmonised national approach, avoiding conflicting state and territory legislation.²¹

By focusing specifically on genetic information, the 1998 Bill can be seen as reflecting an exceptionalist approach to regulation. Such an approach is based on a belief that genetic information is unique in the risks that it poses, and therefore warrants a specific regulatory response.²² Senator Stott Despoja explained in her second reading speech on the 1998 Bill that 'advances [in genetic technologies] also bring the need to develop new laws to deal with the new possibilities to make sure we achieve the full benefit of the new technologies'.²³ Stott Despoja also acknowledged the influence of the US Model Genetic Privacy Act.²⁴ Discussing the drafting of the US Act, Annas, Glantz and Roche argued that 'to the extent that we accord special status to our genes and what they reveal, genetic information is uniquely powerful and uniquely personal, and thus merits unique privacy protection'.²⁵

The 1998 Bill was an attempt to avert the possible negative repercussions of the implementation of genetic technologies, in particular those related to privacy and discrimination.²⁶ In 1995, Gostin explained the threat to privacy posed by the collection of genetic and genomic information and its storage in information networks, placing individuals at risk of harm 'from unwanted disclosures of these sensitive genomic data'.²⁷ Thus the harms that flow from breaches of genetic privacy are closely related to the prospect of genetic discrimination. Genetic discrimination is 'the differential treatment of asymptomatic individuals or their relatives on the basis of their actual or presumed genetic characteristics'.²⁸ In the

19 Ibid pt 7.

20 Ibid cl 27.

21 Commonwealth, *Parliamentary Debates*, Senate, 11 March 1998, 839 (Natasha Stott Despoja) ('*Second Reading Speech*').

22 See, eg, Annas, Glantz and Roche (n 11).

23 Stott Despoja, *Second Reading Speech* (n 21) 838.

24 Ibid.

25 Annas, Glantz and Roche (n 11) 365.

26 *Second Reading Speech* (n 21) 839–40 (Natasha Stott Despoja).

27 Lawrence O Gostin, 'Genetic Privacy' (1995) 23(4) *Journal of Law, Medicine and Ethics* 320, 324.

28 M Otlowski, S Taylor and Y Bombard, 'Genetic Discrimination: International Perspectives' (2012) 13(1) *Annual Review of Genomics and Human Genetics* 433, 434, citing Paul R Billings et al, 'Discrimination as a Consequence of Genetic Testing' (1992) 50(3) *American Journal of Human Genetics* 476.

late 1970s, concerns were raised about the risk of psychological, social, or economic harm to individuals identified by newly-established genetic screening programs as carriers of genetic diseases including Tay-Sachs, Sickle-Cell Anaemia, Huntington's Disease and Haemophilia.²⁹ Since then, the potential for negative repercussions has been identified in the realms of personal and family relationships, the ability to access health and life insurance, and in employment.³⁰ Some instances of genetic discrimination have been documented in Australia, as well as cases of reluctance to access genetic testing out of fear of subsequent discrimination.³¹

The contemporaneous discussion of the 1998 Bill revealed different opinions about whether regulation should anticipate or respond to these challenges. At the time of the 1998 Bill, the evidence before the Senate Legal and Constitutional Legislation Committee was that genetic technology was in its infancy and 'genetic information [was] not yet in wide use in the community'.³² For its proponents, the 1998 Bill was an opportunity to get ahead of predictable risks to privacy and discrimination.³³ This is an example of what Sabatello and Juengst have recently described as the 'anticipatory ethical concerns' of the exceptionalist approach.³⁴ While such concerns may be regarded as premature, or even dismissed as 'hype', Sabatello and Juengst argue that they reflect genuine concerns about the implementation of new technologies informed by past experience.³⁵

Accordingly, the position advanced by proponents of the 1998 Bill was that the novel nature of genetic technology, along with its accompanying risks to individuals, required the introduction of separate national legislation. However, a different position was taken by the Senate Legal and Constitutional Legislation Committee, which considered that it was 'premature to regulate on genetic privacy and non-discrimination'.³⁶ The Committee agreed that an advantage of the 1998 Bill would be the creation of a national approach, which would provide clarity and consistency, enable Australia to better participate in international efforts, and best protect community interests and concerns.³⁷ However, the Committee feared that premature or excessive regulation would stifle research and innovation, leading to

29 Regina H Kenen and Robert M Schmidt, 'Stigmatization of Carrier Status: Social Implications of Heterozygote Genetic Screening Programs' (1978) 68(11) *American Journal of Public Health* 1116, cited in Otlowski, Taylor and Bombard (n 28) 434.

30 Otlowski, Taylor and Bombard (n 28) 435–7.

31 Ibid 438.

32 *Provisions of the Genetic Privacy and Non-Discrimination Bill 1998* (n 3) 34–5 [5.10]–[5.11].

33 Natasha Stott Despoja, Submission to Senate Legal and Constitutional Legislation Committee, Parliament of Australia, *Provisions of the Genetic Privacy and Non-Discrimination Bill 1998 (as Introduced in the 38th Parliament)* (March 1999) 23–6 [4.4].

34 Sabatello and Juengst (n 12).

35 Ibid S12.

36 *Provisions of the Genetic Privacy and Non-Discrimination Bill 1998* (n 3) 34 [5.10].

37 Ibid 33–4 [5.4]–[5.8].

loss of future benefits.³⁸ In addition, the ethical debate in Australia on genetic technology was seen as far from settled, making it difficult to know what position should be adopted in legislation.³⁹ The self-regulation of research was described as a 'useful interim position, while the ethics and legal issues become clearer'.⁴⁰ The Committee recommended the establishment of a national working party, continued review of emerging issues, and that any additional regulation be made through amendments to existing legislation.⁴¹

Underlying the differing views of the Bill's proponents and the Committee's ultimate position was the assumption that if genetic technology carries special risks, a novel response is required. This premise of the exceptionalist debate was not always clear, nor interrogated, in the terms of the early exceptionalist debate. Central to the 1998 Bill were the propositions that, since genetic information posed exceptional risks, specialised legislation should govern its use. However, even if it is accepted that genetic information is exceptional, it does not necessarily follow that an exceptional approach to regulation is required. As Lipworth points out, the characterisation of emerging biomedical technologies as exceptional or non-exceptional is a separate question to that of the appropriate regulatory response.⁴² A new phenomenon, such as genetic testing, may or may not be exceptional in its characteristics, in its scale, or in its effects on specific populations.⁴³ In either case, the regulatory response to that phenomenon may be syncretic or asyncretic. A syncretic approach entails a preference for existing regulation except in cases where there are both unique ethical and legal challenges, and existing regulation is demonstrably inadequate.⁴⁴ An asyncretic approach would mean a preference for novel regulation even where an emerging technology has commonalities with existing ones, or where new regulation is not strictly necessary.⁴⁵ Thus, even if genetic technologies are exceptional, there is still a choice to be made about whether to develop new regulation.⁴⁶

Lipworth outlines a series of benefits and drawbacks of both the syncretic and asyncretic approaches to regulation of new biomedical technologies. Benefits of a syncretic approach include simplicity, in the sense that there are a smaller number of regulatory instruments; the ability to apply existing knowledge and ethical norms which have normally been refined over a long period; and the ability to

38 Ibid 35 [5.12].

39 Ibid 35–6 [5.13].

40 Ibid 37 [5.22].

41 Ibid vii.

42 Wendy Lipworth, 'Generating a Taxonomy of Regulatory Responses to Emerging Issues in Biomedicine' (2005) 2(3) *Journal of Bioethical Inquiry* 130.

43 Ibid 131.

44 Ibid 133.

45 Ibid.

46 Ibid.

further refine existing regulation in the light of new technologies.⁴⁷ On the other hand, asyncretic regulation permits regulation that targets the specific issues that arise with a new technology, which offers simplicity in the sense that less interpretation is required to apply existing rules in a new context, and the development of asyncretic regulation provides opportunities to focus public interest and debate, and trial novel regulatory approaches.⁴⁸

In more recent contributions to the genetic exceptionalism debate, the assumption that the risks of genetic and genomic technologies require an exceptional regulatory response has been widely criticised.⁴⁹ Murray writes that ‘genetic information has certain properties that warrant close attention. But nothing that launches it into some unique universe of moral, legal, and policy concerns.’⁵⁰ Garrison et al describe a false binary, where it is assumed either that the exceptional nature of genetic testing and information means that specific regulation and policy is required, or that its commonalities with other forms of testing and information mean that no exceptional regulation is required.⁵¹ Such reasoning, they argue, obscures important questions, such as whether there are aspects of genomic testing or information that merit specific regulatory approaches.⁵² The rejection of exceptionalist regulation should not mean the abandonment of critical questioning on the ethical, social, and legal implications of genomic technologies.⁵³ As will be seen below, despite Australia’s reluctance to adopt exceptional legislative measures for genetic and genomic technology in 1998, debate regarding the appropriate regulatory response continues.

III RECONSIDERING EXCEPTIONALISM: THE *ESSENTIALLY YOURS* REPORT (2003)

The publication of *Essentially Yours* in Australia in March 2003 was based on extensive public engagement and consultation.⁵⁴ The inquiry investigated whether new regulation was required to protect the privacy of genetic samples and information, and protect individuals from genetic discrimination.⁵⁵ Additionally,

47 Ibid 136–8.

48 Ibid 139.

49 See, eg, Thomas H Murray, ‘Is Genetic Exceptionalism Past Its Sell-By Date? On Genomic Diaries, Context, and Content’ (2019) 19(1) *American Journal of Bioethics* 13, 13–14 (‘Is Genetic Exceptionalism Past Its Sell-By Date?’); Daniel P Sulmasy, ‘Naked Bodies, Naked Genomes: The Special (But Not Exceptional) Nature of Genomic Information’ (2015) 17(5) *Genetics in Medicine* 331. See also Lipworth (n 42).

50 Murray, ‘Is Genetic Exceptionalism Past Its Sell-By Date?’ (n 49) 14.

51 Garrison et al (n 10) 53.

52 Ibid.

53 Ibid.

54 *Essentially Yours* (n 4) vol 1, 33.

55 Ibid.

the inquiry was asked to examine ‘whether, and to what extent, a regulatory framework is required ... to reflect the balance of ethical considerations relevant to the collection and uses of human genetic samples and information in Australia’.⁵⁶

The inquiry dealt head on with the genetic exceptionalist position, which it defined as ‘the idea that genetic information is so fundamentally different from, and more powerful than, all other forms of personal health information that it requires different or higher levels of legal protection’.⁵⁷ This framing of the exceptionalist position continued the assumption seen in debate on the 1998 Bill that demonstrating the exceptional qualities of genetic information would also provide an answer on appropriate regulatory choices. *Essentially Yours* surveyed the characteristics of genetic information that were said to make it special.⁵⁸ In particular, the report considered the ways in which genetic information was ‘ubiquitous’, being contained in enduring form in almost every cell in the human body; ‘familial’, containing information that is personal but shared with genetic relatives; and ‘predictive’, revealing information about future health risks that may be both of great significance and hard to evaluate.⁵⁹ Separately, the report identified two opposing philosophical approaches to regulating genetic information: genetic exceptionalism, which views ‘genetic information as uniquely powerful and posing special threats to privacy and discrimination that mandate dedicated and higher levels of legal protection’; and genetic inclusivism, which regarded genetic information as ‘just one of a number of sources of personal health and medical information ... [with] no need for any higher or special protections’.⁶⁰

Rather than adopting an exceptionalist approach, the *Essentially Yours* report concluded that the better approach was a ‘middle ground’⁶¹ or a ‘contextual approach’.⁶²

The Inquiry accepts enough of the inclusivist or anti-exceptionalist argument to believe that it would be a mistake to deal in isolation with the issues surrounding genetic information through a single piece of dedicated legislation — for example, a Genetic Privacy, Discrimination and Research Act. To do so would unfairly privilege genetic information as against all other forms of relevant health and medical information — so that, for example, a person suffering from a genetically linked cancer is ‘in’, but someone suffering a cancer that is not (currently) known to be genetically linked is ‘out’. Equally importantly, such an approach would divorce

56 Ibid vol 1, 13–14.

57 Ibid vol 1, 37.

58 Ibid vol 1, 132–7 [3.16]–[3.40].

59 Ibid.

60 Ibid vol 1, 137 [3.41].

61 Ibid vol 1, 140 [3.56], quoting Mark Severs and Rebecca Walker, ‘Genetic Testing’, *Life Sciences Values & Society Program* (Web Page) 1, archived at <<https://web.archive.org/web/20030415041538/http://www.lifesciences.umich.edu/pdf/GeneTest.pdf>>.

62 *Essentially Yours* (n 4) vol 1, 140.

genetic information from the principles, processes and institutions that have been developed over time to provide ethical oversight of research, ensure best practice in clinical medicine, protect personal privacy, and prohibit unlawful discrimination.⁶³

Nevertheless, *Essentially Yours* recognised that there are ‘special features and issues attaching to genetic information such that it is necessary to engage in a thorough inspection of the existing legal, ethical and regulatory landscape to ensure that they are adequate to the task’.⁶⁴

The report referred to this approach as a ‘contextual approach’,⁶⁵ and proceeded by ‘examin[ing] the use of genetic information in a variety of different contexts’, identifying inadequacies, gaps, or inappropriate laws and processes and proposing reforms.⁶⁶

The outcome of the inquiry was 144 law reform recommendations that represented ‘modest amendments to existing laws and practices — to extend coverage to genetic information, or clarify or modify the current position’.⁶⁷ The recommendations relating to genetic privacy were to extend the definition of personal information and health information within existing privacy legislation to include ‘bodily samples from an individual whose identity is apparent or can reasonably be ascertained from the sample’; a right of access to one’s own bodily samples for genetic testing as well as those of genetic relatives where access is ‘necessary to lessen or prevent a serious threat to his or her life, health, or safety, even where the threat is not imminent’.⁶⁸ More broadly, the inquiry recommended the Commonwealth, states and territories ‘pursue the harmonisation of information and health privacy legislation as it relates to human genetic information’.⁶⁹

That report led to reforms of the *Privacy Act* in 2006 relating specifically to genetic information which included, among other provisions, the express inclusion of ‘genetic information about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual’ within the definition of ‘health information’⁷⁰ and the inclusion of ‘genetic information about an individual that is not otherwise health information’ within the definition of

63 Ibid vol 1, 140–1 [3.57].

64 Ibid vol 1, 141 [3.58]. For discussion, see Margaret Otowski and Lisa Eckstein, ‘Genetic Privacy’ in Ian Freckelton and Kerry Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 283, 285.

65 *Essentially Yours* (n 4) vol 1, 140.

66 Ibid vol 1, 142 [3.62].

67 Ibid vol 1, 164 [4.58].

68 Ibid vol 1, 55–6.

69 Ibid vol 1, 54. For discussion, see Margaret Otowski, ‘Essentially Yours: An Overview of the ALRC/AHEC Report on the Protection of Human Genetic Information in Australia’ (2003) 12(2) *Australian Health Law Bulletin* 20, 23 (‘Essentially Yours: An Overview’).

70 *Privacy Legislation Amendment Act 2006* (Cth) sch 2 cl 2 (‘*Privacy Legislation Amendment Act*’).