From a Right to a Preference: Rethinking the Right to Genomic Ignorance

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Abstract

The "right not to know" has generated significant discussion, especially regarding genetic information. In this paper I will argue that this purported right is better understood as a preference, and that treating it as a substantive right has led to confusion. To support this claim I will present three critiques of the way the right not to know has been characterised. Firstly, I will demonstrate that the many conceptualisations of this right have hampered debate. Secondly, I show that the way autonomy is conceptualised in this literature is also problematic. Thirdly, I examine the notion of a right in more detail, to support my third critique: that the right *to* know and the right *not* to know genetic information are often erroneously treated as having equivalent status. On my understanding, the claim being made is better thought of as a preference not a right, and a preference not to know certain information becomes only one of several considerations relevant to medical decision-making.

This is a pre-copyedited, author-produced version of an article accepted for publication in *The Journal of Medicine and Philosophy* following peer review. The version of record Dive, Lisa (2021) "From a Right to a Preference: Rethinking the Right to Genomic Ignorance" *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, 46(5):605–629 is available online at: https://academic.oup.com/jmp/article-abstract/46/5/605/6378725 DOI: 10.1093/jmp/jhab017

Embargo period for JMP: 24 months from online publication

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Introduction

The right not to know (RNTK) one's genetic or genomic[1] information has been subject to considerable debate in recent decades. Despite these discussions there is no consensus about the meaning of the RNTK. Without clarity on the concept, it is impossible to evaluate how the term should be used in normative arguments.[2] In this paper I will outline three main objections to the way the RNTK has been characterised: firstly that there is a significant lack of conceptual clarity in how the RNTK is understood, so that it has been taken to mean various different things by different authors who presume they are arguing about the same thing when, in fact, they are not. Secondly, this conceptual confusion relates in large part to the way autonomy is conceptualised. Thirdly, I will argue that the RNTK is often (incorrectly) treated as having equivalent normative status with the *right to know* one's genetic or genomic information. To inform this third point I will explore the concept of rights and show that – if they are to be characterised as rights at all – the right to know and the RNTK are not normatively equivalent. Based on this three-point critique, I will argue that the use of "rights" language has contributed to confusion in this debate. In contrast, preferences[3] offer a better way of conceptualising patients' and family members' wishes in relation to their genetic or genomic information. Understanding the so-called RNTK as a preference, rather than a right, not only improves conceptual clarity, but also enables health services and practitioners to better support patient autonomy.[4]

My argument will be informed by a critical appraisal of a selection of literature about the RNTK, to represent both the diversity of positions in relation to the RNTK and the varying conceptions of autonomy that underpin the arguments made. I will show how such different conceptions of autonomy have been used to argue both for and against the RNTK, variously understood. This will, in turn, be used to support my first two objections, namely that the debate about the RNTK is characterised by a lack of conceptual clarity, which is in large part attributable to the varying ways that

autonomy is conceptualised in these discussions. However in relation to the RNTK this confusion has generated contrasting understandings of what it means to have a right not to know. To illustrate these fundamental conceptual differences, I will consider how the RNTK differs from the right to know, addressing my third objection that these purported rights are often mistakenly treated as being of equivalent status, or being "mirrored" rights. Based on these three objections I will argue that the language of "rights" brings unhelpful baggage to the question of how we ought to respond to patients' preferences not to receive their genetic or genomic information. Instead, understanding patients' requests not to receive genomic information as a preference (which can then be balanced against other relevant ethical claims) provides a way of responding to such requests. Such an account is more effective than a choice-based conception of autonomy because it enables healthcare professionals to support patients' capacity to direct their lives according to their own values and preferences (Dive and Newson 2018).

First objection: Different understandings of the RNTK

To untangle the RNTK, we first need to grasp the diverse ways that this concept is discussed in the literature. I will show that there is a lack of consistency in how the RNTK is understood, and that these different perspectives relate in some ways to varying conceptualisations of autonomy (which I discuss in the following section). To demonstrate the different perspectives on the RNTK, I begin in this section by setting out some of the arguments that have been made by key theorists. This is not an exhaustive review of the literature, [5] but a selection of arguments chosen to illustrate the diversity of perspectives on and arguments about this purported right.

An early and influential position on the RNTK is that of David Ost (1984), who argues against a right to ignorance in all medical decision making (not specifically genetics). He argues that, like other requests for ignorance, the RNTK is incoherent. Ost's argument rests on two key claims: firstly that rationality is a requirement for autonomy, and secondly that refusing information is irrational. Information is considered a requirement for autonomy, and so autonomy cannot be used as a justification for

refusing information. Further, Ost claims that "autonomy is the basis of rights" (1984, 304) because it is by virtue of our status as an autonomous agent that we are entitled to certain rights. Drawing on these premises, Ost argues that if refusing information is irrational, and rationality is a requirement for autonomy, then a person who refuses information cannot be autonomous. Further, if autonomy is what entitles us to rights, then someone refusing information cannot be a bearer of rights. This chain of reasoning leads Ost to the conclusion that the RNTK is incoherent, because honouring the right turns the purported right-holder into a non-autonomous person – since they have irrationally refused information – who is therefore a non-holder of rights.

Rhodes (1998) also argues against a RNTK one's genetic information, or a "right to genetic ignorance" (Rhodes 1998, 14). She equates the refusal of such information with a driver who chooses to drive blindfolded (Rhodes 1998, 16), claiming that we are all "ethically required to be informed" (Rhodes 1998, 18) where that information is significant in relation to a decision we have to make. This argument is based on Kant's notion of autonomy as self-determination, which is not only something to which we are entitled, but implies a responsibility of all moral agents. The responsibility to be informed is a form of duty[6] to others. 'Others' here are to be understood as society or our community broadly construed, since we all have a moral duty to be autonomous. However, on this view, in relation to genetic information we have a particular duty towards those with whom we have close social or familial ties.

However, Takala, by contrast, invokes autonomy to argue in favour of the RNTK (Takala 1999). Her argument espouses an account of autonomy as self-determination, and denies the idea that information provision is a necessary condition for autonomy. Takala claims that while there are strong intuitions against the right to remain in ignorance, the reasons for these intuitions are often not clearly articulated. She identifies the two most prevalent and convincing reasons given *against* the RNTK and argues against them, thus claiming to establish the existence of the RNTK. The first argument she addresses is that a person should be free to choose whether or not to receive information about themselves except when refusing information that could harm someone else, specifically family

members to whom the information is also relevant. To refute this argument she presents practical solutions for how an individual can avoid receiving their own genetic information (if that is their preference), without withholding important health-related information from family members. Her view is that everyone has the right to seek or to refuse their own genetic information, and that the right to obtain information and the right to refuse it should be treated as mirrored equivalents. The second argument Takala addresses is one based in a Kantian conception of autonomy which confers a duty to be informed on all moral agents. Takala however argues that since complete knowledge is impossible, people should be allowed to choose what information they use as the basis for their decision making. This includes the right to choose whether or not to seek genetic information to inform healthcare decisions, even when that information might be relevant to the decision. She claims that "people are allowed to be foolish in liberal societies" (Takala 1999, 292). The practical strategies she outlines are examples of how a person's preference to avoid knowing their genetic information can be accommodated without harming their relatives who might benefit from that information. Her argument rests on a default to a "presumption of freedom," the claim that we should be free to choose what information we receive, including genetic information. It also depends on the equivalence of the RNTK and the right to know one's genomic information, a claim that is more explicitly defended in another paper (Takala and Häyry 2000).

A crucial feature of Takala's (1999) argument for the right to genetic ignorance (her nomenclature for the RNTK) is that it is justified by an argument based on her refutation of a duty to be informed. Takala argues persuasively against the existence of a duty to know one's genetic information, and concludes that the lack of a duty to know proves that there is a RNTK. She characterises Kantian autonomy-based arguments against the RNTK (such as Rhodes') as taking the form:

> $A \Rightarrow B$ ("A implies B"), where:
>
> A = there is a duty (or obligation) to know our genetic information, and
>
> B = there is *no* right to remain in ignorance of (*not* to know) our genetic information.

Takala shows how a person's ignorance can be maintained without harming others, and also argues that information is not required for autonomy in the sense of self-determination. Therefore, in the argument above she can be taken to have established "not A" or that proposition A (the antecedent in the premise A $\Rightarrow$ B) is false. However, the falsity of A does not entail the negation of B. This is an instance of the logical fallacy called *denying the antecedent*. Denying the antecedent does not disprove the consequent, it is perfectly possible for the consequent of a conditional to be true, even when the antecedent is false. In other words, the lack of a duty or obligation to know one's genetic information is quite compatible with the lack of a RNTK. Therefore, Takala has failed to establish conclusively the right to genetic ignorance.

While Takala has not established a right to genetic ignorance as a moral "trump" (as it is typically assumed to be), she makes an important point: that an obligation to prevent harm to others (such as family members) does not necessarily warrant overriding a preference to avoid receiving one's own genetic information. Her case examples demonstrate the possibility of health professionals respecting patients' preferences to avoid receiving information, while still supporting their capacity to be autonomous and fulfil their obligations to family members.

Andorno (2004) is another author who argues in favour of the RNTK based on the premise that we should all be free to choose what information about ourselves we do or do not access. While his is a similar argument to Takala's, I will discuss it further in the section about rights as it illustrates one of the ways in which the concept of a right is articulated in this debate.

As I have demonstrated, different writers argue both for and against the RNTK, appealing to different conceptions of autonomy and different understandings of what the RNTK means. This has been noted before in the literature and some writers have used possible distinctions about the disputed concept of autonomy to explore different possible positions in relation to the RNTK. For example, Husted makes an autonomy-based argument about the right not to know one's genetic information, where he distinguishes between two conceptions of autonomy and shows that they can lead to different positions on the question of the right to genetic ignorance (Husted 2014). What Husted refers to as the

"thin conception" of autonomy is similar to the influential account articulated by Beauchamp and Childress (2013). He contrasts this with a "thick conception" of autonomy based on procedural accounts such as Dworkin's (1988). Ultimately Husted does not take a position on the RNTK genetic information, but demonstrates that different conceptions of autonomy can lead to different attitudes to the provision of genetic information.

Like Husted, Harris and Keywood (2001) highlight that the way that autonomy is understood matters for an analysis of the RNTK. They note that it is possible for an autonomous person to constrain their future autonomy in ways that are compatible with autonomy as an ethical concept, but also to do so in ways that are incompatible. They give examples of joining a religious order or the military service as choices to restrict one's future autonomy that can be made autonomously. However, there are some other choices to restrict one's future autonomy that are incompatible with one's autonomy. They give the example of a person whose blood was mistakenly tested for HIV, with the result that their doctor knows that they are HIV positive. The patient in question has a desire to continue having unprotected sex with several partners and has a desire not to cause harm to their partners, but has also expressed a desire not to know their HIV status. In this case, their refusal of information is frustrating one of their known desires (not to harm their sexual partners), therefore refusing to know their HIV status compromises their autonomy. Harris and Keywood argue that a right to refuse information does not "trump" all other considerations, but must be balanced against the rights of and duties towards others. In the example given, the doctor's duty to protect others (in this case, the patient's sexual partners) is "at least as strong or stronger than" (Harris and Keywood 2001, 427) their duty to respect their patient's preferences about information disclosure.

From this review of some prominent positions on the RNTK it is clear that there are several points of ambiguity in relation to how this concept is understood. One is the question of the extent to which information is required for autonomy, and whether there is an obligation to accept relevant information or a right to refuse it. There are various obligations that play different roles: some authors argue that there are obligations to family members to acquire relevant information, others argue for a

more Kantian moral obligation to be autonomous which requires us to be informed. Another point of ambiguity in the debate is the extent to which any RNTK can or should override other moral considerations. This relates to confusion about how to conceptualise rights. As I explain in a later section on rights, this supports my position that the language of rights is inappropriate for decisions about disclosing genetic or genomic information. Having demonstrated the fundamental inconsistency in the literature about the RNTK, I suggest that it is important to be clear about what we mean by it.

Second objection: The different meanings and implications of autonomy

The way the RNTK is understood has often been closely linked with the concept of autonomy. As we saw in the preceding section, different authors invoke various accounts of autonomy to argue either in favour of or against the RNTK. In this section I demonstrate in more detail what difference this makes to the claim of a RNTK. I will first set out some of the different ways that autonomy has been conceptualised in arguments about the RNTK, and how such concepts have been used in those arguments. This will illustrate the point that differing conceptions of autonomy have contributed significantly to the confusion that is characteristic of the debate. I will also argue that a substantive, perfectionist understanding of autonomy – which has been defended elsewhere (Dive and Newson 2018), a detailed explication of which is beyond the scope of this paper – is the best for responding to practical questions like the RNTK.

Beauchamp and Childress' highly influential account of biomedical ethics includes respect for autonomy as one of the main principles. They state that as part of respecting patients' autonomy, health professionals have an obligation to ensure "that patients have the right … to accept or to decline information" (Beauchamp and Childress 2013, 110). Their conception of autonomy (which I will refer to as the *default conception*) is typically invoked to argue in favour of the RNTK. Beauchamp and Childress' requirement for "understanding" allows for some flexibility informed by patients' preferences as to how much information they require to inform their (autonomous) decision.[7]

The default conception of autonomy has received criticism, and I have previously argued for a conception of autonomy that draws on perfectionism as a moral theory (Dive and Newson 2018). Briefly, perfectionism is a moral theory based in the concept of a flourishing human life, and directs people to pursue their conception of their best possible life. (Hurka 1993, Raz 1986). There are variations in the extent to which the features of a flourishing human life are considered objective, and the role that individual preferences play. Without committing to any particular version of perfectionism, I am suggesting that the general notion of a flourishing human life as the basis for informing moral decisions shows promise for addressing complex normative questions related to autonomy in bioethics, such as the question of the RNTK. The requirement for substantiveness builds on Walker's critique of the default conception of autonomy (Walker 2008), and it means that the content of people's choices or preferences is significant in the determination of whether they represent an exercise of autonomy. Substantive perfectionist autonomy also draws on the neo-Kantian notion of 'normative competence', which describes people's capacity to evaluate different choices based on their normative content (Wolf 1986). I will argue that understanding autonomy in this way can form the basis for responding effectively to bioethical dilemmas such as whether or not to uphold a request not to know one's genomic information.

It is acknowledged in the literature that there are different ways of conceptualising autonomy in the context of a RNTK. As mentioned earlier, Husted distinguishes between two ways of understanding autonomy in relation to the RNTK. He explains that on a "thin" conception of autonomy (such as the default conception), any information relevant to a medical decision can and should be given to a patient. This is contrasted with what he terms a "thick conception" of autonomy, a richer notion of autonomy as self-determination based on views such as those of Dworkin (1988), and incorporating Raz's notion of the importance of the quality of available choices (Raz 1986). On this understanding of autonomy, a person is autonomous to the extent to which they determine the kind of life they wish to lead, in accordance with their values and preferences as determined by a process of "reflective self-evaluation" (Husted 2014, 31). Here Husted describes the doctor's role as guiding the patient to

exercise their self-determination by clarifying values and possibilities, and "as far as possible, creat[ing] valuable options" (Husted 2014, 33). In this case it is less clear that more information will necessarily enhance autonomy. Husted does not take a specific position on the RNTK genetic information, but draws attention to the complexity of the relationship between information provision and autonomy. He points out that provision of genetic information does not clearly constitute an enhancement of, nor a requirement for, the patient's autonomy. As I will argue below, the connection between provision of *genomic* information and autonomy is even more tenuous.

It is important to note that on Husted's analysis, the question about the RNTK genetic information is understood as the question of whether a person can ethically refuse information and still be considered to be someone who takes responsibility (autonomously) for their life. This is distinct from others such as Rhodes (1998), who consider the RNTK to be the negation of the existence of a duty to be informed, for example, for the sake of one's relatives, since Husted's analysis does not depend on obligations to others.

A Kantian conception of autonomy as a moral obligation (to oneself or to others) forms the basis for arguments both for and against the RNTK. Ost (1984) appeals to a Kantian conception of autonomy as self-determination, based on rationality and freedom. This understanding of autonomy places greater emphasis on individuals' obligations to exercise their autonomy by obtaining information relevant to decisions about their lives. Ost appeals to a Kantian conception of autonomy to argue that information refusal generally – and in particular a RNTK – is incoherent. This differs from other arguments based on a Kantian understanding of autonomy. Conceptions of autonomy derived from Kant's view tend to be associated with a requirement to provide the maximum amount of information to patients, because information is seen as a precondition for autonomous choosing. As such, this conception of autonomy is typically the basis of arguments against the RNTK, since the requirement for patients to be fully informed can justify providing information to them even when they do not wish to receive it. While Rhodes also draws on a neo-Kantian understanding of autonomy, she places particular emphasis on the familial nature of genetic information (Rhodes 1998). For Rhodes, our moral obligations as

autonomous individuals include obligations to be informed of our genetic information both as a way of enacting our own autonomy, as well as out of obligation towards other family members.

Concepts of autonomy that go beyond freedom of choice to a more complex notion of self-determination – but differ from Kantian approaches that understand autonomy as an obligation – have also been used to argue both in favour of and against the RNTK. An example of such an argument for the RNTK is Takala's (1999). She draws on autonomy as self-determination – rather than mere freedom of choice – to argue that people should be free to remain ignorant and make decisions without relevant information if that is their preference. Harris and Keywood also base their argument on a conception of autonomy as self-determination, but they argue *against* a right to remain ignorant of relevant genetic information (Harris and Keywood 2001). Two features of their argument are particularly salient to the connection between the RNTK and autonomy. Firstly, they demonstrate that how we understand autonomy makes a difference to the RNTK. If autonomy is construed as freedom, then it seems straightforward to make an autonomy-based argument that patients are free to choose whether or not to receive their genetic information. However they consider (and I would agree) that autonomy is not the same as liberty, and they argue that when autonomy is understood more broadly as self-determination, then in some instances the refusal of information does not support a patient's autonomy.

A second key feature of Harris and Keywood's argument is that the concept of autonomy as self-determination is associated with a correlation between information provision and autonomy. Harris and Keywood trace the legal basis for patient autonomy back to a notion that in order to exercise their autonomy, patients must both receive *and* understand relevant information. There tends to be a presumption particularly in legal contexts that a person either is autonomous or they are not, and the determination of whether a person is autonomous can have implications for their legal capacity to make decisions. However when considering how information provision bears upon a patient's autonomy, it becomes evident that a person's autonomy ought to be treated as a scalar property (one that admits of degrees), rather than a binary one. The default conception of autonomy considers

autonomy to be a scalar property of *choices*, namely one that admits of degrees (Beauchamp and Childress 2013, p. 102), but this can be associated with the notion that in relation to *people* it is a binary property. While a choice can be more or less autonomous, people are either autonomous decision-makers, or they are not. There tends to be a misconception that in order to be autonomous patients require as much information as possible. As Takala and others have argued, providing more information does not necessarily enhance patients' autonomy (Takala 1999; Dive and Newson 2018). There comes a point when additional information can undermine autonomy, and the nature of the information also plays a role in whether that information will enhance or diminish the person's autonomy. A substantive, perfectionist conception of autonomy is advantageous because it draws attention to the role that information can play in supporting (or undermining) a person's capacity for self-determination and, ultimately, their wellbeing.

The supposedly binary nature of autonomy as a property of persons comes under even more pressure in the context of shifting from genetic to genomic information.[8] The potential for information provision to undermine autonomy is increasingly evident in the context of genomic information, due to the nature of that information. Genomic testing can yield a far greater quantity of information, which is of greater uncertainty, complexity and sometimes less utility, compared to genetic testing (Newson et al. 2016). It is recognised that providing patients with complete information about the possible outcomes of a genomic test is not possible (Green et al. 2013), but for some patients even a robust exploration of the different possible results and their implications could be an overwhelming amount of information to digest and impede their capacity to make the best decision. The complexity of the relationship between genomic information and autonomy requires autonomy to be a scalar property (of persons), namely one that admits of degrees and can change over time. This contrasts with Beauchamp and Childress' understanding of autonomy as a scalar property of *choices*. However taking autonomy to be a property that people can have in greater or lesser degrees enables health professionals to seek to foster or enhance their patients' autonomy, rather than treating patients either as autonomous or not.

While the debate about the RNTK originated in the context of *genetic* information, it is increasingly important to consider how arguments may be extended to the RNTK *genomic* information, as genomic testing becomes more widespread. In particular, how does knowledge of genomic information bear on a person's autonomy? The RNTK genetic information is typically concerned with tests for a specific genetic variant that indicates a susceptibility to a particular health condition. Genetic testing is usually of high validity and clinical utility, even if the prognostication that occurs as a result has some uncertainty associated with it. As such, the information resulting from a genetic test is likely to have some practical relevance to the patient and their family. In such cases, an argument can be made that the information generated by a genetic test has the capacity to enhance a patient's autonomy. Genomic testing differs from genetic testing in three main ways that could be relevant to the RNTK (Newson and Schonstein 2016). Firstly, the amount of information generated increases, as does its complexity. Secondly, there is an increased likelihood of findings that might have clinical relevance, but are not related to the initial clinical indication for testing. Thirdly, genomic testing increases the prevalence of results of uncertain significance. There are many sources of uncertainty in the context of genomic information (Newson et al. 2016), including unknown accuracy of the test itself, as well as the probabilistic nature of the information generated, and uncovering variants of unknown significance, among others. Therefore, in applying debates about the RNTK genetic information to the context of genomic medicine, we need to acknowledge that in genomics we are dealing with greater quantities of information and associated increased complexity and uncertainty. This means that the capacity for this information to undermine, rather than enhance, autonomy is magnified. With the increased likelihood that genomic information will fail to provide answers and clear clinical direction, genomic information is even more likely than genetic information to confuse and possibly distress patients.

The notion that we require as much information as possible in order to make autonomous decisions is influential (to varying degrees) in the arguments of Ost, Rhodes and (initially) Husted. However, a broader understanding of what it means to be an autonomous person motivates Husted to put forward an alternative position, which is more similar to Takala's approach. The question of the extent

to which information is required for the exercise of autonomy is a central issue. I agree with Takala's view that provision of information does not necessarily increase a person's capacity for autonomy (construed as self-determination). However, I would go further and argue that respecting autonomy requires more than freedom of choice – whether or not that choice requires maximum amounts of information. On a substantive, perfectionist understanding, autonomy involves critical reflection on a person's goals and preferences, and an assessment of how different available choices affect their fulfilment (Dive and Newson 2018). Therefore information provision is not correlated with capacity for autonomy. Taking this position I would argue – as Takala did – that more information does not necessarily enhance autonomy.

So far I have shown that arguments for the RNTK have invoked various philosophical conceptions of autonomy as a capacity (of people) for self-determination (for example by Takala (1999), among others), but so have arguments against this purported right (Ost 1984). A more Kantian understanding of autonomy in which self-determination is not only a right of all individuals but also a moral obligation has been the basis for arguments *against* the RNTK, based on our duties towards others (Rhodes 1998). Duties towards others are particularly relevant in the context of genetic or genomic information, because of the familial nature of such information. However, understanding autonomy as self-determination in a substantive, perfectionist way leads us to consider how a person's autonomy can either be enhanced or undermined by provision of information. Enhancing someone's capacity for autonomy requires critical reflection on their goals and preferences – which are embedded in the person's relational context – and consideration of how to enable them to make decisions that help them achieve the kind of life they want for themselves (Dive and Newson 2018). A perfectionist approach to autonomy provides a justification either for providing or not providing information to a patient, based on whether it will contribute to or undermine their pursuit of a flourishing life.

The different ways of understanding autonomy have contributed to the confusion in the literature about the RNTK. To make progress on resolving this issue we need to examine more fundamentally what it means to invoke a right, because clarity about what we mean by rights will help to articulate

the connection between autonomy and rights. This decomposition will allow us to get a clearer grip on the RNTK itself. The resulting conceptual clarity will also support my third main objection to the way the RNTK is understood, namely that it is often mistakenly assumed to be normatively equivalent to the right to know.

What is a right?

To clarify the RNTK, first I will consider what we understand a right to be and the relationship between rights and obligations. This clarification supports my first critique of how the RNTK is presented in the literature, namely that there is considerable confusion because the RNTK is not consistently characterised as the same kind of right. Furthermore, examining the nature of rights enables us to distinguish between the right to know (RTK) and the RNTK, and my third objection is against the assumption of their mirrored equivalence. Clarifying how the RNTK might be conceptualised also supports my positive claim that "rights" as a conceptual framework are an unsatisfactory way of describing patients' preferences not to receive their genomic information.

There is a rich legal and philosophical literature on the topic of rights, which can be drawn upon to make some clarifications. First, there is an important distinction between legal rights and moral rights. Legal rights are those that are enshrined in a specific legal instrument, such as a constitution, legislation or declaration. They only exist within a specific legal context or jurisdiction, namely that in which they are recognised and enforced. For example, a law can only protect a right in the country where it is legislated. Similarly, a professional code of conduct enshrining patients' rights will only affect the behaviour of those clinicians who are subject to sanctions if they violate the patient rights in that code. By contrast, moral rights are those that are grounded in morality, namely a theory about what is right or good. For present purposes, we are interested in the moral justification of the right not to know genomic information. This is a particularly important consideration given that various policy documents assume its existence. If the RNTK lacks a sound moral justification, then its inclusion in these policy instruments requires some other justification to defend it.

To help understand the nature of rights, we can consider Hohfeld's influential analysis of the forms of rights (Hohfeld 1919, Rainbolt 2006) as privileges, claims, powers and immunities. His primary interest was in legal rights, but his classification has also been influential in accounts of moral rights. Hohfeld postulated two kinds of first-order rights: privileges and claim rights. *Privileges* are best understood as *liberties* or freedoms, and take the form:

A has a right to ϕ iff A has no duty not to ϕ

Privileges are straightforward liberties and do not involve another party. A person has a right to do some action ϕ if and only if they have no duty not to do so.

Claim rights, in contrast, take the following form:

A has a claim that B ϕ iff B has a duty to A to ϕ

In other words, A has a claim that requires B to do something (ϕ, which represents some action) if and only if B has a duty to A to perform that action. It is significant here that this right involves another party apart from the right-holder, someone who has an obligation to the right-holder to take some action necessary for the fulfilment of the right.

The other kinds of rights that Hohfeld postulated are *powers* and *immunities*. These are second-order rights that can modify first-order rights (such as privileges and claims). For present purposes we are more concerned with first-order rights but in brief, a Hohfeldian *power* is the ability to alter one's own or another person's duties or claim rights. A person has an *immunity* if others lack the ability to modify that person's duties or claim rights.

There is significant ambiguity in the type of right the RNTK is taken to be. Some arguments do treat the RNTK as a liberty right (that is, a lack of an obligation to refrain from doing something), despite the problems with such an approach. Rhodes' Kantian autonomy-driven argument is based on a liberty-rights analysis of the RNTK (Rhodes 1998). She argues that each of us has an ethical duty to be self-governing (autonomous), and that to do so effectively and rationally we require appropriate information. She claims that genetic information is of the nature that it helps us to be rationally self-

governing, therefore we have a duty to obtain such information if it is available to us. Andorno (2004) takes the opposing view, but also treats the right not to know as a liberty right. He also appeals to autonomy, but implies a "wider sense" of the concept. His argument is that an individual should be free to decide if they wish to receive information or not, but if they wish to decline certain information (such as that arising from genetic testing) then they must explicitly "activate" this right. Andorno considers that the ability to decide what information to receive (or not) is part of self-determination, and therefore is required for autonomy. This is another liberty-right conception of the RNTK, because it is an assertion of the individual's freedom to determine what information they do or do not receive. I will argue that conceptualising the RNTK as a liberty right is an error that results from treating it as having equivalent status to the RTK. This view is based on an understanding of autonomy as freedom, which I consider to be a simplification of what it means for a person to be autonomous.

Wilson has argued that *claim rights* are "the core of the concept of moral rights" (Wilson 2007). His position is that *liberties* (privilege rights in Hohfeld's terminology) are essentially permission to do something, and do not entitle the holder to some benefit or consideration in the way that we would expect as being central to rights. I will accept this stance and argue that the RNTK genomic information should be understood primarily as a *claim right*. This is both because of Wilson's position that *claim rights* are the paradigmatic case of what we mean when we talk about rights, and also because the RNTK lacks practical significance if there are no correlated duties or obligations on others. *Liberty rights* are effectively freedoms that are bounded by the harm principle; in other words they are freedoms that may be exercised up to the point at which they risk harming another person.[9] Since they do not produce corresponding obligations for other parties – beyond not interfering with their exercise – they do not confer a benefit on the right-holder in the same way that claim rights do.

O'Neill (2005) argues that rights are only meaningful if they involve a means of securing what one has a right to. Her argument therefore supports Wilson's position that the more meaningful interpretation of rights is as *claim rights*, because these confer obligations on another party for their fulfilment. This obligation provides the required means for fulfilling the right. *Liberty rights* have no such means

because they are mere freedoms. O'Neill distinguishes between rights that are treated as aspirational, and those that are normative. If we are content with treating rights as aspirations, then no one is at fault if they are not met. Effectively, this means that "human rights are not real claims" because without correlated obligations they do not entitle the claim-holder to anything in a way that we would expect a claim to do. Alternatively, if we treat them as normative claims, then there must be corresponding obligations on specific parties to fulfil the rights, because "without the obligations there are no rights" (O'Neill 2005, 431). Thus in order for rights to have the capacity to translate into real actions that secure their delivery, they need to be construed as *claim rights*. Specifically, their corresponding obligations need to be articulated and the responsible parties identified. Here we are able to see that the RNTK must be understood as a claim right, because without any other party having any corresponding obligations invoking such a right seems meaningless.

Another characteristic of rights relevant to the RNTK goes back to Ronald Dworkin's notion of rights as "trumps" (Dworkin 1981). However, the notion that the RNTK should override all others – or all but the most weighty – moral considerations is not defensible. The literature on the RNTK assumes that those who have the RNTK as a claim right are immune from having this right to refuse genetic information modified. This is evident from the language used to describe it, for instance the UNESCO declaration says that the right "not to be informed … should be respected" and the World Medical Association qualifies that this right can only be overturned "for the protection of another person's life." This ability to override the majority of other moral considerations is reflected in the bioethics literature on the RNTK. For example Takala argues that a preference for genetic ignorance can be accommodated in any circumstances, implying that one is never justified in overriding this right (Takala 1999). The RNTK is also reflected in the ethos of non-directiveness which is a paradigmatic (though not unchallenged) principle in genetic counselling (Elwyn et al. 2000). Indeed, there might be a parallel between questioning the RNTK and a shift away from non-directiveness in genetic counselling (Kessler 1992, Onduncu 2002). Harris and Keywood conclude that the RNTK – or a patient's preference not to receive certain information – might often be accommodated, but it is not a right that has the ability to

override all other moral considerations. This is one reason why "rights" language is not well suited to describing patients' preferences with respect to their genomic information.

Typically the RNTK is considered with reference to a particular clinical context, and refers to the patient's right to refuse either to take a test or to receive information obtained by performing a test. This requires the clinician to refrain either from conducting (or requesting) the test or from conveying the information to the patient. The RNTK is therefore invoked when the health professional has some reason for recommending the test or providing the information (and the patient has some reason to refuse). On this explanation, a factor which might override a person's RNTK is a health professional's obligation towards them. If their doctor's view is that the information will be beneficial to them – for example, to allow them to take preventive measures to avoid or minimise the impact of a health condition which they are either certain or highly likely to get – then the question is whether the doctor's obligation to try to achieve the best health outcome for their patient should take priority over the patient's preference not to receive the information. In such a situation the RNTK should be understood as a preference, however if it is a right at all, it has to be a claim right because it places an obligation on the clinician to refrain from providing the information or conducting the test despite the fact that she believes it is information the patient would be better off having.

By contrast, the right to know (RTK) one's health information does not apply to a specific clinical interaction, but describes a person's freedom more broadly to seek information about their own health, with a focus on preventing actions that might restrict a person from seeking such information. No particular clinician or technician is obliged to provide this information, because the individual can always seek it elsewhere. For this reason, in the following section I will argue that the RTK is a *liberty right*, not a *claim right*, and on this basis I will argue that the RNTK does not follow from, and therefore is not mirrored with, the right to know one's genetic or genomic information.

Third objection: Untangling the RNTK from the RTK

One source of confusion in the debate about the RNTK is that this right is often held to be normatively equivalent to the RTK, especially in the context of one's own genomic information. There is a tendency to assume that if I have a RTK certain information, then I automatically have a right to choose which information I do and do not receive, and hence the RTK is normatively equivalent to the RNTK and logically entails it. This presumption is evident in policy instruments such as the UNESCO *Universal Declaration on the Human Genome and Human Rights* (1997) Article 5(c). In the academic literature also, the RNTK is assumed to follow logically from the right to know one's genetic information (Takala and Häyry 2000). The two rights are either taken to apply in all the same circumstances, or it is assumed that the RNTK follows from the RTK. These two positions are also confused, and sometimes the latter is used to justify the former. However as Morrissey and Walker point out, it is important to distinguish a right to know from a right not to know (Morrissey and Walker 2018). I will argue that the RTK one's genomic information is best understood as a *liberty right* while, as outlined above, the RNTK must be a *claim right* in order to be meaningful. Therefore these two rights should not be assumed to be equivalent, and the RNTK does not follow logically from the RTK. This means we have no reason to see them as holding in the same circumstances.

The RTK one's genomic information is generally construed as a freedom or liberty. Sequencing a genome yields a large data file that requires both computer analytics and bioinformatic interpretation in order to have any meaning. The right to "know one's genome" can be understood as a right to access certain services to interpret the results of sequencing, which is a liberty right. Although most individuals would need to rely on technical and clinical expertise to interpret their genomic information, the right to have access to this information about oneself does not require a specific obligation on another party to provide that information. It is usually grounded in the argument that information about an individual belongs in some sense to that individual,[10] and as such they ought to have the freedom to access that information and services to interpret the information for them. Construed in this way, a supposed right to our genomic information could be a right to access the raw

data that results from sequencing our genome, however useful this might or might not be to an individual. However, it can also be understood as the right to access analysis of one's own genome, either in a clinical context or directly from a commercial provider. There is no obligation on a particular clinician or service provider[11] to perform that analysis for anyone, because if the individual is unable to obtain the service from one provider (for example, if their doctor does not believe it is clinically warranted to perform a whole genome sequence) then they are free to seek this service from another provider (such as a direct to consumer commercial testing provider).

The RTK one's own genomic information is therefore, in Hohfeldian terms, a *liberty right* (or privilege). Recall that the form of a liberty right is:

A has a right to ϕ iff A has no duty not to ϕ

For the right to know one's genomic information, this translates as *A has a right to know her genomic information iff she has no duty not to know her genomic information*. The right to access information or acquire knowledge can be seen as a liberty right, because it involves a freedom to access certain information. There is no obligation to refrain from seeking our own genomic information.

By contrast, the right *not* to know cannot be understood as a liberty. As argued earlier, the RNTK necessarily involves other parties who have correlated obligations to uphold the right. The obligations are required to ensure a means of upholding the right, otherwise it is not meaningful in practice (O'Neill 2005). Furthermore, Wilson has argued that claim rights are "the core of the concept of moral rights" (Wilson 2007) and that liberties are essentially permission to do something, and do not entitle the holder to some benefit or consideration in the way that we would expect rights to do. Since the RNTK one's genomic information must be a *claim right* in order to be coherent and have any practical impact, and the RTK is a *liberty*, they are therefore neither logically nor morally equivalent. The RNTK cannot be assumed as a corollary of the RTK one's genomic information, because my having a certain freedom (the RTK) cannot automatically confer obligations on another party (which is required to establish my RNTK) without further argument. This means that even if the RTK one's genome is a right that we ought to uphold, the RNTK does not follow from it.

Based on this understanding of the RTK as a liberty right and the RNTK as a claim right, it becomes clear that these are not equivalent rights, and as a result it becomes easier to see the flaws in many arguments for the RNTK. Some arguments about the RNTK focus on whether or not we have a duty to know (or seek) genetic information (Shaw 1987, Kielstein and Sass 1992, Takala 1999). Arguments that treat a RTK and a RNTK as equivalent are often based on a conception of autonomy as freedom of choice, which aligns with an understanding of both these rights as liberty rights. For example, for Takala – although she has a more sophisticated understanding of autonomy than freedom of choice – the RNTK follows logically from the RTK, both being grounded in the freedom to which we are entitled as autonomous individuals (Takala 1999). On this view, respecting patients' autonomy equates to giving them the freedom to choose whether (or not) they receive health information.

The lack of clarity in how the RNTK is understood underpins the conflation of the RNTK with the RTK, the varying conceptions of autonomy that are used to argue both for and against the RNTK, and also the implied absoluteness of "rights" language. Based on this lack of conceptual clarity, I will suggest that conceiving of the RNTK as a preference is a better way to support health professionals to foster patient autonomy.

From rights to preferences

It is significant that the philosophical disagreement about the existence and persuasiveness of the RNTK one's genetic information is at odds with that purported right's acceptance in a range of legal and policy instruments. Thus far, I have shown that the debate about the RNTK – while broadly accepted in various policy and clinical contexts – is characterised by a lack of conceptual clarity. I have argued for three main critiques of the debate about the RNTK: the lack of clarity in how the RNTK is conceptualised; the inconsistency with which autonomy is used in various arguments for and against the RNTK; and the presumption that the RNTK is normatively equivalent to the right to know one's genetic or genomic information. In order to progress the debate in a way that responds to these objections, I suggest there are two main reasons to abandon "rights" language in the context of

patients' wishes with respect to knowing their genomic information: firstly, describing such wishes as preferences allows greater conceptual clarity, largely by avoiding the misleading baggage that comes with the language of rights. Secondly, considering patients' preferences with respect to their genomic information is consistent with a substantive, perfectionist account of autonomy and thereby is better suited to guiding health professionals who need to respond to patients' requests. In presenting this alternative conceptualisation to the purported RNTK, I recognise that such an approach raises significant issues to explore including the relationship between preferences and interests. While such an analysis is beyond the scope of this paper, my intention is to signal that treating the so-called RNTK as a preference seems a plausible alternative to the language of rights, and as such warrants further exploration.

Some of the conceptual confusion around the RNTK arises from the use of "rights" language. In exploring the nature of rights, I have shown that the RNTK – if it is a right – must be understood as a claim right, namely one that confers corresponding obligations on another party. As illustrated earlier, not only is there a lack of consistency in the type of obligation that is conferred by the RNTK, but also in the party to which the obligation belongs. For example, one argument against the RNTK draws on the patient's obligation to their family members, but another might focus on the clinician's obligation to the patient. There is also variation in the justification provided for the obligation (or lack of one), as well as the understanding of autonomy that justifies the existence (or not) of a RNTK. Further, the concept of rights tends to imply a capacity to override all other moral considerations. The fact that "rights" language leads to such conceptual confusion is one reason why it is not a productive way of conceptualising the so-called RNTK.

One of the shortcomings of "rights" as they are tacitly understood is that they contain an often unstated assumption that a right can (or should) override all other considerations. This is an important feature of arguments about the RNTK that has only occasionally been acknowledged (for example by Harris and Keywood (2001) and McDougall (2004)). Understanding rights as moral factors that should override all others is widespread, for example in Ronald Dworkin's influential account of rights

(Dworkin 1978), and tends to be assumed tacitly in the debate about the RNTK. The RNTK is typically taken to be an absolute right that "trumps" all other moral considerations. Few arguments about the RNTK state this explicitly, although McDougall (2004) points out that calling it a "right" implicitly elevates it above other moral considerations. Harris and Keywood (2001) also understand a "right" to mean a moral entitlement that trumps competing claims. Not only is this assumed absoluteness unjustified in the case of the RNTK, it also quickly becomes incoherent when the RNTK comes into conflict with another purported right. Since in any moral decision-making scenario there will be multiple factors to consider, we need a way of trading off different moral commitments against each other, and preferences seem a promising avenue. [12]

If it is at least conceivable that in some situations, a patient's right not to know their genomic information ought not to be upheld, then this reinforces the claim that understanding the RNTK as a preference, rather than a right, seems a plausible alternative. If the RNTK is understood as a claim right, it confers an obligation on a health professional to refrain from providing certain information when that is the patient's preference. So far this position aligns with Takala's claim that if an individual does not wish to know their genetic information, there are other ways for them to uphold their obligations to family members that do not involve disclosing the information. However – contra Takala – if we take this obligation as one factor that must be balanced against other considerations (such as the potential impact on the patient's wellbeing or that of their family members), the RNTK cannot be considered as a "right" which overrides all other factors. Determination of the weight of this purported right in relation to other moral considerations is highly contextual and should not be decided in advance for all cases. Treating the RNTK as a "right" has a tendency to obscure this complexity and the importance of considering context and other relevant factors when responding to requests not to receive information.

Another compelling reason for abandoning "rights" language in this context is that it can offer a route to enhancing patients' autonomy, broadly understood in a substantive, perfectionist way. If a person has a preference – that is, a desire that has some degree of alignment with their values and goals – not

to know certain information, then this confers an obligation on their health professional(s) to refrain from providing this information *where this action does not conflict with other moral considerations*. In any medical decision-making scenario, decisions must take into account many different factors including not only the relevant medical facts, but also the patient's social and familial context, their goals, and their preferences for the kind of life they wish to lead. In this context, it is likely that a preference not to receive genomic information may often be able to be accommodated (as Takala argued). Indeed, it is probably more likely in the case of *genomic* information which – with its greater degrees of complexity and uncertainty compared to *genetic* information – is arguably less likely to have a positive impact on the patient's health or their life more generally.[13] While knowledge of a particular genetic variant might be beneficial, knowledge of a range of probabilistic and otherwise uncertain information could be less helpful.

While a patient might have a preference to refuse genomic information, I would argue that there could be situations in which clinicians do not have a moral obligation to uphold this preference. The basis for my argument is that the ultimate goal of medicine is to support the patient to flourish,[14] that is, to help them live the best kind of life that they would choose for themselves. This view will not be defended here, but is consistent with a substantive, perfectionist account of autonomy. In order to achieve the best outcomes for patients – understood in this way – clinicians need to balance different, and sometimes competing, considerations. On such a view, if a patient has a preference not to receive some particular information, then usually the best outcome for that patient can be achieved without disclosing that information. However, it is possible to conceive of scenarios in which the patient's own preferences for the kind of life they desire cannot be fulfilled without divulging[15] some of their genomic information.

In order to justify overriding a preference for genomic ignorance, the information would need to be strongly predictive of a health condition, and that health condition must be amenable to preventive interventions that are reasonable and affordable. In other words, if genomic information indicates a high likelihood of a particular outcome, and there are interventions available that can reduce that

likelihood, then a clinician might be justified in being more directive and providing the information "against the patient's wishes".[16] This justification is based in appeals to other relevant moral considerations, such as the clinician's professional obligations and the patient's best interests, which are important factors that – along with the patient's preferences with respect to information provision – play a role in determining the best course of action for that patient. Each instance of a request to avoid receiving genomic information will be distinctive in its details and context, and as such each situation will require an individually tailored response. My suggestion, however, is that in situations where a request to avoid receiving information might conflict with the best interests of the patient (and possibly also members of their family), then treating such a request as a preference rather than a right can lead to a more ethically defensible outcome. Enshrining such requests as 'rights' within policy documents can lead to the problematic assumption that such a request ought to override all other moral considerations.

A scenario involving providing information against a patient's wishes is ethically different to overriding a refusal of treatment. Without knowing what condition they are at risk of and what the treatment or preventive options are, a patient cannot know what they are refusing and what consequences they are risking.[17] Particularly in the case of genomic testing, the range of possible findings is so vast that it is not possible to adequately consider all possibilities. It is important to note that currently there are very few, if any, conditions and test outcomes that would justify overriding a patient's preference not to seek or receive their genomic information. However if there were to be a finding that would satisfy the conditions outlined (strongly predictive of a health condition, which is amenable to preventive interventions that are reasonable and affordable), then an argument based on the patient's best interests can be made in favour of providing the information despite their preference not to receive it. This is contrary to how the RNTK is typically presented, because as previously explained it is treated as a right that has the ability to override or "trump" all other considerations. In part this is because the RNTK evolved in the context of single gene testing and reflects a professional obligation to respect patients' preferences not to know whether they have a genetic mutation that is present in some of

their family members. However the shift from genetic testing to genomic testing reinforces the need to rethink the RNTK, since it is problematic to treat a preference to refuse one's genomic information as a right.

Maximising a person's capacity for autonomy does not justify either forcing information upon them, nor unreflectively agreeing to refrain from giving them information. Health professionals need to balance any request for refusal of information against the potential for that information to contribute to a beneficial outcome for the patient. A concept of autonomy based in a perfectionist approach to wellbeing or flourishing can be helpful in this context, since consideration can be given to whether withholding information might hamper the patient's capacity to flourish. This must be construed not simply in terms of what the clinician considers the best outcome to be, but assessed in reflective dialogue with the patient about what matters to them. It is possible that the refusal of highly clinically significant information might hamper a person's ability even to know what choices are available to them. In such circumstances, a health professional might be justified in undertaking specific tests and providing particular information to ensure that the patient is aware of the implications of the choices they make. For this reason, a preference not to know one's genomic information is one which will almost always be able to be accommodated. However, we should be cautious not to treat such a preference as a right that should always override all other considerations in clinical decision making.

The purported right not to know one's genomic information should not be described as a right, because doing so is misleading and has contributed to the proliferation of contradictory positions. The debate on this topic has been characterised by various parties making arguments for and against the existence of a right with a trump-like quality that can override all other considerations. However, what is really at issue is how to respond to patients' requests not to receive genomic information or undertake a genomic test, particularly when this preference is perceived to be against the patient's best interests or the clinician's obligation to the patient. In such circumstances a substantive, perfectionist understanding of autonomy can provide insight into how clinicians can best support patients.

Conclusion

I have argued that the RNTK genomic information should be understood as a preference rather than a right. Treating it as a right has contributed to conceptual confusion in the debate about how to respond when patients prefer not to know the results of genetic tests. Lack of clarity about the concept of autonomy has also contributed to confusion in the literature, because different conceptions of autonomy are often used as a basis for arguments both for and against the RNTK. An exploration of some arguments about the RNTK genetic information reveals that the RNTK is often conflated with the right to know one's genomic information. Health information can be important for autonomy, but it should not be assumed that more information always increases autonomy. However, neither should it be assumed that the right to refuse information is justified in terms of autonomy. Enhancing or maximising a person's capacity for autonomy requires health professionals to reflect on how certain choices or courses of action will impact on the patient's ability to live the kind of life they want. The so-called RNTK must be considered in this context, and while it is better expressed as a preference that may often be accommodated, it should not be assumed to have the ability to override all other moral considerations in all circumstances.

Acknowledgements

The author gratefully acknowledges Professor Ainsley Newson and Professor Angus Dawson for their insightful comments and feedback on earlier drafts of this paper.

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Endnotes

[1] Philosophical and bioethics debate to date has addressed primarily the right not to know *genetic* information, because the RNTK was originally formulated in the pre-genomic era. As genomic medicine develops as a specialty and genomic testing also becomes more prevalent in other areas of medicine, arguments about the RNTK genetic information have been extended to the RNTK genomic information. I will consider the implications of this shift as it relates to autonomy in the section on the second objection.

[2] Another practical question arising from the meaning of the RNTK is how we should interpret its role in in international policy documents such as the UNESCO *Universal Declaration on the Human Genome and Human Rights* (1997), Article 5(c), which explicitly states that persons have a right to decide "whether or not to be informed of the results of genetic examination." The World Medical Association also proclaims in its *Declaration of Lisbon on the Rights of the Patient* (2015) with respect to information generally, that patients have the right "not to be informed on his/her explicit request" (article 7d) .

[3] The interplay between preferences and interests is acknowledged to be complex, for example as in Scanlon (1975). A patient's preference not to receive genomic information generates an interest in not receiving that information, and this interest is relevant when considering and balancing the patient's competing interests against each other. While it would be interesting to explore the interaction of preferences, interests and autonomy, this is beyond the scope of the current paper. For the purpose of the present argument, I will treat a preference as a desire which has some degree of alignment with the holder's goals and values, and while it will be assumed that there is a connection between preferences and interests, the nature of this relation will not be elaborated.

[4] The discussion in this paper pertains to adults who have capacity; it is beyond the scope of this paper to consider the implications for young children or adults who are unable to make decisions for themselves.

[5] For a more comprehensive review of the literature on the RNTK, see for example the overview provided by Berkman (2016).

[6] I will use the terms "obligation" and "duty" interchangeably to reflect obligations arising from moral law, while acknowledging that they are sometimes used more distinctly, with an obligation being a more practical set of rules and a duty more strictly associated with a moral law.
[7] While usually not stated explicitly, a default conception of autonomy as freedom of choice seems to provide the rationale for policy documents that enshrine the RNTK, such as the UNESCO *Universal Declaration on the Human Genome and Human Rights* (1997).
[8] The World Health Organisation defines genetics as the study of heredity, and genomics as the study of genes and their functions (https://www.who.int/genomics/geneticsVSgenomics/en/ accessed 11 November 2019). Typically a genetic test will look at a single gene or a small panel of genes, while a genomic test examines all the genes in an organism and how they interact with each other.
[9] This is a paraphrasing of the harm principle as articulated by J.S. Mill in 1859 (Mill 1991). He was concerned with when a person or state might be justified in interfering with the freedom of another person, and concluded that it is only justified in order to prevent harm to others. While a detailed exploration of the harm principle is beyond the scope of this paper, it is mentioned here to assist in characterising liberty rights.
[10] The notion of genomic information *belonging* to a person uses the language of property rights, even though in many jurisdictions individuals do not have property rights per se over their own bodies. However, individuals are generally accepted to have certain rights over what happens to their body, and the right to access their genomic information tends to be included as among these rights. It should be noted that legally individuals are unlikely to hold property rights over the information generated from genetic testing, as this information will belong the organisation that performs the sequencing.
[11] In some clinical contexts a particular clinician might have an obligation to provide certain genomic information to their patient. However this claim about the lack of an obligation on a specific clinician refers to a blanket right that every person has – regardless of whether they might have a high chance of a genetic condition – to access information about their genome.
[12] I acknowledge there may be other alternative concepts by which the RNTK might be understood, but here my intention is to put forward the suggestion that taking it to be a preference is one option that warrants further exploration.
[13] It is recognised that genetic testing is still widely used for many clinical indicators, and in many cases where genomic testing methods are used it would still be rare for a whole genome sequence to be reported. However as genomic testing becomes more widespread and readily available it is important to consider the implications of this information being accessible to patients.
[14] While acknowledging there is a complex debate about the goals of medicine, addressing this question is beyond the scope of the current discussion. Generally it can be assumed that medical practitioners have the goal of enhancing the patient's wellbeing or supporting them to make choices that are in their best interests.
[15] When referring to disclosing or divulging information to patients, these terms are intended to be understood in the context of sound medical communication. This means that the patient is not merely informed of test results, but is supported by health professionals to understand the information, its significance for their life and how it relates to any decisions they might need to make.
[16] Providing information against a patient's wishes must also be undertaken within the tenets of ethical medical practice. Clearly a patient cannot forcibly be given information. Rather, the provision of information that the patient has expressed a preference not to receive is likely to consist of attempts to engage with the patient to explain the reasons why the medical team considers the information could be beneficial to the patient. Done well, such conversations should enhance a patient's autonomy by supporting them to reflect on their life goals, and consider how the information might play a role in enabling them to achieve them.
[17] In some circumstances genetic or genomic test results will be relevant to a particular condition, especially if there is a family history that has prompted testing. However, with genomic testing there is also the possibility that it will yield unexpected findings.