Who Owns Your Cells? A Theoretical Examination of Property Rights over Human Genetic Material

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The increasing use of human genetic material in medical research raises important and urgent questions about ownership. This article argues that the broad lack of informed consent present in medical research using human genetic material undercuts individuals' free will. Further, the conventional view that such genetic material is incapable of having property rights attached to it inhibits research participants' personhood. This article advocates for the recognition of information property rights over human genetic material, and concludes that such an approach is consistent with theories of property rights and ownership posited by Georg Hegel and Margaret Jane Radin.

I INTRODUCTION

Imagine you are chopping wood in your backyard. It is a crisp autumn morning. Birds are conversing softly. And the air is still and clear. You have chopped half of the wood you need to chop and you are growing tired. As you wearily heave the next log onto the chopping block, your mind begins to wander. You bend down to pick up your axe. Your hands slip a little. Suddenly, you experience searing pain — there, on the frosty grass, twitching a little in a widening crimson puddle, is your index finger. Does that finger still belong to you?

In her article "Whose Body Is It Anyway? Human Cells and the Strange Effects of Property and Intellectual Property Law" Robin Feldman uses the example of a man who accidentally severs his finger while chopping wood to illustrate problems with approaches to claims over bodily material. In Feldman's example, the man has a right to that finger ahead of anyone else's competing right (such as, for example, a researcher's right to study that finger).[1] The reason his entitlement to that finger trumps anyone else's is

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1 Robin Feldman "Whose Body Is It Anyway? Human Cells and the Strange Effects of Property and Intellectual Property Law" (2011) 63 Stan L Rev 1377 at 1383.

not because the genetic material encased in his severed finger is information he wishes to keep private. Nor is it an issue of consent.[2] Instead, the finger is his "because it is *his*".[3] It is "intuitively obvious" that the "notion of ownership" cannot begin anywhere but with the "tangible corpus" that constitutes the "me".[4] This sentiment is echoed in Hegel's writings. Hegel states that "[i]t is only through the … self-consciousness's apprehension of itself as free" — by the recognition that one's mind and body are indeed *one's*, to borrow Feldman's emphasis — that a person "takes possession" of herself and, through that, realises that she is hers "and no one else's".[5]

Despite this intuitive sense, personal property rights over one's own body parts and genetic material are not widely recognised. This lack of recognition has various bases. First, if property rights existed over a person's genetic material, it would be more difficult (and require a more arduous consent process than currently exists) for medical professionals to obtain the right to use that genetic material for research purposes. Secondly, there exists a fear that granting property rights over the body will result in its commodification. The body is viewed as fundamental to a person's humanity. To recognise property rights in the body would be to acknowledge that the body has characteristics essential to property: that it can be acquired, possessed and disposed of. As a result, the current status quo does not afford tissue providers enough control over their genetic material.

This article aims to investigate whether acknowledging property rights over genetic material is consistent with Hegelian and Radinian approaches to property. The purpose of investigating property rights is to ascertain whether they are the best way to give providers of genetic material greater control over the collection and use of that material. Greater control is necessary because human genetic material is important to a person's self-identification and free will.

The article focuses more on a theoretical analysis of Hegelian and Radinian approaches to property than on practical mechanisms to increase the control that providers of genetic material have over that material. I will discuss practical considerations, such as incentives and externalities, in a theoretical context rather than in the context of their compatibility with New Zealand law. This is because there has been comparatively little analysis of the interaction between these theoretical approaches to property and the emerging field of medical research that uses Human Genetic Material. This was liberating in some sense, in that it provided the springboard for theoretical analysis.

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2 Feldman somewhat facetiously dismisses the argument that the man "did not properly obtain his own consent before slicing off his finger". At 1383.

3 At 1383.

4 At 1378.

5 Georg Wilhelm Friedrich Hegel *Grundlinien der Philosophie des Rechts* (Nicolaische Buchhandlung, Berlin, 1821) (translated ed: TM Knox (translator) *Hegel's Philosophy of Right* (Clarendon Press, Oxford, 1942) at [57].

In Part II I provide a brief introduction to the use of human genetic material in research. Part III will discuss the current view of property rights in relation to human genetic material. An appraisal of harms that arise out of the status quo will follow in Part IV, focusing on issues of free will, informed consent and the race-identity complex. And, in Part V, I acknowledge the reconcilability of Hegelian and Radinian approaches to property with a recognition of property rights over human genetic material.

However, I argue in Part VI that a property rights framework is not the best way to balance the competing interests at stake: that is, the requirement for greater control of genetic material on one hand, and the need to facilitate medical research on the other. Instead, this article advocates for an information property framework, which I explain in Part VII. Following this, I discuss in Part VIII the appropriateness of enforcing information property rights by way of tort law. Finally, upon brief consideration of New Zealand's legal position in Part IX, this article concludes that an information property framework is reconcilable with New Zealand law.

II HUMAN GENETIC MATERIAL IN RESEARCH

In order to be of value to researchers, human genetic material (such as cells) must be able to be grown "*in vitro*, or outside of their natural body environment".[6] Tissue culture requires extracted cell tissue to be inserted into a medium that allows them to grow.[7] First, the cells must be placed into an environment that contains sufficient nutrients for them to grow.[8] The goal is to create an environment that allows the "motile" cells to move from the tissue (that naturally contains the requisite nutrients for the cells to survive) to the growth medium.[9] Researchers must keep the growth medium contamination-free: for some types of cells, even the most negligible trace of amount of foreign body in the growth medium can be fatal to the cell's survival.[10]

The value of human genetic material in research was most clearly explicated in *Moore v Regents of the University of California*:[11]

> Research on human cells plays a critical role in medical research … [R]esearchers are increasingly able to isolate naturally occurring, medically useful biological substances and to produce useful quantities of such substances through genetic engineering … Products developed

6 Jennifer Lavoie "Ownership of Human Tissue: Life After *Moore v Regents of the University of California*" (1989) 75 Va L Rev 1363 at 1367.
7 Jean de Vellis "Ownership of Cell Lines" (1991) 65 S Cal L Rev 697 at 697.
8 Lavoie, above n 6, at 1367.
9 de Vellis, above n 7, at 697.
10 Lavoie, above n 6, at 1367.
11 *Moore v Regents of the University of California* 793 P 2d 479 (Cal 1990) at 494.

> through biotechnology … include treatments and tests for leukemia, cancer, diabetes, dwarfism, hepatitis-B, kidney transplant rejection, emphysema, osteoporosis, ulcers, anemia, infertility, and gynecological tumors, to name but a few.

Various individuals are involved in research like this and it often takes place at different locations over a lengthy period.[12] This illustrates that it can be difficult to trace downstream ownership of genetic material and even harder for those from whom the material was obtained to exercise control over it. Moreover, it highlights that, for original genetic material to become scientifically and commercially valuable, researchers must invest a significant amount of labour in it.

III THE CURRENT VIEW OF PROPERTY RIGHTS OVER HUMAN GENETIC MATERIAL

In *Moore*, the Supreme Court of California held that the plaintiff did not have a claim in conversion over the excised genetic material the defendant used in patenting the Mo cell line. The Court held that John Moore donated his genetic material and, as such, relinquished any property rights over it. The key reasoning in the case focused on a utilitarian analysis of the effect that recognising property rights in genetic material would have on medical research. Given the "critical" role of genetic material in furthering medical research and the enormous public benefits of such research — such as improved screening and treatment for a variety of cancers, diabetes and problems in both reproductive and somatic cells — the Court ruled to avoid risking disincentives to "socially useful activities".[13] In the Court's view, if Moore's conversion action was successful it would create a "litigation lottery" in which "every cell sample" was a "ticket".[14] Fears of disincentivising medical research being also influenced the outcome in *Greenberg v Miami Children's Hospital Research Institute Inc*.[15]

Aside from this policy reason, a second main consideration underpins the *Moore* decision and the conventional view of property rights over genetic material. This is a Lockean approach: the labour a medical researcher mixes with *raw* genetic material substantially transforms it into a useful product and, therefore, makes it *hers*. As the Court stated in *Moore*:[16]

12 de Vellis, above n 7, at 698.
13 *Moore*, above n 11, at 493–494.
14 At 496.
15 *Greenberg v Miami Children's Hospital Research Institute Inc* 264 F Supp 2d 1064 (SD Fla 2003).
16 *Moore*, above n 11, at 492–493 (citations and footnotes omitted).

> [T]he patented cell line is both factually and legally distinct from the cells taken from Moore's body. … Human cell lines are patentable because "[l]ong-term adaptation and growth of human tissues and cells in culture is difficult — often considered an art" …

From this, we understand that the status quo is based on two important considerations. First, if a person was held to have property rights over their genetic material, it would open the door to veritably endless possibilities of downstream litigation. Furthermore, the innovation and effort required to transform genetic material into material that is usable in research is, in a Lockean sense, enough to shift any proprietary rights over that material from the supplier to the researcher.

In *Greenberg*, the *Moore* decision was upheld. *Greenberg* centred on the use of genetic material that had been supplied to increase access to screening processes for Canavan disease. However, the research findings were patented by the researcher, resulting in reduced access to screening processes. The Court held that there exists "no cognizable property interest in body tissue and genetic matter" where providers had donated it for the purposes of medical research.[17]

IV HARMS TO TISSUE PROVIDERS DUE TO THE STATUS QUO

Moore and *Greenberg* illustrate that the status quo leads to several harms for tissue providers. The nature of research involving human genetic material makes it difficult to predict the endpoint of that research when preliminary collection is taking place. A medical professional may observe an unusual sequence of nucleotides in a patient's DNA and hypothesise that this sequence will have research value. However, at the time of DNA extraction, it is difficult for that medical professional to accurately inform the patient what the ultimate use of research involving his DNA will be. The patient will not be fully cognisant of the downstream implications of him giving consent to the use of his DNA. Given this, it is difficult to say that a patient is truly expressing his free will.

Moreover, conclusions that result from that research could have significant harms to him or the group to which he belongs. For example, research might conclude that his ethnic group is more prone to certain negative health outcomes than other ethnic groups. This could result in discrimination against that ethnic group and make it harder for members of that group to get insurance cover.[18]

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17 *Greenberg*, above n 15, at 1074.

18 Beth M Ford and others "Factors Associated with Enrollment in Cancer Genetics Research" (2006) 15 Cancer Epidemiol Biomarkers Prev 1355 at 1358.

Hegel's Formulation of Free Will

The first issue that emerges is the risk that patients are unable to express their free will. Hegel states that freedom is more than just the "ability to do what we please".[19] The mere act of *choosing* is an arbitrary will, as doing what we please (in Hegel's words) means we are able to will ourselves in any direction we choose.[20] Arbitrary, subjective will is elevated to objective free will by exercising that will in relation to others. An individual's choice to do some action or to acquire an item of property is valid only in that individual's mind. For example, if a person observes an expensive pair of headphones lying unattended on a table in a common room and chooses to claim those headphones as her own, the validity of her entitlement to those headphones solely exists in her mind. On Hegel's view, the "inward idea and will that something is to be mine is not enough to make it [so]".[21] Instead, that inward will must be recognisable to others.[22]

The formation of contracts is one way in which inward will is externally recognised.[23] The process of generating a contract requires two parties to share "one identical will" for a specific point in time (the point of the transaction).[24] When parties are ad idem, the terms of the contract represent an alignment of each party's will that had until this point been subjective. The common will supersedes each party's "arbitrary and alterable" preferences.[25] Therefore, free will is brought into being through person A externally expressing his internal preferences and person B recognising this with his own internal preferences regarding the same thing. This process transforms the will from arbitrary and subjective to free and objective. It is clear that the central component of person A's free will is the requirement that it be identical to person B's will at the time person A expresses it.

This requirement for will to be identical presents problems when human genetic material is being extracted for research purposes.

Informed Consent

Researchers can extract genetic material and seek consent to use it before the research goals are clearly defined. This makes it extremely difficult to obtain the informed consent of suppliers. Prima facie, suppliers cannot give informed consent without an understanding of the specific purposes for which it is sought. Moreover, researchers often do not seek the correct kind

19 Hegel, above n 5, at [15].
20 Thom Brooks *Hegel's Political Philosophy: A Systematic Reading of the* Philosophy of Right (2nd ed, Edinburgh University Press, Edinburgh, 2013) at 31.
21 Hegel, above n 5, at [51].
22 At [51].
23 At [72].
24 At [74].
25 At [79].

of consent. A lack of informed consent — or a lack of awareness of the ultimate goals of the research — risks that the supplier's genetic material could be used for goals that "undermine" their beliefs — "thwarting" their will.[26] The research in question could be "morally repugnant" to the person supplying genetic material.[27] Thwarting the will of patients in this way undermines the right to bodily autonomy.[28]

This lack of informed consent lies at the heart of litigation around ownership of human genetic material. Due to the nature of the extraction process, many patients are unaware that their extracted material is going to be used for research.[29] Henrietta Lacks, whose cells were the first to be successfully cultivated in a laboratory once excised from her body, died at 31 from the cervical cancer that drew the medical profession's attention to her in the first place.[30] Her children were unaware of their mother's contribution to science until two decades after her death, when scientists approached them to collect samples for further study of the cell line she had created.[31] Lacks did not consent to her cancerous cells being used for research. She was unaware of how interesting her cancerous cells were to the medical professionals who administered her radiation therapy in the *coloured* ward of the hospital. As such, she was not able to freely and informedly assent to the use of her genetic material in this way.[32]

Informed consent was also the central issue in the landmark case *Moore*.[33] John Moore sought treatment for hairy cell leukaemia from the medical professionals at the University of California, Los Angeles. Upon the advice of his doctors, he consented to the removal of his spleen. Over the next seven years, Moore travelled from his home in Seattle to Los Angeles, where his doctor continued to perform tests on him and extract tissue. Moore's doctor led him to believe that these tests and samples constituted a necessary element of his leukaemia treatment. In reality, they "played no role in his medical care".[34] Moore instigated action against the University because the cell line that was subsequently created using his genetic material became extremely financially valuable. This is a paradigmatic illustration of how genetic material can be used in a way that undercuts the free will of the supplier. As per Justice Panelli in *Moore*:[35]

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26 Natalie Ram "Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research" (2009) 23 Harv J L & Tech 120 at 125.

27 At 121.

28 Marshall B Kapp "A Legal Approach to the Use of Human Biological Materials for Research Purposes" (2013) 10 Rutgers J L & Pub Poly 1 at 12.

29 JoAnne Belisle "Recognising a Quasi-Property Right in Biomaterials" (2013) 3 UC Irvine L Rev 767 at 774.

30 Feldman, above n 1, at 1381.

31 Dwight Garner "A Woman's Undying Gift to Science" *The New York Times* (online ed, New York, 2 February 2010).

32 Lisa Margonelli "Eternal Life" *The New York Times* (online ed, New York, 5 February 2010).

33 *Moore*, above n 11.

34 Lavoie, above n 6, at 1365.

35 *Moore,* above n 11, at 485 (footnotes omitted).

> … a physician who is seeking a patient's consent for a medical procedure must, in order to satisfy his fiduciary duty and to obtain the patient's informed consent, disclose personal interests unrelated to the patient's health, whether research or economic, that may affect his medical judgment.

Björkman and Hansson discuss this point. The "first principle of bodily rights" is bodily autonomy.[36] In the context of medicine and research, this takes the form of informed consent.[37] A person cannot give informed consent unless he knows what he is consenting to.[38] For example, a person cannot give informed consent to the removal of bodily material unless he knows the purpose of the removal. If the purpose is solely to bring a "therapeutic" benefit to the person himself — that is, the removal of cancerous cells from the body — and the person seeks that therapeutic benefit, then his consent to the removal aligns with its purpose.[39]

This also meets Hegel's criteria if we apply his contractual framework of free will to other decisions between consenting parties, such as medical ones.[40] The features of medical professionals' interactions with patients bear similarities to contract: the professional is providing a service that the patient is seeking; and some form of contract exists already relating to the exchange of medical services for payment (irrespective of whether that payment comes from the patient or from the state through insurance).

Here the medical professional wants to extract bodily material because she wants to bring a therapeutic benefit to her patient. She wants to remove the patient's cancerous cells. The patient similarly wants the therapeutic benefit of having cancerous cells removed from his body. He knows that this is the purpose of the procedure. If he consents to it, he has consented to the totality of the medical professional's aims and, as such, he has made an informed decision. His bodily autonomy has been upheld. In contrast, the medical professional may have the ancillary aim of using the patient's extracted cells to undertake research that would bring about therapeutic advantages for others. If this is so — and the medical professional fails to communicate this to the patient — then the consent he has given to have the cells removed is not fully informed.[41] Most studies using genetic material are not designed to provide a benefit directly to the tissue provider.[42]

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36 B Björkman and SO Hansson "Bodily rights and property rights" (2006) 32 J Med Ethics 209 at 213.

37 At 213.

38 At 213.

39 At 213.

40 Hegel, above n 5, at [74]. We can apply Hegel's contractual framework to non-contractual interactions because the framework's central point is the presence of "identical" will (as opposed to other theories of contract that centre on consideration).

41 Björkman and Hansson, above n 37, at 213.

42 Julie A Burger "What is Owed Participants in Biotechnology Research?" (2009) 84 Chi-Kent L Rev 55 at 60.

The Thwarting of Free Will

Greenberg also addressed informed consent.[43] In contrast to *Moore*, the plaintiffs in *Greenberg* took action because the ultimate goals of the research (to which they consented) were not revealed to them and, ultimately, were ones they disagreed with. This echoes Natalie Ram's discussion of the way in which a lack of informed consent can "thwart" a moral agent's free will by forcing her to participate in projects whose goals she finds objectionable.[44]

Daniel Greenberg was the parent of a child with Canavan disease — a rare disease that results in brain degeneration. He approached a research physician to see whether the physician could gain a better understanding of the disease. In particular, he hoped that the physician would be able to isolate the gene linked to Canavan disease and develop a prenatal test to screen for it.[45] Greenberg recruited a large community of families whose children suffered from Canavan disease and "convinced" them to provide genetic material (such as blood and urine) to aid this research.[46] The material was supplied on the following understanding:[47]

> … that any carrier and prenatal testing developed in connection with the research for which they were providing essential support would be provided on an affordable and accessible basis, and that [the] research would remain in the public domain to promote the discovery of more effective prevention techniques and treatments and, eventually, to effectuate a cure for Canavan disease.

The claim centred on the fact that, after he successfully isolated the gene linked to Canavan disease, the research physician applied to patent the isolated gene. The purpose of the patent was to restrict access to the screening process for Canavan disease that the isolated gene would otherwise have allowed. The patent would enable the medical researcher to monetise his work. However, *crucially*, it stood in stark contrast to both the intention of the plaintiffs — to use the research conclusions to broaden access to diagnosis and treatment for people suffering from Canavan disease — and the agreement they had reached with the researcher. In *Greenberg* the United States District Court for the Southern District of Florida cited *Moore* as authority for the fact that medical researchers had "a duty of informed consent" to inform patients that they were undertaking research using their genetic material *and* that they intended to monetise that research.48 Ultimately, however, the Court held that informed consent did not apply to genetic material that patients had "donated" for research purposes, as to hold

43 *Greenberg*, above n 15.
44 Ram, above n 26, at 125.
45 *Greenberg*, above n 15, at 1066.
46 At 1067.
47 At 1067. The judgment quotes this passage from the plaintiffs' complaint.
48 At 1070.

otherwise would "chill" scientific innovation.49 The judge drew a distinction between the consent researchers obtain and that required of doctors performing medical procedures on patients for therapeutic purposes. This was because research is less likely to result in tangible "egregious" harm to patients than medical procedures.[50] The goal of the former is to yield downstream results, while the goal of the latter is to remedy a pressing wrong within the patient.

This ruling has been criticised. Donna Gitter argues that researchers should be held to a higher duty than physicians to completely disclose their intentions because the power imbalance is greater.[51] Participants in medical research "receive little personal benefit from their involvement".[52] The research that the participant contributes their genetic material to may ultimately be unsuccessful.[53] Also, the medical advances that the research leads to may come about too late for the research participant to obtain a therapeutic benefit.[54] In contrast, a patient being treated by a physician obtains a personal and tangible therapeutic benefit as a result of their treatment.

Moreover, Gitter states that, despite the reliance placed on the research participants' donor status, the *Greenberg* ruling failed to address the nuances of this kind of research. A research participant can be a donor in some circumstances but not in others.

A research participant may volunteer his genetic material for non-commercial research, as was the case in *Greenberg*, where the participants' goal was to increase understanding of and screening for Canavan disease. If, then, the research that results from analysis of the participant's genetic material is used for non-commercial purposes, he is a donor for the purpose of that non-commercial research.[55] If that participant finds that the research to which he consented is actually being used for commercial purposes, he is no longer a donor in the ultimate circumstances of that research.[56]

Put simply, the will of research participants should be used to guide courts when deciding whether their consent was informed. If the outcome of the research contradicts the participants' will, them the outcome was not one they consented to. Their free will was, therefore, not respected.

However, the Court in *Greenberg* recognised the importance of upholding patients' free will (and not forcing patients to participate in projects they disagreed with) via an alternative means: *unjust enrichment*. The Court deemed actionable the plaintiffs' claim that the defendants were

49 At 1070.
50 At 1069.
51 Donna M Gitter "Ownership of Human Tissue: A Proposal for Federal Recognition of Human Research Participants' Property Rights in Their Biological Material" (2004) 61 Wash & Lee L Rev 257 at 334.
52 At 334.
53 At 297.
54 At 297.
55 At 335.
56 At 335.

unjustly enriched by not disclosing their intention to patent their research and restrict access to it.[57] The Court held that, "[h]ad Plaintiffs known that Defendants intended to commercialize their genetic material through patenting and restrictive licensing, Plaintiffs would not have provided these benefits to Defendants under those terms."[58]

We should not construe the Court's decision to recognise the unjust enrichment claim ahead of the informed consent claim as a value judgment on the reasons that drove this litigation.[59] Objectively, an informed consent claim suggests that decisions were made that the plaintiffs did not fully grant their consent to. In Hegel's terms, because they did not possess the requisite information to grant full consent, their minds were not identical to that of the person seeking their consent. In contrast, an unjust enrichment claim suggests the plaintiffs felt the defendants were being financially rewarded for work that was partially theirs. However, the reward that the plaintiffs sought in *Greenberg* was not financial.[60] Instead, their motivations were to improve both the quality and accessibility of information available to Canavan disease patients. The plaintiffs would not have provided "benefits" to the medical researcher (in the form of a large amount of genetic material) if they knew that the researcher's conclusions would be patented and made largely inaccessible to Canavan disease sufferers.[61] The plaintiffs' goals were altruistic, but, instead, the material they supplied was used for a rapaciously capitalist purpose.

Greenberg illustrates how existing ways of handling human genetic material are inadequate. The intention of the supplier at the point she relinquishes control of her genetic material cannot be identical to that of the collector. This is because neither party knows the ultimate use of the material. Furthermore, by *thwarting* the free will of suppliers of genetic material, the process of its collection undermines the *fundamental* right to bodily autonomy.

Issues of Race and Identity

The starting point for a Hegelian assessment of property rights is the concept of free will. Hegel says that free will — or "will which is free in and for itself" — is abstract until it is anchored to something more concrete.[62] It is the anchoring of this abstract free will that brings it into "immediate existence".[63] Hegel argues that property plays a crucial part in anchoring this abstract free will to the tangible and concrete. "[P]roperty is the first

57 *Greenberg*, above n 15, at 1072.
58 At 1072.
59 Namely, lack of profit-sharing as opposed to uninformed consent.
60 Sabrina Safrin "Chain Reaction: How Property Begets Property" (2007) 82 Notre Dame L Rev 1917 at 1934.
61 *Greenberg*, above n 15, at 1072.
62 Brooks, above n 20, at 30.
63 At 30.

embodiment of freedom", meaning that creating contracts and undertaking transactions to acquire property is the clearest example of free will in action.[64] He views free will as an activity, not a possession. People must actively exercise free will — they cannot simply be said to "have" free will.

Property ownership is the "most fundamental comprehension of our freedom in the world" because, by gaining property and gradually creating a domain of our own, "we create an external space where our freedom can become manifest".[65] In David Rose's terms, it is "a system of communication that allows free beings to mark out their distinctiveness and to bring them to an understanding of themselves".[66] The idea that property ownership is an external manifestation of internal free will sheds light on Feldman's discussion of the *intuitive* view of bodily property. When reduced to its essence, the body is the vehicle through which consciousness, thoughts, views, principles and preferences are expressed. The body is the *me* (in Feldman's terms) that catalyses any further external signalling.

If property is an external manifestation of free will, our bodies — the external manifestations of our inner lives — are the starting point for the exercise of that free will. Free will is intimately linked with control, and control with autonomy. A person has free will if she feels as though she is in control of her decision-making and the outcomes that befall her as a result of her choices. A person in control of her decisions is a person who has autonomy. And an autonomous person is able to express her identity to the external world however she chooses — to create her own *external space* based on her own preferences. It is through this process that the person can express her personhood.

The intersection between the expression of personhood and genetic material, therefore, lies in *control*. Genetic materials are the literal building blocks of personhood and, therefore, identity. Genetic material directly creates a person's traits and the traits she might pass on to her offspring.[67] In the context of medical research using human genetic material, analysis of a person's DNA has the potential to reveal that person's predispositions to certain diseases and whether that person's offspring or wider ethnic group share those predispositions.[68]

Given this relationship between genetic material and identity, it is easy to understand why some patients may be unwilling to contribute to research. If a patient believes that his identity or fundamental character traits are communicated through his genetic material, he is cognisant of the way his genetic material contributes to his external space.[69] As such, he may be reluctant to give others the ability to change society's perceptions of his

64 Hegel, above n 5, at [45].
65 Brooks, above n 20, at 32.
66 David Rose *Hegel's Philosophy of Right: A Reader's Guide* (Continuum, London, 2007) at 69.
67 Anya ER Prince "Comprehensive Protection of Genetic Information: One Size Privacy or Property Models May Not Fit All" (2013) 79 Brook L Rev 175 at 175.
68 At 175.
69 Kapp, above n 28, at 19.

external space — for example, by using his genetic material as evidence of negative traits particular to him, his relatives, or people of his ethnic group. Reasons for not participating in research can include cultural fears of those conclusions resulting in "social stigmatization".[70]

This is more than just paranoia. For example, a piece of research may link a particular ethnic group to high rates of obesity. This could result in laypeople unfamiliar with the substance of that research perpetually associating members of that ethnic group with obesity. It is easy to imagine a story like this proliferating through the news media, leading to a widely reported link between a particular identifiable group and a negative trait. Research that results in this serves to strip the autonomy of those individuals to signal to the outside world in the way they would most prefer. Instead, signalling is done for them. As well as this intangible harm of attaching prejudice to particular groups, research that purports to reveal connections between groups and negative health outcomes could have tangible effects. For example, if this information was accessible to third parties, it could make it difficult for the persons or groups concerned to obtain insurance.[71]

A clearer framework is required to allow people to better exercise control over their genetic material once it is no longer part of their body. The best framework may be recognition of property rights in the body; or a framework that falls short of formally recognising property rights, but gives a person greater control over her genetic material.

V RECONCILING HEGEL AND RADIN WITH AN ACKNOWLEDGEMENT OF PROPERTY RIGHTS IN HUMAN GENETIC MATERIAL

At present, the lack of control that people have over their genetic material (which is then used for research) results in significant harms. Most obviously, current frameworks can leave research participants aggrieved at their inability to share in the financial rewards of research that could not have occurred without their involvement. Inadequate consent and the vague nature of medical research when in its infancy can also result in less tangible, but equally significant harms to a person's ability to exercise free will and signal their personhood to the world at large.

This Part will attempt to reconcile Hegel's and Radin's approaches to property rights with an acknowledgement of property rights over human genetic material. It will conclude, after some discussion, that these are, in fact, reconcilable.

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70 At 19.

71 Ram, above n 26, at 130.

Personhood Property and Identity Issues

In Hegel's view, the most significant characteristic of property is that it is "distinct" or "separable" from a person.[72] Alienability is essential. He does not provide an exhaustive list of criteria that we can use to ascertain whether something is alienable or not. Instead, he specifically states that "goods, or rather substantive characteristics" that "constitute [a person's] own private personality" are inalienable.[73] At first glance, this appears to support the view of the body as property. Extracting genetic material is not the same as separating a "substantive characteristic", as the cells will grow back. A "substantive characteristic" is a cognitive lens through which a person's entire life is shaped — including her religion, her "ethical life" and her personality as a whole.[74] Genetic material falls outside Hegel's class of things that should be alienable.

It is instructive to look at his brief discussion of suicide to ascertain whether this class of things extends to the body — a *special case* for Hegel.[75] Property rights only apply to things that are external.[76] Suicide represents taking ownership of one's "immediately single personality".[77] While suicide might result in external harm, it represents the alienation of the very consciousness and life that defines humanity. Bodily autonomy does not go this far. Essentially, Hegel argues that, because property is our way of expressing our preferences through externalising our free will, we can only view as property things we are able to externalise.

For the purpose of discussing the applicability of property rights to human genetic material, this argument is not particularly instructive. It may be anachronistic to criticise Hegel for characterising all property rights in the body as being reducible to the suicide question. However, the fact remains that we can externalise our genetic material without reducing our substantive characteristics to zero in the same way that taking our life would.

Radin's analysis of property rights has a similar focus. Radin states that there are two categories of property: fungible property; and personhood property. Personhood property is not a strict category — rather, it is property that "enables persons to establish and develop a sense of self".[78] Personhood property should not be fungible because to commodify it would be to allow the commodification of the self or the "attributes and things" that are "integral to personhood".[79] It is similarly difficult to reconcile human genetic material with Immanuel Kant's famous statement that the use of "humanity"

72 Hegel, above n 5, at [41].
73 At [66].
74 At [66].
75 JE Penner *The Idea of Property in Law* (Oxford University Press, Oxford, 1997) at 176–177.
76 Hegel, above n 5, at [49].
77 At [70].
78 Carol M Rose "Psychologies of Property (and Why Property is not a Hawk/Dove Game)" in James Penner and Henry E Smith (eds) *Philosophical Foundations of Property Law* (Oxford University Press, Oxford, 2013) at 273.
79 Margaret Jane Radin "Market-Inalienability" (1987) 100 Harv L Rev 1849 at 1906.

in oneself — or in others — should always be for an end in itself, and never merely as a means to an end.[80] As discussed, human genetic material can be a means to the broader end of learning more about illnesses and creating new ways to diagnose and treat them.

Moreover, Radin defines commodification as the "social process by which something comes to be apprehended as a commodity".[81] Once something is commodified it is considered something that is "suitable for trade".[82] It is objectified in the literal sense — it is reduced to an object with monetary or trade value. Radin opposes this due to a moral view that some things are too essential to personhood to be objectified.[83] Radin also raises concerns that recognising property rights over parts of the body will create incentives to trade in it.[84] In particular, the universal commodification of organs and specific bodily operations (such as surrogacy) would disproportionately affect people in lower socio-economic groups as they would be more willing to trade off long-term health outcomes.[85] This argument has parallels in Kantian philosophy. When using humanity as a means to an end, the persons affected are "relegated" to a "sub-huma[n]" status.[86]

From the discussion in Part IV, it is evident that the current lack of property rights conferred over genetic material threatens fundamental aspects of personhood and humanity. It is anachronistic to criticise Hegel, Kant and Radin for neglecting to discuss the extraction and successful replication of human genetic material in their assessment of things we should have property rights over. But it does reveal a gap in their analyses. It is possible to remove genetic material without permanently depriving a person of it — cells replicate and grow back.

Furthermore, it reveals a central tension in this article. On one hand, I have argued that the harms to personhood that arise when genetic material is used in an unauthorised manner strike at the heart of a person's free will. On the other hand, I have dismissed Hegel's arguments about the inalienability of things with ties to our immediate personality on the simple basis that cells grow back and are not permanently alienated. These two points of view can coexist. The harm Hegel and Radin are trying to avoid is the undercutting of personhood by commercial imperatives — essentially, the choice to trade property in the body for commercial gain, resulting in

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80 See Immanuel Kant *Grundlegung zur Metaphysik der Sitten* (Felix Meiner Verlag, Hamburg, 1999) (translated ed: Allen W Wood (translator) Immanuel Kant *Groundwork for the Metaphysics of Morals* (Yale University Press, New Haven, 2002)) at 47.

81 Margaret Jane Radin *Contested Commodities* (Harvard University Press, Cambridge, MA, 1996) at xi.

82 At xii.

83 At 161.

84 At 161.

85 At 151, 152 and 161.

86 BM Dickens "The Control of Living Body Materials" (1977) 27 UTLJ 142 at 145 as cited in Randy W Marusyk and Margaret S Swain "A Question of Property Rights in the Human Body" (1989) 21 Ottawa L Rev 351 at 360.

reduced body property. Due to the nature of genetic material, there is not a finite *amount* that can be given away — there is not necessarily a slippery slope towards trading away the entire corpus. The end point is not in slavery.[87]

Feldman also views the current law as hypocritical. The lack of property rights over the body is ostensibly to protect vulnerable groups from economic exploitation. This is based on the idea that people in financial need are more likely to *sell* their genetic material than those who are financially stable. However, the current law allows researchers who use that genetic material to profit.[88] As seen in *Moore*, this can incentivise researchers to deliberately conceal the purpose of medical procedures to avoid alerting patients to the fact that their material may ultimately be used to create an incredibly lucrative product. This cannot have been Hegel's or Radin's intention. Furthermore, applying Radin's analysis about commodification potentially resulting in an organ market ignores the imperatives behind any potential market for human genetic material. While organs are broadly useful and in demand, human genetic material is not useful in and of itself. Demand for it is curtailed by the fact that the most useful material comes from the small group of people suffering from a particular illness that makes their cells behave in a particular way. Furthermore, patients often supply genetic material for the research benefits that could accrue to them, other sufferers of their affliction and their descendants. It is possible to simultaneously view genetic material as being connected to personality, while dismissing the notion that it is *so* essential to personhood that its commodification would erode our humanity.

Definitional Issues

If we accept the view of Hegel and Radin, it is unclear whether genetic material fulfils the criteria of *property*. Commonly accepted essential features of property rights include: "the unrestricted and exclusive right to a thing; the right to dispose of a thing in every legal way, to possess it, to use it, and to exclude everyone else from interfering with it".[89]

First, Hegel and Radin would argue that genetic material falls short of this definition because there is no right to dispose of it. This is because they include genetic material with the rest of "the body" — and, therefore, personhood property — for the purposes of their discussion about alienability. To them, genetic material falls outside disposable material because to include it would allow us to gradually dispose of a thing that is fundamental to our humanity.

87 Feldman, above n 1, at 1384.
88 At 1384.
89 Henry Campbell Black *Black's Law Dictionary* (5th ed, West Publishing, Minnesota, 1979) at 1095.

Moreover, there is disagreement about whether a person has a right to possess their own genetic material. Possession requires a clear act.[90] In Carol Rose's terms, it requires "some kind of statement".[91] Prima facie, this is at odds with a person's relationship with their genetic material. We do not take possession over it; if anything, we passively acquire or become it at the point we are conceived.

Thom Brooks reads Hegel's definition of property as being *external* to mean that a thing can be property if it gives the "possibility" of externalising free will.[92] Again, genetic material does not give the possibility of externalising free will. As long as it is part of us, it is trapped internally. It is impossible to externalise the fundamentally internal — we cannot remove our consciousness from ourselves, nor can we give another our thoughts.

Harold Demsetz addresses the second half of the definitional issue: that genetic material is not property because the person did not actively possess it. Demsetz states that "[a] primary function of property rights is that of guiding incentives to achieve a greater internalization of externalities."[93] The externalities of the current framework around human genetic material were not existent at the time Hegel and Radin wrote their substantive theories. Technology has advanced such that we can dichotomise genetic material into that which is in the body and that which has been alienated. Once it has been alienated, it is then able to be possessed. Indeed, this is the foundation of the entire problem. Granting greater rights to those whose material is used in research would internalise the two major problems that have emerged due to a lack of property rights: undermining free will; and undermining one's autonomy to signal to the external world. It would ensure that researchers and participants have identical will throughout the process.

VI THE DANGERS OF AN OVER-PRESCRIPTIVE PROPERTY RIGHTS FRAMEWORK

Recognising property rights in human genetic material would grant people far greater control over that material. In doing so, it would mitigate the externalities of medical research that uses human genetic material. However, a strict property rights framework carries its own externalities.

Economic inefficiency is the central argument against recognising a full property right in genetic material. To do so would be to risk "mir[ing]" research in lengthy transaction disputes.[94] It could overly burden the progress of research if each individual's genetic material required the full-

90 *Pierson v Post* 3 Cai R 175 (NY SC 1805).
91 Carol Rose "Possession as the Origin of Property" (1985) 52 U Chi L Rev 73 at 77.
92 Brooks, above n 20, at 33.
93 Harold Demsetz "Toward a Theory of Property Rights" (1967) 57 Am Econ Rev 347 at 348.
94 Charlotte H Harrison "Neither *Moore* nor the Market: Alternative Models for Compensating Contributors of Human Tissue" (2002) 28 Am J L & Med 77 at 86.

blown transfer of property rights. This is the "litigation lottery" referred to in *Moore*.[95] It has been referred to as the "tragedy of the anticommons": the way in which multiple owners of a particular resource can each exclude others from that resource, resulting in its underuse.[96] In other words, "fragmented and overlapping intellectual property rights" could cripple research.[97]

A recognition of property rights could also harm the relationship between doctors and their patients. The issue of trust "plagues a property-rights" system.[98] At best, "bedside bargaining" about acceptable fees for tissue samples could adversely affect the quality of treatment patients receive.[99] If a physician providing therapeutic treatment is also the lead researcher on the project for which he is seeking the patient's genetic material, "an intolerable conflict of interest" could arise.[100]

VII INFORMATION PROPERTY: THE WAY FORWARD

This Part discusses an information property framework and supports it as the most viable way to protect the rights of providers of human genetic material.

Information Property

Natalie Ram proposes a middle ground between a status quo that offers inadequate protection of rights and a property rights framework that is too rigid. She proposes a framework based around informational property. This framework would attach a "property-like" right to the information contained within genetic material.[101] It is "a new way of looking at an old problem".[102] The true value of genetic material lies in its ability to be replicated in a laboratory, so the information it contains can be studied more closely. The value of the genetic material in *Greenberg* was in the information it provided about the gene that carries Canavan disease. The value of Henrietta Lacks' cervical tissue was in its genetic information, which enabled it to be replicable under laboratory conditions. By creating a framework that protects the information within the genetic material, rather than the genetic material itself, we can avoid contravening Hegel's and Radin's ideas about what can and should be alienable. Genetic material is sufficiently distinguishable from

95 *Moore*, above n 11, at 496.
96 Michael A Heller and Rebecca S Eisenberg "Can Patents Deter Innovation? The Anticommons in Biomedical Research" (1998) 280 Science 698 at 698.
97 At 701.
98 Harrison, above n 94, at 91.
99 At 91.
100 At 91.
101 Ram, above n 26, at 143.
102 Jacqueline Lipton "Information Property: Rights and Responsibilities" (2004) 56 Fla L Rev 135 at 170.

the kinds of *things* to which Hegel and Radin refer so as to be exempt from their conclusion that personhood property should be inalienable.

Efficacy

The reason an informational property framework is preferable to a property rights framework lies in its operation. In practice, an informational property framework would operate similarly to open-source licencing. Researchers would present participants with a form that provides for tiers of consent. Ram offers an example:[103]

> 1. My tissue may be kept for use in research to learn about, prevent, or treat cancer. [Yes/No]
> 2. My tissue may be kept for use in research to learn about, prevent, or treat other health problems (for example: diabetes, Alzheimer's disease, or heart disease). [Yes/No]
> 3. Someone from xyz may contact me in the future to ask me to take part in more research. [Yes/No]

Tiered consent only requires "one consent event".[104] This is its key benefit. Tiered consent has also been referred to as "'[t]urbo' consent" due to the way it enables individuals to make the entire spectrum of their preferences clear in a single instance.[105] In other words, researchers would not have to obtain consent from tissue providers at every step of their work. This is especially useful given that a variety of professionals undertake research, often over a long period, and sometimes at different locations. Tissue providers could clearly express their preferences — that is, conditions of use — from the outset to ensure maximum control and mitigate harms to their free will that could arise from use that contradicts their requests. Providers could specify that they do not consent to researchers using their genetic material for eugenic research.

An informational property framework allows tissue providers maximum control. A tissue provider could specify that she wants the outcomes of the research to be widely accessible, meaning that a researcher who intends to restrictively license her findings would be unable to use that person's genetic material.[106] Alternatively, the licence could require that the tissue provider shares in the fruits of the research.[107] Informational property recognises the contribution tissue providers make to medical research and affords them greater control over their material than mere consent.

However, it also acknowledges the fact that most of the benefits of research that uses genetic material are due to the efforts of the researchers

103 Ram, above n 26, at 150–151.
104 At 151.
105 Belisle, above n 29, at 791.
106 Ram, above n 26, at 148.
107 At 148.

themselves. This is why informational property falls short of recognising tissue providers' intellectual property interest in their genetic material — providers "invest no creativity" in creating their genetic material.[108] It also answers the question of possession. Informational property falls short of being a full property right. It, therefore, avoids having to answer questions about, for example, the ability of tissue providers to possess their tissue.

Moreover, an informational property framework that draws on open-source licencing would allow individuals to withdraw their consent at any time.[109] Crucially, this would not mean that existing research using their material would have to be abandoned. The nature of open-source licencing is such that the licence-holder cannot retrospectively revoke licences she has granted. However, she does have the option of restricting future grants of that licence.

In practice, the ability to withdraw would be granted to the tissue provider based on the terms of his original licence. A tissue provider may state that he wishes the researcher to contact him before the researcher commences research that is different to that which the tissue provider originally consented to. In this way, the tissue provider can control downstream uses of his genetic material.[110] Indeed, tissue providers frequently elect to require being re-contacted ahead of future, distinct research (as opposed to granting unfettered and absolute consent to any and all future research).[111] This highlights the importance of recognising providers' long-term preferences.

Minority Groups

The terms of the tissue provider's original consent could prohibit research that directly links a minority group to negative health outcomes. This is because participants would be able to specify the areas of research to which they consent. A survey of Jewish research participants revealed they were more likely to consent to research about preventable, treatable illnesses than to research about perceivably undesirable characteristics that could reflect badly on their community, such as frugality and homosexuality.[112] This also bridges the current utilitarian difficulty of undertaking research that uses material from persons or groups with religious — or other — objections to genetic research.

108 At 143.
109 At 149.
110 At 151.
111 Donna T Chen and others "Research with Stored Biological Samples: What Do Research Participants Want?" (2005) 165 Archives of Internal Med 652 at 654 as cited in Burger, above n 42, at 67.
112 Marc D Schwartz and others "Consent to the Use of Stored DNA for Genetics Research: A Survey of Attitudes in the Jewish Population" (2001) 98 Am J Med Genet 336 as cited in Burger, above n 42, at 70.

A tiered consent process would also address the fact that ethnic minorities tend to be more distrustful of medical researchers than ethnic majorities. African-Americans, for example, consent to genetic research at a lower rate than white patients.[113] 41.7 per cent of surveyed African-American patients were likely to distrust that their physician would fully explain the implications of participating in research, compared to just 23.4 per cent of surveyed white patients.[114] Similarly, more African-American respondents (45.5 per cent) expressed fear that their physician would expose them to unnecessary risks during surgery than white respondents (38.4 per cent).[115]

This distrust from ethnic minorities is also seen in New Zealand. In a study by the Health Services Research Centre at Victoria University of Wellington, researchers conducted interviews with Māori board representatives at public health organisations. One conclusion drawn was that "an element of fear" pervades Māori interaction with the health system.[116]

This is not only an indictment on the health system's treatment of minority groups. It also causes the utilitarian harm of reducing the pool of willing research participants. One of the primary aims of research using human genetic material is to build a comprehensive, multifaceted understanding of different diseases. In doing so, researchers strive to find new ways to screen for and even treat those diseases. Different ethnic groups have different genetic predispositions to particular conditions (as well as different autoimmune responses to those conditions). If an externality of the current system is that people from minority groups distrust the health system, this important research goal is undermined.

A further externality is that reduced trust in the medical system can result in worse health outcomes. It may be harder for doctors to "maintain therapeutic relationships" with patients if there is an underlying distrust of the doctors' intentions.[117]

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113 Donna T Chen and others "Research with Stored Biological Samples: What Do Research Participants Want?" (2005) 165 Archives of Internal Med 652 at 654 as cited in Ram, above n 26, at 127; Beth M Ford and others "Factors Associated with Enrollment in Cancer Genetics Research" (2006) 15 Cancer Epidemiol Biomarkers Prev 1355 at 1357 as cited in Ram, above n 26, at 127–128; Geraldine M McQuillan, Qiyuan Pan and Kathryn S Porter "Consent for Genetic Research in a General Population: An Update on the National Health and Nutrition Examination Survey Experience" (2006) 8 Genetics Med 354 at 357 as cited in Ram, above n 26, at 128; and Patricia G Moorman and others "Racial Differences in Enrollment in a Cancer Genetics Registry" (2004) 13 Cancer Epidemiol Biomarkers Prev 1349 at 1350 as cited in Ram, above n 26, at 128.

114 Giselle Corbie-Smith, Stephen B Thomas and Diane Marie M St George "Distrust, Race and Research" (2002) 162 Arch Intern Med 2458 at 2459.

115 At 2459.

116 Lynne Russell (Pere), Kirsten Smiler and Hilary Stace "Improving Māori Health and Reducing Inequalities between Māori and non-Māori: Has the Primary Health Care Strategy Worked for Māori?" (Health Services Research Centre, Victoria University Wellington Health Services Research Centre, September 2013) at 32.

117 Harrison, above n 94, at 85.

An informational property framework could go some way to assuage the concerns of minority groups. Importantly, it would grant members of these groups greater control over their genetic material through a clearer consent process.

VIII ENFORCEMENT OF INFORMATION PROPERTY RIGHTS IN TORT

Once established, information property rights would be enforced in tort. Tort law already affords baseline protection to tissue providers through the causes of action of *negligence*, *conversion*, *breach of privacy* and *informed consent*.[118] However, tort generally defines harm as tangible — for instance, physical or economic.

As we have seen, many harms that arise from poorly regulated tissue use are intangible. The chain of liability in tort is also unlikely to stretch sufficiently far to protect tissue providers. At present, it is likely that tortious uses of genetic material occurring downstream to the original consent event would only arise out of the failure of a person with a direct relationship to the tissue provider to obtain the necessary permissions.[119] However, this may still be weak ground for action in tort because the duty owed to the tissue provider wanes the further downstream the breach takes place.[120]

In contrast, an information property framework affords tissue providers greater control downstream. This is because, while an ordinary action in tort for downstream unauthorised use of material hinges on a breach of duty, information property "undergirds" that breach with a recognisable quasi-property interest in the material.[121]

There is also scope to enforce informational property rights under a liability rule.[122] One benefit of an informational property framework is that it avoids the significant cost of establishing on a case-by-case basis the value of the particular genetic material. Liability rules allow for a "collective determination" of value, meaning that the almost insurmountable burden of establishing value at the beginning of every transaction is overcome.[123] Liability rules also "facilitat[e] a combination of efficiency and distributive results" that would be hampered by the absolutism of a property rule.[124]

118 Ram, above n 26, at 156.
119 At 160.
120 At 160.
121 At 161.
122 Harrison, above n 94, at 88.
123 Guido Calabresi and A Douglas Melamed "Property Rules, Liability Rules, and Inalienability: One View of the Cathedral" (1972) 85 Harv L Rev 1089 at 1106.
124 At 1110.

In the context of genetic material, Charlotte Harrison advocates for establishing "predictable standards" around compensation.[125] In her formulation, the first step after a participant gives his turbo consent and establishes his informational property interest in the genetic material is to assess the material for its utility.[126] If it meets a requisite standard of utility — to be set by an independent tribunal — the tissue provider is eligible for standardised amounts of compensation. In practice, it might be difficult to arrive at an objective, widely accepted *price* for genetic material. Furthermore, ascertaining its utility would be time-consuming. However, Harrison's proposal offers a path to compensating tissue providers in a way that does not threaten to derail the entire research process.

IX COMPATIBILITY WITH NEW ZEALAND LAW

This section explores whether an information property framework can be implemented in New Zealand by considering its compatibility with New Zealand law.

In New Zealand, genetic material used for research purposes is governed by the Human Tissue Act 2008 and the Code of Health and Disability Services Consumers' Rights. The Human Tissue Act stipulates that researchers must specifically seek consent for the purpose for which they intend to use the genetic material.[127] The Code provides that genetic material extracted during a medical procedure can only be used with the informed consent of the tissue provider.[128] The Code further provides that tissue providers are able to withdraw their consent from services at any time.[129]

New Zealand already recognises the importance of obtaining consent based on the purpose for which the genetic material will be used. An informational property framework would be consistent with the current ethical approaches to research. Therefore, New Zealand should implement an information property approach to human genetic material. Health professionals and researchers should obtain turbo consent from every patient or research participant. An external body could independently valuate genetic material, resulting in standardised compensation. And participants should be given the opportunity to specify from the outset the research to which they do and do not consent. Furthermore, they should be given the ability to control downstream use of their genetic material *and* withdraw

125 Harrison, above n 94, at 88.
126 At 88.
127 Human Tissue Act 2008, s 9(1)(a).
128 Code of Health and Disability Services Consumer Rights, Right 7(10)(a).
129 Right 7(7).

their consent at any time. These measures will protect participants' free will and autonomy.

Overall, implementing an information property framework would be a landmark opportunity for New Zealand to lead the world by protecting the rights of tissue providers.

X CONCLUSION

Using human genetic material in medical research reaps enormous benefits. Its use has already greatly improved screening and treatment processes for a variety of diseases. However, it brings with it "psychosocial risks".[130] Individuals whose genetic material has been used for research can feel as though their free will has been undermined. This may occur through either a lack of the individuals' informed consent or an unawareness that researchers would use their material for purposes to which they fundamentally object. Moreover, research can deprive individuals of the ability to represent themselves to the wider world in a manner of their choosing. Research that casts aspersions on particular ethnic groups, for example, can undermine the personhoods of those individuals whose genetic material contributed to those conclusions.

This indicates a strong need to afford greater control over genetic material to the individuals that supply it. A property rights approach can be reconciled with the views of Hegel and Radin. However, an information property framework is the most effective way forward. This framework is reconcilable with New Zealand law.

The impetus for this article was Ta-Nehisi Coates' *Between the World and Me*.[131] Coates' book addresses the violence the United States police force directs towards African-Americans and is a lengthy meditation on what it means to be in control of one's own body. The question of our relationship to our body is a fundamental one that is easy to ignore amidst more pressing concerns. However, it is one that is important to answer and there are few better places to begin than with the building blocks of our existence — our genetic material.

130 Harrison, above n 94, at 92.
131 Ta-Nehisi Coates *Between the World and Me* (Spiegel & Grau, New York, 2015).