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CRITICALLY RETHINKING THE RIGHT NOT TO KNOW: LEGAL AMBIGUITY AND THEORETICAL FRAGILITY

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Abstract

In an era marked by unprecedented access to information and rapid advancements in health care technologies, the Right Not to Know ('RNTK') has emerged as a key yet contentious concept within legal discourses. RNTK grants individuals the capacity to refuse knowledge about their health care or genetic profile, thereby strengthening personal autonomy and self-determination. This right is increasingly incorporated into international legal frameworks and human rights principles as a protection against paternalistic tendencies in health care and the overwhelming flood of contemporary data. Despite this development, its legal enforcement remains inconsistent, situated in a regulatory grey zone characterised by uncertainty and diverse interpretations. Theoretically, RNTK's validity is both supported and challenged. The current study employs a thorough examination of these aspects to evaluate whether RNTK represents an established right in the field of human rights or a contentious right in international and domestic law, especially Australia. This analysis aims to clarify its broader implications for societies.

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I Introduction

In the current era, marked by the spread of information and groundbreaking advancements in the health care field, the Right Not to Know ('RNTK') has emerged as a contentious issue, sparking significant legal discourse. RNTK encapsulates an individual's right to refuse certain information—most notably related to their health care or genetic makeup—thereby exercising control over the boundaries of personal knowledge. This right is evidently grounded in the principles of human rights, which grant individuals the sovereign capacity to shape their mental, existential, and physical identities without undue intrusion. Furthermore, RNTK reflects an increasing recognition of the need to balance the flood of contemporary information with the maintenance of personal dignity and control. However, its legal and theoretical validity remain subjects of vigorous debate.

Legally, RNTK is enshrined as an expression of human rights principles, emphasising the intrinsic link between conscious decision-making and the capacity to guide one's life path. This framework positions RNTK as a safeguard against paternalistic tendencies in health care, challenging the traditional preference for disclosure over patient choice. Yet, this legal recognition is not absolute; it exists within a grey zone of law, where existing regulations introduce uncertainty and inconsistency, complicating its enforcement in countries. Theoretically, RNTK is supported through multiple perspectives that enrich its conceptual basis. Firstly, it is framed as a response to the challenges of genetic knowledge. Secondly, it is presented as an extension of natural rights, suggesting that the option to remain uninformed is a fundamental human right. Thirdly, RNTK is defended as a means to protect collective interests and social cohesion, consistent with utilitarian principles that prioritise social well-being.

The current article seeks to provide a critical and thorough examination of RNTK, encompassing its legal recognition, theoretical foundations, and the paradoxes that define its application. Despite the existence of significant literature on RNTK, none of these works have simultaneously explored its dual aspects of law and theory.[1] This division creates conflicting ideas and, with respect to the consistency of these aspects, undermines the clarity of the research. By consistently examining them, this study questions whether RNTK constitutes an established right in the field of human rights or a contentious right in

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1 Ruth Chadwick, Mairi Levitt and Darren Shickle, *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility* (Cambridge University Press, 2014); Graeme Laurie, 'In Defence of Ignorance: Genetic Information and the Right Not to Know' (1999) 6(2) *European Journal of Health Law* 119; Rosalind McDougall, 'Rethinking the "Right Not to Know"' (2014) 23(1) *Monash Bioethics Review* 22; Roger Brownsword and Jeff Wale, 'The Right to Know and the Right Not to Know Revisited: Part One' (2017) 9(1–2) *Asian Bioethics Review* 3.

international and domestic law, especially Australia. Through a detailed assessment of international legal instruments and philosophical viewpoints, this study aims to highlight the complexities of RNTK, promoting a balanced approach that respects personal choice while protecting the broader social well-being.

The current research employs a range of research methods to thoroughly investigate the topic under consideration. These methods include descriptive research methods such as doctrinal, comparative, critical, and policy research. The research also uses the historical method to analyse the evolution and development of legal doctrines and practices over time, thereby providing a deeper understanding of the topic. The paper is organised as follows: A) Legal Recognition and Theoretical Foundations, B) Analysis of Legal Aspects, C) Analysis of Theoretical and Practical Aspects, D) Australian Law, and E) Alternative Approaches and Suggestions.

II Legal Recognition and Theoretical Foundations

This section addresses the legal recognition and theoretical foundations behind RNTK. It first explores how this right is grounded in core principles of autonomy and self-determination, which are enshrined in various international human rights frameworks. Furthermore, this section examines the theoretical foundations that support RNTK, aiming to provide a thorough analysis of Individuals may opt to avoid certain information to safeguard their mental well-being, maintain personal aspirations, or preserve a sense of control over their life's trajectory. Moreover, people may choose ignorance about genetic or health data to avoid distress, stigma, or pressure while fostering personal dignity and societal stability.

A *Legalising Not to Know*

The core of human existence is intrinsically linked to the capacity to engage in conscious decision-making, which forms the foundation for guiding one's life path.[2] Legally, these ideas reflect the principles of autonomy and self-determination, which are codified in various international human rights frameworks.[3] These principles confirm that individuals have an inherent right to make informed choices regarding their lives, without undue external influence, as an expression of their

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2 Lawrence Haworth, *Autonomy : An Essay in Philosophical Psychology and Ethics* (Yale University Press, 1986).

3 *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, UN Doc A/810 (10 December 1948) arts 1, 3, 22; *International Covenant on Civil and Political Rights,* opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) arts 1(1), 9(1), 18(1), 19(2).

personal dignity and capacity for control.[4] As a result, individuals are regarded as independent agents capable of exercising control over their identities, life choices, and relationships, bearing responsibility for their actions.[5] This framework serves to protect individuals from compulsive or overly prescriptive interventions while simultaneously obligating governments and institutions to respect and support the exercise of these principles, ensuring that legal systems achieve a balance between personal freedoms and the collective well-being.[6]

Consent and refusal represent fundamental legal expressions of individual autonomy, as recognised within international human rights instruments. These actions serve as essential safeguards against undue intrusion, embodying both an individual's understanding of their own interests and their inherent capacity to decide their life's course without compulsion.[7] Courts in countries have consistently affirmed consent and refusal as essential components to autonomy, emphasising their significant role in protecting human dignity and legal identity.[8] To conclude, consent and refusal transcend mere ethical obligations, emerging as essential legal principles that support the context of individual autonomy. A life can be considered authentically one's own when it is shaped by choices an individual makes from a range of options.[9] This includes, notably, the deliberate choice to avoid certain information when it poses a risk to one's mental well-being or personal goals for the future. In other words, the practice of autonomy encompasses not only making informed choices but also deciding whether specific knowledge aligns with one's well-being and values.[10] Depriving an individual of the ability to decide whether to know or not know constitutes a clear wrong, specifically a wrongful usurpation of their decision-making right.[11]

Additionally, self-determination extends beyond a mere political right, particularly evident in fields such as health care ethics and bioethics. Here, the principle of informed consent encapsulates not only

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4 *Planned Parenthood v Casey*, 505 US 833 (1992).

5 Ruth Chadwick, Mairi Levitt and Darren Shickle, *The Right to Know and the Right Not to Know* (Avebury, 1st ed,1997).

6 *Cruzan v Director, Missouri Department of Health*, 497 US 261 (1990).

7 Ruth R Faden, *The History and Theory of Informed Consent* (Oxford University Press, 1986).

8 *Schloendorff v Society of New York Hospital*, 211 NY 125(1914); *Pretty v United Kingdom* (2002) 35 EHRR 1.

9 Haworth (n 2).

10 Graeme Laurie, 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity' in Ruth Chadwick, Mairi Levitt and Darren Shickle (eds), *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility* (Cambridge University Press, 2nd ed, 2014) 38.

11 Ruth Chadwick, Mairi Levitt and Darren Shickle, 'The Right to Know and the Right Not to Know : The Emerging Debate' in Ruth Chadwick, Mairi Levitt and Darren Shickle (eds), *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility* (Cambridge University Press, 2nd ed, 2014).

the right to access information but also the ability to refuse it.[12] If an individual possesses the sovereign capacity to decide their own path, this must logically include the capacity to avoid knowledge that might erode their perception of control over their life.[13] Legal frameworks that support the right to refuse health care interventions or to define one's own identity implicitly affirm that self-determination is reduced without the option to reject undesired information. Within these contexts, not to know transcends passive avoidance, emerging instead as a deliberate exercise of control, protecting individuals as the main architects of their own futures.[14] The concept of self-determination within legal systems is vividly demonstrated by the clear right to refuse health care treatment, a right supported even when such a choice may result in permanent injury or death.[15] This deeply rooted recognition of the principle sets a significant ethical standard: if society deems it essential to protect self-determination in refusing life-preserving intervention, then refusals involving seemingly less significant issues, such as opting out of receiving personal information, must be granted equivalent respect.[16] Although these informational rejections may not carry the immediate weight of health care choices, they are equally essential to self-determination, embodying an individual's sovereign authority to shape their mental and existential identity.[17]

Based on the above issues, not to know has been established as a recognised legal entitlement, particularly within the field of health care law, deriving from core human rights principles. This right explicitly grants individuals the ability to refuse information that might profoundly affect their mental well-being or sense of self, even if such information holds significant health care relevance.[18] Fundamentally, RNTK functions as an essential safeguard to the overwhelming flood

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12 *American Medical Association, Code of Medical Ethics*: Opinion 2.1.1 — Informed Consent (2016); *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* (opened for signature 4 April 1997, ETS No 164, entered into force 1 December 1999) art 10(2); *Declaration of Lisbon on the Rights of the Patient*, World Medical Association (1981, revised 2005) art 3(a).

13 Roberto Andorno, 'The Right Not to Know: An Autonomy Based Approach' (2004) 30(5) *Journal of Medical Ethics* 435.

14 Chadwick, Levitt and Shickle (n 11).

15 Tom Beauchamp and James Childress, 'Principles of Biomedical Ethics: Marking Its Fortieth Anniversary' (2019) 19(11) *American Journal of Bioethics* 9; G Laurie, 'Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications' (2014) 42(1) *Journal of Law, Medicine & Ethics* 53; *Mental Capacity Act 2005* (UK) ss 24–6.

16 *Declaration of Lisbon on the Rights of the Patient* (n 12) art 7(a), (d); Ben Davies, 'The Right Not to Know and the Obligation to Know' (2020) 46(5) *Journal of Medical Ethics* 300.

17 Andorno (n 13).

18 Australian Law Reform Commission and National Health and Medical Research Council, *Protection of Human Genetic Information* (Discussion Paper No 66, August 2002); Laurie, 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity' (n 10).

of information characteristic of contemporary society. From this perspective, denying this right would not only undermine an individual's autonomy and self-determination over their personal life story but also compromise the legal system's commitment to minimizing harm and supporting human dignity.[19] Furthermore, this right challenges long-standing paternalistic tendencies in health care, which often place a doctor's obligation to disclose information above a patient's personal preferences.[20] The emergence and development of RNTK thus reflect a significant shift in legal thinking.[21]

RNTK is enshrined in two international legal instruments, both of which emphasise the principles of individual autonomy and self-determination concerning health care-related data. The first, the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine ('the Oviedo Convention'), introduced by the Council of Europe in 1997, addresses this in art 10(2), which stipulates, 'Everyone has the right to access any information gathered about their health; nonetheless, an individual's preference to remain uninformed must be respected.' Likewise, the Universal Declaration on the Human Genome and Human Rights ('UDHGHR'), supported by the General Conference of the United Nations Educational, Scientific and Cultural Organisation in 1997, reinforces this position. Article 5(c) of the declaration provides, 'the right of each person to determine whether to be informed of the outcomes of genetic testing and their implications must be upheld.' A significant and growing body of academic research has consistently interpreted these provisions as deliberately embedding RNTK within legal frameworks, indicating a global consensus on its importance.[22]

B *Theoretical Foundations*

Engaging in the theoretical foundations of rights is of utmost importance, as it elevates discourse beyond simplistic, emotional, or case-specific reasoning toward a rational, coherent, and philosophically grounded explanation of rights. Generally, the theoretical foundations of rights establish a context through which the origins, legitimacy, scope, and functions of rights can be rigorously assessed against complex philosophical enquiries, ethical dilemmas, and practical demands of the current era. Without such a foundational approach,

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19 Beauchamp and Childress (n 15).

20 Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry* (Basic Books, 2nd ed, 2017).

21 Raanan Gillon, *Principles of Health Care Ethics* (Wiley, 2nd ed, 1996); Peter S Harper and Angus Clarke, *Genetics, Society, and Clinical Practice* (BIOS Scientific Publishers, 1997).

22 Laurie, 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity' (n 10); Davies (n 16); Chadwick, Levitt and Shickle (n 5).

rights risk being perceived as a disconnected collection of laws and regulations lacking intellectual coherence or the depth required to address the uncertainties and contradictions inherent in contemporary life. To this end, RNTK may be examined through three perspectives: 1) a response to the challenges of genetic knowledge; 2) rooted in natural rights; and 3) protection of collective interests and social stability. Together, these perspectives construct a multifaceted and robust basis for RNTK, not only highlighting its necessity within contemporary society but also enabling its balanced and comprehensive integration into everyday life.

1 *A Response to the Challenges of Genetic Knowledge*

The choice to remain uninformed, particularly in the field of genetic testing, may be defended as a legitimate response to the evolving demands of contemporary society. Supporters contend that as genetic and health care knowledge spreads within society, the capacity of individuals to opt for ignorance emerges as an increasingly important consideration.[23] The accessibility of genetic data, for example, enables individuals to gain insight into their genetic composition and related health care risks, potentially leading to mental, social, and financial consequences.[24] From this perspective, the formal recognition of RNTK is framed as an essential protective mechanism, empowering individuals to avoid the potentially harmful consequences of information they are not equipped to process, which might otherwise unpredictably disrupt their lives.[25] Consequently, establishing a legal basis for RNTK appears not only beneficial but essential for protecting individuals' mental well-being, social cohesion, and autonomy and self-determination in managing life-altering choices.

Moreover, in the absence of an explicit right to refuse knowledge, individuals might face undue pressure—whether from health care providers, relatives, or societal expectations—to undergo testing and confront the results, regardless of their emotional or psychological readiness. Genetic information, in particular, could expose individuals to discrimination or social stigma, especially if it reveals predispositions to hereditary disorders or conditions that carry negative

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23 Chadwick, Levitt and Shickle (n 5).

24 Julianne O'Daniel, 'Genetic Testing, Psychological Implications' [2020] *Encyclopedia of Behavioral Medicine* 932; Lynn Rew et al, 'Systematic Review of Psychosocial Benefits and Harms of Genetic Testing' (2010) 31(10) *Issues in Mental Health Nursing* 631.

25 Laurie, 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity' (n 10); Richard J Blauwhoff, 'Tracing Down the Historical Development of the Legal Concept of the Right to Know One's Origins Has "To Know or Not to Know" Ever Been the Legal Question?' (2008) 4(2) *Utrecht Law Review* 116.

cultural connotations.[26] Within this context, RNTK is justified as a legal protection against such compulsion and bias, affording individuals the ability to exercise choice amid an otherwise unavoidable predicament.[27] Put differently, by legally protecting individuals from being compelled to confront their genetic information, RNTK supports their capacity to make self-determined, informed choices, thereby maintaining their dignity and mental well-being.[28] This issue becomes particularly significant in scenarios where no viable treatment exists, rendering awareness of a condition more burdensome than beneficial for the individual.

2 *Rooted in Natural Rights*

The concept of RNTK can be interpreted as an essential human entitlement, akin to the views of natural rights theorists who posit that certain inherent rights exist beyond societal frameworks.[29] Within the historical context of the natural rights, as articulated by thinkers like John Locke, it is asserted that individuals possess intrinsic rights by virtue of their human condition, encompassing life, liberty, and property.[30] Based on this paradigm, RNTK might be regarded as an element of personal autonomy and self-determination, whereby individuals are naturally endowed with the right to maintain ignorance regarding specific truths, such as genetic or health care data. This entitlement could be seen as an extension of the broader human right to privacy, protecting individuals from unwanted information that might disturb their psychological or emotional well-being.[31] Furthermore, the principle of bodily integrity, rooted in natural law, could encompass an individual's right to avoid knowledge of genetic predispositions that lack immediate applicability, thereby aligning RNTK with other natural rights that safeguard personal dignity and self-determination over one's

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26 Merle Spriggs, Craig A Olsson and Wayne Hall, 'How Will Information about the Genetic Risk of Mental Disorders Impact on Stigma?' (2008) 42(3) *Australian and New Zealand Journal of Psychiatry* 214; Lizabeth A Barclay and Karen S Markel, 'Discrimination and Stigmatization in Work Organizations: A Multiple Level Framework for Research on Genetic Testing' (2007) 60(6) *Human Relations* 953.

27 Agnes G Schuurman et al, 'Maximising the Efficiency of Clinical Screening Programmes: Balancing Predictive Genetic Testing with a Right Not to Know' (2015) 23 *European Journal of Human Genetics* 1124.

28 Chadwick, Levitt and Shickle (n 5); Emma C Bullock, 'Mandatory Disclosure and Medical Paternalism' (2016) 19(2) *Ethical Theory and Moral Practice* 409; Lisa Bortolotti and Heather Widdows, 'The Right Not to Know: The Case of Psychiatric Disorders' (2011) 37(11) *Journal of Medical Ethics* 673.

29 John Locke, *Two Treatises of Government* (Lawbook Exchange, 2010).

30 Richard Tuck, *Natural Rights Theories: Their Origin and Development* (Cambridge University Press, 1979).

31 Laurie, 'Privacy and the Right Not to Know: A Plea for Conceptual Clarity' (n 10).

physical and mental state.[32] Lastly, RNTK may be justified as a natural right, emerging directly from the widely recognised right to obtain health care-related information. If there is a recognised natural right to pursue and access health care knowledge, it logically follows that a corresponding right exists to opt for ignorance of such information. Indeed, the widespread support of the right to access personal health care data implicitly presupposes the presence of a corresponding natural right to decline, reject, or refrain from seeking such knowledge.[33]

3 *Protecting Collective Interests and Stability*

From a utilitarian perspective, RNTK can be defended by focusing on the improvement of collective well-being. John Stuart Mill's utility principle posits that policy decisions should maximise the happiness of the greatest possible number of people.[34] Within this framework, allowing individuals to opt out of receiving certain genetic information might foster a more balanced and cohesive society. By sparing individuals the emotional turmoil related to awareness of potentially severe or fatal conditions, this approach could reduce widespread anxiety and strengthen the mental health of the community as a whole.[35] Such a strategy seems consistent with utilitarian reasoning, which prioritises the societal advantages gained from protecting individuals' emotional and psychological balance.[36] Additionally, supporting RNTK might contribute to social stability by enabling people to maintain a state of unawareness that shields them from undue distress and the burden of irreversible decisions.[37] This paternalistic stance is sometimes justified by the notion that individuals may lack the capacity to effectively navigate complex genetic data. In conclusion, by supporting the option of ignorance, a society might maintain personal contentment and social cohesion, indicating that the broader welfare could be advanced by protecting individuals from potentially unsettling realities.

III Analysis of Legal Aspects: Grey Zone of Law

RNTK could naively be considered as an attempt to deny the inevitability of medical truths, akin to rejecting one's fate. However,

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32 Chadwick, Levitt and Shickle (n 5).

33 Rosalind McDougall, 'Rethinking the "Right Not to Know"' (2014) 23(1) *Monash Bioethics Review* 22.

34 John Stuart Mill, *Utilitarianism* (CreateSpace Independent Publishing Platform, 2010).

35 Beauchamp and Childress (n 15).

36 JJC Smart and Bernard Williams, *Utilitarianism: For and Against* (Cambridge University Press, 1973).

37 Graeme Laurie, 'In Defence of Ignorance: Genetic Information and the Right Not to Know' (1999) 6(2) *European Journal of Health Law* 119.

from a legal standpoint, framing it as a denial of reality oversimplifies the issue. Indeed, the right is less about rejecting fate and more about asserting control over the timing and manner of receiving life-altering information. The notion of RNTK emerged as a topic in the late twentieth century, particularly following breakthroughs in genetic testing. The identification of a genetic marker for Huntington's disease in 1983 prompted debates regarding whether individuals at risk should retain the option to remain unaware, considering the profound psychological and societal consequences.[38]

RNTK has surfaced in international discourse as an ostensibly progressive recognition of individual autonomy and self-determination, yet its implementation reveals a concerning range of inconsistencies and limitations. One of the earliest formal recognitions emerged in 1992 with the Council of Europe's Recommendation No R (92) 3 on Genetic Testing and Screening for Health Care Purposes (rec (92)3), an instrument that posited individuals should have the freedom to decide whether to receive genetic test results.[39] This marked an initial gesture toward patient autonomy and self-determination, which gained further momentum in 1997 with UDHGHR.[40] It endorsed an individual's prerogative to remain uninformed about genetic test outcomes, framing autonomy and self-determination as a global ethical ideal. Furthermore, the World Health Organization ('WHO') supports this issue, supporting the legitimacy of preferring genetic ignorance and advocating that genetic tests be offered in ways that respect individuals' and families' freedom to refuse knowledge based on personal or moral convictions.[41] It is important to note, however, that all of the aforementioned documents are non-binding. In other words, they do not impose any legal obligation for enforcement; rather, they advocate for the recognition of patient autonomy and self-determination regarding the decision to be informed or remain ignorant of genetic test results. Moreover, none of these documents explicitly state that RNTK should be recognised as a right. Although UDHGHR provides the clearest statement on this issue, it stops short of classifying it as a right. In fact, UDHGHR also focuses solely on the importance of respecting the right to decide whether to receive information about genetic test results and the related consequences.

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38 E Asscher and BJ Koops, 'The Right Not to Know and Preimplantation Genetic Diagnosis for Huntington's Disease' (2010) 36(1) *Journal of Medical Ethics* 30.

39 *Recommendation No R (92)3 of the Committee of Ministers to Member States on Genetic Testing and Screening for Health Care Purposes*, Council of Europe (adopted 10 February 1992) principles 5-7.

40 *Universal Declaration on the Human Genome and Human Rights*, UNESCO Gen Conf Res 29 C/Resolution 19, 29th sess, (11 November 1997) art 5(c).

41 Institutional Repository for Information Sharing, 'Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services', *World Health Organization* (1997) <https://iris.who.int/handle/10665/63910>.

Ultimately, the Oviedo Convention formally recognises the option to refuse health care-related information, establishing it as a core principle for member states.[42] In contrast to previous instances, it introduces a legally binding framework. Nevertheless, the effectiveness of this decision is compromised by exceptions that permit the disclosure of such information when deemed necessary in a democratic society for reasons such as public safety, prevention of crime, protection of public health, or safeguarding the rights and freedoms of others.[43] Indeed, RNTK exists in tension between respecting and prioritising individual and collective rights, particularly when non-disclosure could harm others. This dilemma is most acute in the context of hereditary conditions, such as Huntington's disease, where one person's decision to remain ignorant of their genetic status could deprive family members of essential information for their own health care decisions.[44] For instance, in the UK, the court rejected a patient's claim to the RNTK regarding hereditary Huntington's disease, emphasising the necessity of disclosing information that affects reproductive autonomy.[45]

Nevertheless, the imprecise nature and broad scope of these exceptions generate a range of interpretations, which may compromise the integrity of RNTK. Although these exceptions pragmatically address the risks associated with non-disclosure, they are deficient in setting clear standards. First, on one hand, the threshold for overriding an individual's RNTK remains inadequately defined, thereby vesting health care providers and judicial courts with considerable discretion to determine whether an individual's autonomy and self-determination ought to take precedence, resulting in uncertainty rather than clarity. Furthermore, the principle of relational autonomy—which acknowledges that an individual's decisions impact others, particularly within family contexts—introduces additional complexity into the legal framework.[46] For example, how should laws resolve the conflicting preferences of siblings, wherein one opts for ignorance of a genetic predisposition while another seeks awareness? Ought health care providers bear an obligation to inform family members, even if doing so violates an individual's RNTK?

Conversely, in the absence of explicit directives, health care providers may incline toward disclosure, prioritising the prospective

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42 *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine* (n 12) art 10(1)–(2).

43 Ibid art 26.

44 Asscher and Koops (n 38).

45 *ABC v St George's Healthcare NHS Trust* [2020] EWHC 455 (QB).

46 *Safer v Estate of Pack*, 677 A2d 1188 (NJ Super Ct App Div, 1996); Carlos Gómez-Vírseda, Yves De Maeseneer and Chris Gastmans, 'Relational Autonomy: What Does It Mean and How Is It Used in End-of-Life Care? A Systematic Review of Argument-Based Ethics Literature' (2019) 20(1) *BioMed Central Medical Ethics* 1.

benefits to third parties over individual autonomy. Such an approach erodes the core essence of RNTK, relegating it to a matter of discretion rather than a safeguarded legal prerogative. Even national laws, which ostensibly offer greater specificity, often fall short of providing definitive resolutions, thereby consigning health care providers and families to a complex legal domain. By way of illustration, Belgium's Law on Patient Rights, introduced in 2002, represented one of the earliest legislative recognitions of RNTK, though not explicitly as a right.[47] This legislation empowered patients to categorically decline medical information, affording robust safeguards for those electing to remain uninformed through a straightforward and unequivocal mechanism. Nonetheless, this provision is limited by conditions and exceptions, such as instances involving serious risk to the health of the patient or third parties, thereby constraining the scope of RNTK. In a similar vein, France's Public Health Law of the same year adopted a largely similar stance by incorporating RNTK. While this framework permits individuals to remain oblivious to a diagnosis or prognosis, it refrains from designating RNTK as a formal right. Instead, it mandates that such preferences be respected, save for circumstances wherein third parties face a risk of transmission.[48] Consequently, the approaches of these national laws, akin to the aforementioned convention, remain ambiguous and deficient in required specificity. This lack of precision not only weakens the enforceability of the right but also imposes an undue burden on individuals to navigate a complex legal landscape in order to uphold their prerogative.

Second, the Convention's influence is constrained by its incomplete ratification among members of the Council of Europe and certain non-member states, thereby limiting its applicability to only a portion of the signatory and ratifying nations.[49] On a broader international level, the lack of a comprehensive global treaty addressing RNTK undermines its consistency and effectiveness, particularly in jurisdictions where genetic testing is increasingly prevalent without corresponding legal safeguards. Third, it should be observed that, akin to UDHGHR and the above national law, the Oviedo Convention upholds individuals' rights to access health care-related information; however, it neither explicitly nor implicitly establishes a right not to know. Instead, it prioritises respect for individuals' preferences to remain uninformed.

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47 *Loi relative aux droits du patient* [Law on Patient Rights] 2002 (Belgium) art 7(3).

48 *Code de la santé publique* [Public Health Law] 2002 (France) art L1111-2.

49 *Chart of Signatures and Ratifications of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Council of Europe*, opened for signature 4 April 1997, ETS No 164 (entered into force 1 December 1999); Roberto Andorno, 'The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law' (2006) 2(4) *Journal of International Biotechnology Law* 133.

To genuinely uphold patient autonomy and self-determination, legislative frameworks must advance—expressly designating RNTK as a recognised right, defining its scope with precision, and ensuring its consistent application across countries. In light of this, policy-makers are urged to consider the introduction of distinct statutory provisions for RNTK, supported by clear directives to balance individual interests with societal interests. Enhanced international collaboration, potentially through the establishment of a specific treaty or convention, could serve to standardise protections and address the existing disparities in global implementation.

IV Analysis of Theoretical and Practical Aspects

RNTK faces significant theoretical and practical challenges that undermine its legitimacy when subjected to rigorous scrutiny. The first and most crucial foundation for the establishment of a new right is the identification of societal needs.[50] As social structures, technologies, and cultural norms shift, new rights may become essential to protect individuals from emerging threats or to address gaps in existing legal frameworks. [51] For example, in a society where information is increasingly produced every second, the right to remain uninformed may emerge as a necessary safeguard against overwhelming or potentially harmful information. The second foundation, rooted in the theory of natural rights, posits that certain rights are inherent to individuals by virtue of their humanity, independent of societal recognition or legal enactment. These rights are considered fundamental, non-negotiable, and are typically seen as essential to the preservation of human dignity.[52] Can establishing RNTK be justified as a natural right, allowing individuals the option to avoid certain information that may disrupt their lives or health? The third aspect involves utilitarian considerations and the broader consequences of establishing a new right for people's well-being. From a utilitarian perspective, any objective should aim to maximise overall well-being and minimise harm.[53] In this context, RNTK can be seen as a safeguard against psychological distress, unnecessary anxiety, and the disruptive impact of certain information on individuals' lives. However, recognizing RNTK may also have consequences that affect both individual and societal interests in the long term. From this perspective, the fundamental question arises: Can the establishment of RNTK be

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50 Charles R Beitz, *The Idea of Human Rights* (Oxford University Press, 1st ed, 2011).

51 Paul Gordon Lauren, *Evolution of International Human Rights : Visions Seen* (University of Pennsylvania Press Inc, 3rd ed, 2013).

52 Brian Tierney, *The Idea of Natural Rights, Natural Law and Church Law, 1150-1625* (William B Eerdmans Publishing Co, Reprint, 2001).

53 Smart and Williams (n 36).

justified on utilitarian grounds? The fourth aspect focuses on how it fits with social and relational dynamics, especially the tug-of-war between personal autonomy and the shared nature of genetic info. How do you strike a balance between an individual's right to call their own shots and the need to keep the social ties that boost collective well-being? Is it possible to implement RNTK uniformly across all individuals? These ambiguous reckon that RNTK's legitimacy depends on its knack for lining up with community values and keeping trust solid in human connections. These theoretical and practical perspectives will be thoroughly examined in the subsequent sections.

A *Unnecessity of Establishing a Separate Right*

It should be noted that informed consent is a non-negotiable ethical and legal standard in health care.[54] It requires doctors to disclose significant risks and benefits of medical interventions, ensuring patients can make informed decisions.[55] RNTK would undermine this framework by allowing patients to refuse critical information, potentially leading to preventable harm. Indeed, a patient who knows nothing about their health status might not fully understand the risks of refusing information. This creates a kind of paradox with RNTK. Even, without informed consent, certain medical procedures could be seen as a breach.[56] Furthermore, a small amount of information, enough to understand that refusing more details could be risky, can create an obligation to learn more.[57] Nevertheless, health professionals should exercise caution when disclosing information to patients who express a desire to remain uninformed.[58]

A further legal analysis of the argument for RNTK reveals that the justification for establishing such a right is not as robust as initially proposed. The principles of autonomy and self-determination, which are central to the rationale for RNTK, are already embedded in the existing body of human rights law.[59] That is, these regulations enshrine

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54 *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine* (n 12) art 5; *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*, World Medical Association (adopted 18th WMA General Assembly, June 1964, revised 64th WMA General Assembly, October 2013) arts 25-32.

55 *Hii Chii Kok v Ooi Peng Jin London Lucien* [2017] SGCA 38; *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

56 *Canterbury v Spence*, 464 F 2d 772 (DC Cir, 1972); RT Hull, 'Informed Consent: Patient's Right or Patient's Duty?' (1985) 10(2) *Journal of Medicine and Philosophy* 183.

57 Manne Sjöstrand et al, 'Paternalism in the Name of Autonomy' (2013) 38(6) *Journal of Medicine and Philosophy* 710.

58 Rosamond Rhodes, 'Genetic Testing: Is There a Right Not to Know?' (2005) 31(3) *American Journal of Maternal/Child Nursing* 135.

59 *Universal Declaration of Human Rights* (n 3) arts 1, 3, 12, 18; *American Declaration of the Rights and Duties of Man*, OAS Res XXX, OAS OR, 1st sess, 6th plen mtg (2 May 1948) arts

the protection of individuals from arbitrary interference in their private lives and the freedom to seek, receive, and impart information.[60] In other words, no one should be compelled to receive information they do not want, thanks to the existing framework of human rights law.[61] Therefore, from a legal perspective, the need for a separate, distinct right to not know becomes redundant, as the principles of autonomy and self-determination are enshrined in both national and international legal instruments, already provide.

Finally, if an individual faces unfair discrimination in society, for example, in the workplace, due to genetic information, the fault lies with the management practices and ineffective policies, not with knowing genetic information.[62] In other words, the primary issue is not in the knowledge gained from information, but in how that information is used. The fact that genetic information itself does not cause harm, but its misuse can lead to inequality, indicates that the core problem lies within institutions that apply this information unfairly. Therefore, efforts to combat discrimination based on genetic information should not focus on establishing RNTK, but rather on reforming and reviewing policies and approaches. Moreover, critics of the RNTK contend that the adverse effects of receiving unwanted medical information are often neither severe nor long-lasting. They argue that in most cases, the emotional or social harm caused by such disclosures is temporary and relatively minor, thus challenging the need to uphold a right to remain uninformed.[63]

In conclusion, while the concept of RNTK may seem attractive in addressing emerging societal concerns related to genetic testing, the need for such a right is ultimately unnecessary. The principles of

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1, 5; *European Convention on Human Rights*, opened for signature 4 November 1950, 213 UNTS 221 (entered into force 3 September 1953) art 8; *International Covenant on Civil and Political Rights* (n 3) art 1; *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) art 1.

60 Jonathan Herring and Charles Foster, '"Please Don't Tell Me". The Right Not to Know' (2012) 21(1) *Cambridge Quarterly of Healthcare Ethics* 20; Matti Häyry and Tuija Takala, 'Genetic Information, Rights, and Autonomy' (2001) 22(5) *Theoretical Medicine and Bioethics* 403; Andorno (n 13); Mark Sheehan, 'Can Broad Consent Be Informed Consent?' (2011) 4(3) *Public Health Ethics* 226; Roger Brownsword and Jeff Wale, 'The Right to Know and the Right Not to Know Revisited: Part One' (2017) 9(1–2) *Asian Bioethics Review* 3.

61 Victoria Chico, 'Requiring Genetic Knowledge: A Principled Case for Support' (2015) 35(3) *Legal Studies* 532; Emma C Bullock, 'Free Choice and Patient Best Interests' (2016) 24(4) *Health Care Analysis* 374.

62 Robert Samuel Wachbroit, 'The Question Not Asked: The Challenge of Pleiotropic Genetic Tests' (1998) 8(2) *Kennedy Institute of Ethics Journal* 131; Michele Loi, 'Food Labels, Genetic Information, and the Right Not to Know' (2014) 24(4) *Kennedy Institute of Ethics Journal* 323.

63 Benjamin E Berkman, Sara Chandros Hull and Leslie G Biesecker, 'Scrutinizing the Right Not to Know' (2015) 15(7) *American Journal of Bioethics* 17; Lisa Bortolotti, 'The Relative Importance of Undesirable Truths' (2013) 16(4) *Medicine, Health Care and Philosophy* 683; Chico (n 61).

autonomy and self-determination are already embedded in international human rights law and provide a sufficient legal foundation for protecting individuals from compulsion and unwanted information. Moreover, the ethical principle of informed consent is central to health care practice, ensuring that individuals must make decisions based on an understanding of the significant risks and benefits of receiving genetic information. This principle should not be undermined by establishing a right to remain uninformed. Furthermore, the issue of discrimination based on genetic information lies not in the knowledge itself, but in how that information is misused by societal institutions. Therefore, instead of establishing a new right, the legal focus should be on strengthening and enhancing existing protections to ensure that individuals have the freedom to make informed choices about their personal and genetic information, free from undue pressure.

B *Lack of Basis in Natural and Reverse Rights*

While appealing in its philosophical foundations, the argument that RNTK is a natural right is laden with legal complexities. The concept of natural rights has been subject to criticism for its lack of clear and universally accepted definitions.[64] Contemporary legal systems are built on the premise that rights are conferred through laws established by social institutions, rather than derived from a presumed natural state.[65] This creates a significant legal gap in classifying RNTK as a natural right. As noted, RNTK does not meet the criteria of being a universally recognised or actionable right under international law since no major legal international document widely recognises RNTK. For instance, the Oviedo Convention does not explicitly recognize such a right, and its closest provisions are often interpreted in ways that allow for exceptions when public health care or safety is at risk.[66] This approach shows that ignorance is permitted only when it does not conflict with broader rights or duties. Therefore, promoting ignorance as a right would disrupt legal order by prioritising individual preferences over collective well-being.

Second, rights do not function in a tidily symmetrical way.[67] That is, the possession of a right to A does not necessarily imply the corresponding right not to have A. For example, the right to a basic education does not seem to imply a similarly significant right to refuse such an education. Similarly, the right not to be tortured does not imply

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64 Tuck (n 30).

65 Herbert Lionel Adolphus Hart, *The Concept of Law* (Oxford University Press, 3rd ed, 2012).

66 Daniel J Solove and Paul M Schwartz, *Privacy Law Fundamentals* (International Association of Privacy Professionals, 4th ed, 2017).

67 *Pretty v United Kingdom* (2002) 35 EHRR 1.

a corresponding right to be tortured.[68] Based on this, the argument for RNTK as a corresponding right can be challenged by considering the broader implications of the right to know, which is enshrined in international human rights law. Indeed, the idea that the right to know has an equivalent counterpart in RNTK reflects a misinterpretation of the nature of rights, particularly when it comes to information essential.[69] The right to access information is a fundamental human right, recognised in legal instruments.[70] These laws emphasise that the right to seek, receive, and impart information is essential for informed choices and the well-being of individuals and communities.[71] The right to avoid certain information, particularly in situations where it may adversely affect others' well-being, conflicts with these broader ruling. For instance, in legal cases, courts have emphasised that information should not be withheld that could be essential to others' health care or safety.[72] Thus, the notion that RNTK is a counterpart to the right to know oversimplifies the complex interplay between individual rights and collective obligations.[73]

Ultimately, although natural and corresponding rights theory holds significant theoretical appeal within the discourse of RNTK, it encounters substantial challenges. These challenges include the uncertainty surrounding the exact definition of natural rights, the lack of universal consensus and recognition, and its incompatibility with the concept of the corresponding rights. Put differently, these factors collectively weaken the capacity of RNTK to be fully and unequivocally incorporated into the body of natural and corresponding rights.

C *Endangering Public Health and Societal Stability*

The principle of accountability in international law is grounded in the obligation of governments and individuals to act responsibly to prevent harm to others. This principle is enshrined in legal instruments, which mandate governments to ensure the highest attainable standard of

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68 McDougall (n 33); Juha Räikkä, 'Freedom and a Right (Not) to Know' (1998) 12(1) *Bioethics* 49.

69 MW Shaw, 'Testing for the Huntington Gene: A Right to Know , a Right Not to Know , or a Duty to Know' (1987) 26 *American Journal of Medical Genetics*; T Austad, 'The Right Not to Know - Worthy of Preservation Any Longer? An Ethical Perspective' (1996) 50 *Clinical Genetics*.

70 *Universal Declaration of Human Rights* (n 3) art 19; *International Covenant on Civil and Political Rights* (n 3) art 19.

71 Ann Florini, *The Right to Know : Transparency for an Open World* (Columbia University Press, 2012).

72 *Guerra and Others v Italy* (1998) 26 EHRR 357.

73 Bartha Maria Knoppers, 'Introduction: From the Right to Know to the Right Not to Know' (2014) 42(1) *Journal of Law, Medicine and Ethics* 6; Jane Wilson, 'To Know or Not to Know? Genetic Ignorance, Autonomy and Paternalism' (2005) 19(5–6) *Bioethics* 492.

physical and mental well-being.[74] Such an obligation inherently requires the sharing of essential information, such as health care warnings during pandemics.[75] RNTK would directly contradict these obligations by legitimising wilful ignorance, enabling individuals or entities to avoid responsibility for harm caused by withholding knowledge.[76] While initial mental comfort may be gained by individuals avoiding health care knowledge, this choice can erode the collective well-being in significant ways.[77] If individuals are unaware of their health care predispositions to certain diseases, they may fail to seek early intervention or treatment, leading to the decline of public health care.[78] The burden on the health care system may increase as a result of preventable diseases progressing untreated, thus harming not only the individual but the collective well-being. This situation illustrates a tragic paradox where the temporary relief of distress for the individual through ignorance risks jeopardising the health care and safety of society as a whole.[79] Even if patients' autonomy and self-determination mean they should not be compelled to receive information they do not want for their own benefit, this reasoning does not apply when the harm affects others. Numerous examples in the literature suggest that RNTK might be rejected in situations where it harms third parties.[80] For instance, a person who does not want to know their HIV status but continues to be sexually active, potentially endangering others' health care.[81] The RNTK, therefore, cannot serve as a protection for individuals whose refusal to know or share essential genetic information threatens the health care and well-being of others.[82]

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74 *International Covenant on Economic, Social and Cultural Rights* (n 59) art 1; Committee on Economic Social and Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights) (E/C.12/2000/4)* (2000) <https://undocs.org/E/C.12/2000/4>.

75 *International Health Regulations* (adopted by Resolution WHA58.3, 23 May 2005, entered into force 15 June 2007) art 6.

76 Chadwick, Levitt and Shickle (n 11).

77 George Gaskell and Martin W Bauer, *Genomics and Society : Legal, Ethical and Social Dimensions* (Earthscan, 2007).

78 World Health Organization, *Genomics and World Health. Geneva, Switzerland: World Health Organization* (2002) <https://www.who.int/publications/i/item/9241545542>.

79 Davies (n 16).

80 Robert C Green et al, 'ACMG Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing' (2013) 15(7) *Genetics in Medicine* 574.

81 J Harris and K Keywood, 'Ignorance, Information and Autonomy' (2001) 22(5) *Theoretical Medicine and Bioethics* 415.

82 Angus Clarke et al, 'Genetic Professionals' Reports of Nondisclosure of Genetic Risk Information within Families' (2005) 13(5) *European Journal of Human Genetics* 556; A Surbone, 'Genetic Medicine: The Balance between Science and Morality' (2004) 15 *Familial Breast Cancer Screening: Ethical and Social Implications* 60; Michael Parker and Anneke M Lucassen, 'Genetic Information: A Joint Account?' (2004) 329(7458) *British Medical Association* 165; Ann Sommerville and Veronica English, 'Genetic Privacy: Orthodoxy or Oxymoron?' (1999) 25(2) *Journal of Medical Ethics* 144; T Austad, 'Medical Ethics: The

Furthermore, the utilitarian argument for RNTK falls short when considering the broader implications for public health care policy. Preventive measures, early detection, and proactive health care interventions depend on individuals being informed of their health care risks.[83] By embracing a policy of ignorance, the capacity for collective action to address health care crises is significantly reduced.[84] If individuals choose not to know their health care risks, the social mechanisms designed to prevent the spread of health care disorders or ensure timely treatments become ineffective. This erodes the social contract in which individuals agree to share information for the collective benefit of preventing harm and ensuring public health care.[85] Thus, the potential harm caused by widespread ignorance may outweigh any perceived short-term benefits. Put differently, rights must exist within a context of competing priorities, which requires a careful evaluation of their relative importance in a given situation.[86]

In conclusion, while RNTK may initially seem to align with utilitarian principles that prioritise individual well-being, it ultimately jeopardises collective health care and social stability. The failure to address genetic risks can have far-reaching consequences, both for individuals and the wider community. The health care of society is contingent upon individuals being informed, not only to protect their personal well-being but to safeguard the public interest. Therefore, any support for RNTK must be rigorously examined and ultimately rejected in favour of a more responsible and informed approach to health care and well-being.

D *Practical Challenges of Implementation*

RNTK faces significant practical challenges against non-professional individuals, such as family members, that undermine its feasibility as a legal construct. Genetic information is inherently collective, shared within families due to its hereditary nature, which complicates efforts to shield individuals from unwanted knowledge.[87] For instance, if a sibling exhibits symptoms of or tests positive for a genetic condition like Huntington's disease, their visible symptoms or decision to

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Right Not to Know—Worthy of Preservation Any Longer? An Ethical Perspective' (1996) 50(2) *Clinical Genetics* 85.

83 Beauchamp and Childress (n 15); Rosamond Rhodes, 'Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge' (1998) 23(1) *Journal of Medicine and Philosophy* 10.

84 John Harris, *The Value of Life : An Introduction to Medical Ethics* (Routledge, 2006).

85 Jean-Jacques Rousseau, *The Social Contract* (CreateSpace Independent Publishing Platform, 2014).

86 Jeremy Waldron, *Theories of Rights* (Oxford University Press, 1984).

87 Barbara Prainsack, 'DIY Genetics: The Right to Know Your Own Genome' in Ruth Chadwick, Mairi Levitt and Darren Shickle (eds), *The Right to Know and the Right Not to Know* (Cambridge University Press, 2014) 100; Davies (n 16).

disclose their diagnosis could inadvertently inform another family member of their own risk, rendering RNTK moot.[88] This interconnected nature of genetic information raises a fundamental question: does RNTK hold meaning or value when biological realities make ignorance practically unattainable? In other words, genetic information often surfaces organically through conversations, observed symptoms, or shared medical histories,[89] and legally regulating such exchanges is nearly impossible without infringing on personal freedoms, such as freedom of expression.[90] Imposing a legal duty on individuals to withhold genetic information to respect another's RNTK would likely violate personal autonomy and be unenforceable in practice, as courts cannot realistically police casual conversations or prevent relatives from sharing their health concerns. The administrative burden and ethical implications of such enforcement would be immense. For example, restricting family members from discussing their genetic conditions could exacerbate disability discrimination by limiting their ability to seek support or accommodations under anti-discrimination laws, which protect individuals from unfair treatment based on genetic predispositions.

In contrast, enforcing RNTK against professionals and institutions, such as medical practitioners or hospitals, is more feasible but still presents challenges.[91] Healthcare providers operate within structured legal and ethical frameworks, including strict privacy and confidentiality obligations. However, healthcare providers may face ethical dilemmas when withholding information that could benefit the patient or others, such as in cases of preventable conditions.[92] That is, a disease might be preventable and treatable, and disclosing it to the patient may not violate professional frameworks, but the patient, due to their RNTK, may have no desire to learn about the disease. Additionally, systemic issues like fragmented healthcare records or communication errors could lead to unintended disclosures, and enforcing RNTK in multidisciplinary settings, where multiple professionals (eg, geneticists,

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88 Laurie, 'Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications' (n 15); Brownsword and Wale (n 60).

89 Kadri Simm, 'Biobanks and Feedback' in Ruth Chadwick, Mairi Levitt and Darren Shickle (eds), *The Right to Know and the Right Not to Know* (Cambridge University Press, 2014) 55; Prainsack (n 87).

90 John Harris, 'Is There a Right Not to Know?' (2020) 46(6) *Journal of Medical Ethics* 414.

91 Davies (n 16); Andorno (n 13); Ben Davies and Julian Savulescu, 'The Right Not to Know: Some Steps towards a Compromise' (2021) 24(1) *Ethical theory and moral practice : an international forum* 137.

92 Pascal Borry, Mahsa Shabani and Heidi Carmen Howard, 'Is There a Right Time to Know?: The Right Not to Know and Genetic Testing in Children' (2014) 42(1) *Journal of Law, Medicine and Ethics* 19; Lorraine Cowley, 'What Can We Learn from Patients' Ethical Thinking about the Right "not to Know" in Genomics? Lessons from Cancer Genetic Testing for Genetic Counselling' (2016) 30(8) *Bioethics* 628; Benjamin E Berkman, 'Refuting The Right Not To Know ' (2016) 19(1) *Journal of Health Care Law and Policy* 1.

GPs, and specialists) access and share patient data, adds further complexity. The key difference lies in the degree of regulation and accountability: institutions can implement policies and training to respect RNTK, whereas no equivalent mechanism exists for controlling family dynamics or informal disclosures in private, unregulated spheres.[93] In summary, while RNTK is conceptually appealing as an extension of autonomy, its practical value is limited by the shared nature of genetic information, competing legal and ethical duties, and the challenges of enforcing it in both regulated and unregulated contexts.

V Australian Law

While the proponents of RNTK highlighted a preference for individuals to be shielded from information yielded by their own bodies or the bodies of their relatives, particularly genetic information with potentially profound implications, there is no specific recognition or protection of RNTK within Australian statutes or common law.[94] Moreover, RNTK is recognised in both the Universal Declaration on the Human Genome and Human Rights and the European Convention for the Protection of Human Rights and Dignity of the Human Being according to many scholars' opinion. With regard to the declaration, compliance is not legally binding on Australia, as the instrument is classified as soft law and is therefore only recommendatory in nature. As for the convention, although it is open to non-European states, Australia has not yet acceded to it. However, the existing privacy framework may provide some indirect protection for the concept in certain contexts. It governs the collection, use, and disclosure of personal information, which includes health information and, importantly for this context, genetic information.

The Privacy Act's framework interacts with the idea of RNTK, primarily through provisions related to consent.[95] Indeed, in most circumstances, genetic testing of an individual will not proceed without their consent.[96] The requirement for voluntary and informed consent before collecting and using personal information, including genetic data, provides individuals with a mechanism to refuse testing or the collection of their genetic information, thereby implicitly allowing them to avoid receiving the results or information derived from such testing if they so choose. In other words, the ability to refuse

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93 Davies (n 16); Simm (n 89).

94 D Nicol and M Otlowski, 'Legal and Regulatory Issues of Precision Medicine' in *The Future of Precision Medicine in Australia* (Australian Council of Learned Academie, 2017) 1; Jane Tiller et al, 'Privacy Implications of Contacting the At-Risk Relatives of Patients with Medically Actionable Genetic Predisposition, with Patient Consent: A Hypothetical Australian Case Study' (2023) 12(2) *BioTech* 45.

95 *Privacy Act 1988* (Cth) ss 6, 6D, 16A, 16B, sch 1 (Australian Privacy Principles (APP) 3, 5, 6).

96 Ibid APP 3.3(A).

participation serves as a de facto protective measure for those wishing to exercise a RNTK, as it prevents the generation of the potentially unwanted information in the first place.[97] However, the Centre for Law and Genetics noted that other provisions in the *Privacy Act* might actually encourage inappropriate disclosure of information to the individual about whom it is collected in an effort to comply diligently with legislative requirements. It means that the current legal framework is not explicitly designed to uphold RNTK and may even contain provisions that work against it in certain applications. The Centre advocated for the explicit recognition of RNTK under privacy legislation in Australia.[98]

Furthermore, the *Insurance Contracts Act* was specifically framed to prevent insurers from indirectly coercing applicants into undergoing genetic testing. The Act achieves this by outlining what an applicant is required to disclose.[99] While applicants generally have a broad duty to disclose information known to be relevant to the insurer, including genetic information already known to them, the framework prevents insurers from requiring or requesting genetic testing. By doing so, the legislation implicitly aims to respect an applicant's RNTK about a genetic disorder or predisposition they might carry.

Although Australian regulations do not explicitly mention RNTK, key court decisions like *Rogers v Whitaker* (1992) and *Chappel v Hart* (1998) show a strong emphasis on doctors' duty to fully inform patients, which implicitly clashes with any notion of RNTK. In *Rogers v Whitaker*, the High Court ruled that doctors must disclose all material risks a reasonable patient might consider significant, highlighting a legal priority on the right to know.[100] Similarly, in *Chappel v Hart*, failure to disclose even a minor risk (like oesophageal perforation) led to liability, reinforcing the obligation to provide information.[101] These cases demonstrate that Australian common law not only fails to implicitly support RNTK but are fundamentally at odds with it, emphasizing a right not to know instead.

Despite the indirect protections of some regulations and explicit conflicts in common law, the overarching status of RNTK in Australia remains characterised by a lack of specific, broadly applicable legal recognition. The absence of a dedicated legal right means its protection relies on the interpretation and application of existing privacy principles, consent requirements, and insurance-specific regulations. The call from submissions, such as that from the Centre for Law and Genetics, for the

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97 Chadwick, Levitt and Shickle (n 5).

98 Centre for Law and Genetics, Submission G048, 14 January 2002.

99 *Insurance Contracts Act 1984* (Cth) ss 21, 22.

100 *Rogers v Whitaker* (1992) 175 CLR 479.

101 *Chappel v Hart* (1998) 295 CLR 232.

explicit recognition of RNTK under Australian law highlights the view that the current status, relying on indirect mechanisms, is insufficient to provide adequate protection. At the moment, its status is perhaps best described as an ethical consideration and a guiding principle that receives varying degrees of implicit protection through existing legislative frameworks.[102] Thus, RNTK holds status as an ethical principle and a point of ongoing discussion and potential reform in the Australian context, rather than a fully established legal right.

V Alternative Approaches and Suggestions

In the field of medicine, exclusive reliance on RNTK may, in the long term, be detrimental to patients, as awareness of their health status can facilitate better disease management, informed decision-making, and improved quality of life. Consequently, rather than solely depending on RNTK alternative approaches can be adopted to enable individuals to engage with their health status in a healthier, more informed, and better-supported manner. These alternatives are outlined as follows:

1) Development of Guidelines and Protocols for Delivering Health-Related News: A critical alternative to RNTK is the establishment of clear guidelines and protocols for communicating health-related information to patients. These guidelines should train healthcare professionals, particularly doctors and nurses, to convey sensitive information accurately and empathetically. Training in communication skills should encompass active listening to patients' concerns and questions, using plain and accessible language instead of complex medical terminology, and delivering information gradually to allow patients time to process it. Furthermore, selecting an appropriate time for delivering news is a key component of these protocols. For instance, sharing adverse health news during inappropriate circumstances, such as when a patient is under severe stress or immediately post-surgery, may exacerbate negative outcomes. Healthcare providers should assess the patient's physical and psychological state and choose a time when the patient is best equipped to receive and process the information.

2) Encouraging Patients to Choose the Timing of Disclosure: Instead of completely withholding information, patients can be empowered to select an appropriate time for receiving health-related news. This approach allows patients to determine when they are emotionally and psychologically ready to receive such information, fostering a sense of control and mitigating the risk of feeling overwhelmed. For example, a patient recently diagnosed with cancer may need time to process initial emotions before receiving detailed information in subsequent days or weeks. To implement this approach, a system could be designed

[102] Tiller et al (n 94).

whereby patients indicate, verbally or in writing, their readiness to receive information, and healthcare providers coordinate accordingly. This method prevents complete avoidance of information and supports patients in gradually coming to terms with their condition.

3) Providing Adequate Support Systems: Offering robust support to patients who become aware of their health status is another effective alternative to RNTK. Such support may include psychological counselling to address fear, anxiety, or depression, establishing support groups for patients to share experiences with others in similar circumstances, and providing accessible resources such as brochures, videos, or websites that offer reliable information about the condition, treatment options, and management strategies. By referring patients to these resources, healthcare providers can ensure that individuals are not left to cope alone after receiving health-related information and are equipped with the tools needed to manage their condition effectively.

4) Addressing Concerns Related to Discrimination: Many individuals avoid learning about their health status due to fears of discrimination, barriers to accessing healthcare services, or the high costs of treatment. To address these concerns, robust anti-discrimination laws should be enacted and enforced in workplaces, educational institutions, and communities, alongside efforts to raise public awareness about health conditions to reduce social stigma.

5) Educating Patients About Their Condition and Its Management: Providing patients with comprehensive education about their condition, treatment options, and symptom management strategies can enhance their sense of control and empowerment. Such education may include in-person or online sessions with specialists, written or digital resources such as booklets and instructional videos, and training in practical skills, such as appropriate dietary practices or stress-reduction techniques. These educational initiatives enable patients to confront their condition with knowledge and confidence, rather than avoiding reality.

These strategies collectively promote a patient-centred approach that balances autonomy with informed engagement, ultimately fostering better health outcomes and quality of life.

VI Conclusion

This article has undertaken a thorough investigation of RNTK, exploring its legal recognition, theoretical foundations, theoretical and practical challenges, its status in Australian Law, and alternative suggested approaches. The findings reveal that while RNTK is grounded in principles of autonomy and self-determination and it cannot be considered as an attempt to deny medical truths and to reject one's fate, its application is laden with challenges that necessitate an approach to balancing individual choice with social well-being.

From a legal perspective, RNTK is recognised in international frameworks such as the Oviedo Convention and the UDHGHR, which uphold individual autonomy in refusing health-related information. These instruments position RNTK as a counter to paternalistic healthcare practices. However, RNTK's legal status is ambiguous, with inconsistencies across jurisdictions. Exceptions in the Oviedo Convention allow information disclosure for public safety or healthcare protection, complicating RNTK's enforceability. Moreover, while UDHGHR is not legally binding, the Oviedo Convention, though binding, frames RNTK as a preference rather than a definitive right. Limited ratification of the latter further undermines RNTK's global support, rendering it more a matter of discretion than a robust legal entitlement.

Theoretically and practically, RNTK is bolstered by multiple perspectives. Firstly, it serves as a shield against the psychological burdens of genetic knowledge, safeguarding individuals from potentially distressing information. Secondly, RNTK is framed as an extension of natural rights, positing the choice to remain uninformed as a fundamental human entitlement. Thirdly, it is justified on utilitarian grounds, aiming to minimise mental distress and promote social cohesion. However, these arguments face scrutiny. Critics argue that RNTK is redundant, as autonomy and self-determination are already enshrined in existing human rights frameworks. The classification of RNTK as a natural right lacks clarity and universal acceptance. Additionally, the utilitarian rationale falters when considering potential public health risks, as deliberate ignorance may lead to preventable harm and undermine collective well-being. Finally, RNTK faces significant practical challenges due to the collective nature of genetic information, which is often shared organically within families, rendering legal enforcement against non-professionals infeasible and potentially infringing on personal freedoms. although enforcing RNTK is more viable against healthcare professionals and institutions, unintended disclosures and ethical dilemmas persist, particularly in multidisciplinary settings.

In Australia, RNTK lacks explicit recognition in statutes or common law. Some regulations offer some indirect protection, such as consent, allowing individuals to refuse genetic testing and thus avoid unwanted information, but it is not designed to uphold RNTK and may even encourage disclosure in some cases. Moreover, there are landmark cases that prioritise a patient's right to know, clashing with RNTK. In this situation, the Centre for Law and Genetics suggests explicit RNTK recognition, as its current status as an ethical principle, rather than a legal right, leaves it inadequately protected and ripe for reform.

The uncertain status of RNTK has significant implications beyond its legal, theoretical, practical challenges. This ambiguity risks

undermining public trust in legal and healthcare systems, as individuals may perceive their rights as inconsistently applied. In healthcare, unclear application of RNTK may lead to poor decision-making, with individuals opting out of critical information, potentially endangering themselves and others, particularly in cases of contagious diseases or genetic conditions with broader impacts. Overemphasis on individual autonomy without robust regulatory frameworks could exacerbate healthcare access disparities, especially for vulnerable groups lacking awareness or support. Socially, these tensions may deepen fragmentation, complicating the balance between individual choice and collective well-being. Without global consensus and strong legal backing, RNTK risks becoming a source of confusion and inaction rather than empowerment.

In conclusion, to mitigate the potential adverse effects of exclusive reliance on RNTK in medical practice, several strategies can be implemented to foster informed patient engagement and enhance health outcomes. Firstly, establishing clear guidelines and protocols for delivering health-related news is essential, equipping healthcare professionals with empathetic communication skills and ensuring information is shared at an appropriate time based on the patient's physical and psychological readiness. Secondly, empowering patients to choose the timing of health information disclosure enables them to process sensitive news when emotionally prepared, promoting a sense of control. Thirdly, providing robust support systems, such as psychological counselling, support groups, and accessible resources, ensures patients are equipped to manage their condition effectively. Fourthly, enacting and enforcing anti-discrimination laws, coupled with public awareness campaigns, can alleviate fears of stigma or barriers to healthcare access. Finally, comprehensive patient education through specialist sessions, digital resources, and practical skill training enhances patients' confidence and autonomy in managing their health. These patient-centred approaches collectively promote informed engagement, ultimately improving quality of life and health outcomes.