Making the Case for a Privacy Law Approach to Human Biomaterial Regulation

by

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A thesis submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Faculty of Law
University of Alberta

Abstract

Human biomaterials are in high demand from a wide variety of stakeholders, giving rise to tension and debate about the amount of control individuals should have over materials derived from their own bodies. As biobanks, universities, governments, and corporations increasingly assert control over biomaterials, individuals are left with a paltry set of legal options to protect their interests or obtain remedies when their interests are infringed. This thesis therefore identifies the limitations of existing regulatory options and proposes privacy law as a new legal tool to better recognize and protect individual interests in biomaterials. This is accomplished through a doctrinal examination of relevant law and literature applicable to biomaterial regulation and privacy law across common law jurisdictions.

This work considers a range of statutory instruments and governance frameworks that regulate certain biomaterial uses (such as transplantation, research, and assisted reproduction) and shows that these instruments lack enforceable rights and remedial mechanisms. This work then considers the prospect of property law to fill this remedial vacuum, an issue that has dominated the literature in biomaterial regulation. An examination of relevant case law demonstrates that, where there are genuine contests of control over biomaterials between individuals and institutions, property rights will likely be allocated to institutions. This is, in part, because property law is better suited to recognize and protect the economic and market-based interests at stake for institutions rather than the dignity and autonomy-based interests of individuals.

Privacy law, on the other hand, is designed to protect autonomy and dignity-based interests. This work therefore considers whether information privacy statutes and privacy torts could be useful to recognize and remedy violations of these interests. With respect to information privacy statutes, this thesis considers whether there is scope for physical biomaterials to be treated as a form of "personal information", thus attracting new legal rules for their collection, storage, use, and transfer. This idea originates from discourse identifying an "informatization" of the human body currently underway. As the genetic information within

biomaterials continues to grow in value and becomes increasingly accessible, there is less reason to maintain regulatory distinctions between "physical" biomaterials and the "information" within them.

With respect to privacy torts, this thesis argues that there are both informational and personal privacy interests in biomaterials that, when violated, could be remedied through these privacy-based causes of action. This thesis considers situations of surreptitious genetic testing, biomaterials used in research without consent, and interferences with the deceased bodies of a plaintiff's loved one, to illustrate the potential operation of privacy torts to biomaterial cases where a plaintiff might otherwise be left without a remedy. This analysis shows that privacy torts may offer protection in some circumstances, however, there is great jurisdictional variability in the privacy tort landscape, and individual success may therefore depend on the factual underpinnings and location of the relevant claim.

Overall, the field of privacy law is growing in scope, and both legislatures and judiciaries have demonstrated a willingness to respond to social harms from advancing technologies by expanding the boundaries of this legal field. While current privacy frameworks may need to evolve further to meaningfully address and overcome the limitations of other relevant frameworks, this thesis argues that it is possible and potentially beneficial for the law to evolve in this direction to provide individuals greater control over their biomaterials. This possibility calls for greater scholarly attention to the potential role of privacy law in this context. At a minimum, a privacy law comparison provides insights into how legal claims, rights, and remedies need to be structured to provide individuals with the protection they currently lack as the quest to solve the complex problem of human biomaterial regulation continues.

Acknowledgements

I would like to express my heartfelt gratitude to the following individuals and organizations whose support and guidance were instrumental in completing this thesis:

First and foremost, I am immensely thankful to my primary supervisor, Professor Timothy Caulfield, for inducting me into life as an academic. From our many collaborations, I have become a better writer, researcher, and scholar, and I am deeply grateful to have had such a strong and supportive figure in this project, and my career more broadly, from which to model my own academic journey.

I am also very grateful for the time, attention, and support of my supervisory team: Professors Timothy Caulfield, Erin Nelson, Cameron Jefferies, and Lori West, who thoroughly engaged with my concept for this work and helped shape the direction of this project. I would like to specifically express my appreciation for Professor Nelson's constructive feedback on a later draft of my work, which helped me refine the thesis into its final form. And I am deeply grateful for Dr West's mentorship over the years, including a cross-border pep talk in Adelaide mid-way through this endeavour to help keep me going.

I would also like to thank the various colleagues who have served as Associate Dean of Graduate Studies throughout this journey for their support, including Professor Matthew Lewans and Dean Barbara Billingsley, who helped initiate me to the PhD program, Professor Linda Reif, who served as Chair for my candidacy examination and oral defence, and Associate Professor Jessica Eisen for helping me cross the finish line.

I am grateful to the external examiners, Professor Dorit Reiss and Dr Brendan Leier, for engaging with my work and offering their expertise. I thoroughly enjoyed discussing my research with them and hearing their perspectives on my work, and appreciate their thoughtful feedback.

I would also like to thank and acknowledge the Law Society of Alberta for their financial support of this project through the Viscount Bennett Scholarship, and the University of Adelaide Law School for providing travel assistance for me to attend my candidacy examination.

I am also indebted to the many colleagues at both the University of Alberta and the University of Adelaide who have provided guidance, support, and encouragement throughout this journey. Words cannot adequately express my gratitude to Professor Ngaire Naffine, whose support throughout this process has been invaluable. From reading drafts of my work to the countless hours she has spent with me, discussing and challenging my ideas, Professor Naffine's support has been the epitome of collegiality. I consider myself very fortunate to have a standing invitation to pop across the hall into her office for words of wisdom and encouragement (sometimes over a glass of wine) any time I need it.

I am also grateful to my colleague and friend, Dr Josh Curtis, for his words of guidance and his comments on an early draft of my Introduction, as well as my sister, Alicia Toews, for support with proof-reading. I am also appreciative of the support shown by Professor Judith McNamara, Dean of Adelaide Law School, and former Dean, Professor Melissa de Zwart, both of whom have

shown great understanding and encouragement of my efforts to complete this dissertation while performing my other duties as a full-time academic.

I must also express my profound gratitude to my family and friends for their unwavering support throughout this endeavour. As with most doctoral dissertations, there have been ups and downs with periods of inspiration and moments of despair, and through it all, I have been able to count on my community, both domestic and international.

I am especially grateful to my parents, Lorne and Marilyn Toews, and my sister, Alicia Toews, for always believing in me and enthusiastically cheering me on. I am grateful to Aunty Vera for routinely checking in with me to offer me love and support. I am grateful to my nieces and nephew, Ivy, Ayla, and Kian, as sources of inspiration and joy throughout this process. And I am grateful to Poncho, the greatest cat in the whole wide world, who has kept my lap warm for most of the writing of this work (including the words in this Acknowledgement).

Last, but certainly not least, I extend my heartfelt thanks to my husband, Christian Haebich. Throughout the countless hours of research, writing, and revising, his patience, encouragement, and belief in my abilities have been a constant source of strength.

I am deeply grateful to all those who have contributed to this thesis in various ways. Your support has been instrumental in helping me reach this milestone.

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Abbreviations

ALRC: Australian Law Reform Commission

DTC genetic testing: direct-to-consumer genetic testing

ECHR: European Convention on Human Rights

GDPR: General Data Protection Regulation

NPRM: Notice of Proposed Rule-making

PIPEDA*:* Personal Information Protection and Electronic Documents Act

1. Introduction

A. Biomaterial Regulation: A Complex Problem

We are entering the "post-digital age"[1] amidst a "genetic revolution"[2] during the "century of biology".[3] While the status of our current technological era may be debatable, and the language surrounding these proclamations often hyperbolic in nature,[4] it is clear that developments in digital and biotechnologies are altering the way we experience the world and even raising questions about human identity.[5] In particular, technology has changed the way we value our bodies and bodily materials, the latter becoming a highly sought-after resource.

Thousands of research biobanks around the globe[6] store hundreds of millions of human samples as a genetically rich resource for researchers.[7] Millions of people have paid for direct-to-consumer (DTC) genetic testing from private corporations.[8] And governments forcibly require suspects of crime to provide samples to aid in criminal investigations.[9] These examples illustrate not only that human biomaterials are in high demand by a wide variety of stakeholders, but also

[1] Adam Tinworth, "How to survive in the Post-Digital Era" (30 May 2019), online: *NEXT Conference* <nextconf.eu> [perma.cc/8S3K-2L5K].
[2] Robert Chapman, "Are We Really Prepared for the Genetic Revolution?" *Scientific American* (27 May 2018), online: <www.scientificamerican.com> [perma.cc/DG42-P38Q]; Javier Yanes, "CRISPR, the Genetic Revolution of the 21st Century" (30 March 2018), online: *OpenMind* <www.bbvaopenmind.com> [perma.cc/DN6U-NXF7].
[3] Craig Venter & Daniel Cohen, "The Century of Biology" (2004) 21:4 New Perspectives Q 73; Nikolas Rose, "The Human Sciences in a Biological Age" (2013) 30:1 Theory, Culture & Society 3.
[4] Neil C Ramiller, "HYPE! Toward a Theory of Exaggeration in Information Technology Innovation" [2006]:1 Academy Management Annual Meeting Proceedings A1; Timothy Caulfield, "Popular Media, Biotechnology, and the Cycle of Hype" (2004) 5 Hous J Health L & Pol'y 213.
[5] Peter Nagy & Bernadett Koles, "The Digital Transformation of Human Identity: Towards a Conceptual Model of Virtual Identity in Virtual Worlds" (2014) 20:3 Convergence 276; Slavomír Gálik, "On Human Identity in Cyberspace of Digital Media" (2019) 7:2 European J Transformation Studies 33; Muireann Quigley, *Self-Ownership, Property Rights, and the Human Body: A Legal and Philosophical Analysis*, Cambridge Bioethics and Law (Cambridge: Cambridge University Press, 2018) [Quigley, *Self-Ownership*].
[6] Researchers have recently counted over 1000 biobanks in Canada, Australia, and Europe, alone: Sheila O'Donoghue et al, "How Many Health Research Biobanks Are There?" (2022) 20:3 Biopreservation & Biobanking 224.
[7] As of 1999, there were already over 300 million samples stored in the US alone: Elizabeth R Pike, "Securing Sequences: Ensuring Adequate Protections for Genetic Samples in the Age of Big Data" (2016) 37:6 Cardozo L Rev 1977 at 1982–83.
[8] *Ibid* at 1983.
[9] David B Wilson, David McClure & David Weisburd, "Does Forensic DNA Help to Solve Crime? The Benefit of Sophisticated Answers to Naive Questions" (2010) 26:4 J Contemporary Crim Justice 458; Jeremy Gans & Gregor Urbas, *DNA Identification in the Criminal Justice System*, Report No 226 (Canberra: Australian Institute of Criminology, 2002).

that it is increasingly the genetic information within or extracted from these materials that makes them so valuable.

As the value of biomaterials has changed and increased over time, these materials have become contested.[10] An ongoing point of tension and debate underlying the vast uses for biomaterials and genetic information is the amount of control individuals should have over materials derived from their bodies.[11] In the biomedical research context, for example, there are debates about whether a right to withdraw can or should exist for biomaterials accessed through biobanks[12]; whether one-time broad consent conflicts with an individual's ongoing rights and interests in their biomaterials[13]; and whether consent should be required for the collection and use of all biomaterials in research, regardless of their identifiability.[14] The public interest served by the progress of science needs to be balanced against individual autonomy and privacy.[15] There is a feeling among segments of the public,[16] patient and consumer rights groups,[17] and academics,[18]

[10] Imogen Goold, "Why Does it Matter how we Regulate the Use of Human Body Parts?" (2014) 40:1 J Med Ethics 3 [Goold, "Why Does it Matter"].
[11] *Ibid*.
[12] Søren Holm, "Withdrawing from Research: A Rethink in the Context of Research Biobanks" (2011) 19:3 Health Care Anal 269; Ubaka Ogbogu, Sarah Burningham & Timothy Caulfield, "The Right to Control and Access Genetic Research Information: Does McInerney Offer a Way out of the Consent/Withdrawal Conundrum?" (2014) 47:1 UBC L Rev 275.
[13] Neil C Manson, "The Ethics of Biobanking: Assessing the Right to Control Problem for Broad Consent" (2019) 33:5 Bioethics 540; Timothy Caulfield & Blake Murdoch, "Genes, Cells, and Biobanks: Yes, there's still a Consent Problem" (2017) 15:7 PLoS Biol, DOI: <10.1371/journal.pbio.2002654>.
[14] Sara Reardon, "Controversial Patient-Consent Proposal Left Out of Research-Ethics Reforms" (2017) 541:7638 Nature 449; Kathy L Hudson & Francis S Collins, "Bringing the Common Rule into the 21st Century" (2015) 373:24 New Eng J Med 2293.
[15] Ogbogu, Burningham & Caulfield, *supra* note 12 at 276.
[16] Beth Daley & Ellen Cranley, "'Biorights' Rise: Donors Demand Control of their Samples", *Boston Globe* (10 October 2016), online: <www.bostonglobe.com> [perma.cc/7DZE-LFLT]; Brenda Lau, "Patients are More Aware about their 'Biorights' and Demand to be Compensated", *MIMS News* (22 October 2016); Forrest Briscoe et al, "Evolving Public Views on the Value of One's DNA and Expectations for Genomic Database Governance: Results from a National Survey" (2020) 15:3 Plos One, DOI: <10.1371/journal.pone.0229044>.
[17] Reardon, *supra* note 14.
[18] For example, see Quigley, *Self-Ownership, supra* note 5 at 15–16, who argues that the contributions of biomaterial providers are being marginalized and that there is an imbalance in control between individuals, on one hand, and researchers and biotech companies, on the other; See also Simon Douglas, "Property Rights in Human Biological Material" in Imogen Goold et al, eds, *Persons, Parts and Property: How Should We Regulate Human Tissue in the 21st Century?*, 1st ed (London: Hart Publishing, 2014) 89, who argues that we need property law to avoid being dispossessed of our bodily materials by the many others who are interested in acquiring them; See also Donna Dickenson, "Alternatives to a Corporate Commons: Biobanking, Genetics and Property in the Body" in Goold et al, *ibid,* 177, who argues the common law concept of "the commons" can be used to push back against increasing corporate control of biomaterials.

however, that individuals have lost too much control over these valuable materials, with the balance tipped too far in the other direction.

Some researchers and corporations collecting and using biomaterials have responded to this sentiment by developing new ways to enable stronger and more meaningful individual control, such as "dynamic consent" models in biobank research[19] and a new breed of compensation-based DTC genetic testing companies.[20] The success of these innovations, however, is by no means guaranteed nor has their uptake been ubiquitous. Broad consent in biobanking currently remains the norm[21] and most DTC testing companies continue to assert complete control over user data.[22] Further, these innovations give rise to their own sets of ethical concerns.[23]

The law, for its part, has done little to clarify or solidify the interests individuals have in biomaterials derived from their bodies. There are some statutes that govern specific biomaterials in specific contexts.[24] There is also a mix of legal and ethical norms that apply to biomaterials in the research setting. In terms of more generalizable legal principles, however, the law is in a state of flux. Property law has emerged as a possible source of protection for the interests that exist in biomaterials, however, the patchwork of emerging property case law suffers from a significant lack of conceptual grounding.[25] As a result, it is not yet clear when a particular biomaterial will be

[19] Harriet JA Teare et al, "Towards 'Engagement 2.0': Insights from a Study of Dynamic Consent with Biobank Participants" (2015) 1 Digital Health, DOI: <10.1177/2055207615605644>.
[20] Richard Harris, "Startup Offers to Sequence your Genome Free of Charge, Then Let you Profit from It", *NPR* (15 November 2018), online: <www.npr.org> [perma.cc/GA9K-CPGP]; Brad Jones, "Nebula Genomics Will Let You Rent Out Your Genetic Information", (21 February 2018), online: *Futurism* <futurism.com> [perma.cc/KJ5M-Q42D]; Eric Rosenbaum, "Harvard Genetics Pioneer wants to Monetize DNA with Digital Currency, and Defeat 23andMe", *CNBC* (8 February 2018), online: <www.cnbc.com> [perma.cc/QW5C-CKXU].
[21] Teare et al, *supra* note 19.
[22] Henry T Greely, "The Future of DTC Genomics and the Law" (2020) 48:1 J Law Med Ethics 151; Linnea I Laestadius, Jennifer R Rich & Paul L Auer, "All Your Data (Effectively) Belong to Us: Data Practices Among Direct-to-Consumer Genetic Testing Firms" (2017) 19:5 Genet Med 513.
[23] Eman Ahmed & Mahsa Shabani, "DNA Data Marketplace: An Analysis of the Ethical Concerns Regarding the Participation of the Individuals" (2019) 10 Frontiers in Genetics, DOI: <10.3389/fgene.2019.01107>; Julian J Koplin, Jack Skeggs & Christopher Gyngell, "Ethics of Buying DNA" (2022) Bioethical Inquiry, DOI: <10.1007/s11673-022-10192-w>; Kristin Steinsbekk, Bjørn Myskja & Berge Solberg, "Broad Consent versus Dynamic Consent in Biobank Research: Is Passive Participation an Ethical Problem?" (2013) 21 EJHG 897.
[24] For example, assisted reproduction and organ donation are two contexts that often are governed by specific statutes. See Chapter 2 for more examples.
[25] Muireann Quigley, "Property in Human Biomaterials - Separating Persons and Things?" (2012) 32:4 Oxford J Leg Studies 659 at 661 [Quigley, "Property in Human Biomaterials"]; Loane Skene, "Raising Issues with a Property Law Approach" in Goold et al, *supra* note 18, 263 at 267; Jesse Wall, "The Legal Status of Body Parts: A Framework" (2011) 31:4 Oxford J Leg Stud 783 at 784 [Wall, "Legal Status"].

considered an object of personal property or who the property rightsholder will be, leaving scholars divided over how best to theorize biomaterial ownership.[26]

Given how valuable and contested these materials have become, this lack of legal clarity and protection for individual interests is a problem. It is a problem that has birthed reams of books, articles, and reports debating the merits of different regulatory approaches, whether that be property law,[27] research ethics rules,[28] or *sui generis* statutory frameworks.[29] Despite many great minds working to clarify the law and address the many challenges posed by biomaterial regulation, progress has been slow, and a clear regulatory path has yet to be found. Perhaps the strongest point of agreement among those engaged in this work is the complexity of the problem under consideration.[30]

This thesis will bring a fresh perspective to the complex problem of biomaterial regulation by highlighting the benefits and feasibility of a privacy law approach. Recent developments in law and technology make privacy law an important contender for biomaterial regulation, yet its applicability to this subject matter has received little attention in the literature. This thesis will argue that privacy law could have important roles to play in grounding individual claims and providing remedies when biomaterials have been wrongfully collected, used, and/or destroyed. This topic is ripe for consideration given that (i) traditional conceptions of the human body and biomaterials are currently in a state of flux, raising informational privacy questions like never before, and (ii) the field of privacy law across the common law world is in the midst of an evolution, offering new remedial possibilities.

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[26] Quigley, *Self-Ownership, supra* note 5; Meredith Render, "The Law of the Body" (2013) 62:3 Emory LJ 549; Rohan Hardcastle, *Law and the Human Body: Property Rights, Ownership and Control* (Oxford: Hart Publishing, 2007); Jesse Wall, *Being and Owning: The Body, Bodily Material, and the Law* (Oxford: Oxford University Press, 2015) [Wall, Being and Owning]; James Penner, *The Idea of Property in Law* (Oxford: Oxford University Press, 2000); J W Harris, *Property & Justice* (Oxford: Oxford University Press, 2002) at 351–59.

[27] Render, *supra* note 26; Quigley, *Self-Ownership, supra* note 5; Remigius N Nwabueze, *Biotechnology and the Challenge of Property* (Aldershot: Ashgate Publishing, 2007) [Nwabueze, *Biotechnology*].

[28] Dianne Nicol et al, "Impressions on the Body, Property and Research" in Goold et al, *supra* note 18, 9.

[29] Jonathan Herring, "Why We Need a Statute Regime to Regulate Bodily Material" in Goold et al, *supra* note 18, 215.

[30] Herring notes, for example, that "[n]early everyone agrees that the current legal regime dealing with bodily materials is inadequate," requiring reform, "[b]ut at that point, consensus breaks down": *Ibid* at 215; Goold discusses a range of potential regulatory approaches and notes "the task of choosing an approach is understandably a vexed one": Imogen Goold, "Property or Not Property? The Spectrum of Approaches to Regulating the Use of Human Bodily Material" (2013) 21:2 J Law Med 299 at 302 [Goold, "Property or Not Property?"].

B. The "Informatized" Body

The human body is undergoing an "informatization"[31] or "datafication".[32] Technology is changing our conceptualization of the human body from something purely physical in nature to something with an informational dimension. In other words, the body is being "(re)cast as an entity constituted by information".[33]

Through the "internet of bodies", for example, the human body has become the "latest data platform",[34] with wearable devices recording and transmitting our biological processes in datafied form, and surgical implants becoming hubs for internet communication.[35] Biometric technologies, found in security devices, phones, laptops, and smart homes, view our bodies as data to be processed.[36] Clinical treatment has been reconfigured to view the body through monitors and devices.[37] Prospective parents can now meet their children for the first time through a 4D ultrasound scan.[38] Our bodies' geographical locations and health have been surveilled to an unprecedented degree since the onset of the COVID-19 pandemic.[39] And genetic information within our bodies is a valuable and highly sought-after resource for corporations,[40] researchers,[41] governments,[42] and individuals.[43] Our bodies contain, represent, and transmit information and data in vast quantities.

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[31] Irma van der Ploeg, "Biometrics and the Body as Information: Normative Issues of the Socio-Technical Coding of the Body" in David Lyon, ed, *Surveillance as Social Sorting* (London: Routledge, 2002) 57; Lee A Bygrave, "The Body as Data? Biobank Regulation via the 'Back Door' of Data Protection Law" (2010) 2:1 L Innovation & Technology 1 [Bygrave, "The Body as Data?"].
[32] Deborah Lupton, "How do Data Come to Matter? Living and Becoming with Personal Data" (2018) 5:2 Big Data & Society 1.
[33] Bygrave, "The Body as Data?", *supra* note 31 at 6.
[34] Bernard Marr, "What is the Internet of Bodies? And How is it Changing Our World?" *Forbes* (6 December 2019), online: <www.forbes.com> [perma.cc/XU2A-GFA6].
[35] *Ibid*.
[36] Michele Rapoport, "Being a Body or Having One: Automated Domestic Technologies and Corporeality" (2013) 28 AI & Soc 209.
[37] Susan Flynn, "Medical Surveillance and Bodily Privacy: Secret Selves and Graph Diaspora" in Susan Flynn & Antonia Mackay, eds, *Spaces of Surveillance: States and Selves* (Cham: Springer International Publishing, 2017) 229 at 232.
[38] *Ibid* at 241.
[39] Kees Boersma, Monika Büscher & Chiara Fonio, "Crisis Management, Surveillance, and Digital Ethics in the COVID-19 Era" (2022) 30:1 J Contingencies & Crisis Management 2 at 3.
[40] Meg Tirrell, "GlaxoSmithKline Strikes $300 Million Deal with 23andMe for Genetics-Driven Drug Research", *CNBC* (25 July 2018), online: <www.cnbc.com> [perma.cc/X327-JNW2].
[41] O'Donoghue et al, *supra* note 6; Pike, *supra* note 7 at 1982–83.
[42] Wilson, McClure & Weisburd, *supra* note 9; Gans & Urbas, *supra* note 9.
[43] Pike, *supra* note 7 at 1983.

Not long ago, the idea of having a "data double" [44] was a provocative way to grapple with the vast quantities of personal data each of us has brought into existence. Scholars have now moved on to study "human-data assemblages"[45] and "data bodies" to signify "the inseparability of the physical body from its 'virtual,' 'semiotic,' 'sign' dimensions".[46] This new lens is being brought to many academic disciplines, with calls to "rethink the legal and ethical status of our bodies as bodies of data".[47]

Historians, for example, are tracing the origins of datafication.[48] Sociologists and political scientists are exploring how informatization, digitization, and datafication are impacting our world views,[49] ideologies,[50] notions of citizenship,[51] use of language (with a new "language of bodies"[52] emerging), and individual agency and choice.[53] The impact of datafication on the delivery of health care is also being studied.[54] For example, the popularity of DTC genetic testing and the move to personalized medicine illustrate how we are shifting toward "a probalistic way of thinking about bodies and health",[55] keeping "one eye of [sic] the graph".[56]

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[44] David Lyon, "Surveillance, Power, and Everyday Life" in Chrisanthi Avgerou et al, eds, *The Oxford Handbook of Information and Communication Technologies* (Oxford: Oxford University Press, 2009) 449 at 463.
[45] Lupton, *supra* note 32 at 1.
[46] Astrid Mager & Katja Mayer, "Body Data—Data Body: Tracing Ambiguous Trajectories of Data Bodies Between Empowerment and Social Control in the Context of Health" (2019) 8:2 Momentum Q 95 at 96.
[47] Jeffrey M Skopek, "Big Data's Epistemology and Its Implications for Precision Medicine and Privacy" in Effy Vayena et al, eds, *Big Data, Health Law, and Bioethics* (Cambridge: Cambridge University Press, 2018) 30 at 41.
[48] Erik Koenen, Christian Schwarzenegger & Juraj Kittler, "Data(fication): 'Understanding the World Through Data' as an Everlasting Revolution" in Gabriele Balbi et al, eds, *Digital Roots: Historicizing Media and Communication Concepts of the Digital Age* (Berlin: De Gruyter Oldenbourg, 2021) 137.
[49] Alberto Romele, "The Datafication of the Worldview" (2020) AI & Soc, DOI: <10.1007/s00146-020-00989-x>.
[50] Flynn, *supra* note 37.
[51] Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton: Princeton University Press, 2009) at 131–54.
[52] Flynn, *supra* note 37 at 237.
[53] Wendy H Wong, "Opinion: Our Faces Are Who We Are to the World. What Happens When They Become Data?", *The Globe and Mail* (2 July 2021), online: <www.theglobeandmail.com> [perma.cc/9M75-EC7H].
[54] Minna Ruckenstein & Natasha Dow Schüll, "The Datafication of Health" (2017) 46:1 Annual Rev Anthropology 261.
[55] Flynn, *supra* note 37 at 236.
[56] *Ibid*.

Legal scholars are also grappling with this fundamental shift in human existence, taking a critical look at the internet of bodies,[57] and biometric technologies.[58] Biometric technologies comprise "systems for determining or verifying the identity of persons based on their bodily characteristics".[59] Biometric technologies "read" the human body as data to be processed.[60] A fingertip, for example, can be scanned for the purpose of confirming identity. The actual physical characteristics (ridges, bumps, gaps) have become decipherable data points.

These technologies are used for surveillance, raising important legal questions about the liberty, privacy, and autonomy interests at stake for individuals.[61] And while there is a field of legal scholarship taking up these issues as they pertain to the informatization of the intact, living human body datafied by biometric technologies, a parallel discourse on the legal implications of the informatization of *separated* human biomaterials has only just begun. Separated biomaterials are similarly undergoing an informatization. While biometric technologies have transformed our outward physical structures into identifying, readable information, so too have genetic technologies transformed our internal physical DNA molecules, separated from our bodies, into identifying, readable information. While we interpret our genetic code in terms of a sequence of As, Gs, Ts, and Cs, these represent the *physical* structure of our DNA.

This is not to say that scholarship considering the myriad ethical, legal and social issues pertaining to genetic information is in any way meagre. Indeed, "ELSI" research is a significant and robust field of scholarship that has long considered many of the same questions posed by biometric technologies in terms of the collection, use, and control over genetic information and biomaterials.[62] Within this discourse, there are also many parallels between regulatory questions

[57] Moufid El-Khoury & Cenk Lacin Arikan, "From the Internet of Things Toward the Internet of Bodies: Ethical and legal Considerations" (2021) 30:3 Strategic Change 307; Andrea M Matwyshyn, "The Internet of Bodies" (2019) 61:1 Wm & Mary L Rev 77.
[58] Nancy Liu, *Bio-Privacy: Privacy Regulations and the Challenge of Biometrics* (London: Routledge, 2011); Emilio Mordini & Dimitros Tzovaras, *Second Generation Biometrics: The Ethical, Legal and Social Context* (Dordrecht: Springer Science & Business Media, 2012).
[59] Lee Andrew Bygrave, *Data Privacy Law: An International Perspective* (Oxford: Oxford University Press, 2014) at 127 [Bygrave, *Data Privacy Law*].
[60] Rapoport, *supra* note 36 at 211.
[61] Wong, *supra* note 53.
[62] Lisa S Parker et al, "Normative and Conceptual ELSI Research: What it is, and Why it's Important" (2019) 21:2 Genet Med 505.

surrounding genetic information and the biomaterials it is contained in, including whether exceptional regulation is warranted,[63] and if so, what legal frameworks are best suited to the task.[64]

While there are many great minds focused on countless ethical, legal and social issues arising from biotechnological developments, the point being made here is that this field of study is generally based on the assumption that genetic information is distinct from the physical samples and bodies from which it is derived. However, the informatization of the body is challenging this assumption. It is now worth questioning what happens when we take literally the informatization underway and treat physical biomaterials not as things *containing* information, but as *information itself.* Whereas not long ago this question would not have made sense to ask, it now reveals new opportunities for privacy law.

The vast quantity of personal information and data that now exist are raising complex regulatory questions for privacy law. Whether biomaterials should be included in this discussion has been considered by only a handful of scholars who have examined the potential for information privacy frameworks to regulate physical biomaterials in the research and biobanking contexts.[65] These works rely on a small body of legislation,[66] case law,[67] and governmental reports,[68] that support an informatized view of biomaterials as a type of "personal information".

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[63] Debates about genetic exceptionalism emerged in the 2000s and have continued, with Garrison et al calling for a new perspective on the issue they call "genomic contextualism": Nanibaa' A Garrison et al, "Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism" (2019) 19:1 American J Bioethics 51.

[64] Debates have occurred since the early 2000s about whether property or privacy is better suited to regulate genetic information: Tufik Y Shayeb, "You Are What You Own: Reopening the Discussion on Universally Recognizing a Property Right in Genetic Information and Material" (2017) 38 Whittier L Rev 181.

[65] Bygrave, "The Body as Data?", *supra* note 31; Dara Hallinan & Paul De Hert, "Many Have It Wrong – Samples Do Contain Personal Data: The Data Protection Regulation as a Superior Framework to Protect Donor Interests in Biobanking and Genomic Research" in Brent Daniel Mittelstadt & Luciano Floridi, eds, *The Ethics of Biomedical Big Data* (Cham: Springer International Publishing, 2016) 119; Worku Gedefa Urgessa, "The Feasibility of Applying EU Data Protection Law to Biological Materials: Challenging 'Data' as Exclusively Informational" (2016) 7:2 JIPITEC, DOI: <10.2139/ssrn.2840764>; See also Mark Taylor, *Genetic Data and the Law: A Critical Perspective on Privacy Protection* (Cambridge: Cambridge University Press, 2012) c 7; See also Ogbogu, Burningham & Caulfield, *supra* note 12, who argue biomaterials can potentially be viewed as part of a patient's medical "record".

[66] *Privacy and Personal Information Protection Act 1998* (NSW), 1998/133; *Health Records and Information Privacy Act 2002* (NSW), 2002/71; *Government Information (Public Access) Act 2009* (NSW) 2009/52.

[67] *R v Chief Constable of South Yorkshire Police ex parte LS; R v Chief Constable of South Yorkshire Police ex parte Marper*, [2004] UKHL 39 [*Marper* UKHL]; *S and Marper v the United Kingdom* [GC], No 3056/04, [2008] ECHR 1581 [*Marper* ECtHR]; *Gaughran v the United Kingdom*, No 45245/15, [2020] Eur Ct HR (1st Sec), online: <hudoc.echr.coe.int/?i=001-200817> [perma.cc/D5S2-AYHS] [*Gaughran*].

[68] Australia, Australia Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia*, ALRC Rep 96 (Commonwealth of Australia, 2003) [ALRC, *Essentially Yours*].

The work in this dissertation will examine this nascent body of law and scholarship and contextualize it in relation to the common law world. If biomaterials are treated as information, then information privacy statutes and privacy commissioners may have new work to do. Privacy law, as a legal field, however, is broader than these statutory frameworks. This breadth is evidenced in many common law countries, which have undergone a significant privacy law evolution in recent years with new statutory instruments and privacy torts responding to modern privacy challenges brought by developing technologies. A holistic look at the privacy landscape reveals both statutory and tort-based regulatory avenues for biomaterial regulation.

C. Recent Evolutions in Privacy Law

Privacy is an amorphous concept with spatial, personal, and informational dimensions that are generally understood as safeguarding individual dignity and autonomy interests.[69] While there is a common understanding that certain activities, spaces, and information are private and not for public consumption, where that line is drawn and how the law protects it are moving targets. Other than in the United States, where four distinct privacy torts have long been recognized,[70] common law countries have been reticent to recognize causes of action grounded in privacy violations. The last decade, however, has seen a significant evolution in privacy law across the common law world, with Canada, England, and New Zealand recognizing various privacy torts, and Australia enacting a relatively robust statutory scheme.

This evolution is attributable, in part, to the influence of human rights law, where privacy protection has been an important feature of international and domestic human rights instruments. In addition, advancing technologies have created privacy problems that "cry out" for remedies.[71] As a result, through combinations of statutory instruments and judicial decisions, the field of privacy law has grown considerably.

For example, common law torts of intrusion upon seclusion and public disclosure of private facts have been recognized in Canada and New Zealand,[72] and a tort of misuse of private

[69] *R v Dyment*, [1988] 2 SCR 417 at para 30 [*Dyment*] (La Forest J).
[70] William L Prosser, "Privacy" (1960) 48:3 Cal L Rev 383 at 389.
[71] *Jones v Tsige*, 2012 ONCA 32 at para 69 [*Jones*] (Sharpe JA).
[72] *C v Holland*, [2012] NZHC 2155 [*Holland*]; *Hosking v Runting*, [2004] NZCA 34 [*Hosking*]; *Jones*, *supra* note 71; *Jane Doe 464533 v DN*, 2016 ONSC 5431 [*Jane Doe 1*].

information has been recognized in England.[73] Additionally, several Canadian provinces have enacted statutory privacy torts to ground claims for privacy violations as well.[74] The result is a legal field that is malleable, with the potential to evolve in any number of directions. Decisions by courts and legislatures have demonstrated a willingness to address wrongs against individuals committed in the wake of new technological advancements by creating new causes of action and a robust set of remedial options. It is therefore timely and appropriate to consider whether this nascent field is capable of evolving to encompass biomaterials.

This thesis will therefore demonstrate a close alignment between the interests individuals have in their biomaterials and the interests privacy law is designed to protect. The possibility for privacy law to address these interests will be contextualized in relation to other, more traditional legal frameworks that are typically looked to in the quest to improve and identify appropriate regulations for biomaterials. This will shed light on the conceptual problems, underlying points of tension, and regulatory gaps that plague existing regulatory frameworks, and highlight the ways in which a privacy approach may prove valuable as a regulatory tool.

D. Methodology

The approach this thesis takes in analyzing biomaterial regulation is based on the macro legal analysis methodology developed by environmental law scholar, Stephen Turner, for use in global environmental governance.[75] While environmental governance and biomaterial regulation involve markedly different subject matters, both fields are responding to complex regulatory problems that raise legal questions across various areas of law. The result is legal compartmentalization, with scholars developing expertise in sub-disciplines (e.g., property law, privacy law, consent frameworks, etc.), with the result that "research that cuts across and includes aspects of a wide variety of legal disciplines in a coherent and integrated manner is inevitably less common".[76] The benefits of taking a more macro approach include "discovering and analyzing the full range of laws, legal institutions and quasi-legal initiatives that have an influence"[77] on a

[73] *Google v Vidal-Hall*, [2015] EWCA Civ 311 [*Vidal-Hall*].
[74] *Privacy Act*, RSNL 1990, c P-22 [*Privacy Act* (Nfld)]; *Privacy Act*, RSBC 1996, c 373 [*Privacy Act* (BC)]; *The Privacy Act*, RSS 1978, c P-24 [*Privacy Act* (SK)]; *The Privacy Act*, RSM 1987, c P125 [*Privacy Act* (MB)].
[75] Stephen J Turner, "The Use of Macro Legal Analysis in the Understanding and Development of Global Environmental Governance" (2017) 6 TEL 237.
[76] *Ibid* at 246.
[77] *Ibid* at 242.

complex subject-matter; identifying "intellectual blind spots";[78] and providing more "synoptic insights" than what a micro analysis can accomplish.[79] Macro analyses can serve to facilitate cohesive reform by offering generalizable insights into the strengths, weaknesses, and interconnectedness of different "micro analyses".[80]

In accordance with Turner's methodology, this analysis comprises the following three core components: (i) identifying the areas of law to be considered, (ii) identifying the specific aspects of each area of law comprising the "root cause" of the problem under investigation, and (iii) analyzing the relationships between these areas of law to provide appropriate groundwork for future reform.[81] These three components are undertaken in service to an overarching target outcome, where the areas of law, principles, and reform are analyzed with a view to achieving the specified goal.[82]

The target outcome for this thesis is to identify a legal path forward that provides robust protection and remedies for individuals in relation to biomaterials originating from their own bodies. The areas of law identified for this analysis are: (i) Legislative governance frameworks, including research ethics guidelines, that regulate many different specific uses and activities for biomaterials, filling what would otherwise be a gaping legal hole from the common law; (ii) property law, which has been used, to varying degrees of success, to provide much-needed remedies for individuals whose biomaterials have been misused; and (iii) privacy law, including both information privacy statutes and privacy torts, which align closely with the individual interests needing protection, provide great remedial flexibility, and are in a current state of evolution with the potential to develop in any number of ways. This thesis ultimately concludes that privacy law could be extended to include biomaterials in a way that complements and strengthens the meagre protection that is otherwise afforded to individuals under statutory and property-based rules.

As the problems arising in biomaterial regulation are not unique to any one jurisdiction and as common law jurisdictions tend to borrow heavily from one another in terms of both statutory

[78] *Ibid* at 252, quoting E Fisher et al, "Maturity and Methodology: Starting a Debate about Environmental Law Scholarship" (2009) 21(2) J Envtl L 213 at 241.
[79] *Ibid* at 255.
[80] *Ibid* at 242–46.
[81] *Ibid* at 253.
[82] For Turner's six step process in this respect, see *ibid* at 254–55.

and common law principles, the macro analysis employed in this thesis is not restricted to the legal system of any one country. Instead, the analysis applies, generally, to common law jurisdictions, but takes into account nuances, where appropriate. For example, Chapter 6, which outlines the current state of privacy law, identifies the notable differences between jurisdictions in terms of statutory and tort-based privacy norms and explains how these differences may impact biomaterial regulation.

With respect to each area of law, the doctrinal research methodology was employed[83] whereby statutes, case law, and, where applicable, non-binding regulatory instruments (e.g., research ethics guidelines) were identified through a combination of legal database searches (such as Westlaw and LexisNexis) and secondary sources. This research is reform-oriented,[84] arguing for a new application of privacy law to fill legal gaps that otherwise exist. In terms of the categorizations of legal scholarship articulated by former Dean of Harvard Law School, Martha Minow, this work also serves significant "recasting" and "critical" purposes, in that different lines of authority are compared to demonstrate how they fit together, including points of tension and legal gaps.[85]

With respect to the terminology employed in this thesis, the term "biomaterials" is used to denote, broadly, all biological substances derived from the human body, with more specific language used (e.g., gametes, organs, etc.) as needed in discussions of particular contexts. The term, "biomaterial provider", is used to refer to the individual from whom a biomaterial was derived. This language is a deliberate attempt to move away from terminology based on "gifts" and "donations", which suggest passivity on the part of providers and a relinquishment of all rights and interests. Instead, language that recognizes "participants" and "providers" of "biomaterials" aligns more closely with the underlying position of this thesis that the transfer of physical possession of one's biomaterials does not eradicate all of one's individual rights and interests in them.[86]

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[83] Terry Hutchinson & Nigel Duncan, "Defining and Describing What We Do: Doctrinal Legal Research" (2012) 17 Deakin L Rev 83.
[84] *Ibid* at 101.
[85] Martha Minow, "Archetypal Legal Scholarship: A Field Guide" (2013) 63:1 J Leg Educ 65 at 66–68.
[86] Michael A Lensink et al, "Better Governance Starts with Better Words: Why Responsible Human Tissue Research Demands a Change of Language" (2022) 23:1 BMC Medical Ethics 90 [Lensink et al, "Better Governance"].

E. Dissertation Structure and Aims

This thesis will show the benefits and limitations of a privacy approach to biomaterial regulation in relation to the more dominant regulatory approaches and demonstrate why this regulatory option requires greater attention in academic literature and policy discussions. This will be accomplished first, in Part 1 of this work (Chapter 2 to 5), by exploring existing legal frameworks and their limitations. These chapters will reveal the underlying tension that exists between individual interests and the interests of institutions and demonstrate that the current regulatory landscape is imbalanced against individual interests. Chapters 2 and 3 will focus on legislative governance frameworks, including statutes and soft law instruments, and Chapters 4 and 5 will consider property law.

Chapter 2 will examine legislation governing biomaterial donation for therapeutic, educational, and research purposes and show the regulatory gaps and remedial void left by these statutory frameworks. Chapter 3 will then consider research ethics instruments, which play a crucial role in supplementing legislation by fleshing out specific consent and other regulatory requirements to use biomaterials in research. This chapter will show an imbalance created by these regulations where institutional interests are protected over individual biomaterial providers'.

As a result of these limitations, property law has been hailed as a promising alternative that provides a set of generalizable legal rules and remedies. Indeed, a body of jurisprudence is evolving that has recognized, in limited circumstances, that separated biomaterials give rise to property rights. The dissertation will therefore explore the current property law landscape, tracing the development of case law and scholarship throughout the common law world in Chapters 4 and 5. These chapters will show that there is reason to question the optimism surrounding property law as a tool to enhance protection for individual rights, as the current state of the law is unpredictable and conceptually unsettled and the values property law is designed to protect align closer with institutional versus individual interests.

Overall, Part 1 will establish that legislative governance and property law frameworks are not providing adequate protection for individual interests over biomaterials. As a result, there is value in exploring new regulatory possibilities. Part 2 of this dissertation (Chapters 6 through 8) will therefore compare privacy law to the statutory governance and property law frameworks

considered in Part 1 to highlight its advantages in regulating biomaterials in terms of offering individuals new paths for legal redress.

Chapter 6 will explain the current state of privacy law across common law countries, encompassing both privacy statutes and torts, to highlight the malleability of this field and outline the potential regulatory options it provides. Chapter 7 will then examine the informatization of the body and the implications for information privacy statutory regulation whereby biomaterials can be conceptualized as a form of "personal information". Chapter 8 will then focus on privacy torts and demonstrate how they could be used to address a range of situations identified in Part 1 where individuals are in need of stronger protection. Chapter 9 will then conclude by addressing how privacy law could interact with other legal frameworks, ultimately showing the value of exploring privacy law as a new and innovative regulatory possibility in the ongoing effort to solve the complex problem of biomaterial regulation.

This work will contribute to scholarship across a range of disciplines examining how the informatization of the body is re-shaping our world. Looking at biomaterial regulation through this new lens squarely addresses the informatization underway as a matter of legal scholarship and builds on an inventive idea that has yet to truly grab hold in relevant law and literature. The initial scholarship that exists on this issue focuses on whether terms like "personal information" or "personal data" are capable of being interpreted to include physical biomaterials, and why such interpretations might be useful to fill current regulatory gaps.[87] This dissertation will build on this work by situating this idea in common law legal frameworks and taking a more macro approach by directly comparing privacy law to regulatory approaches that have received much more scholarly attention. This approach will shed new light on the merits and potential shortcomings of a privacy approach to biomaterial regulation.

This dissertation will also contribute to growing efforts to organize scholarship in this area. The law pertaining to the human body is starting to be discussed as if there is a collection of principles forming a distinct body of law. This is reflected by calls for the creation of a new legal

[87] Bygrave, "The Body as Data?", *supra* note 31; Hallinan & De Hert, *supra* note 65.

discipline on Law of the Body;[88] law school courses being offered on Law and the Human Body;[89] the creation of an international research network on Law and the Human;[90] and a Law of the Body Symposium held to explore the "perfect tension" that exists between individual autonomy over one's body and competing societal interests.[91] As one symposium participant put it: "[t]his tension and the regulations that define it constitute a law of the body".[92] By addressing this tension head-on, and exploring how legal regulations can better balance the competing interests at stake, this dissertation will contribute to this emerging field of legal scholarship.

The central argument advanced in this work is that privacy law is a promising regulatory option that ought to be taken seriously in discussions about the regulation of biomaterials. The current regulatory environment is tipped in favour of institutional control over these materials at the expense of the individual. As a result, litigants seeking to enforce individual rights will need to look elsewhere for sources of legal redress. Even though the law and scholarship behind this novel regulatory option is small and not without limitations, privacy law provides a real possibility for securing greater individual control over biomaterials.

Ultimately, this work is about injecting a fresh perspective on the complicated question of how biomaterials should be regulated. While property law has dominated the discourse on biomaterial regulation, it is time to step back and consider the individual interests at stake and remedies required, and question which legal frameworks are well-suited to provide them. By directly comparing existing statutory frameworks, property law, and privacy law, this work will uncover current limitations of the more dominant legal frameworks and propose a new option for biomaterial regulation warranting further attention in this debate.

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[88] Render, *supra* note 26.
[89] University of Southampton, "Law and the Human Body | LAWS3141 |", online: <www.southampton.ac.uk/courses/modules/laws3141>; University of Adelaide, "LAW 2574 - Law and the Body | Course Outlines", online: <www.adelaide.edu.au/> [perma.cc/YBF2-4X67].
[90] University of Kent, "Law and the Human Network - Research at Kent", online: *Law and the Human Network* <research.kent.ac.uk> [perma.cc/WZ7Z-CPPB].
[91] Richard Birke, "Law of the Body Symposium Introduction" (2008) 45:1 Willamette L Rev 1 at 2–3.
[92] *Ibid* at 3.

Part 1: The Lack of Protection for Individual Interests in Existing Biomaterial Regulation

There are longstanding and well-established legal principles and frameworks governing the living, intact human body. For example, the tort of battery and criminal offence of assault exist to protect individual autonomy and bodily integrity. Should biomaterials be removed from a living person without valid consent in non-emergent circumstances, that person will have suffered an actionable legal wrong.

The legal difficulty arises when biomaterials are validly separated from one's body and then subsequently accessed and used for a new purpose by others. So long as consent was validly given for the initial removal of the biomaterial, no criminal assault would be committed nor would an action lie in battery, as there is no violation of the individual's bodily integrity.[93] While property law might provide causes of action for wrongful interferences with separated biomaterials, as Chapters 5 and 6 will show, the property status of biomaterials remains unclear and conceptually confused. In the context of validly separated biomaterials, then, there is a lack of established common law principles to govern the actors, rights, obligations, and remedies pertaining to the use (or misuse) of these substances.

This lack of clear legal rules is a problem because the human body is "leaky".[94] We shed biomaterials all the time, unknowingly, and consent to their removal in a wide range of circumstances from haircuts to diagnostic testing. Given the wealth of information our biomaterials contain and given how many stakeholders are interested in acquiring them, their lack of legal regulation makes them vulnerable to taking.[95] Indeed, health law expert, Henry Greely, asserts that surreptitious collection and genetic testing of biomaterials is the biggest legal issue needing to be resolved as genetic testing becomes increasingly available directly to the public.[96] And as scientists are now able to extract high quality DNA from the air around us,[97] the need for regulation in this respect is all the more pressing.

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[93] For example, an appellate court in the UK made it clear that no personal injury was suffered by men whose stored sperm was negligently destroyed: *Yearworth v North Bristol NHS Trust*, [2009] EWCA Civ 37 [*Yearworth*].
[94] Herring, *supra* note 29 at 220–23.
[95] Douglas, *supra* note 18.
[96] Greely, *supra* note 22.
[97] Margaret Osborne, "Scientists Can Now Pull Human DNA From Air and Water, Raising Privacy Questions" *Smithsonian Magazine* (18 May 2023), online: <www.smithsonianmag.com> [perma.cc/EV7D-6ZHF].

The lack of applicable common law norms to separated biomaterials is addressed, to a degree, by statutory instruments establishing the legality of using biomaterials for specific purposes. These instruments employ a consent paradigm, whereby an individual can consent to the removal and donation of their biomaterials for use in medical education, therapeutic purposes (e.g., transplantation into another person or storage for assisted reproductive treatment), or research. Chapter 2 in this Part will therefore begin by setting out and exploring some of these frameworks. This Chapter will show that the consent paradigm employed by these frameworks does not adequately protect individual interests which can persist beyond the initial point of consent. They further lack a remedial function when individual interests are wrongfully infringed.

Chapter 3 will then consider the research ethics environment, which provides a crucial piece of the biomaterial regulatory framework by supplementing legislation and establishing some rules as to how biomaterials are used in research beyond the initial point of excision. This Chapter will show that although there are some protections in place for research participants, these protections are under increasing stress, raising questions about their adequacy, which will only become more pressing as time goes on. Further, as the biotechnological environment has evolved, a new *status quo* has emerged, giving primacy to institutional interests over those of individual biomaterial providers.

While the need for greater individual control over biomaterials is recognized by many, there remain significant differences of opinion in terms of how to address this concern. In this respect, property law has come to dominate discourse in this area. This dominance is reflected by a dichotomy in the literature between regulatory frameworks based on "property rights" versus "non-property" alternatives. Rohan Hardcastle's seminal work, *Law and the Human Body,* for example, has respective chapters on "Property Rights" and "Non-Proprietary Interests".[98] Medical law and ethics scholar, Imogen Goold, has similarly described a "spectrum of approaches to regulating the use of human bodily material," presented in terms of "property" and "not property" options.[99] Additionally, a group of prominent experts in this field compiled an edited collection querying "How Should We Regulate Human Tissue in the 21st Century?", titled "Persons, Parts

[98] Hardcastle, *supra* note 26.
[99] Goold, "Property or Not Property?", *supra* note 30.

and *Property*", with chapters devoted to addressing the benefits and limitations of property versus property "alternatives".[100]

As property law has been hailed as a promising solution to the problems left by legislative governance frameworks, Chapters 4 and 5 of this thesis will evaluate this proposition. Chapter 4 will analyze the existing body of case law applying property principles to biomaterials and demonstrate that this body of law is currently in a state of conceptual disarray. Chapter 5 will demonstrate that, in the context of disputes between individuals and institutions where control over biomaterials is genuinely contested, property law is unlikely to offer sufficient protection for individual interests. This can be explained, in part, by the fact that property law is better suited to protect the types of interests institutions have in biomaterials when compared to those of individuals. Overall, this Part will demonstrate the limitations of current legal and regulatory norms in protecting individual interests and the need for alternative frameworks that protect individual interests and provide meaningful remedies when those interests are infringed.

[100] Goold et al, *supra* note 18.

2. The Lack of Rights and Remedies Under Legislative Governance Frameworks

Human bodies and biomaterials have historically been excluded from the realm of property law through what is known as the "no-property rule". As a result, there is no set of generalizable legal rules and principles to govern separated biomaterials. For many years this posed little problem, as these materials were not very useful. However, as technology has evolved, the value and uses for biomaterials have expanded significantly, and in the absence of a property (or other common law) framework to govern these substances, various statutory instruments have been created in response to biotechnological developments.[101]

For example, as organ transplantation emerged as a successful therapeutic treatment for organ failure, the need for donated organs arose, resulting in organ and tissue donation legislation to set legal parameters and safeguards for this activity. Legislation was passed beginning in the 1960s, such as the UK's *Human Tissue Act*[102] in 1961, and the US's *Uniform Anatomical Gift Act*[103] in 1968, and continued in other jurisdictions throughout the 1970s and 80s. Similarly, as assisted reproduction technologies created viable therapeutic options for people struggling with infertility, legislation emerged to govern the ways in which gametes can be procured, stored, and used, such as South Australia's *Assisted Reproductive Treatment Act,*[104] passed in 1988, and Western Australia's *Human Reproductive Technology Act,*[105] in 1991. Following the cloning of Dolly, the sheep, legislation emerged prohibiting human cloning and certain other biotechnological applications for human biomaterials, such as Canada's *Assisted Human Reproduction Act,*[106] passed in 2004, and Australia's *Prohibition of Human Cloning for Reproduction Act*[107] and *Research Involving Human Embryos Act,*[108] both passed in 2002. Most recently, mitochondrial donation has been legislatively enabled through the UK's *Human Fertilisation and Embryology*

[101] Wall, *Being and Owning, supra* note 26 at 176.
[102] *Human Tissue Act 2004* (UK) [*Human Tissue Act* (UK)].
[103] National Conference of Commissioners on Uniform State Laws, *Revised Uniform Anatomical Gift Act (2006)* (Hilton Head, South Carolina, 2009).
[104] *Assisted Reproductive Treatment Act 1988* (SA).
[105] *Human Reproductive Technology Act 1991* (WA).
[106] *Assisted Human Reproduction Act*, SC 2004, c 2.
[107] *Prohibition of Human Cloning for Reproduction Act 2002* (Cth), 2002/144.
[108] *Research Involving Human Embryos Act 2002* (Cth), 2002/145.

(Mitochondrial Donation) Regulations,[109] passed in 2015, and Australia's *Mitochondrial Donation Law Reform (Maeve's Law) Act*[110] in 2022.

As it is beyond the scope of this thesis to cover every statutory instrument pertaining to biomaterials across the common law world, this chapter will, instead, demonstrate some of the shared features and limitations of legislative regulatory approaches to biomaterials through a selection of examples from case law involving the application of different statutes. These examples will encompass cases alleging wrongful interferences with separated biomaterials in the organ donation, post-mortem examination, and assisted reproduction contexts. They will collectively show the limitations of relying solely on a legislative governance model and the need for more comprehensive regulation.

These statutes, for example, tend to regulate certain *activities* (such as consent, storage, and specific uses of biomaterials) in specific contexts (such as biomaterial donation or assisted reproduction).[111] In contrast, a property law framework regulates the *materials themselves*, imposing an exclusionary boundary, entailing obligations of non-interference held by everyone other than the rights-holder to the relevant object of property. This enables the rights-holder to engage in an open-ended set of activities with the property.[112] The significance of this distinction is that, by focusing on specific activities, legislative governance mechanisms tend to impose a consent paradigm, enabling certain uses for biomaterials provided initial consent was obtained.[113] This can be seen, for example, in organ and tissue donation legislation, where tissue can generally be used for research, medical education, or transplantation provided valid consent has been given.[114] Similarly, legislation governing assisted reproduction imposes consent requirements for the storage and use of gametes and embryos.

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[109] *The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015* (UK), 2015/572.
[110] *Mitochondrial Donation Law Reform (Maeve's Law) Act 2022* (Cth), 2022/26.
[111] Wall, *Being and Owning, supra* note 26 at 178–79.
[112] *Ibid* at 178–79.
[113] *Ibid* at 178; See also Imogen Goold & Muireann Quigley, "Human Biomaterials: The Case for a Property Approach" in Goold et al, *supra* note 18, 231 at 261, who describe this type of framework as a "consent-based legislative scheme".
[114] See Kenyon Mason & Graeme Laurie, "Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey" (2001) 64:5 The Modern Law Review 710–729 for a critique of the consent model imposed by the UK *Human Tissue Act 2004*.

The importance of consent in medical treatment and research came to the fore in the 1970s in the wake of several key court decisions in the US[115] and the uncovering of egregious abuses of research participants in several high-profile cases.[116] This coincided with the emergence of the field of bioethics, where the principle of autonomy was recognized as one of four bioethical pillars.[117] As a result of these developments, stronger consent requirements emerged, including the standard of "informed consent" to facilitate informed and active patient decision-making in response to the largely paternalistic model of medical treatment existing at the time.[118]

Imposing a consent paradigm for the use of biomaterials would therefore appear a good option to facilitate autonomous decision-making for individuals over their bodily substances. However, there is a question of whether modern applications of medical law and ethics now place too much emphasis on the importance of consent. Forensic medicine expert, Kenyon Mason, and health law scholar, Graeme Laurie, for example, note that in contemporary approaches to autonomy, autonomy has been reduced and treated synonymously with the requirement for informed consent, when in fact, "the true concept [of autonomy] reflects a number of different aspects of personhood that are thought to be worthwhile and deserving of respect, such as choice, independence, freedom of action, self-governance and control".[119] Their point, and the one presented in this chapter, is that although "[c]onsent has a crucial role to play within the framework…it does not go far enough".[120]

The reasons the consent paradigm reflected in legislation does not go far enough are because: (a) the legislation does not provide positive, enforceable rights or associated remedies; and (b) as a result, claimants must rely on common law causes of action, which are no longer fit for purpose. The following discussion will consider these issues, in turn, and demonstrate that the result is a gaping remedial void for those whose interests in biomaterials have been wrongfully infringed. This void reflects a lack of clarity surrounding the rights and interests that exist in

[115] Tom L Beauchamp, "Informed Consent: its History, Meaning, and Present Challenges" (2011) 20:4 Camb Q Healthc Ethics 515 at 515–17.
[116] T O'Shea, *Green Paper Report: Consent in History, Theory and Practice* (Essex: Essex Autonomy Project, 2011) at 15–18.
[117] TL Beauchamp & JF Childress, *Principles of Biomedical Ethics*, 1st ed (New York: Oxford University Press, 1979).
[118] See Beauchamp, *supra* note 115 at 515–17 for a discussion of the historical evolution of "informed consent".
[119] Mason & Laurie, *supra* note 114 at 719.
[120] *Ibid*.

biomaterials post-separation and a lack of control for individuals over these materials. And it is the lack of ongoing control that makes reliance on consent mechanisms inadequate in terms of protecting individual autonomy.

A. Lack of Positive, Enforceable Rights

Biomaterial legislation can sometimes be prohibitory, banning certain uses of biomaterials, such as human cloning or maintaining *in vitro* embryos beyond 14 days. In other respects, it can be permissive, allowing biomaterials to be used therapeutically or for other valid purposes provided consent has been obtained and any other regulatory requirements have been met. While these frameworks *permit* or *authorize* biomaterials to be used for certain purposes, they do not create legal entitlements or rights to biomaterials. Legislation sometimes creates statutory offences for certain activities involving biomaterials but does not generally create civil remedies when biomaterials are used without consent.[121] As a result, actions must be brought under common law principles.[122] The following discussion will demonstrate this point using examples from case law arising in the contexts of organ donation, post-mortem examinations, and assisted reproduction. These cases will illustrate that the legislative instruments governing these activities fail to provide enforceable rights grounding claims for remedies, leaving claimants with the common law as their only avenue for redress.

i. Organ Donation

The case of *Colavito v New York Organ Donor Network* involved a woman who directed that her deceased husband's kidneys go to Colavito, a friend in need of a transplant.[123] The relevant donation organization allocated one kidney to Colavito, which was then inspected by a surgeon who discovered an aneurism of the renal artery, rendering it unsuitable for transplant. When the surgeon tried to obtain the other kidney, they were informed it had been allocated to someone else.[124] Although subsequent immunological testing revealed the kidney would not have been

[121] Wall, *Being and Owning, supra* note 26 at 179–80; Remigius N Nwabueze, "Donated Organs, Property Rights and the Remedial Quagmire" (2008) 16:2 Med Law Rev 201 at 223 [Nwabueze, "Donated Organs"]; Mason & Laurie, *supra* note 114 at 727–28.
[122] Nwabueze, "Donated Organs", *supra* note 121 at 223.
[123] *Colavito v New York Organ Donor Network*, [2006] 8 NY 3d 43 (NY Court of Appeals) [*Colavito*].
[124] *Ibid* at 47.

suitable for transplantation into Colavito in any event, Colavito nevertheless believed he had been wronged, as the donated kidneys had been directed to him.

As a result, Colavito brought a claim against the New York Donor Network alleging fraud, conversion, and violations of articles 45 and 45-A of the *New York Public Health Law,* which set out the conditions under which deceased donations can be made. In granting summary judgment against Colavito, the District Court found, *inter alia,* "that in the absence of a clear legislative expression, neither Public Health Law article 43 nor article 43-A gives donees standing to bring a lawsuit".[125] On appeal, the Second Circuit Appeals Court certified three questions to be determined, including whether the *New York Public Health Law* vested Colavito with rights grounding either a common law action in conversion or "a private cause of action inferred from the New York Public Health Law".[126]

In rejecting Colavito's contention that the legislation gave rise to a cause of action, Rosenblatt J (on behalf of the Court) noted that although the Act provided that the "rights of the donee created by the gift are paramount to the rights of others", the legislation was otherwise "silent as to what rights a donee has in a donated organ".[127] The Court ultimately found against Colavito as a result of section 4302(4) of the Act, which allows a donor to make a gift to a specified recipient "for therapy or transplantation *needed by him*".[128] As the subsequent immunological testing revealed that the kidney would not have been suitable for Colavito, it was not an organ "needed by him".[129] The ability to give an organ under the Act is conditional upon the intended recipient being in need of that organ. As that condition was not met, the Act did not provide a cause of action for Colavito's claim.[130]

ii. <u>*Post-mortem Examinations*</u>

A similar problem was faced in the UK by parents who learned that organs from their deceased children had been removed and retained during post-mortem examinations without their consent. In 1999, it was revealed that certain hospitals in the UK had been removing and retaining

[125] *Ibid* at 49.
[126] *Ibid*.
[127] *Ibid* at 55 [citations omitted].
[128] *Ibid* at 57 [emphasis in original].
[129] *Ibid*.
[130] *Ibid*.

organs and tissues in this manner since the 1980s. This became known as the organ retention scandal and attracted significant public outrage. A group of affected parents commenced litigation under the Nationwide Organ Group Litigation, comprised of 2140 claims.[131] Three lead claims were chosen to go to trial to potentially resolve some of the fundamental legal questions underlying these claims. The claimants sought damages for the mental distress they suffered upon learning that their children's organs had not been returned to them along with the bodies.

While the *Human Tissue Act 1961* was in force at the relevant time and applied to post-mortem examinations, there was no dispute about the fact that this statute "provide[d] for no criminal sanctions nor any civil remedies".[132] Instead, the Act employed "a system of consent or dissent to legitimate certain key uses in the contexts of therapy, education or research" without "giv[ing] any substantive rights over a human body".[133] As a result, the claimants had to frame their claims in terms of an asserted cause of action based in the wrongful interference with a deceased body (which Gage J rejected) and, alternatively, in negligence for a breach of disclosure and informed consent obligations (for which only one of the three claimants succeeded).

Following the public revelations about the widespread practice of retaining organs from post-mortem examinations, the Retained Organs Commission was established and tasked with investigating and making recommendations for future regulation and practice.[134] Upon finding the 1961 Act outdated and unclear, the Commission made recommendations for a new legislative framework, resulting in the current *Human Tissue Act 2004*.[135] While the impetus behind the Commission and revised Act was to address the gaps left by the prior statute that enabled the scandal to occur, this was done primarily by creating statutory offences for certain conduct rather than any set of enforceable rights.[136] As a result, while there may be a greater deterrent under the revised legislation from violating consent provisions given the newly created statutory offences, were their claim to arise today, it is not clear the parents in *AB and Others* would have any new cause of action available to them to ground their claims.

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[131] *A B and Others v Leeds Teaching Hospital*, [2004] EWHC 644 at paras 1–3 [*AB and Others*].
[132] *Ibid* at para 122.
[133] Mason & Laurie, *supra* note 114 at 715.
[134] Ian Ellis, "Beyond Organ Retention: The New Human Tissue Bill" (2004) 364 The Lancet 42 at 42.
[135] *Ibid* at 43.
[136] Goold & Quigley, *supra* note 113 at 246.

The lack of enforceable rights over biomaterials not only limits remedial avenues but also results in a lack of clarity in terms of the rights to possess, use, and control biomaterials post-separation. Health law scholars, Imogen Goold and Muireann Quigley, provide the following example to illustrate the need for legal rules to govern control over biomaterials past the point of initial extraction and consent:

> Anne undergoes a biopsy to determine whether a lump in her breast is cancerous. Initially, the biopsied tissue is held by the hospital pathology laboratory, where it is tested. She subsequently agrees to donate it to a research project being conducted by a research team attached to the hospital… Imagine Anne wants to regain control of her tissue. Perhaps she wants to move it to another research study. Perhaps she wants to gain access to it for further testing to avoid another biopsy, or to use information from the lump at the time it was first biopsied. This might be for her own health, or for legal purposes. Let us also imagine that the research team refuses to give up factual possession.[137]

The point they make is that the *Human Tissue Act 2004* would not be able to resolve these competing claims to control Anne's tissue. Instead, the authors advocate for a property law framework, which provides established rules for possessory title.[138] While the limitations of the legislation are certainly concerning and demonstrate the appeal of property law in this context, the subsequent discussion in Chapters 4 and 5 will argue that property law would likely operate to deprive Anne of any ongoing rights to her sample save for a limited right to refuse future research uses. Nevertheless, property law is viewed by many as the best source of rights over biomaterials to supplement the limited nature of legislative governance frameworks.[139] One reason for this is that violations of property rights give rise to civil remedies, the importance of which can be seen in the next case below.

iii. Assisted Reproduction

While the *Colavito* and *AB and Others* cases demonstrate the lack of enforceable rights under organ and tissue donation legislation, the same problem also exists in the assisted reproduction context, demonstrated by *Yearworth v North Bristol NHS Trust*.[140] This case involved the negligent destruction of stored sperm samples from plaintiffs who had been undergoing chemotherapy.[141] The plaintiffs brought a claim for the mental distress they suffered as a result of

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[137] *Ibid* at 247 [footnotes omitted].
[138] *Ibid* at 252.
[139] For example, see Goold & Quigley, *supra* note 113; Nwabueze, *Biotechnology, supra* note 27; and Mason & Laurie, *supra* note 114.
[140] *Yearworth*, *supra* note 93.
[141] *Ibid*.

learning their samples had been destroyed. The transfer and storage of the sperm was regulated by the *Human Fertilisation and Embryology Act 1990.* While this Act contained various requirements pertaining to the storage of the sperm, the plaintiffs pleaded their claim solely in terms of common law principles of negligence,[142] presumably because the Act provided no independent cause of action.[143]

Indeed, as the defendant pointed out, the effect of the relevant Act was to leave the plaintiffs without any positive, enforceable rights to the sperm. Under the Act, only licensed facilities had any ability to store, transport, test, and supply the sperm.[144] The men had no ability to do these things themselves or to demand the return of the sperm. The Act further required that, before allowing the sperm to be used for reproductive purposes, a licensed facility must first consider the welfare of any potential future children born from the procedure.[145] As a result, the men did not even enjoy a right to direct the sperm be used for their own reproductive purpose, as any such use was subject to the facility's discretion.[146]

The absence of any enforceable rights did not, in the end, prove fatal to the plaintiffs' claim. Despite the lack of positive rights to the sperm, the Court concluded the men enjoyed a negative control right in that the sperm could not be used without their consent and they could withdraw consent for the sperm's storage at any time, thus depriving the facility of their possession of the sperm.[147] As will be explored further in Chapter 4, this negative control right was sufficient to establish the sperm was the men's property, thus allowing them to recover damages for a breach of the terms of a bailment. For present purposes, it is sufficient to note the men's lack of enforceable rights under the statutory scheme and need to pursue causes of action based in the common law.

Colavito, AB and Others, and *Yearworth* show the limitations of legislative governance mechanisms and the consent paradigm they employ. Although organ donation, post-mortem examinations, and assisted reproduction were all governed by legislation, these statutes did not create and allocate any enforceable rights to the respective biomaterials nor any causes of action

[142] *Ibid* at para 13.
[143] Wall, *Being and Owning, supra* note 26 at 179.
[144] *Yearworth*, *supra* note 93 at para 42.
[145] *Ibid*.
[146] *Ibid* at paras 42–43.
[147] *Ibid* at paras 44–45.

to ground the plaintiffs' claims. Instead, the claimants had to ground their claims in common law causes of action, the limits of which will be turned to now.

B. Inadequacy of Common Law Actions

The need to look beyond statutory regulation for remedial options when biomaterials have been wrongfully interfered with creates challenges for potential claimants. These challenges entail difficulties in identifying applicable causes of action in which to ground a claim as well as difficulties in meeting requirements for compensation. This is because beyond the initial removal of a biomaterial, it is not clear what rules, rights, and duties exist, as Goold's and Quigley's example of "Anne's biopsy" illustrates above. In addition, the type of harm that is often experienced is psychological and emotional in nature, which tort law remains reticent to recognize as compensable harm.

The consent paradigm employed by relevant legislation is typically limited to the removal of biomaterials for certain purposes. This process is protected by the common law tort of battery. Any non-consensual physical interference with one's body gives rise to a valid cause of action even in the absence of any physical harm. This tort provides robust protection for the right to bodily integrity and potential remedial avenues including compensatory, aggravated, and punitive damages.

However, there are many contexts in which biomaterials are used that fall outside the scope of this tort. For example, when body parts are removed and retained from deceased bodies, no action in battery lies.[148] The claimants in *AB and Others,* for example, needed to rest their claims on negligence and a controversial cause of action based on the wrongful interference with a deceased body, the existence of which was rejected by Gage J.

Similarly, when biomaterials are consensually removed for a particular purpose and then subsequently used for a different purpose, it is unlikely an action in battery would lie absent any fraudulent intent by the person obtaining the consent. Consent in the medical context is valid so long as the person providing it has capacity, is providing consent voluntarily, and is informed as to the basic nature of the procedure.[149] Where the very nature and purpose of the procedure has

[148] Mason & Laurie, *supra* note 114 at 727.
[149] O'Shea, *supra* note 116 at 19.

been deliberately misrepresented, there is some common law authority to suggest that consent may be vitiated.[150] However, as Chapter 3 will demonstrate, most secondary uses of biomaterials are undertaken on materials that have been consensually separated for a valid initial purpose, leaving very limited scope for battery claims in this regard.

In the absence of battery, negligence becomes a promising remedial candidate. However, unlike battery, negligence requires proof of compensable harm, which does not ordinarily encompass mental distress unless it amounts to a recognized psychiatric illness or is consequent upon underlying physical injury or property damage.[151] Further, claimants must surmount foreseeability and remoteness requirements to receive compensation, the difficulty of which is acutely demonstrated in *AB and Others.*

The three lead claimants in *AB and Others* (Mrs. Shorter, Mrs. Harris, and Mrs. Carpenter) sought damages for their mental distress. All three claimants proved that they suffered recognized psychiatric illnesses that were caused or contributed to by learning the news that their children's organs had been removed and retained without their knowledge,[152] yet only one (Mrs. Shorter) ultimately succeeded.

In Mrs. Carpenter's case, the post-mortem examination was ordered by the coroner. As a result, her consent (informed or otherwise) was not necessary for the examination to occur, and Gage J found "[t]he claimants' case in negligence only arises in the context of *hospital* post-mortems" (as opposed to a *coroner's* post-mortem).[153] Despite the fact that Gage J found that the Carpenters were "not given any information about the nature of the post-mortem investigation nor

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[150] *Gerula v Flores*, [1995] OJ No 2300 (ONCA), for example, involved a surgeon who accidentally operated on the wrong vertebrae in the patient's spine. The doctor sought consent for a second operation on the correct vertebrae but did not disclose the original error as the reason why a second operation was needed. This failure amounted to "a misrepresentation by omission", meaning that "the appellant's consent to being operated on a second time by the respondent was not a true consent" and amounted to a battery (para 72) ; See also *Dean v Phung*, [2012] NSWCA 223, where a dental surgeon misrepresented the therapeutic nature of $75,000 worth of dental treatments, which were not necessary to treat the patient's condition. As a result, the patient was found not have given valid consent to the treatments, which amounted to a battery (at para 66).

[151] The Supreme Court of Canada has recognized that compensable mental harm does not require an expert psychiatric diagnosis, and instead, the plaintiff must show "that the disturbance suffered…is 'serious and prolonged and rise[s] above the ordinary annoyances, anxieties and fears' that come with living in civil society": *Saadati v Moorhead*, [2017] SCC 28 at para 37 [*Saadati*], quoting *Mustapha v Culligan of Canada Ltd*, 2008 SCC 27 at para 9 [citations omitted]. They noted, however, that this represented a departure from the law of negligence in the UK, Australia, and New Zealand (at para 28).

[152] *AB and Others*, *supra* note 131 at paras 248, 267 & 278.

[153] *Ibid* at para 163 [emphasis added].

were they told that the brain was going to be retained",[154] there was no exploration as to whether a duty of care was owed to communicate this information to them.

In Mrs. Shorter's and Mrs. Harris's claims, Gage J found a duty of care was owed by the physicians who sought their consent for the post-mortem examinations. As the *Human Tissue Act 1961* required non-objection by the parents as a pre-requisite for the examinations, Gage J found this requirement must have entailed "some explanation of to what the parents [were] being asked not to object".[155] In both cases, the duty was breached by failing to inform the parents that organs might be retained following the examinations.[156] In both cases, Gage J accepted that had the parents been properly informed, they would still have consented to the examinations but either would have delayed the funerals until their children's bodies could be buried whole[157] or would have subsequently interned the removed organs.[158] And in both cases, the subsequent news of the organ retention caused or contributed to the claimants' recognized psychiatric illnesses.[159]

However, despite overcoming these legal hurdles, only Mrs. Shorter was able to recover, as Mrs. Harris's claim failed on principles of remoteness. Gage J found Mrs. Harris to be "a robust person" who was "unlikely to collapse under the strain" of being informed about the possibility that her child's organs would be retained.[160] As a result, it was not foreseeable that a subsequent revelation that her child's organs had been so retained would cause her to suffer a psychiatric illness.[161] In contrast, Mrs. Shorter's illness was foreseeable given her extreme distress at the time and her presentation as an "emotionally fragile person".[162] As a result, she was awarded £2750 in compensatory damages.[163]

The perversity of this reasoning is that one of the key justifications offered for not informing these parents at the time that their children's organs might be retained was a concern about not adding to their distress.[164] The very fact that Mrs. Harris appeared robust enough to be

[154] *Ibid* at para 73.
[155] *Ibid* at para 206.
[156] *Ibid* at paras 254 & 270.
[157] *Ibid* at para 107.
[158] *Ibid* at para 58.
[159] *Ibid* at paras 248 & 267.
[160] *Ibid* at para 253.
[161] *Ibid*.
[162] *Ibid* at para 268.
[163] *Ibid* at para 275.
[164] *Ibid* at para 237.

able to handle that information is all the more reason it should have been disclosed to her. Yet her mental fortitude at the time was the sole reason her claim failed.

Similar hurdles were faced by the claimants in *Yearworth.* The claimants in that case did not advance a breach of contract claim for the destruction of their sperm, as their samples had been stored gratuitously with no exchange of consideration.[165] While the defendant admitted it owed and breached a duty of care, it denied liability in negligence on the basis that the claimants could not prove an underlying personal injury or damage to property to ground their claims for mental harm.[166] On appeal, the claimants asserted a new cause of action based in the law of bailment.[167] They argued that a bailment existed, the terms of which had been breached, enabling them to claim damages for the resulting mental harm they suffered.

Lord Judge CJ, on behalf of the Court of Appeal, first addressed the question of whether the damage to the men's sperm constituted a "personal injury". The reason this argument was advanced was because if the damage to the sperm itself was a personal injury, there would be no difficulty for the men in recovering for their consequential mental harm.[168] The claimants argued that although the sperm was physically separated from the men's bodies, it was being stored to serve the same function as if it had remained inside them and remained "biologically active", "retain[ing] a living nexus with the men whose bodies had generated it".[169] However, these arguments were rejected on the basis it would be "a fiction" to hold that an interference with material separated from one's body amounts to a bodily injury to them.[170]

The claimants, however, succeeded in arguing the sperm was their property that had been negligently destroyed. The Court's reasoning in this respect will be fully explored in Chapter 4. For present purposes, it is enough to note that their success on this finding of negligent property destruction did not completely resolve the question of entitlement to damages for mental distress. As the Court of Appeal found the trial judge erred by rejecting the claim of property ownership by the men, the result of the appeal was to remit the case back to the trial judge to determine the

[165] *Yearworth*, *supra* note 93 at paras 6 & 17.
[166] *Ibid* at para 14.
[167] *Ibid* at para 17.
[168] *Ibid* at para 18.
[169] *Ibid* at para 19.
[170] *Ibid* at para 23.

remaining issues, such as the quantum of damages.[171] The Court of Appeal therefore did not definitively resolve the issue of damages but nevertheless made some relevant points in this regard. They noted that prior case law involving mental harm arising from negligent property damage involved situations where the plaintiff witnessed the damage or destruction of their property (such as the burning down of one's house) rather than hearing about the damage later.[172] As a result, they questioned whether such a distinction might have consequences for the claimants in determining their damages award, as similar distinctions have been drawn in the personal injury context to place limits on damages for mental harm arising from negligence.[173]

The Court of Appeal did not resolve that issue, however, because they also found in favour of the claimants in the law of bailment. Having found the sperm was the men's property, the Court was able to conclude that a gratuitous bailment existed between the Trust, as bailees, and the men, as bailors.[174] The Court further found that the Trust not only breached its obligations as a gratuitous bailee to take reasonable care of the sperm, but they also breached a particular promise made to the claimants to store their sperm at a specific temperature.[175] This breach was therefore more akin to a breach of contract than a breach of tort law obligations, and as such, Lord Judge CJ found the claimants were entitled to have their damages assessed as a matter of contract law rather than the more narrowly construed tort law principles.[176] As damages for mental distress can be awarded for breaches arising from contracts aimed at preserving a party's "peace of mind", and the arrangement between the Trust and the claimants was for such a purpose, "[t]he law of bailment provides them with a remedy under which, in principle, they are entitled to compensation for any psychiatric injury (or actionable distress) foreseeably consequent upon the breach".[177]

While the plaintiffs in *Yearworth* ultimately succeeded in their claims using common law principles, it is notable that their success depended on a novel application of property law and a controversial application of contract law principles to a situation lacking any underlying contract. As mentioned at the outset of this chapter, bodies and biomaterials have historically been excluded

[171] *Ibid* at para 60.
[172] *Ibid* at para 55.
[173] *Ibid*.
[174] *Ibid* at paras 49–50.
[175] *Ibid* at paras 49 & 58.
[176] *Ibid* at paras 56–59.
[177] *Ibid* at para 58.

from the realm of property law. This case therefore represents a significant turning point for property law jurisprudence (explored further in Chapter 4) and begins to highlight the utility and appeal of property law to fill what would otherwise be a remedial gap in the law under statutory and non-property based common law frameworks.

Health law scholar, Remigius Nwabueze, has written extensively on the ability of property law to fill this remedial vacuum.[178] He uses an example of "a claimant's tissue [being] non-consensually tested for HIV/AIDS when consent was only given for a diabetic test" to illustrate this point.[179] In his analysis, no action in battery would lie as the tissue was validly removed with consent.[180] An action in negligence based on a failure to obtain informed consent would be possible, but unlikely to succeed given the difficulty in recovering damages for mental harm.[181] And a breach of contract claim would require proof that a contract existed and that it either expressly or impliedly prohibited the test conducted.[182] He therefore contends that property law provides the best remedial option. If the claimant's blood is regarded as their property, then "a non-consensual and prejudicial use of [the] claimant's blood should amount to a conversion".[183]

While he similarly dismisses the application of privacy torts, his later work acknowledges the case of *Doe v High-Tech Institute,* which involved a college student who consented to a blood test for rubella which was actually tested for HIV (which will be returned to in Chapter 8).[184] The student succeeded in the privacy tort of public disclosure of private facts and successfully appealed a summary dismissal of his claim for the privacy tort of intrusion upon seclusion.[185] Nwabueze further acknowledges the possibility that this situation could give rise to a statutory claim under the UK's *Data Protection Act 1998*.[186] While the applicability of privacy torts and statutes will be returned to in Part 2 of this thesis, for present purposes it is sufficient to note that non-consensual

[178] Nwabueze, *Biotechnology, supra* note 27, c 5; Nwabueze, "Donated Organs", *supra* note 121; Remigius N Nwabueze, "Cadavers, Body Parts and the Remedial Problem" in Goold et al, *supra* note 18, 157 [Nwabueze, "Cadavers"].
[179] Nwabueze, "Donated Organs", *supra* note 121 at 216.
[180] *Ibid* at 217.
[181] *Ibid* at 216–17.
[182] *Ibid* at 217.
[183] *Ibid*.
[184] *Doe v High-Tech Institute*, 972 P2d 1060 (Colo App 1998) [*Doe v High-Tech Institute*]; Nwabueze, "Cadavers", *supra* note 178 at 167.
[185] *Doe v High-Tech Institute*, *supra* note 184.
[186] Nwabueze, "Donated Organs", *supra* note 121, n 72 (at 216).

testing of another's biomaterials is a problem needing to be addressed and that both property and privacy law present potential solutions to this gap left by legislative governance frameworks.

Indeed, as mentioned in the introduction to Part 1 of this work, Greely has indicated that surreptitious testing of genetic samples is the most pressing and unresolved problem arising from DTC genetic testing. [187] Greely explains that, with the exception of some US states that have legislated to impose property rights over genetic information, there is likely nothing to legally prohibit someone from collecting and analyzing another person's DNA without their consent or knowledge.[188] The reason for this is because genetic material can be collected and analyzed from discarded waste, which, at least under US law, is likely regarded as abandoned property.[189] While expanding a property approach is one option to address this issue, it is not one Greely finds appealing, as "the language of 'property' or 'ownership' will likely cause confusion".[190] Instead, he suggests "require[ing] that whoever analyzes a DNA sample must have good evidence that it was either collected consensually or under an applicable exception".[191] Chapter 8 of this thesis will return to this issue and explain how privacy law could be used to create such an obligation and corresponding cause of action to overcome this remedial limitation of the legislative governance model.

An additional remedial limitation of the legislative governance model can be seen in exclusion of liability provisions. For example, donation and transplantation statutes often have immunity provisions that can vary in scope from relatively narrow (such as in Australian and some Canada statutes, which exclude from liability acts done in good faith and without negligence)[192]

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[187] Greely, *supra* note 22.
[188] *Ibid* at 155.
[189] *Ibid*; Note: Goold has explored the doctrine of abandonment in relation to human biomaterials and found it is less settled outside the US than what some commentators have assumed: Imogen Goold, "Abandonment and Human Tissue" in Goold et al, *supra* note 18, 125 [Goold, "Abandonment"].
[190] Greely, *supra* note 22 at 157.
[191] *Ibid*.
[192] For Australian examples, see: *Human Tissue Act 1985* (TAS), 1985/118, s 29; *Human Tissue Act 1982* (VIC), 1982/9860, s 43; *Transplantation and Anatomy Act 1983* (SA), s 36; *Human Tissue and Transplant Act 1982* (WA), s 31; For Canadian examples, see: *Human Tissue Gift Act*, RSBC 1996, c 211, s 9; *Human Tissue Gift Act*, RSNB 2014, c 113, s 11; *Human Tissue Act*, RSNL 1999, c H-15, s 17; *Human Organ and Tissue Donation Act*, SNS 2019, c 6, s 29; *Human Tissue Donation Act*, SNWT 2014, c 30, s 16; *Human Tissue Donation Act*, RSPEI 1988, c H-121, s 14; *Human Tissue Gift Act*, RSY 2002, c 117, s 9; *The Human Tissue Gift Act*, CCSM 1987-88 c 39, s 14.

to very broad (such as in other Canadian jurisdictions[193] and some US jurisdictions[194]), which preclude liability for all acts or omissions in good faith regardless of whether they are done with negligence.[195] These provisions can create additional obstacles for claimants to overcome.

For example, although Colavito's claim failed because he was not someone "in need of" the relevant kidney due to its immunological incompatibility, had the kidney been useable by him, he would nevertheless have had to overcome the relevant statutory immunity provision, which the defendant argued shielded them from liability.[196] The Appeals Court did not need to decide whether the alleged mis-delivery of the kidney came within the immunity provision given their finding that the statutory provision allowing for deceased directed donation did not apply in the first place.[197] However, the meaning of "good faith" has been given a broad interpretation in this context,[198] and similarly worded donation immunity provisions have been upheld as valid in a range of US states.[199] As a result, this could have been a further obstacle for Colavito to overcome.

C. Conclusion

The legislative governance model plays an important role in regulating biomaterials. When new uses emerge for biomaterials, there may be activities that should be prohibited or facilitated through legislation. Given the unique nature of reproductive materials, for example, in that they hold the potential to develop into human beings, there are legitimate reasons for direct regulation

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[193] *The Human Tissue Gift Act*, SS 2015, c H-151, s 15; *Human Tissue and Organ Donation Act*, SA 2006, c H-145, s 11; *Gift of Life Act*, RSO 1990, c H20, s 9.

[194] The *Uniform Anatomical Gift Act* provides a model statute for individual states to implement in their respective jurisdictions, and its model immunity language provides that "[a] person that acts in accordance with this [act] or with the applicable anatomical gift law of another state, or attempts in good faith to do so, is not liable for the act in a civil action, criminal prosecution, or administrative proceeding": National Conference of Commissioners on Uniform State Laws, *supra* note 103, s 18(a).

[195] See *Ramirez v Health Partners of Southern Arizona*, 972 P2d 658 (Ariz App Div 2 1998) [*Ramirez*], where a version of the UAGA's immunity provision in Arizona law was held to exclude negligent acts done in good faith from liability. Pelander J (Espinosa and Howard JJ concurring) noted "there are sound policy reasons for requiring more than negligence to impose liability on those who participate in good faith in the organ procurement process" (at para 29).

[196] *Colavito*, *supra* note 123 at 56.

[197] *Ibid* at 57.

[198] Pelander J in *Ramirez*, *supra* note 195 noted that "good faith" in this context tends to mean "honest belief, the absence of malice and the absence of a design to defraud or to seek an unconscionable advantage" (para 15); The Uniform Law Commission similarly recommends in its commentary to the UAGA that "good faith" be given "a liberal interpretation" as imposing a subjective mental standard of "honesty of intent": National Conference of Commissioners on Uniform State Laws, *supra* note 103 at 48.

[199] Pelander J in *Ramirez*, *supra* note 195 notes that the UAGA's good faith immunity provision has been upheld in case law from Minnesota, Michigan, New York, Pennsylvania, and Texas (at para 15).

of the purposes to which they can be put. Further, the consent paradigm employed by statutory frameworks has a strong counterpart in the common law of battery, at least at it pertains to consent for excision of biomaterials. However, as the *AB and Others, Yearworth,* and *Colavito* cases illustrate, this approach is not comprehensive in nature and requires supplementation by other legal principles.

In considering what frameworks are best suited for this purpose, it is worth making some initial observations about the nature of the interest at stake for the claimants in these cases. While individuals' interests in biomaterials are sometimes described as autonomy interests, autonomy does not go all the way in justifying their existence. It inescapably raises the question as to why an individual should have freedom to self-determination in relation to a particular state of affairs. When one drills down deeper, one uncovers the much more amorphous and difficult to define concept of human dignity.[200] Charles Foster, author of *Human Dignity in Bioethics and Law*, explores the many meanings attributed to "dignity" by scholars over the ages.[201] As the concept suffers from a significant lack of precision, it can be difficult to ground arguments based on notions of dignity, as there is no uniform understanding of what this concept represents. However, a lack of precision does not mean the concept is completely devoid of meaning or irrelevant as a conceptual consideration in some contexts. Foster points to examples of medical students who, while dissecting a body, take an ear and turn it into an ashtray, or kids kicking a human head in the street to make the point that, as ill-defined as it is, there are dignity interests at stake in the human body and its separated parts.[202]

In whatever way one might define "dignity", when considering the parents in *AB and Others,* the men in *Yearworth,* and Mr. Colavito, it is clear that the interests of the claimants in all three cases were deeply personal, cutting to core of their sense of personhood and identity. The parents in *AB and Others* experienced an interference with their parental roles and responsibilities. As medical law scholar, Jonathan Herring, points out, when a parent loses a child, the last act of care that can be provided is to arrange a funeral, which, to some parents, might be "devalued and

[200] See Charles Foster, who questions, "Why should one have any respect for persons at all? Or, for that matter, respect for their autonomy? To give an account of that respect one has to go to a level below the respect itself, and whatever that level is, it is at the metaphysical altitude of dignity": Charles Foster, *Human Dignity in Bioethics and Law* (Oxford: Bloomsbury Publishing, 2011) at 61.
[201] *Ibid* c 3.
[202] *Ibid* at 5–8 & 173–75.

damaged" when it is undertaken without full information as to the state of their child's body.[203] The wrong in this case is "a relational wrong", which "can only be understood in the context of the child-parent relationship".[204] In this respect, it is a deeply personal wrong. As medical law and legal philosophy scholar, Jesse Wall, points out, "where a parent, patient, donor or a widow, is deprived of their entitlements in bodily material, they are being deprived of the opportunity to exercise their rights *as a parent, as a wife or as an embodied person*. Their interest in the bodily material represents a very personal interest".[205]

This is in contrast to property wrongs. While the law of personal property is good at dealing with physical things, and deceased bodies and separated biomaterials are certainly physical in nature, the personal interests in these "things" often go beyond the interests property law exists to address. The wrong done to the parents in the organ retention scandal that evoked visceral public outrage was not a property wrong. As Herring points out, "[t]here would have been nothing like this outcry had doctors been keeping, say, pieces of clothing from the children".[206] Similarly, to the men in *Yearworth,* the destruction of their sperm entailed deeply personal consequences different from the destruction of any other piece of "property" in that their very ability to step into a parent-child relationship was affected. And to Colavito, had the kidney been biologically compatible, his very existence in the world would have been at stake by its deprivation.

What is lacking in a property approach, in this respect, is its ability to "capture the 'me-ness' of our bodily material" in that "[o]ur bodies can represent us to others and play a role constituting our identity".[207] Our interests in bodily materials can go beyond their physical properties, where our control over them "is more about *us* (our personality, personhood or our relationships)".[208] Despite the amorphous meaning of human dignity, it is clear the interests in these cases are very personal in nature.

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[203] Herring, *supra* note 29 at 227, quoting M Maclean, "Letting Go. Retention of Human Material after Post Mortem" in A Bainham et al, *Body Lore and Laws* (Oxford, Hart Publishing, 2001).
[204] *Ibid*.
[205] Jesse Wall, "The Trespasses of Property Law" (2014) 40:1 J Med Ethics 19 at 20 [Wall, "Trespasses"] [emphasis in original].
[206] Herring, *supra* note 29 at 217.
[207] *Ibid*.
[208] Wall, "Trespasses", *supra* note 205 at 21 [emphasis in original].

As the cases explored in this chapter show, the legislative governance and consent paradigm strategy lacks enforceable rights to protect these deeply personal interests and leaves claimants reliant on ill-suited common law frameworks to ground their claims. Further, by focusing on initial consent to separation of biomaterials, this regulatory approach fails to fully recognize individual autonomy interests in biomaterials that are ongoing in nature. While the consent paradigm provides robust protection for the right to bodily integrity, when materials are taken from a deceased body or misused after they have been validly separated from a living person, there is little protection for individuals' continuing interests in their biomaterials. Mrs. Shorter and Mrs. Harris in *AB and Others*, for example, consented (without being fully informed) to the post-mortem examinations. As a result, they enjoyed no enforceable statutory rights to the organs despite their ongoing interests in them, and the common law left two out of three claimants with no remedy.

The regulation of *activities* through legislative governance as opposed to the *materials themselves* through an exclusion strategy (such as property law) produces a regulatory framework that is inherently incomplete as the uses for biomaterials continue to expand.[209] As the value of biomaterials continues to rise and as control over these materials becomes increasingly contested, the governance framework's inability to provide rights and remedies for the ever-expanding uses for biomaterials will become all the more problematic.[210] For this reason, some assert that the two frameworks should operate jointly, with an exclusion strategy (through property law) providing default protection for an open-ended set of activities and a legislative governance strategy imposing necessary parameters and limits.[211]

The cases in this chapter begin to show the appeal of the exclusion strategy offered by property law. Had the parents in *AB and Others* been found to have had a property interest in the bodies of their children, they may have succeeded in their claim for wrongful interference. Similarly, the novel application of property law in *Yearworth* was essential to the claimants' success in securing a remedy for their mental distress through the law of bailment. Further, had the kidney been Colavito's property, his conversion claim would have had grounding in the

[209] Wall, *Being and Owning, supra* note 26 at 179; Goold & Quigley, *supra* note 113 at 246.
[210] Goold & Quigley, *supra* note 113 at 246.
[211] Wall, *Being and Owning, supra* note 26 at 184–85; Mason & Laurie, *supra* note 114 at 727; Nwabueze, "Cadavers", *supra* note 178 at 174; Goold & Quigley, *supra* note 113 at 261–62.

common law that the statute failed to provide (although he would still have needed to overcome the statute's immunity provisions).

Property law, however, is not the only legal framework imposing an exclusionary boundary. As Part 2 of this thesis will demonstrate, and as alluded to by Nwabueze, privacy law operates in a similar fashion, making it a potentially useful regulatory tool. For present purposes, it is enough to note the appeal of the exclusionary boundary as one of the key reasons property law seems a promising choice to fill the remedial void left by the legislative governance and consent paradigm approach. Prior to exploring property and privacy frameworks in more detail, the next chapter will build on the critique offered in the present chapter of the legislative governance framework by narrowing the focus to the biomedical research context.

Given that the legislative governance framework does little to clarify the ongoing rights and interests that exist in biomaterials, there is considerable scope and work to do for soft law regulatory instruments in this space. The research context is particularly relevant in this respect, as this area is fueled by biomaterials and operates under a wealth of ethical guidelines and instruments pertaining to these substances. As a result, the next chapter will examine this context to evaluate whether research regulatory frameworks provide any of the much-needed clarity for the law governing separated biomaterials. This chapter will demonstrate, however, that research ethics frameworks have adapted to biotechnological developments in a way that preferences the supply of biomaterials for research over the protection of individual participants from whom these valuable materials are derived.

3. Research Ethics Frameworks: Facilitating Biomaterial Supply over the Protection of Individual Interests

The biomedical research environment has changed. The use of biomaterials has altered the traditional research paradigm of individual participants engaging with investigators in single research studies. Now, research often no longer requires ongoing participation by participants themselves. Rather, it is participants' biomaterials and associated information that researchers require. To increase efficiency and enable access to vast quantities of biomaterials, biobanks have developed to collect and store these materials, not for a single research study, but as an ongoing resource for any number of future research projects. Other biorepositories, such as newborn screening cards, pathological samples, and DTC testing databases, also provide a rich resource of biomaterials and data for researchers.

As research practices have changed, there has been a concomitant need to reconsider the legal and ethical norms governing the researcher-participant relationship. This is, in part, because the interests and risks inherent in research solely conducted on separated biomaterials are qualitatively different than in research with ongoing participation by living persons.[212] There are also practical constraints and burdens that arise when trying to meet and maintain standards that were designed for a fundamentally different model of research participation.

However, rather than striking a fair balance between individual interests and scientific progress, this chapter will show that modern evolutions to research ethics norms prioritize facilitating researcher access to biomaterials over safeguarding the robust autonomy interests individuals have in these materials. The primacy given to researcher access can be seen in the consent structures governing biomaterials, which reflect the same limited view of autonomy as the legislative governance frameworks explored in the previous chapter. This chapter will show how both unknowing participants and consenting participants have interests in their biomaterials and genetic information that are not adequately protected. This point will be made by (a) questioning the validity of the distinction between identifiable and non-identifiable biomaterials that underpins

[212] David Wendler, "What Research with Stored Samples Teaches us about Research with Human Subjects" (2002) 16:1 Bioethics 33.

consent requirements; and (b) demonstrating that broad consent, alone, is an inadequate substitute for the traditional informed consent standard.

These examples reflect the imbalanced nature of the present research environment. They are two areas where a stark disconnect can be seen between concerns voiced by participants and the public, on the one hand, and research practices and policies that forge ahead in opposition to them, on the other. The unyielding nature of research bodies and institutions in this regard represents a problematic disconnect for a sector dependent on public trust. And in the face of such strong opposition, new and creative avenues to assert individual rights over biomaterials may be appealing.

A. The Problem with "Identifiability" as the Touchstone for Consent

Research ethics frameworks aim to protect participants while allowing scientific progress to be made. Participant consent is a fundamental ethical norm that protects participants' bodily integrity and autonomy. Nazi experimentation on prisoners during World War II and the Tuskegee syphilis experiments from Alabama are prominent and egregious examples of the harms that arise when people are experimented on without consent.[213]

The use of biomaterials in research, however, entails different interests and risks than participation of human beings, which may justify a different set of consent norms.[214] For example, when biomaterials are collected primarily for a non-research purpose (e.g., clinical diagnosis) and then later used in research, the research itself poses no real risk of physical harm to the participant. Any physical risk the participant faced from the extraction of the material would have been faced in any event. To the extent that information can be learned about the participant from their separated biomaterials, however, the participant maintains an informational privacy interest in those materials and faces privacy risks should their information be collected, used, or disclosed in a manner they disagree with.

The risk analysis in terms of participant harm, therefore, differs depending on how the biomaterials are collected, whether research was the primary purpose for their collection, and whether personal information can or will be learned about the individual. These differences may

[213] O'Shea, *supra* note 116 at 16–18.
[214] Wendler, *supra* note 212.

justify different requirements for consent. Indeed, most research ethics guidelines make distinctions along these lines. For biomaterials collected directly from an individual specifically for a research purpose, explicit consent is generally required, and this aligns with legal norms protecting the right to bodily integrity. For biomaterials collected for a different purpose (e.g., a therapeutic procedure or a previous research study), participant consent is not generally required unless the biomaterials are "identifiable".[215]

For example, in Canada, researchers wishing to use identifiable biomaterials for a secondary research purpose must either obtain consent or be granted permission from a research ethics board to use them without consent.[216] For non-identifiable materials, however, while oversight by a research ethics board is still required, participant consent is not.[217] In the UK, the *Human Tissue Act* provides that the use of human biomaterials for "[r]easearch in connection with disorders, or the functioning, of the human body" is legal if done with consent.[218] This provision does not apply, however, to such research if the biomaterials were taken from a living body, the research has been ethically approved under relevant regulations, and is to be carried out such that the researcher is "not in possession, and not likely to come into possession, of information from which the person from whose body the material has come can be identified".[219] Research in these circumstances is lawful in the absence of consent.[220]

In the US, research ethics rules are the most permissive in terms of allowing access to biomaterials without consent. The Common Rule (the key federal research ethics framework in the US) only applies to research involving "human subjects", defined as research where information or biomaterials are obtained by the researcher directly from the individual or where identifiable personal information or identifiable biomaterials are otherwise obtained, used, or

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[215] The following discussion illustrates this point with examples from Canada, the US, and the UK. Additional distinctions based on identifiability can be found in international research ethics guidelines: *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*, by WMA (World Medical Association, 2013), art 32 [*Declaration of Helsinki*]; *International Ethical Guidelines for Health-related Research Involving Humans* (Geneva: Council for International Organizations of Medical Sciences (CIOMS), 2016) (see Commentary on Guideline 10).

[216] *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, by Government of Canada (Ottawa, 2014), art 12.3A [*TCPS2*].

[217] *Ibid,* art 12.3B.

[218] *Human Tissue Act* (UK), *supra* note 102, s 1(1)(f) & Sch 1, Part 1.

[219] *Ibid*, ss 1(8) & (9).

[220] *Ibid*, s 1(10); Human Tissue Authority, "Code 3: Research", (2023), online: <www.hta.gov.uk> at 17 [perma.cc/5ZTT-DTJU].

analyzed.[221] This means that where biomaterials are not "identifiable" and obtained other than through direct interaction with the participant, the entire body of research ethics rules and guidelines, such as requirements for consent, simply do not apply.[222]

The idea that consent should only be required when biomaterials used in research are identifiable is a point of controversy, highlighted by the debate that arose in the lead-up to the 2018 revisions to the US Common Rule. The initial text of the Notice of Proposed Rulemaking (NPRM) contained an expanded definition of "human subject" to encompass anyone whose biospecimens are used in research, regardless of identifiability.[223] Had this proposal been adopted, it would have meant that initial consent would have to be obtained for all biomaterials.

The proposal sparked controversy and a strong backlash by the research community. While there were many proposed changes in the NPRM, in the public consultation process, almost 50% of the comments received pertained to this specific change.[224] While most comments from members of the public "strongly supported" the change,[225] overall, more than 80% of comments received were opposed.[226] Those objecting to the revision ultimately prevailed. Reasons given by members of the research community for their opposition included: (i) a lack of risk or evidence of harm arising from current practice; (ii) the administrative burden of increasing consent requirements; and (iii) too much importance being given to the principle of autonomy over other foundational research ethics principles, such as justice and beneficence.[227]

In contrast, two main arguments arose against maintaining a distinction based on identifiability. The first pertains to the limited interests protected by the distinction. Providing stronger protection for biomaterials deemed "identifiable" than those that are not certainly recognizes that individuals have an informational privacy interest in their biomaterials, but there may be interests beyond informational privacy that are also worthy of protection. In this respect, the identifiability distinction could be under-inclusive. The second argument questions the

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[221] *Protection of Human Subjects (2018 Common Rule)*, by HHS, 45 CFR 46 (Department of Health and Human Services, 2018) at §46.101 & 46.102 [*Common Rule*].
[222] *Notice of Proposed Rulemaking*, 80:173 Federal Register 53933 (2015) at 53943 [NPRM].
[223] *Ibid* at 53944 & 54047.
[224] National Human Genome Research Institute, "Highlights of Revisions to the Common Rule", (2017), online: *Genome.gov* <www.genome.gov/> [perma.cc/2G8Z-N9HL].
[225] NPRM, *supra* note 222 at 53943–44.
[226] National Human Genome Research Institute, *supra* note 224.
[227] NPRM, *supra* note 222 at 53943–44.

assumption underlying the identifiability distinction: that participants' informational privacy is adequately protected for biomaterials deemed non-identifiable. Advancing technologies and privacy-breaching strategies are casting doubt on the strength of "de-identification" practices given re-identification techniques and the inherently identifiable nature of genetic material within biomaterials. Each argument will be addressed, in turn, below.

i. Consent Requirements Based on Identifiability are Under-inclusive

The rationale behind the distinction based on identifiability is that it protects participants from substantial harm. If biomaterials are non-identifiable, participants are not exposed to privacy risks, and research can therefore be categorized as minimal risk and proceed with only limited review. In this way, privacy protection is its core function. However, this line of thinking misunderstands the concept of privacy and purpose of consent.

Privacy is about much more than concealment of identity.[228] While privacy does entail an informational component, it also entails spatial and personal dimensions.[229] The focus on concealment of identity as a justification for failing to obtain consent reflects an overly narrow view of the interests privacy protects and justifications for individual control. As law and bioethics scholar, Deryck Beyleveld, notes, in relation to the right to privacy enshrined in the *European Convention of Human Rights* (*ECHR*), "the right is explicitly not restricted to a right to concealment of one's identity", entailing, instead "a right to all constituent parts of an individual's personality that are not protected by other rights in the Convention".[230] He argues that anonymization can actually serve to violate privacy, providing an example of a patient who is devoutly Catholic and vehemently opposed to hormonal contraception whose anonymous health information is provided by her doctor to a researcher conducting research on hormonal birth control.[231] In Beyleveld's view, the patient's "legitimate interest goes far beyond mere concealment of her identity" and anonymization serves to violate this interest by removing all of her control over her health information.[232]

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[228] Deryck Beyleveld, "Data Protection and Genetics: Medical Research and the Public Good" (2007) 18:2 King's LJ 275 at 281–83.
[229] *Dyment*, *supra* note 69 at para 30 (La Forest J).
[230] Beyleveld, *supra* note 228 at 282.
[231] *Ibid*.
[232] *Ibid*.

Indeed, people feel a range of connections with their biomaterials beyond the information they can yield. Sometimes this connection can be spiritual,[233] functional,[234] cultural,[235] or emotional in nature.[236] As discussed in the previous chapter, notions of human dignity[237] and respect for autonomy underly these interests. While somewhat amorphous,[238] Chapters 6 through 8 will demonstrate that these interests are capable of coming within a robust understanding of privacy, which protects the same amorphous autonomy and dignity-based interests reflected in this list.

The assertion that the current framework does not harm participants therefore needs to be evaluated against the multiplicity of interests and feelings people have in relation to biomaterials. Even where there is no physical harm or informational privacy infringement, there can be palpable emotional harm when people discover their biomaterials have been used without their consent. Discovery of the organ retention scandal, discussed in Chapter 2, was met with outrage and disgust by the public and resulted in a legal claim by the affected parents for the emotional harm they suffered.[239] The infamous cases of Henrietta Lacks[240] and John Moore,[241] each of whom had diagnostic biomaterials taken and used to create highly lucrative cell lines without their knowledge, also highlight the sense of violation and exploitation that arises when biomaterials are taken and commercialized without permission. The NPRM recognized the legitimacy of individuals' autonomy interests in their biomaterials, and this formed part of the rationale for requiring consent for all biospecimens and not just those that are identifiable.[242]

The use of identification as a dividing line for when consent is or is not required not only reflects an overly narrow view of privacy, but also the purpose of consent. Consent frameworks in

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[233] such as beliefs the body must be burred whole: see Natalie Ram, "Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research" (2009) 23 Harv J L & Tech 119 at 126.
[234] See Wall's functional unity justification for individual control over biomaterials: Wall, *Being and Owning, supra* note 26.
[235] The Havasupai tribe, for example, objected to genetic investigations using their biomaterials that conflicted with important cultural stories about their origins: Ram, *supra* note 233 at 128–29.
[236] For example, as discussed in Chapter 2, the parents of deceased children who discovered that organs had been removed from their children's bodies after autopsies and retained without proper consent sued for the emotional distress they experienced: *AB and Others*, *supra* note 131.
[237] Ram, *supra* note 233 at 125–29.
[238] Herring, *supra* note 29 at 217–18.
[239] *AB and Others*, *supra* note 131.
[240] Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (New York: Crown Publishers, 2010).
[241] *Moore v Regents of University of California*, [1990] 51 Cal3d 120 (Sup Ct of California) [*Moore*].
[242] NPRM, *supra* note 222 at 53944.

research serve a broader purpose than simply protecting participants from harm. The research model has moved beyond one singularly focused on risk protection to one that recognizes research can impact participants in many different ways.[243] In this regard, "the doctrine of informed consent is based, not on individuals' right to avoid risks, but on their right to control the course of their lives".[244] Indeed, the legal standard of disclosure for informed consent goes beyond a mere recitation of risks and includes a need to disclose the benefits, alternative options, and for research studies, the question being studied and goals of the project.[245] Therefore, even if one maintains that there are no serious risks to participants beyond informational privacy violations, there is nevertheless reason to consider whether consent norms based on identifiability are serving this broader function.

It is not immediately apparent, however, that the use of biomaterials in research has much impact on the "course of biomaterial providers' lives". In this respect, prominent bioethicist, David Wendler, offers an "argument from contribution". He asserts that individuals have an interest in deciding whether their biomaterials are used in research regardless of whether the research will impact them personally, and that this interest is grounded in the contribution their biomaterials make to the research endeavour.[246]

The argument is helpfully illustrated by way of example. For instance, a person's biomaterials might be used in Alzheimer's research to bring about a cure to this disease. Even if that individual and everyone they hold close in their life never develop Alzheimer's or need to make use of the discovery, the individual nevertheless contributed to a remarkable scientific advancement. The individual has an interest in that scientific achievement because their very biomaterials contributed to its realization. One's contributions say something important about one's life.[247] Individuals therefore have an interest in making decisions about what they contribute to. A contribution account may, therefore, provide reason to allow individuals a say in how their biomaterials are used, regardless of whether the risk of harm they are exposed to is small.

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[243] Wendler, *supra* note 212 at 36–37.
[244] *Ibid*.
[245] *Declaration of Helsinki*, *supra* note 215 art 26.
[246] Wendler, *supra* note 212 at 38–53.
[247] *Ibid* at 41–43.

This justification is echoed in the work of David Price, legal scholar and expert in organ donation and transplantation law and ethics. Price notes that "[t]he primary moral right of control is broader than simply a right not to be *harmed*"[248] as biomaterial providers "are also concerned with their contribution to certain types of research by way of their own bodily materials".[249] When biomaterials are used without permission, "a person is disenfranchised from exercising their right to control the future use of the tissue *per se*".[250]

When applied to the above-mentioned examples, this argument can help illustrate why Lacks, Moore, and the parents in the organ retention scandal ought to have been asked whether they wanted to make the contributions they did. While contributing to scientific progress may be regarded as valiant and noble, it cannot be assumed that all people would see it this way. As a black American woman in the 1950s, Lacks, for example, may have had legitimate concerns about whether to contribute to the advancement of healthcare in a system that continues to reflect racial inequalities in health outcomes and access.[251] Moore may have had legitimate concerns about whether to contribute to a multi-billion-dollar Big Pharma industry, which is perceived, by many, to prioritize profits over patient health.[252] Some of the parents in the organ retention scandal indicated a clear belief that the bodies of their children should be buried "whole" and claimed they would have refused to consent to a post-mortem examination had they known organs would be retained.[253] While not everyone might feel this way, these examples highlight the need to allow individuals to determine what contributions they make, as these contributions reflect on them personally.

That is not to say that such personal interests are absolute. Indeed, Wendler acknowledges that the weight and nature of the say someone should have over a particular state of affairs will vary depending on how central the state of affairs is to the individual and whether others may have a competing claim.[254] The burden that consent requirements impose on researchers, and questions

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[248] David Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge: Cambridge University Press, 2009) at 178 [emphasis in original].
[249] *Ibid* at 179.
[250] *Ibid* at 178.
[251] Richard David & James W Collins, "Why Does Racial Inequity in Health Persist?" (2021) 41:2 J Perinatol 346.
[252] Justin McCarthy, "Big Pharma Sinks to the Bottom of U.S. Industry Rankings", *Gallup.com* (3 September 2019), online: <news.gallup.com> [perma.cc/J4CS-4K54].
[253] *AB and Others*, *supra* note 131 at paras 30–32 & 73.
[254] Wendler, *supra* note 212 at 39–41.

of whether too much emphasis is being placed on autonomy over the other bioethical pillars, therefore, might justify reducing the scope of one's input over how one's biomaterials are used. However, the strength of this position is seriously undermined when one considers the full breadth of the proposed change to the Common Rule.

The proposal was relatively modest in that (i) it would not apply retrospectively to biomaterials already in existence; (ii) there would have been a 3-year transition period for researchers to adjust to the new requirements, and (iii) it would not have required informed consent for the collection and use of biospecimens each time they are used in research, but rather, a one-time "broad consent".[255] While there certainly would be a burden to researchers, it would have been mitigated to a large degree by these parameters. Arguments to maintain the *status quo* are further undermined by the fact that there were two alternative proposals on the table that would have allowed the majority of current research protocols to proceed as they always had, but simply would have required broad consent for some protocols involving genome sequencing.[256] The rejection of all three proposals reflects a failure to move even slightly toward any middle ground in recognizing the say that individuals have in the contributions they make.

Even if one disagrees that there are any significant interests beyond a narrow view of informational privacy needing respect and that individuals need not have any say over their non-identifiable biomaterial contributions, there are, nevertheless, practical reasons to consider expanding consent requirements. There is strong evidence showing that people want some control over their biomaterials.[257] One survey specifically evaluated the distinction based on identifiability and found that 72% of respondents thought it moderately to very important to be informed when their biomaterials were used in research, even when used anonymously.[258] Only 17% of

[255] NPRM, *supra* note 222 at 53944.
[256] *Ibid* at 53945.
[257] David J Kaufman et al, "Public Opinion about the Importance of Privacy in Biobank Research" (2009) 85:5 American J Human Genetics 643; E Vermeulen et al, "A Trial of Consent Procedures for Future Research with Clinically Derived Biological Samples" (2009) 101:9 Br J Cancer 1505; S B Trinidad et al, "Research Practice and Participant Preferences: The Growing Gulf" (2011) 331:6015 Science 287; Jeffrey R Botkin et al, "Public Attitudes Regarding the Use of Residual Newborn Screening Specimens for Research" (2012) 129:2 Pediatrics 231; B A Tarini et al, "Not Without my Permission: Parents' Willingness to Permit use of Newborn Screening Samples for Research" (2010) 13:3 Public Health Genomics 125; Kieran C O'Doherty, Alice K Hawkins & Michael M Burgess, "Involving Citizens in the Ethics of Biobank Research: Informing Institutional Policy through Structured Public Deliberation" (2012) 75:9 Soc Sci Med 1604.
[258] Sara Chandros Hull et al, "Patients' Views on Identifiability of Samples and Informed Consent for Genetic Research" (2008) 8:10 Am J Bioeth 62 at 65.

respondents had preferences aligned with current requirements, viewing it moderately to very important to know about identifiable biomaterial research but not when biomaterials were used anonymously.[259]

Biomedical research depends on public trust. To disregard this mounting evidence is potentially dangerous for the research environment and public interest it serves. The NPRM explicitly noted that using biomaterials without consent "places the publicly-funded research enterprise in an increasingly untenable position because it is not consistent with the majority of the public's wishes, which reflect legitimate autonomy interests".[260] And yet, when push came to shove, the Department of Health and Human Services (HHS) relented to the concerns and interests of researchers. The fact that none of the three proposed changes to the Common Rule were adopted while the HHS explicitly acknowledged the untenable nature of the *status quo* represents a spectacular capitulation to the research community and disregard for the individual autonomy interests it recognized as valid.

ii. Distinctions based on Identifiability do not Adequately Protect Privacy

The second argument against distinctions in consent norms based on identifiability is that these distinctions do not adequately fulfill their underlying purpose of protecting individual informational privacy. The implication of the identifiability distinction, addressed above, is that individuals have legitimate informational privacy interests needing protection when research involves identifying participant information. For this reason, participants should be given the opportunity to decide for themselves whether to take on those risks by giving consent. It follows, then, that if research involving "non-identifiable" biomaterials similarly gives rise to significant informational privacy risks, that individuals should also be asked whether they consent. This argument, therefore, questions the assumption that there are only minimal informational privacy risks when "non-identifiable" biomaterials are used in research.

The meaning of "identifiability" is a necessary starting point in evaluating this contention. Although distinctions are made between "identifiable" and "non-identifiable" biomaterials, the concept of identifiability actually represents a spectrum rather than a binary choice.[261] The

[259] *Ibid*.
[260] NPRM, *supra* note 222 at 53944.
[261] Hull et al, *supra* note 258 at 63.

identifiability of a biomaterial can range from very easy (e.g., a biomaterial labelled with an identifying piece of information) to very difficult (e.g., a biomaterial with no associated pieces of identifying information). This spectrum is reflected in the same research ethics guidelines and instruments canvassed above, which impose different thresholds of identifiability in terms of whether to characterize a biomaterial as "identifiable" or not.

The Canadian research ethics guidelines, for example, impose a standard of reasonableness. These guidelines provide that "[h]uman biological materials that may reasonably be expected to identify an individual, alone or in combination with other available information, are considered identifiable biological materials for the purposes of this Policy".[262] As an example, these guidelines indicate that biospecimens that have been coded (i.e., where direct identifiers are removed and replaced with a code) are "non-identifiable" provided the researcher does not have access to the key.[263]

The UK threshold appears to be stricter, based on the mere possibility of identification. The criterion in the *Human Tissue Act* is whether the investigator is in possession or likely to come into possession of "information from which the person whose body the material has come *can* be identified".[264] However, as shown below, this standard has been interpreted and applied similarly to the Canadian standard of reasonableness. In contrast, the US Common Rule imposes the most permissive threshold in terms of enabling biomaterials to be characterized as "non-identifiable", thus avoiding the need for ethics oversight and consent. This threshold is based on whether the participant's identity can be "readily ascertained".[265]

These thresholds represent a spectrum of identifiability requirements, based on whether the identity of the biomaterial source can (UK), can reasonably (Canada), or can readily (US) be ascertained. What is clear from these definitions is that biomaterials in all these jurisdictions are not considered inherently identifiable. The assumption underlying these requirements is that there needs to be a connection to other pieces of information for the identity of the participant to become

[262] Government of Canada, *supra* note 216 at 165.
[263] *Ibid* at 170.
[264] *Human Tissue Act (UK)*, *supra* note 102, s 1(9)(b) [emphasis added].
[265] Common Rule, *supra* note 221 at §46.102(e)(6); NPRM, *supra* note 222 at 53942–43.

ascertainable. The question then becomes: what pieces of additional information are needed to trigger these thresholds?

Genetic information is unique to the individual. Given its uniqueness, one might expect that its association with a biomaterial would render that material identifiable. After all, genetic information is often used for identification purposes to identify criminals, confirm parentage, and locate genetic relatives. Its identifying features are also being exploited for biometric purposes, where rapid PCR testing is being developed for potential biometric applications in law enforcement and border control.[266] Advancements are also being made in understanding how DNA contributes to one's physical appearance. Scientists have developed a method for constructing a 3D model predicting what a person's face looks like based on their DNA.[267] While this technology will never full predict a person's appearance given the influence of non-genetic factors, and its use in law enforcement creates concerns about racial profiling,[268] it may prove useful in terms of narrowing down the list of potential people to whom a DNA fragment belongs.[269]

And yet, despite the identifying features of one's genetic information, genome sequencing of biomaterials used for a secondary research purpose does not automatically trigger the identifiability thresholds at either end of the spectrum set out above. As of 2015, it was estimated that there were 898 genomic research studies in the US resulting in genome sequencing data unique to the individual that were not subject to oversight under the Common Rule.[270] Indeed, the HHS has confirmed that whole genome sequencing is not considered something "produc[ing] identifiable private information unless additional information is available to the investigator that would enable the investigator to 'readily ascertain' the identity of the individual", but acknowledged that the time at which this threshold will be met "may not be far away".[271]

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[266] Erica L Romsos & Peter M Vallone, "Rapid PCR of STR Markers: Applications to Human Identification" (2015) 18 Forensic Sci Int Genet 90 at 97; "DNA Biometrics", (2018), online: *National Institute of Standards and Technology: NIST* <www.nist.gov> [perma.cc/3THU-XHXP].
[267] Peter Claes et al, "Modeling 3D Facial Shape from DNA" (2014) 10:3 PLOS Genetics, DOI: <10.1371/journal.pgen.1004224>.
[268] Lauren Sue, "'Dangerous Snake Oil': DNA Phenotyping in Canada Threatens to End in Even More Racial Profiling", (7 October 2022), online: *Daily Kos* <www.dailykos.com/> [perma.cc/V76J-R6AZ].
[269] "Building the Face of a Criminal from DNA", *BBC News* (17 June 2015), online: <www.bbc.com/> [perma.cc/F25E-H44R]; Jennifer Kulynych & Henry T Greely, "Clinical Genomics, Big Data, and Electronic Medical Records: Reconciling Patient Rights with Research when Privacy and Science Collide" (2017) 4:1 J Law Biosci 94 at 101.
[270] NPRM, *supra* note 222 at 54025.
[271] *Ibid* at 53943.

Even the UK's *Human Tissue Act,* which appears to be the most inclusive in terms of the biomaterials deemed to be identifiable, does not regard DNA has inherently identifying. The Act creates an offence for non-consensual DNA analysis, which criminalizes the possession of bodily material where there is an intention to analyze DNA from the material without consent.[272] There are exceptions to this offence, however, such as using the results of a DNA analysis for research provided the biomaterial analyzed is from a living person, the research is ethically approved, and "the analysis is to be carried out in circumstances such that the person carrying it out is not in possession, and not likely to come into possession, of information from which the individual from whose body the material has come can be identified".[273] The implication from this exception is that the genetic information extracted from a biomaterial does not, on its own, constitute information from which the individual can be identified.[274] DNA analysis can therefore proceed in research without consent without triggering the criminal offence.

These thresholds for identifiability fail to reflect the reality that DNA is individually identifying, and the identifiability of this substance is only increasing as time goes on.[275] There is a full range of "genetic privacy breaching strategies" that are aimed at overcoming the protections offered by de-identification techniques[276] and increasing examples of re-identification of researcher data.[277] As a result, there are increasing calls for research ethics frameworks to recognize genetic information as identifying. Greely and health privacy expert, Jennifer Kulynyk, have recently proclaimed, "it is no longer ethically defensible or legally sound to maintain that gene sequence data are anything other than identifiable health information".[278]

Some maintain that re-identification of research data remains a relatively low risk, in part, because researchers would be acting against their interests should they seek to breach the privacy

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[272] *Human Tissue Act (UK)*, *supra* note 102, s 45(1).
[273] *Ibid* at Sch 4, s 10.
[274] Human Tissue Authority, *supra* note 220 at 19.
[275] Kulynych & Greely, *supra* note 269 at 106.
[276] Yaniv Erlich & Arvind Narayanan, "Routes for Breaching and Protecting Genetic Privacy" (2014) 15:6 Nat Rev Genet 409.
[277] Khaled El Emam et al, "A Systematic Review of Re-Identification Attacks on Health Data" (2011) 6:12 Plos One, DOI: <10.1371/journal.pone.0028071>; Mark A Rothstein, "Is Deidentification Sufficient to Protect Health Privacy in Research?" (2010) 10:9 Am J Bioeth 3; Melissa Gymrek et al, "Identifying Personal Genomes by Surname Inference" (2013) 339:6117 Science 321; Robert A Philibert et al, "Methylation Array Data Can Simultaneously Identify Individuals and Convey Protected Health Information: An Unrecognized Ethical Concern" (2014) 6:1 Clin Epigenetics 28.
[278] Kulynych & Greely, *supra* note 269 at 111–12.

of their participants, and also because the time, energy, and resources it would take for others to re-identify a de-identified dataset makes it unlikely to occur.[279] With respect to the first point, while most researchers would probably seek to avoid breaching their participants' privacy, there are nevertheless risks from hackers and rogue employees.[280] Further, some funding requirements require researchers to transfer and share their resulting data with others, including for use in government databases.[281] The more widely the data is shared, the more likely it is to come into the hands of those with unscrupulous motives.

To the second point about the likelihood of re-identification occurring, while re-identification may be difficult, it is becoming easier with time.[282] Particularly with genetic information, the wealth of genetic databases that currently exist greatly facilitate the ease of finding a match between an unknown person's genetic sequence and that of a family member who has undergone genetic testing.[283] Even those defending de-identification techniques acknowledge there is no longer such thing as a guarantee of anonymity.[284] And the point being made in this chapter is a relatively modest one. It is not that de-identification serves no purpose because re-identification is inevitable; but given there is an undeniable risk that is increasing in likelihood and that could cause real harm,[285] people ought to be asked whether to take it on.

Imposing consent requirements would better align with people's concerns over their genetic material. Whether it is justified or not, people view their genetic information as particularly sensitive, and something over which they want control.[286] In addition, evidence shows that potential research participants have strong concerns over privacy, which can impact their decisions

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[279] *Dispelling the Myths Surrounding De-identification: Anonymization Remains a Strong Tool for Protecting Privacy*, by Ann Cavoukian & Khaled El Emam (Toronto: Information and Privacy Commissioner, 2011) at 1–6.
[280] For example, the Privacy Commissioner of Ontario indicated that of the 300-350 privacy complaints brought each year in the health sector, two to three per month involve inappropriate snooping: see Jeff Berryman, "Remedies for Breach of Privacy in Canada" in Jason Varuhas & NA Moreham, eds, *Remedies for Breach of Privacy* (Portland, Oregon: Hart Publishing, 2018) 323 at 343.
[281] Kulynych & Greely, *supra* note 269 at 98; Holly K Tabor et al, "Genomics Really Gets Personal: How Exome and Whole Genome Sequencing Challenge the Ethical Framework of Human Genetics Research" (2011) 155A:12 Am J Med Genet A 2916.
[282] NPRM, *supra* note 222 at 53940.
[283] Kulynych & Greely, *supra* note 269 at 100.
[284] Cavoukian & El Emam, *supra* note 279 at 4.
[285] Kulynych and Greely note that "medical identity theft is one of the fastest growing, and most expensive consequences of health care data breaches": Kulynych & Greely, *supra* note 269 at 108.
[286] Rebecca Dresser, "Public Preferences and the Challenge to Genetic Research Policy" (2014) 1:1 JL & Biosciences 52; Hull et al, *supra* note 258; Trinidad et al, "Research Practice", *supra* note 257.

about whether to participate.[287] Allowing researchers access to this information without consent ignores both the identifiable nature of this information and the wishes of the public.

Widening the circumstances in which researchers must ask for consent to use biomaterials would better acknowledge the full range of interests individuals have in their biomaterials and facilitate greater privacy protection. This change would also align with the wishes of the public, who have expressed a desire to be asked when their biomaterials are used. But simply asking participants for consent may not be enough to fully respect and protect their interests. The extent to which widening the circumstances for consent will offer such protection will depend also on what form such consent takes.

B. The Inadequacies of Broad Consent

Even when consent is sought from participants to use their biomaterials, there is persisting tension between the legal and ethical requirements of informed consent and the practice of "broad consent" that pervades the biobanking sphere.[288] Informed consent requires the disclosure of information enabling an individual to make a meaningful choice about a medical procedure or participation in a research study, and consent in this context is best understood as an ongoing state of affairs that must be maintained beyond the initial point of agreement.[289] Broad consent departs from the traditional doctrine of informed consent both in terms of (i) lowering the standard of disclosure, and (ii) operating as a one-time event. Each of these issues will be considered below to demonstrate the limitations of this consent model.

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[287] *Clinical Data as the Basic Staple of Health Learning: Creating and Protecting a Public Good: Workshop Summary*, by Claudia Grossmann et al, (Washington, DC: Institute of Medicine, 2010), online: <nap.nationalacademies.org> [perma.cc/5BU3-HK55]; Amy L McGuire et al, "To Share or not to Share: A Randomized Trial of Consent for Data Sharing in Genome Research" (2011) 13:11 Genet Med 948; J M Oliver et al, "Balancing the Risks and Benefits of Genomic Data Sharing: Genome Research Participants' Perspectives" (2012) 15:2 Public Health Genomics 106.

[288] Palmira Granados Moreno & Yann Joly, "Informed Consent in International Normative Texts and Biobanking Policies: Seeking the Boundaries of Broad Consent" (2015) 15:4 Medical Law Intl 216 at 236–37; Teresa Edwards et al, "Biobanks Containing Clinical Specimens: Defining Characteristics, Policies, and Practices" (2014) 47 Clin Biochem 245 at 247.

[289] Michelle O'Reilly, Nicola Parker & Ian Hutchby, "Ongoing Processes of Managing Consent: The Empirical Ethics of Using Video-Recording in Clinical Practice and Research" (2011) 6:4 Clinical Ethics 179; note 215 at Commentary on Guideline 4.

i. Lowering the Standard of Disclosure

Under the common law, informed consent generally requires disclosure of information, including material risks, benefits, and alternative options, that a reasonable person would want to know.[290] In the research context, this includes disclosing the "aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail, post-study provisions and any other relevant aspects of the study" as well as "the right to refuse to participate in the study or to withdraw consent to participate at any time without reprisal".[291] Risks can encompass physical or health-related risks as well as informational privacy risks where personal information about participants is being collected, used, and stored.[292]

Given the potentially wide ranging and unknown future uses that might be made of biomaterials transferred to biobanks, the full extent of this information cannot be given to participants at the time biomaterials are collected. And it is often claimed to be impractical or impossible to re-contact biomaterial providers and obtain truly informed consent for each research protocol seeking access to their biomaterials.[293] One of the main advantages of biobanking is the efficiency it provides to researchers who do not have to individually recruit participants to obtain the biomaterials needed for their studies. As a result, at the time biomaterials are collected, biobanks generally obtain broad consent to use the sample for potentially wide-ranging research purposes.[294]

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[290] Seminal cases from across the common law include: *Reibl v Hughes*, [1980] 2 SCR 880; *Montgomery v Lanarkshire Health Board*, [2015] UKSC 11; *Rogers v Whitaker*, [1992] HCA 58; and *Canterbury v Spence*, [1972] 464 F 2d 772 (DC Cir).

[291] *Declaration of Helsinki*, *supra* note 215, art 26; see also: Common Rule, *supra* note 221 at §46.116; and Human Tissue Authority, *supra* note 220 at 12.

[292] *Declaration of Helsinki*, *supra* note 215, art 32.

[293] Bernice S Elger & Arthur L Caplan, "Consent and Anonymization in Research Involving Biobanks: Differing Terms and Norms Present Serious Barriers to an International Framework" (2006) 7:7 EMBO Rep 661 at 662; Donna M Gitter, "Big Data and Informed Consent: The Case of Estimated Data" in Vayena et al, *supra* note 47, 193 at 201.

[294] Clarissa Allen, Yann Joly & Palmira Granados Moreno, "Data Sharing, Biobanks and Informed Consent: A Research Paradox?" (2013) 7 McGill JL & Health 85 at 92; Granados Moreno & Joly, *supra* note 288 at 236–37; Edwards et al, *supra* note 288 at 24.

The ethics of broad consent have been widely debated.[295] Although the debate is not yet settled, research ethics standards are increasingly endorsing broad consent as a legitimate form of consent for biobanking[296] and in practice, broad consent is widely used in the biobanking sector.[297] Despite this shift in research ethics instruments and practice, the question of whether broad consent meets the legal standards of disclosure has yet to be resolved.[298]

As there are hundreds of millions of biomaterial samples stored in biobanks around the world, the questionable legal foundation of the broad consent model is far from academic. For example, the Swedish biobank, LifeGene, was ordered to stop collecting samples and was prohibited from using data already collected as the broad consent obtained from participants failed to meet informed consent standards required by law.[299] In Texas and Minnesota, millions of blood samples from newborn screening programs were destroyed on court order due to problems with the consent process.[300] While the US cases did not address the broad versus specific consent question (the issue, instead, was a lack of consent), they nevertheless demonstrate the magnitude of potential consequences should a court find that consent has not been properly obtained.

The legality of broad consent for the *collection* of biomaterials also only represents one half of the equation. If researchers want to *use* banked biomaterials in a study where they will be genetically sequenced, broad consent also needs to be permissible under information privacy law. These two bodies of law, however, are not always congruent.

For example, in the UK, the *Human Tissue Act* has been interpreted by its statutory oversight body, the Human Tissue Authority, as allowing for broad consent when bodily materials

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[295] Timothy Caulfield & Jane Kaye, "Broad Consent in Biobanking: Reflections on Seemingly Insurmountable Dilemmas" (2009) 10:2 Med L Intl 85; B Hofmann, "Broadening Consent—and Diluting Ethics?" (2009) 35:2 J Med Ethics 125–129; Christine Grady et al, "Broad Consent for Research With Biological Samples: Workshop Conclusions" (2015) 15:9 Am J Bioeth 34; Mats G Hansson et al, "Should Donors be Allowed to Give Broad Consent to Future Biobank Research?" (2006) 7:3 The Lancet Oncology 266.
[296] Common Rule, *supra* note 221 at §46.116; Human Tissue Authority, *supra* note 220 at 13; *Declaration of Helsinki, supra* note 215, Guideline 11; *National Statement on Ethical Conduct in Human Research*, by Commonwealth of Australia (National Health and Medical Research Council (NHMRC), 2018), s 2.2.14 [NHMRC Guidelines].
[297] Granados Moreno & Joly, *supra* note 288 at 236–37; Edwards et al, *supra* note 288 at 247.
[298] Caulfield & Murdoch, "Genes, cells, and biobanks", *supra* note 13; Allen, Joly & Moreno, *supra* note 294 at 89.
[299] Pär Segerdahl, "The Swedish Data Inspection Board Stops Large Biobank", (20 December 2011), online: *The Ethics Blog* <ethicsblog.crb.uu.se> [perma.cc/MY7U-2LBG]; Roger Brownsword, *Law, Technology and Society: Reimagining the Regulatory Environment* (Abingdon: Routledge, 2019) at 319–20.
[300] Pike, *supra* note 7 at 1985–86.

are provided for research.[301] However, privacy law scholars, Dara Hallinan and Paul de Hert, point out that regardless of what is permitted with respect to the physical tissue by the *Human Tissue Act*, as soon as a sample is sequenced, the UK's *Data Protection Act* applies, and "[i]t is far from clear that broad consent is a legitimate form of consent in data protection law, which requires consent to be specific to a processing operation".[302] Indeed, the EU's *General Data Protection Regulation* (*GDPR*) upon which the *Data Protection Act* is based, defines consent to mean "any freely given, *specific, informed* and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her".[303] As the *GDPR* applies across all EU countries, this may prove problematic for the uses of data associated with biomaterials collected via broad consent.[304]

The legality of broad consent represents an important challenge to this shift in consent practice. The question then becomes whether the law should evolve to keep up with this change in practice or insist on traditional disclosure requirements. Before this question can be answered, however, it is important to first consider the other shortcoming of broad consent: its reduction of consent to a singular event.

ii. Broad Consent as a One-Time Event

Traditional informed consent in the medical treatment and research contexts is not properly regarded as a one-time event. It is an ongoing process.[305] The status of a patient's or participant's consent needs to be maintained as the medical procedure or research protocol progresses. Should anything change during the course of a research protocol that might impact a participant's decision to continue, that information needs to be continuously disclosed.[306] The corollary is that individuals have a right to withdraw their consent and remove themselves from therapeutic treatment and research protocols as they like.[307]

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[301] Human Tissue Authority, *supra* note 220 at 13.
[302] Hallinan & De Hert, *supra* note 65 at 127.
[303] *General Data Protection Regulation*, Regulation (EU) 2016/679, art 4 [*GDPR*] [emphasis added].
[304] Brownsword, *supra* note 299 at 320.
[305] O'Reilly, Parker & Hutchby, *supra* note 289; *Declaration of Helsinki, supra* note 215, Guideline 9.
[306] *Declaration of Helsinki, supra* note 215, Guideline 9.
[307] Bernice Elger, "Withdrawal of Consent and Destruction of Samples" in Bernice Elger, Nikola Biller-Andorno & Alexander M Capron, eds, *Ethical Issues in Governing Biobanks* (London: Routledge, 2008) 131 at 132.

In contrast, broad consent essentially renders consent a one-time event in which participants transfer their interests and control over their biomaterials.[308] In this respect, it operates more like a legal waiver[309] than a mechanism designed for ongoing participant protection. While there may be a limited right to withdraw consent for future uses of one's biomaterials, the extent of the right continues to be debated[310] and its parameters inconsistent and dependent on individual biobank guidelines and policies.[311] It is certainly not as established or enshrined as in informed consent doctrine.

It might be the case that a singular broad consent event is justified in research solely involving biomaterials. Indeed, the rationale for allowing a fulsome right to withdraw has been questioned in this context on the basis that the immediate risk of physical harm to participants is absent in secondary research uses of biomaterials.[312] However, this line of argument, again, represents an overly narrow and risk-oriented view of the purpose of consent. To fully consider whether one-time consent is sufficient, it is useful to return to Wendler's contribution argument. As discussed above, consent serves a broader purpose than simply protecting individuals from harm and individuals have an interest in being asked what kinds of contributions they want to make, as these contributions reflect on them personally. What needs to be considered, then, is whether individuals have interests in their biomaterials needing to be respected beyond the initial point of being asked.

Laurie makes the point that, for those with a strong desire to participate in research, "the one-off event of consent is disempowering, because it fails to recognize the individual subject or, indeed, the community of research subjects, as a party with an interest in the overall endeavour".[313] In contrast, Wendler allows for broad consent.[314] His justification is that individuals have an interest in deciding, generally, whether to contribute to scientific research because that decision says something significant about the individual. In contrast, the choice to contribute between one

[308] Lensink et al, "Better Governance", *supra* note 86.
[309] Brownsword, *supra* note 299 at 320–22.
[310] Holm, *supra* note 12 at 275–80; Karen Melham et al, "The Evolution of Withdrawal: Negotiating Research Relationships in Biobanking" (2014) 10:16 Life Sci Soc Policy, DOI: <10.1186/s40504-014-0016-5> at 4–13; Elger, *supra* note 307.
[311] Melham et al, *supra* note 310.
[312] Holm, *supra* note 12 at 272 & 277; Melham et al, *supra* note 310 at 5.
[313] Graeme T Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambridge University Press, 2002) at 87.
[314] Wendler, *supra* note 212 at 50.

project or another (e.g., Parkinson's research versus Alzheimer's) says comparatively little.[315] As a result, less weight should be given to an individual's interests when it comes to particularizing the scientific uses of one's contribution, and further consent from the participant need only be sought when it is relatively easy to do so.[316]

However, Wendler allows for an exception where the research question being investigated is central to an individual's interests such that contributing to its progress would run counter to other goals the individual has sought to achieve in their life.[317] The example Wendler provides is that of someone dedicated to outlawing abortion who would object if their biomaterials were used in abortion-related research.[318] This echoes Beyleveld's earlier example of a patient opposed to contraception whose health data is used anonymously in contraception research. In such a case, further consent should be obtained.[319]

The need to respect individuals' preferences over the issues they regard as of central importance cuts to the root of the problem with broad consent. This is, in part, because individuals grow and evolve, and issues of central importance to someone now might carry a very different level of significance to the same person thirty years down the road. The other problem is that new bioethical issues arise all the time. When Wendler's paper was published twenty years ago, it might have made sense for someone to exclude "abortion research" when transferring a sample to a biobank. That same person, however, would not have thought (or likely been asked) to indicate their preferences on whether their tissue be used in chimaera research, or to create organoids modeling embryos or even the human brain.[320] That is because human biomaterials used for these purposes would have been merely hypothetical at that time. And we cannot make assumptions, one way or the other, about whether they are of central importance to any given biomaterial provider.

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[315] *Ibid* at 49–50.
[316] *Ibid* at 50.
[317] *Ibid* at 49–50.
[318] *Ibid*.
[319] *Ibid*.
[320] Michael A Lensink et al, "Responsible Use of Organoids in Precision Medicine: The Need for Active Participant Involvement" (2020) 147:7 Development, DOI: <10.1242/dev.177972> at 2; Lensink et al, "Better Governance", *supra* note 86 at 3.

Similarly, the research funding environment is changing. There is great commercialization pressure on researchers to develop patentable and translatable innovations.[321] University-industry partnerships and funding models have become the norm.[322] And biobanks, which are very expensive to operate, are looking to the private sector to help ensure their sustainability, raising a host of new ethical issues.[323] Studies indicate that the involvement of private industry in research can negatively impact the level of trust people have in that research.[324] To some, this may form an issue of central importance, providing further reason for allowing individuals to maintain ongoing input into how their biomaterials are used.[325]

If broad consent is only justified to the extent that it protects individual preferences regarded as being of central importance, then there need to be mechanisms enabling the expression and protection of these preferences in an ongoing manner. Indeed, there are growing calls for change to biobank regulation and governance to better respect the interests and wishes of biobank participants. Potential changes include altering the broad consent model to one of dynamic consent, thereby allowing ongoing participation by biomaterial providers;[326] incorporating participants to a larger degree in the governance of biobanks;[327] acknowledging and increasing transparency regarding the commercialization of biobank research;[328] and implementing benefit-sharing approaches to enable greater reciprocity in the participant-researcher relationship.[329]

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[321] Sarah Burningham, Adam Ollenberger & Timothy Caulfield, "Commercialization and Stem Cell Research: A Review of Emerging Issues" (2013) 22:S1 Stems Cells & Development 80; Maeghan Toews, "Commercialisation of Human Genetic Research" in *eLS* (Chichester: John Wiley & Sons, 2015) DOI: <10.1002/9780470015902.a0005651.pub2>.

[322] Ubaka Ogbogu & Amy Zarzeczny, "Ethical, Legal and Social Implications of Translational Stem Cell Research: Effects of Commercialization on Public Opinion and Trust of Stem Cell Research" in Kristina Hug & Göran Hermerén, eds, *Translational Stem Cell Research: Issues Beyond the Debate on the Moral Status of the Human Embryo* (Totowa, NJ: Humana Press, 2011) 341 at 352–55; Klaus Hoeyer, "Trading in Cold Blood?" in Peter Dabrock, Jochen Taupitz & Jens Ried, eds, *Trust in Biobanking* (Berlin, Heidelberg: Springer, 2012) 21 at 27–29.

[323] Timothy Caulfield et al, "A Review of the Key Issues Associated with the Commercialization of Biobanks" (2014) 1:1 JL & Biosciences 94.

[324] Ogbogu & Zarzeczny, *supra* note 322 at 356–57; Caulfield et al, *supra* note 323 at 97–102.

[325] Lensink et al, "Better Governance", *supra* note 86 at 3–4; Hoeyer, *supra* note 322 at 34–37.

[326] Dorit T Stein & Sharon F Terry, "Reforming Biobank Consent Policy: A Necessary Move Away from Broad Consent Toward Dynamic Consent" (2013) 17:12 Genet Test Mol Biomarkers 855.

[327] Lensink et al, "Better Governance", *supra* note 86.

[328] Hoeyer, *supra* note 322.

[329] Gillian Haddow et al, "Tackling Community Concerns about Commercialisation and Genetic Research: a Modest Interdisciplinary Proposal" (2007) 64:2 Soc Sci Med 272; Daley & Cranley, *supra* note 16; Lau, *supra* note 16.

However, the biobank sector has been slow to respond.[330] Dynamic consent models remain nascent[331] and biobank regulation has moved toward facilitating commercialization while doing little to address participant concerns.[332] On one hand, this is unsurprising given that the broad consent *status quo*, which has now been endorsed by many research ethics instruments, requires a comparatively minimal effort to obtain consent from participants and enables almost unfettered uses of biomaterials into the indefinite future. On the other hand, one might expect that the legal uncertainty on which this enterprise has been built might cause some trepidation.

Further, even if one maintains that broad consent in its current form is ethically and legally acceptable, there are, again, practical reasons to listen and respond to the calls for greater participant involvement and control. While public opinion is far from unanimous on the broad versus specific consent debate, there is a significant proportion of people who want ongoing input over how their biomaterials are used.[333] As the HHS recognized above, disregarding people's desires for greater control renders the research environment untenable.[334] And yet, just like the debate over changes to the Common Rule, this truth does not appear to be recognized as raising any immediate or pressing concerns by those content with the *status quo*.

While broad consent has become entrenched, its ethical validity depends on supplementing decreased disclosure with increased alternatives for ongoing participant control. The practical limitations of fitting traditional ethics norms into the new biomedical research environment should not be resolved by simply diluting ethical standards for ease of application. This is inconsistent with the robust purposes informed consent in research is designed to serve and incompatible with participant desires for increased control.

C. Conclusion

There is a clear push to enhance individual control over separated biomaterials in the research context, reflected in calls to change the Common Rule, and facilitate ongoing

[330] Lensink et al, "Better Governance", *supra* note 86.
[331] Teare et al, *supra* note 19.
[332] Hoeyer, *supra* note 322.
[333] Susan Brown Trinidad et al, "Informed Consent in Genome-Scale Research: What Do Prospective Participants Think?" (2012) 3:3 AJOB Prim Res 3; Juli Murphy et al, "Public Perspectives on Informed Consent for Biobanking" (2009) 99:12 Am J Public Health 2128; Christian M Simon et al, "Active Choice But Not Too Active: Public Perspectives on Biobank Consent Models" (2011) 13:9 Genet Med 821.
[334] NPRM, *supra* note 222 at 53944.

participation in biobanking. Individuals are questioning the fairness of the research environment which depends on altruistic donations of biomaterials from individuals and allows researchers, institutions, and private enterprise to reap all the financial benefits that follow.[335]

Public survey evidence suggests that as members of the public become increasingly aware of the financial value inherent in their biomaterials as well as the privacy risks of genomic databases, their desire for greater control over their genomic data increases.[336] In recent years, there have been many high-profile news stories about data leaks and security issues with DNA databases.[337] Additional privacy concerns stem from the use of DNA databases by law enforcement to investigate crime. The controversial use of a DNA database to find the Golden State Killer, for example, was reported everywhere from Rolling Stone[338] to Forbes.[339] The financial value of these databases has also become a newsworthy matter, as seen, for example, in headlines proclaiming the $300 million investment by GlaxoSmithKline in the popular 23andMe DTC testing company.[340] As the public becomes increasingly informed as to the financial worth of their genetic material and the associated privacy concerns that exist in large collections of biomaterials and genetic data, there is reason to believe that public demands for increased control will continue to grow.[341]

In this respect, the scale of the issue is worth considering. At the time the NPRM was being considered, evidence indicated that an estimated 250,000 studies per year in the US were using biospecimens without oversight by the Common Rule (or FDA regulations) on the basis that the biospecimens were non-identified.[342] This represents roughly 15 million Americans whose

[335] Daley & Cranley, *supra* note 16; Lau, *supra* note 16.
[336] Briscoe et al, *supra* note 16.
[337] "Security breach at MyHeritage website leaks details of over 92 million users", *Reuters* (5 June 2018), online: <www.reuters.com/> [perma.cc/6D7F-Q2KG]; Heather Murphy, "Why a Data Breach at a Genealogy Site Has Privacy Experts Worried", *The New York Times* (1 August 2020), online: <www.nytimes.com> [perma.cc/HNP2-BHZB]; Aaron Schaffer, "Analysis | Hacks of Genetic Firms Pose Risk to Patients, Experts Say", *Washington Post* (21 July 2022), online: <www.washingtonpost.com> [perma.cc/CXA3-5SXM].
[338] Andrea Marks, "DNA Search Method that Caught Golden State Killer No Longer Available", (23 May 2019), online: *Rolling Stone* <www.rollingstone.com/culture/culture-news/dna-search-method-that-caught-the-golden-state-killer-no-longer-available-839315/>.
[339] J V Chamary, "How Genetic Genealogy Helped Catch The Golden State Killer", (30 June 2020), online: *Forbes: Science* <www.forbes.com> [perma.cc/7AKE-LZM9].
[340] Matthew Herper, "23andMe Gets $300 Million Boost From GlaxoSmithKline To Develop New Drugs", (25 July 2018), online: *Forbes* <www.forbes.com> [perma.cc/R866-3TYP].
[341] Briscoe et al, *supra* note 16.
[342] NPRM, *supra* note 222 at 54004.

biomaterials were used in research annually without their knowledge or consent.[343] The widespread use of biomaterials highlights the importance of striking a fair balance. Fifteen million additional consent conversations amount to more than a small burden for the research community. Conversely, if there are legitimate reasons why individuals should be consulted when their biomaterials are being used, 15 million people in America are wrongfully having their interests infringed each year.

In a research environment that has proven reluctant to respond to the concerns of the public, this point of tension is likely to increase. The experience with the Common Rule shows that even the most modest proposal for reform where new consent requirements would only be imposed for genetic sequencing that reveals information unique to the individual failed to gain traction. At the same time, consent requirements that do exist have moved from the robust standard of informed consent to the more flaccid mechanism of broad consent, the legality of which remains an open question, raising very serious potential consequences for the many biobanks housing biomaterial samples on this basis.

While evolving technologies and understandings of the human body present incredibly exciting opportunities for discovery and scientific advancements that serve the public interest, balance needs to be restored to better protect individual interests. Although most individual researchers certainly work with a view to serving the public through their research projects, on a more macro level, these examples cast some doubt about whether the public interest is truly being served by such adamant reluctance to change. The HHS explicitly recognized that "failure to acknowledge and give appropriate weight to this distinct autonomy interest in research using biospecimens could, in the end, diminish public support for such research, and ultimately jeopardize our ability to be able to conduct the appropriate amount of future research with biospecimens."[344] And yet, calls for reform have gone unanswered. This inability to compromise reflects a short-sightedness in which the very foundation on which biomedical research exists is being risked by the research community to fulfill immediate demands for access to biomaterials.

As debates continue about how to remedy this imbalance, these examples also highlight the importance of looking beyond the physical properties of biomaterials. The broad consent

[343] *Ibid*.
[344] *Ibid* at 53492.

debate illustrates a need for congruence between consent norms for biomaterials and those for genetic information. In addition, the idea that physical biomaterials can be differentiated based on identifiability is being increasingly questioned given the identifying nature of DNA inextricably housed within them.

As discussed in the introductory chapter to this thesis, some have suggested the entire discussion about biomaterials in research needs to be reframed, moving away from language of "gifts" and "donations" towards recognizing "participants" and "providers" who are actively involved in the research endeavour and have continuing interests in their contributions.[345] While this thesis agrees with this re-framing effort, and has thus adopted this suggested terminology, the language of "gifts" is pervasive in this field. And as the next two chapters will show, these terms have specific legal meanings in the property law context that may be difficult to shake.

Chapter 2 showed a lack of enforceable rights and remedies for individuals in statutory governance frameworks, using organ donation, post-mortem examinations, and assisted reproduction as examples. This chapter has focused on the research context to further demonstrate how the governance framework and consent paradigm provides inadequate protection for individual interests. Both chapters demonstrate how consent is being reduced in a manner that diminishes autonomy. This is a problem for individuals asserting claims against institutions, as demonstrated by the *AB and Others*, *Yearworth*, and *Colavito* cases in the previous chapter, and for research participants who are not able to exercise ongoing control past the point of excision, and in some cases, might not even know their biomaterials are being used.

Some view property law as the answer to correct the current imbalance and restore protection for individuals' interests in their biomaterials. Whereas the governance frameworks considered thus far leave individuals with a remedial void, property rights are enforceable against others and provide avenues for redress when they are violated. However, the next two chapters will explore the property law landscape and show that property law may not be quite as promising to individuals as it first appears.

[345] Lensink et al, "Better Governance", *supra* note 86.

4. The Conceptual Confusion Underlying Property Case Law

Property law is a potential solution to fill the dearth of common law rules governing separated biomaterials demonstrated in the previous two chapters. It certainly has an intuitive appeal as the legal framework that typically regulates tangible things and has attracted considerable scholarship and discussion. Property advocates hail its predictability,[346] remedial nature,[347] potential to fill legal voids,[348] exclusionary function,[349] and reflection of reality in that we already treat these materials in a proprietary manner.[350] Many assumptions tend to be made, however, about why property law would be a useful tool for both individuals, on one hand, and researchers and institutions on the other, without much attention paid to the fundamental question of whether property law will strike the right balance between the two.[351] This chapter will therefore examine property case law to identify whether there is evidence to support the notion that property law will lead to greater protections for individual rights.

The first part of this chapter will provide a brief history of the "no-property" rule to explain why clear justifications for property rights over biomaterials are needed. The chapter will then catalogue the range of justifications reflected in case law throughout the common law world. This analysis will demonstrate that although this body of case law is growing, it remains conceptually confused. No singular dominant explanation has emerged as to how biomaterials become property or who their original owner is. As a result, there is a malleability to this body of law. Chapter 5 will then argue that this malleability works against individuals when there are genuine contests of control over biomaterials between individuals and institutions. This is because the values property law is designed to protect are misaligned with the values individuals have in their biomaterials.

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[346] Lyria Bennett Moses, "The Problem with Alternatives: The Importance of Property Law in Regulating Excised Human Tissue and In Vitro Embryos" Goold et al, *supra* note 18, 197 at 197–207 & 213–14; Goold & Quigley, *supra* note 113 at 231–62.
[347] Nwabueze, "Cadavers", *supra* note 178 at 157–75; Remigius N Nwabueze, "Proprietary Interests in Organs in Limbo" (2016) 36:2 LS 279 [Nwabueze, "Organs in Limbo"].
[348] Douglas, *supra* note 18 at 98–104.
[349] Wall, *Being and Owning, supra* note 26 at 113–21; Render, *supra* note 26 at 557–82.
[350] Goold & Quigley, *supra* note 113 at 131–32; R Alta Charo, "Skin and Bones: Post-Mortem Markets in Human Tissue" (2002) 26 Nova L Rev 421.
[351] Jonathan Herring has noted, for example, that what he "find[s] striking about much of the writing in favour of property interests is that there is no attempt to explain how the property approach sufficiently balances the individual and societal interests in bodies and body parts": Herring, *supra* note 29 at 222.

A. The "No-Property" Rule and Need for Clear Property Justifications

Traditionally, bodies and body parts have not been regarded as objects of personal property. Their exclusion from property frameworks has been termed the "no-property rule". While the precise origin of this rule is difficult to trace, its place in the common law has been attributed, in part, to the historical division in England between ecclesiastical and common law courts.[352] As a jurisdictional issue, the burial of dead bodies was the responsibility of the Church and not a matter for the common law.[353]

Early challenges to this rule arose from individuals who suffered emotional harm from wrongful interferences with the deceased bodies of their loved ones. Were the deceased bodies objects of personal property, torts of trespass and conversion could give rise to aggravated damages awards to compensate plaintiffs for their emotional harm. However, the refusal to recognize bodies as property meant judges had to either employ some creativity to provide remedies or allow wrongs to go unaddressed.[354] A review of these early cases is beyond the scope of this chapter, and the history of this line of case law has been extensively covered elsewhere.[355] The present chapter will focus, instead, on cases involving separated biomaterials, which have presented similar difficulties.

For example, some early US cases involving reproductive materials involve property-adjacent reasoning. *Davis v Davis* involved a dispute between a separated couple over the fate of pre-embryos they had created prior to their separation.[356] Justice Daughtrey (with Reid CJ, Drowota, O'Brien, and Anderson JJ concurring) found the parties did not have a "true property interest" in the pre-embryos, but that "they do have an interest in the nature of ownership, to the extent that they have decision-making authority concerning disposition of the pre-embryos, within the scope of policy set by law".[357] The subsequent decision of *Hecht v Kane* involved Kane, who

[352] Hardcastle, *supra* note 3 at 25-28; Nwabueze, *supra* note 3 at 45-49.
[353] Hardcastle, *supra* note 26 at 25–28; Nwabueze, *supra* note 27 at 45–49; Mark Pawlowski, "Property in Body Parts and Products of the Human Body" (2009) 30:1 Liverpool LR 35 at 36.
[354] For example, see *Davidson v Garrett*, [1899] CarswellOnt 94 (ONCA) [*Davidson*]; and *O'Connor v Victoria (City)*, [1913] CarswellAlta 279 (AB Sup Ct, Trial). *Davidson* involved an alleged unauthorized autopsy at the plaintiff's house, and O'Connor involved the removal of bodies by a municipality in the construction of a roadway. The claims in both cases were framed in terms of trespass to land rather than interference with the bodies themselves, as they were not property "and a trespass cannot be committed in respect of [them]" (*Davidson*, at para 1).
[355] Nwabueze, *Biotechnology, supra* note 27, c 2; Hardcastle, *supra* note 26, c 2.
[356] *Davis v Davis*, (Tenn 1992) 842 SW2d 588.
[357] *Ibid* at 597.

bequeathed 15 vials of his sperm to his partner, Hecht, through his will. After Kane's death, the will and fate of the sperm was contested by Kane's two adult children (born from a different partner). Relying on *Davis v Davis,* Lillie PJ (Johnson and Woods JJ, concurring) similarly found the sperm to be a "unique type of 'property'"[358] sufficient to fall under the jurisdiction of the probate court, even though it may not be governed by the general law of personal property.[359]

The reason courts initially struggled to fully and directly apply property law to biomaterials is because neither deceased nor living bodies are regarded as property (at least since abolishing slavery). Individuals are not regarded as "owning" their own bodies as a matter of property law. The common law maxim, *dominus membrorum suorum nemo videtur,* means "no one is to be regarded as the owner of his own limbs".[360] The House of Lords made this point abundantly clear in *R v Bentham,* where Lord Rodger reiterated that, not only are we not owners of our attached body parts, we do not even have a more limited right to possess them.[361]

Because we do not "own" deceased bodies or our own living bodies as a matter of property law, when materials are separated from bodies, an explanation is needed to justify how and why these materials give rise to property rights as an exception to the default no-property rule. The proper starting point for legal analyses applying property law to disputes involving biomaterials is to therefore explain the basis on which the relevant biomaterial has been transformed from *res nullius* (a thing belonging to no one) into a *res* (a thing capable of giving rise to property rights).[362] Since *Davis* and *Hecht,* there have been a number of cases where property rights have been recognized in relation to biomaterials, however, the reasons underpinning these departures from the no-property rule are varied. The next part of this chapter will therefore highlight the range of explanations and approaches to this fundamental question reflected in common law cases.

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[358] *Hecht v Kane*, [1993] 16 CalApp4th 836 at 850 [*Hecht*].
[359] *Ibid* at 846.
[360] *Yearworth*, *supra* note 93 at para 30.
[361] *R v Bentham*, [2005] UKHL 18 at para 14 [*Bentham*]. This case pertained to a criminal appeal where a man was charged with possessing an imitation firearm after using his hand to mimic the appearance of a gun through his jacket. The issue was whether his hand could be regarded as an imitation firearm that he "possessed". The House of Lords confirmed that his hand was not something he could possess.
[362] Hardcastle, *supra* note 26 at 125–28.

B. The Range of Property Justifications in Common Law Cases

As the body of relevant case law remains relatively small, jurisdictions tend to borrow and rely on principles from cases throughout the common law world. As a result, the cases highlighted here encompass key decisions from Canada, the US, the UK, and Australia. While scholarship analyzing this body of case law tends to be organized chronologically, by tissue type (e.g., reproductive material vs research tissue vs diagnostic tissue, etc.), or along jurisdictional lines,[363] this thesis will take a novel approach by organizing these cases according to the judicial justifications given for either recognizing or denying property rights in biomaterials.

This analysis has identified four categories of analytical approaches to the questions of how property rights arise in relation to biomaterials and to whom they are allocated: (i) the work or skill exception; (ii) ongoing control as the key; (iii) focusing on property transfer rather than the origin of property rights; and (iv) judicial pragmatism. While these categories are not mutually exclusive (for example, judicial pragmatism is imbued in many cases), this organizational framework is useful because the extent to which property law will benefit individuals very much depends on how property rights arise. This analysis will show that this field of law remains unsettled with many unanswered conceptual questions of fundamental importance. The significance of this lack of clarity will then be considered in Chapter 5, which will demonstrate why this is a problem for individual claimants.

i. The Work or Skill Exception

One of the earliest and most influential exceptions to the no-property rule is the work or skill exception, first articulated in the Australian High Court decision, *Doodeward v Spence.*[364] *Doodeward* involved a plaintiff who purchased the preserved body of conjoined stillborn twins and then exhibited the fetal remains as a public curiosity. The twins' body was confiscated by police and the plaintiff successfully sued in detinue to recover it on the grounds that it was his property. This case has often been referred to as establishing a "work or skill" exception to the no-property rule, as one of the two majority judgments, written by Griffith CJ, recognized that

[363] While Hardcastle addresses different explanations for the creation and allocation of property rights (Chapter 6), his chapters highlighting case law are organized in terms of the "dead body" (Chapter 2) and "living body" (Chapter 3), the latter of which is broken into sub-sections by tissue type: Hardcastle, *supra* note 26; Nwabueze organizes his discussion of biomaterial case law by jurisdiction and legal framework: Nwabueze, *Biotechnology, supra* note 27.
[364] *Doodeward v Spence*, [1908] HCA 45 [*Doodeward*].

property rights could exist in the body because it had been altered from its original form through the process of preservation using skill and labour. His Honour explained:

> when a person has by the lawful exercise of work or skill so dealt with a human body or part of a human body in [their] lawful possession that it has acquired some attributes differentiating it from a mere corpse awaiting burial, [they] acquire[] a right to retain possession of it, at least as against any person not entitled to have it delivered to [them] for the purpose of burial…[365]

The application of work or skill to a body provides one possible explanation for how a body (or separated body part) can be transformed into something capable of giving rise to property rights. Griffith CJ does not fulsomely explain why this might be so in relation to established property principles. One scholar has suggested the work or skill exception might be an evolution of the principle of specification, "the principle that applies to the manufacture of new objects", such as making wine from grapes.[366] However, this justification is far from explicit in *Doodeward* (or the subsequent cases applying the exception), and scholars have expressed doubt as to whether the level of transformation present in relevant cases would be sufficient to attract the application of the principle.[367]

Despite its lack of clear origins in property doctrine, the work or skill exception has been influential in a range of circumstances. However, the parameters of the exception have not been consistently maintained in terms of (i) what type or how much work or skill is needed for the transformation to take effect, (ii) the identity of the property rights holder upon transformation, and (iii) which rights arise from this transformation.[368] The above passage from *Doodeward* provides some guidance to these questions, indicating that a right to possession (rather than a broader array of property rights and entitlements) is acquired by the person applying the work or skill. The fact that the work or skill applied in *Doodeward* merely involved preserving the fetus in a jar of spirits also indicates a low threshold in terms of degree of work or skill needed to trigger the exception.

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[365] *Ibid*.
[366] Hardcastle, *supra* note 26 at 131–43.
[367] Hardcastle, for example, ultimately concludes that the preservation techniques applied to biomaterials in relevant cases that have been deemed sufficient to trigger the work or skill exception would be unlikely to fulfil the requirements of specification, which require the creation of a "new thing": *Ibid* at 141.
[368] Hardcastle and Quigley make similar points in their respective works: *Ibid* at 38–39; Quigley, "Property in Human Biomaterials", *supra* note 25 at 662–64.

The first major case to consider the exception was *Dobson v North Tyneside Health Authority,* a case involving an autopsy conducted after a woman died from brain tumors that had been undiagnosed.[369] An action was subsequently brought by her next of kin asserting a negligent failure to diagnose the tumors. The action depended, in part, on whether the tumors were cancerous or benign, but the autopsy did not involve a histological analysis to answer this question. The plaintiffs therefore sought to have the brain examined, as it had been removed in the autopsy and fixed in paraffin. However, they were told the hospital had subsequently disposed of it. The plaintiffs then brought an action against the relevant Health Authority in conversion for wrongfully disposing of the brain.[370] Their claim for conversion was struck out by the district judge for failing to disclose a valid cause of action given that there is no property in a corpse. The plaintiffs unsuccessfully appealed that decision.

In dismissing the appeal, Peter Gibson LJ (with whom Thorpe and Butler-Sloss LJJ agreed) acknowledged that the existence of a work or skill exception was "properly arguable" in light of *Doodeward,*[371] but questioned how solidly the exception was grounded in the case given it was only found in Griffith CJ's judgment.[372] Regardless, Peter Gibson LJ held that an application of the exception did not lead to the conclusion that by fixing the brain in paraffin, the brain was transformed "into an item the right to possession of which or the property in which belonged to the plaintiffs".[373] The plaintiffs' claim was therefore struck out:

> There is nothing in the pleading or evidence before us to suggest that the actual preservation of the brain after the post mortem was on a par with stuffing or embalming a corpse or preserving an anatomical or pathological specimen for a scientific collection or with preserving a human freak such as a double-headed foetus that had some value for exhibition purposes…I do not see how the fact that the brain was so fixed rendered it an item to possession of which the plaintiffs ever became entitled for the purpose of interment or any other purpose, still less that the plaintiffs ever acquired the property in it.[374]

It is not clear from this passage, however, whether the exception was not triggered because the brain had undergone an insufficient degree of transformation when compared to the examples

[369] *Dobson and another v North Tyneside Health Authority and another*, [1996] 4 All ER 474 [*Dobson*].
[370] *Ibid* at 475–78.
[371] *Ibid* at 478–79.
[372] *Ibid*.
[373] *Ibid* at 479.
[374] *Ibid*.

listed, or because the work or skill applied to the brain was not for one of the listed purposes, such as contributing to a scientific collection or exhibition.

The idea that the transformation be done for specific purposes was picked up in the subsequent decision, *R v Kelly.* This case involved a junior technician at the Royal College of Surgeons who removed various specimens from the College (heads, parts of legs, torsos, etc.) and transferred them to an artist, who created molds of the body parts as artwork.[375] Both the artist and the technician were later charged and convicted of theft. Their defence, unsuccessfully asserted at trial and on appeal, was that the body parts were not property and therefore could not give rise to a conviction for theft. The work or skill exception from *Doodeward* was decisive in this regard. Writing on behalf of the court, Rose LJ noted the "many hours, sometimes weeks, of skilled work" that went into preserving and preparing the body parts to be used in anatomical instruction.[376] Rose LJ then relied on *Doodeward* and *Dobson* for the conclusion that "parts of a corpse are capable of being property within s 4 of the *Theft Act*, if they have acquired different attributes by virtue of the application of skill, such as dissection or preservation techniques, for exhibition or teaching purposes".[377]

As a result, the Court concluded the trial judge was correct in ruling that the College had possession of the body parts for the purpose of the *Theft Act*.[378] In this respect, the judgment seems similarly confined as in *Doodeward* to resolving issues of possession rather than broader rights of ownership. The judgment does not, however, speak directly to the question of who is allocated property rights upon the application of work and skill, as the question of whether the College's possession of the body parts was "lawful" was not an issue needing to be decided.[379] In addition, the notion from *Dobson* that the work or skill be applied for specific purposes was reinforced in Rose LJ's finding that the application of skill be for "exhibition or teaching purposes".

The subsequent case, *AB and Others,* also invoked the work or skill exception. As discussed in Chapter 2, this case was brought by parents who learned that organs from their deceased children's bodies had been retained in post-mortem examinations without their

[375] *R v Kelly*, [1983] 3 All ER 741 (CA, Crim Div) at 741 [*Kelly*].
[376] *Ibid* at 743.
[377] *Ibid* at 749–50.
[378] *Ibid* at 750.
[379] *Ibid*.

knowledge or consent.[380] The parents relied on an early Canadian case[381] and a line of Scottish authorities, arguing there is a cause of action for wrongful interference with a body arising from the right to possess the body for the purpose of burial[382] and that this possessory right included a right to possess all the body's organs.[383] In rejecting these arguments, Gage J (i) noted the confusion over the precise cause of action underlying these cases and denied there was such a cause of action in England,[384] and (ii) found, in any event, that the work or skill involved in removing the organs and preparing tissue blocks and slides triggered the *Doodeward* exception, through which "the *hospital* acquired proprietary and possessory rights to the organs".[385]

This finding appears to expand the *Doodeward* exception in that Gage J indicated there are "proprietary rights" in addition to "possessory rights", though he did not explain what these additional rights entail. He also appears to have walked back the criteria in *Kelly* that the application of work or skill be done for exhibition or teaching purposes. He interpreted *Kelly* as establishing an exception to the no-property rule "where part of the body has been the subject of the application of skill such as dissection or preservation techniques",[386] with no mention of this additional criterion.

Gage J also reviewed *Dobson* but did not reconcile or even acknowledge any inconsistency between that case and his own finding on this issue. Both cases involved organs removed during a post-mortem that were preserved for examination and then disposed of, yet in *Dobson* Peter Gibson LJ did not find the work or skill exception applied. Gage J did note, however, that additional skill was required to remove organs from small children compared to adults,[387] which may represent a tacit attempt to distinguish the case from *Dobson,* though no direct comparison was made on this point nor any attempt to explain what level of work or skill is required to trigger the exception.

While *Doodeward* and *AB and Others* indicate the person who applies the work or skill will be the one who acquires the possessory rights, other cases cast doubt on this proposition. For example, the landmark decision of *Yearworth v North Bristol NHS Trust,* discussed in Chapter 2,

[380] *AB and Others*, *supra* note 131.
[381] *Edmonds v Armstrong Funeral Home Ltd*, [1930] CarswellAlta 53 (AB Sup Ct (App Div)) [*Edmonds*].
[382] *AB and Others*, *supra* note 131 at para 128.
[383] *Ibid* at para 141.
[384] *Ibid* at paras 153–61.
[385] *Ibid* at para 257 [emphasis added].
[386] *Ibid* at para 148.
[387] *Ibid*.

suggested the men whose sperm was negligently destroyed would be the property rights-holders under the work or skill exception. The judgment of the Court held that "the easiest course would be to uphold the claims of the men to have had ownership of the sperm for present purposes by reference to the principle first identified in *Doodeward*".[388] Storing the sperm in liquid nitrogen at minus 196 degrees Celsius "was an application to the sperm of work and skill which conferred on it a substantially different attribute, namely the arrest of its swift perishability".[389]

While the Court ultimately did not rest its finding on the work or skill exception, it is clear that, in their view, the possessory rights it gives rise to would have been allocated to the *men*, not the institution or individuals responsible for applying the work or skill.[390] This point is not directly grappled with by the Court other than by pointing out that the institution had undertook to the claimants to continue preserving the samples for their future use. This implication from the Court's judgment is significant given the exception had never been applied previously as giving rise to property rights held by the biomaterial provider. Unfortunately, the Court provided no justification to explain how or why the men would be allocated property rights under the exception.

A similar conclusion was reached in the Australian decision, *Re Edwards.*[391] This case involved a married couple whose plans to pursue IVF treatment were unfulfilled when the husband died in a workplace accident. The wife obtained an urgent court order to have sperm extracted from her husband's deceased body at the hospital immediately after his death.[392] The order for the extraction and storage of the sperm, however, required her to return to court at a later date to pursue an order enabling her to access and use the sperm. Hulme J therefore had to decide whether there was a legal basis for her claim to possess the sperm.[393] His Honour ultimately found the sperm was property based on the work or skill exception, and that it was the property of the wife as the work and skill employed to the sperm at been done on her behalf.[394]

The result of these cases is a lack of clarity on the essential parameters of the work or skill exception. It is not clear whether the exception gives rise merely to a possessory right, as originally

[388] *Yearworth*, *supra* note 93 at para 45(c).
[389] *Ibid*.
[390] *Ibid*.
[391] *Re, Estate of Edwards*, [2011] NSWSC 478 [*Edwards*].
[392] *Ibid* at paras 12–13.
[393] *Ibid* at para 24.
[394] *Ibid* at para 90.

expressed in *Doodeward,* or a broader range of property or ownership rights, as expressed in *AB and Others.* It is similarly unclear when the exception will vest rights in the entity applying the work or skill or someone else. Similarly, the degree of work or skill that is required to trigger the exception remains unsettled as does the question of whether the work or skill needs to be applied for a particular purpose.

The failure of cases to resolve these questions "demonstrate[s] that the legal principle [underlying the work or skill exception]…has not been adequately identified or articulated", preventing coherent legal development.[395] As the next section will show, the status of the work or skill exception is now in doubt given the English Court of Appeal's decision to depart from the exception in *Yearworth.* However, as *Doodeward* was an Australian High Court decision, which has not been overruled in Australia, there is authority to suggest that despite *Yearworth,* the exception might live on in Australia.[396]

ii. Ongoing Control

A seminal case involving property rights to biomaterials is the US decision, *Moore v Regents of University of California.*[397] Although *Moore* cannot readily be distilled into a single explanation or justification, one key part of the Majority's rationale for denying Moore had property rights to his separated biomaterials was that he lacked ongoing control over them. The importance of ongoing control has been picked up in the more recent *Yearworth* decision*,* which has also been an incredibly influential decision in this area. For this reason, the two cases have been grouped together under the topic of ongoing control given the significance of this point in both decisions.

Moore involved a leukemia patient, Moore, whose physicians used his blood and tissue samples for research without his knowledge or consent.[398] Over seven years, Moore's physician continued to take samples from Moore's body during medical examinations and did not disclose to Moore the uniqueness or commercial value of his cells.[399] The research led to the development of a cell line using Moore's tissue which was patented and held enormous commercial value, with

[395] Hardcastle, *supra* note 26 at 40.
[396] *Edwards*, *supra* note 391.
[397] *Moore*, *supra* note 241.
[398] *Ibid*.
[399] *Ibid* at 150 (Broussard J).

an asserted worth of $3 billion.[400] Moore subsequently discovered his tissue had been used in this manner and brought a claim against the doctors and others involved in the research. The claim was based, in part, on the tort of conversion.

Conversion is a tort based on interference with and misuse of property in a manner repugnant to another's right to possession of the property.[401] To succeed in conversion, Panelli J, writing for the Majority of the Supreme Court of California (with Lucas CJ, Eagleson and Kennard JJ concurring), explained that Moore needed to establish interference with "his *ownership* or *right of possession*".[402] As Moore did not have any expectation to possess his cells after they were removed, the Majority found that he needed to establish an ownership interest in his cells once they were removed from his body.[403]

The Court did not have to rule on the merits of the case, merely whether Moore's claim disclosed a valid cause of action. Nevertheless, the Majority felt they needed to rule on the question of ownership, as Moore's asserted ownership represented a novel issue of law underpinning his conversion claim.[404] In rejecting his claim, the Majority found: (i) there was no case law to support his claim of ownership; (ii) the effect of statutory rules regarding the disposition of diagnostic tissue left Moore with so little control over his biomaterials he could not be said to have ownership of them; (iii) the patented cell line is a product of invention of the researchers, and as such, not something Moore has a property interest in;[405] and (iv) policy considerations weighed against extending the tort of conversion in this way as conversion is not needed to protect patients' rights (which are protected by fiduciary duties and disclosure obligations inherent in requirements of informed consent) and would have a deleterious effect on the progress of scientific research.[406]

The Majority's judgment has been widely criticized, particularly with respect to grounds two through four. The policy considerations in ground 4 will be returned to in Chapter 5. For present purposes it is sufficient to note that concerns about the impact on the research environment played a prominent role in the Majority's analysis. With respect to the third ground, the Majority

[400] *Ibid* at 127 (Panelli J).
[401] Hardcastle, *supra* note 26 at 160–61.
[402] *Moore*, *supra* note 241 at 136 [emphasis in original].
[403] *Ibid* at 136–37.
[404] *Ibid* n 19.
[405] *Ibid* at 137.
[406] *Ibid* at 142–47.

indicated that the existence of the researchers' patent confirmed that the cell line was a product of their own invention and not something Moore owned.[407] This ground has been critiqued on the basis that Moore's claim of conversion was based on the appropriation of his cells *prior* to the cell line being created and patented, and the subsequent patent would not, therefore, alter the nature of Moore's interest in his cells at the time they were taken and then used without his consent.[408] As a result, this aspect of the Majority's judgment does little to elucidate why property rights did not arise in relation to the biomaterials at the time they were taken.

On the second ground regarding control, the Majority noted that statutory provisions requiring that excised tissue be disposed of and destroyed were inconsistent with an ownership interest as they severely curtailed the individual's ability to use their tissue.[409] The Majority conceded, however, that "[i]t may be that some limited right to control the use of excised cells does survive the operation of this statute. There is, for example, no need to read the statute to permit 'scientific use' contrary to the patient's expressed wish", but that this right is protected by fiduciary duties and informed consent obligations rather than property law.[410]

In contrast, the level of control exercisable over biomaterials was instrumental in granting individual property rights in the subsequent English Court of Appeal decision of *Yearworth.* As mentioned above, although Lord Judge CJ in *Yearworth* indicated he could have rested his finding on the work or skill exception, he was not content to do so. Part of the reason for this reluctance was due to the potential for the exception to produce illogical results. He queried:

> Why, for example, should the surgeon presented with the part of a body, for example, a finger which has been amputated in a factory accident, with a view to re-attaching it to the injured hand, but who carelessly damages it before starting the necessary medical procedures, be able to escape liability on the footing that the body part had not been subject to the exercise of work or skill which had changed its attributes?[411]

Hardcastle raises a similar concern using an example of a research lab, which might possess biomaterials that have undergone different degrees of processing. Hardcastle questions the logic

[407] *Ibid* at 142.
[408] *Ibid* at 167–68 (Mosk J, dissenting); Hardcastle, *supra* note 26 at 67.
[409] *Moore*, *supra* note 241 at 140–41.
[410] *Ibid* at 141.
[411] *Yearworth*, *supra* note 93 at para 45(d).

of holding some of those materials to be property and not others based on the amount of work or skill applied.[412]

The resulting decision in *Yearworth* to depart from the work or skill exception and decide the case on new grounds was a landmark moment in the development of this body of case law. The Court framed its analysis by acknowledging that "developments in medical science now require a re-analysis of the common law's treatment of and approach to the issue of ownership of parts or products of a living human body".[413] Instead of relying on the work or skill exception, the Court rested its conclusion on findings that (i) the sperm was derived from the men's own bodies; (ii) they retained sufficient control over the sperm; and (iii) the rights of the men over the sperm pertained to its future use, which directly correlated to the breach and harm they suffered from the facility's carelessness.[414]

As discussed in Chapter 2, on the point of control, the Court acknowledged that under the scheme of the relevant legislation, the men did not have a right to "direct" that their sperm be used in a particular way, as the men's ability to use the sperm was subject to the facility's statutory obligation to consider the welfare of any future children before allowing the men to use the sperm.[415] However, the men had a negative control right in that they had the legal authority to direct how the sperm *not* be used.[416] No one, including the facility, could store, use, or access the sperm other than with the men's consent. As a result, while the storage facility had certain statutory duties in relation to the sperm, it was the men, and no one else, who enjoyed *rights* to the sperm.[417] In contrast to *Moore,* the existence of statutory and practical limitations on the men's ability to store and use the sperm were not viewed as inconsistent with the men's ownership interests, as there are many examples of statutory restrictions on how property can be used.[418] For example, pharmacists are subject to legislative restrictions on their inventory and gun-owners are subject to rules about use of firearms without undermining the status of pharmaceutical drugs and firearms as "property".

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[412] Hardcastle, *supra* note 26 at 143.
[413] *Yearworth*, *supra* note 93 at para 45(a).
[414] *Ibid* at para 45(f).
[415] *Ibid*.
[416] *Ibid*.
[417] *Ibid*.
[418] *Ibid*.

The Court framed its analysis by raising the key question of whether the sperm was something "capable of being owned".[419] They then invoked the 11 "incidents of ownership" articulated by renowned jurist, A.M. Honoré,[420] noting the importance of "the right to use". The Court regarded the nexus between the right to use and the harm suffered by the plaintiffs (i.e., the inability to use) as an important factor in deciding that the sperm was capable of being owned.[421] As the men enjoyed a negative control right over the sperm's future use, and it was this very right that was interfered with by the facility's breach, the Court concluded the sperm was owned by the men.[422]

While *Yearworth* marks an important evolutionary step in the law in light of the Court's decision not to rely on the *Doodeward* work or skill exception, the decision does not specify which property rights arise in relation to the sperm.[423] Instead, the Court's reasoning is focused on the "right to use" without fulsomely exploring Honoré's other ten "incidents of ownership". The Court's focus on the right to use is problematic as it fails to elucidate how the right to use and control transformed the sperm into ownable property.[424]

The right to use or control something does not, on its own, ordinarily give rise to property rights, even where that use is wrongfully infringed by another.[425] For example, the Court noted (and did not challenge) the common law maxim, *dominus membrorum suorum nemo videtur* ("no one is to be regarded as the owner of his own limbs").[426] As discussed above, this maxim reflects the common law position that individuals do not have property rights to their intact living bodies. Notwithstanding all kinds of "uses" to which an individual has a right to put their body, there are no remedies *in property law* for wrongful infringements of these uses (they are, instead, protected through the right to bodily integrity). While it would certainly appear unjust to leave the men without a remedy given the nexus in this case, it does not follow as a matter of property law that an interference with use rights is transformative in creating property rights over something not

[419] *Ibid* at para 28.
[420] AM Honoré, "Ownership" in AG Guide, ed, *Oxford Essays in Jurisprudence* (Oxford: Oxford University Press, 1961).
[421] *Yearworth*, *supra* note 93 at para 28.
[422] *Ibid* at para 45(f).
[423] Shawn H E Harmon & Graeme T Laurie, "Yearworth v North Bristol NHS Trust: Property, Principles, Precedents and Paradigms" (2010) 69:3 Cambridge LJ 476 at 486.
[424] See Harmon & Laurie, *supra* note 423.
[425] *Ibid* at 484.
[426] *Yearworth*, *supra* note 93 at para 30.

ordinarily part of property law. It has been pointed out that, "[w]hile this might not be a particularly mighty leap, the fact that one (property) does not necessarily follow the other (control), it was a leap that demanded a lot more justificatory work [from the Court in *Yearworth*]."[427]

As a result of the Court's failure to sufficiently grapple with this fundamental question, *Yearworth* does not do enough to clarify how bodies or body parts are transformed into objects of personal property.[428] When contrasted with *Moore,* this failure becomes apparent. The Majority in *Moore* acknowledged that Moore enjoyed a negative control right to direct that his tissue not be used in scientific research. There was also a clear nexus in that case between that negative control right and the harm Moore suffered when his biomaterials were used in scientific research without his consent. And yet, that control and nexus were not sufficient in *Moore* to give rise to property rights.

While *Moore* was decided in a different jurisdiction and it was therefore not incumbent on the Court in *Yearworth* to distinguish its findings from *Moore*, given the stature of *Moore* in this body of case law and the similarity of the Court's emphasis on the issue of control, the failure to directly grapple with *Moore* on this point represents a missed opportunity for much-needed clarity in the law. The conceptual shortcomings of the case, however, have not prevented it from being relied upon in a line of subsequent cases. These later cases, however, have not clarified the conceptual problems in the decision and have extended the scope of the Court's finding in *Yearworth* beyond its initial parameters.

For example, following *Yearworth*, the British Columbia Supreme Court in *M (JC) v A (AN)* had to consider how to allocate sperm purchased by a couple from a sperm bank in the US when the couple's relationship ended.[429] Russell J found that the sperm was their joint property to be divided equally between them.[430] Her Honour canvassed a range of relevant decisions and found the decisions of *C(C) v W(A)*[431] and *Yearworth* most persuasive in determining that the sperm was property.[432] The *C(C)* case involved a dispute over embryos and will be returned to more fulsomely below. For present purposes it is sufficient to note that Sanderman J remarkably held the embryos

[427] Harmon & Laurie, *supra* note 423 at 486.
[428] *Ibid* at 484–87.
[429] *M (JC) v A (AN)*, [2012] BCSC 584 [*M (JC)*].
[430] *Ibid* at paras 75 & 96.
[431] *C(C) v W(A)*, [2005] ABQB 290 [*C(C)*].
[432] *M (JC)*, *supra* note 429 at para 55.

to be "chattels" without any supporting authority or consideration of the legal or ethical implications of the finding. The complete lack of conceptual grounding in *C(C)* was not, however, viewed as a problem in *M (JC)*. To the contrary, the ease with which Sanderman J found the embryos in *C(C)* to be property represented a "simple approach" applicable to the facts before her, leading to the conclusion that, "[o]nce the claimant and respondent purchased the sperm straws, those sperm straws were their property to be used for their benefit".[433]

In applying *Yearworth,* Her Honour emphasized that the parties before her had the ability to use the sperm vials and had previously used them to create two children. Similar to *Yearworth,* their ability to use the sperm survived certain statutory restrictions.[434] Her Honour acknowledged that the facts before her were different than *Yearworth* insofar as the Court's reasoning in *Yearworth* emphasized that the sperm was ejaculated from the plaintiffs' own bodies and stored for their own future use, and that the nature of the claim in *Yearworth* was a negligence action rather than a marital property dispute.[435] She then justified her extension of *Yearworth* to the facts before her on the basis that "the need for advancements in the common law to keep up with medical science" was not "any less compelling" than in *Yearworth*.[436] While this may be true, it does little to clarify why or how the ability to use and control the sperm in either case was sufficient to ground property rights.

The precedential value of these decisions is further highlighted in the subsequent decision, *Lam v University of British Columbia,*[437] which arose in similar circumstances to *Yearworth*. *Lam* involved a class action in which the plaintiffs' sperm was also ruined due to a failure to maintain an adequate temperature for the samples. One of the issues in this case was whether the sperm constituted "goods" within the meaning of the *Warehouse Receipt Act*, which were defined as "all property other than things in action, money and land".[438] Butler J acknowledged that at the time the statute was enacted, sperm was not intended to have been included in the definition of "goods",[439] but relied on *Yearworth, C(C), M (JC),* and the Australian decision, *Bazley v Wesley*

[433] *Ibid* at para 57.
[434] *Ibid* at para 60.
[435] *Ibid* at paras 61–63.
[436] *Ibid* at para 63.
[437] *Lam v University of British Columbia*, [2013] BCSC 2094 [*Lam*].
[438] *Ibid* at para 18.
[439] *Ibid* at para 34.

Monash IVF[440] (discussed further below), to find that the sperm was the property of the class members in this context.[441]

The precedential value of these cases was strong. Butler J explained the facts and findings of these cases and then concluded:

> [c]ourts in a variety of jurisdictions have come to the conclusion that stored sperm is property. I agree with the conclusion arrived at in these cases. The sperm was ejaculated, frozen and stored for the purpose of using it for conception. Applying the current state of the law of property to the definition in the WRA leads to a conclusion that frozen sperm is 'goods'.[442]

By the time *Lam* was decided, the existence of these previous cases enabled Butler J to avoid any conceptual heavy lifting and simply rely on this body of law. As a result, there is no real attempt in *Lam* to interrogate or clarify the reasons underpinning these decisions.

In Australia, there is some doubt about the strength of *Yearworth* in light of the historical *Doodeward* case, which is an Australian High Court decision that has not been overruled. Two cases decided the same year came to opposite conclusions regarding the applicability of *Yearworth* and *Doodeward.* The first was *Bazley v Wesley Monash IVF,* a case involving a man who provided semen samples to be stored for future reproductive use.[443] After his death, his wife wanted the facility to continue storing the samples for her potential future use, however, unlike *Hecht,* there was no explicit written direction in his will (or otherwise) that control of the sample be transferred to his wife upon his death. The facility was therefore of the view that it did not have the authority to continue storing the samples for the wife.

White J reviewed many cases, including *Doodeward* and *Hecht,* but primarily rested her conclusion that the sperm samples were property on *Yearworth.* Her Honour found the Court's departure from *Doodeward* compelling and applied the Court's findings regarding the existence of a bailment between the men and the facility.[444] She ultimately found that the deceased entered a bailment for reward when he transferred possession of his sperm to the facility, the sperm remaining his property while alive and vesting in his personal representatives after death.[445]

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[440] *Bazley v Wesley Monash IVF Pty Ltd*, [2011] 2 Qd R 207 (Qld Sup Ct) [*Bazley*].
[441] *Lam*, *supra* note 437 at paras 35–41.
[442] *Ibid* at para 41.
[443] *Bazley*, *supra* note 440.
[444] *Ibid* at paras 26–33.
[445] *Ibid* at para 33.

In contrast, in *Re Edwards,* Hulme J applied the work or skill exception to find the applicant could access and use the sperm extracted from her deceased husband's body. His Honour's conclusion ultimately rested on the binding nature of *Doodeward v Spence*: "[w]ork and skill was applied to [the sperm] in that it has been preserved and stored. Accordingly, on this long standing and binding authority [of *Doodeward v Spence*] the sperm removed from the late Mr. Edwards is capable of being property".[446] His Honour then noted that the Court in *Yearworth* was prepared "to extend the law considerably beyond *Doodeward v Spence*" and that *Yearworth* and *Bazley* were persuasive in this regard, but found there was no need for him to follow suit, as the binding High Court authority of *Doodeward* was sufficient to determine the case.[447] As a result, it is not clear whether the *Yearworth* approach or the work or skill exception is the more appropriate avenue for deciding disputes over biomaterials in Australia.

Overall, while control is an important factor in these cases, the rationale as to how or why property rights are created as a result of one's control is far from clear. The lack of clarity becomes apparent when contrasting *Yearworth* from *Moore,* where courts came to opposite conclusions despite recognizing, in both cases, that the plaintiffs enjoyed a type of negative control right. The presence of control as a justification for property rights may also prove problematic for individual claimants, where a lack of *de facto* control is the very problem needing to be remedied.

iii. <u>*Property Transfer*</u>

While *Yearworth* is notable in at least attempting to explain the origin of individual property rights, there is a line of cases that bypass the initial question of how biomaterials become capable of being objects of property and focus, instead, on principles of property transfer to justify allocation of rights to institutions. The conceptual flaw to this line of cases is that, prior to considering whether or how property rights to biomaterials have been transferred, one must first acknowledge and explain how those property rights arose to begin with. In the wake of *Moore,* two US cases arose that also involved biomaterials used in research, reflecting this approach.

The first was *Greenberg v Miami Children's Hospital.*[448] The plaintiffs in *Greenberg* included parents of children with a rare genetic disorder called Canavan disease. Over the course

[446] *Edwards*, *supra* note 391 at para 82.
[447] *Ibid* at para 84.
[448] *Greenberg v Miami Children's Hospital Research Institute*, [2003] 264 FSupp2d 1064 (US District Court, S.D. Florida) [*Greenberg*].

of several years, the families collaborated with Dr Matalon, a researcher/clinician, to provide bodily samples, financial support, and to locate other families affected by the disease to join their research efforts in hopes of locating the responsible gene and developing a diagnostic test. Dr Matalon accomplished these goals but, unbeknownst to the participants, the Miami Children's Hospital (where the research was occurring) patented the genetic sequence for Canavan disease[449] and subsequently limited access to the genetic test through restrictive licensing of the patent.[450] When the plaintiffs became aware of the commercialization of the research results, they brought a claim against Matalon and the Miami Children's Hospital, claiming a breach of informed consent, breach of fiduciary duties, unjust enrichment, conversion, fraudulent concealment, and violation of trade secrets. The defendants brought a motion to dismiss and were successful on all causes of action except unjust enrichment.[451]

In dismissing the conversion claim, District Judge Moreno found there was no property interest in the biomaterials or genetic information "voluntarily given" to the defendants and that "[t]hese were donations to research without any contemporaneous expectations of return of the body tissue and genetic samples".[452] His Honour relied on *Moore* in reaching this conclusion,[453] as well as other authority regarding the limitations of property rights in deceased bodies to conclude, "the property right in blood and tissue samples also *evaporates* once the sample is voluntarily *given* to a third party".[454] His Honour failed to acknowledge or explain, however, how it came to be that the plaintiffs held any property rights to "voluntarily give" or "evaporate" to begin with.

The next case that arose was *Washington University v Catalona*.[455] This case involved Dr Catalona, a researcher at Washington University, who had been performing prostate cancer research using biological samples stored in a biobank. Dr Catalona moved institutions and wrote to the research participants who had provided samples to request they sign an authorization permitting him to move their samples to his new institution. Thousands of participants signed the

[449] Justin Gillis, "Gene Research Success Spurs Profit Debate", *Washington Post* (30 December 2000), online: <www.washingtonpost.com> [perma.cc/N5VC-ELRS].
[450] *Greenberg*, *supra* note 448 at 1066–67.
[451] *Ibid* at 1077–78.
[452] *Ibid* at 1074.
[453] *Ibid*.
[454] *Ibid* at 1075 [emphasis added].
[455] *Washington University v Catalona*, [2007] 490 F3d 667 (8th Cir) [*Catalona*].

authorizations, but Washington University initiated court proceedings and ultimately obtained summary judgment providing that the University owned the biomaterials, from which Dr Catalona unsuccessfully appealed.

Even though the individual participants were not parties to the action, the entire case on appeal pertained to the question of "whether individuals who make an informed decision to contribute their biological materials voluntarily to a particular research institution for the purpose of medical research retain an ownership interest allowing the individuals to direct or authorize the transfer of such materials to a third party".[456] The consent form signed by the participants indicated they could withdraw their consent to use their samples for future research. Despite this ongoing, albeit limited, right to control the samples, Judge Riley, writing on behalf of the Court (with Circuit Judges Wollman and Shepherd agreeing), found that the research participants intended to give their samples to the university and concluded that the university "owns the biological samples".[457]

The Court's analysis avoided direct discussion of whether the samples are capable of constituting property or whether the participants ever had an ownership interest in their excised tissue. By framing the key question in terms of whether the participants "retained" ownership of their biomaterials, the Court's reasoning simply assumes this to be so.[458] Further, in determining that the samples were given as *inter vivos* gifts, the Court noted that such gifts are defined as "a voluntary transfer of *property*…"[459] Therefore, in order for the samples to have been "given", the participants had to initially have had property interests to transfer.

The use of property transfer principles to justify the institutional interests is similar to Judge Moreno's decision in *Greenberg,* where he found the plaintiffs' property rights to the biomaterials "evaporated" once they were "given".[460] In neither case, though, did Their Honours attempt to grapple with the more fundamental question of whether the relevant biomaterials were *capable* of being owned. This line of reasoning also appears somewhat at odds with *Moore*, where the Majority found that Moore did not have property interests in his biological materials once they

[456] *Ibid*.
[457] *Ibid*.
[458] Hardcastle, *supra* note 26 at 77.
[459] *Catalona*, *supra* note 455 [emphasis added].
[460] *Greenberg*, *supra* note 448 at 1075.

were separated from his body other than, possibly, some limited right to refuse that the samples be used in science.[461]

The gift in *Catalona* was conditional, as the participants retained an ongoing right to have their samples withdrawn from future studies. Conditional gifting was also an issue in *Colavito v New York Organ Donor Network.*[462] As discussed in Chapter 2, Colavito sued an organ donation organization after a kidney from his deceased friend that was intended for him was allocated to someone else. The Court of Appeals of New York rejected Colavito's conversion claim. The Court reviewed the common law history of cases dealing with deceased bodies and noted that although they had granted remedies to surviving family members when the bodies of their loved ones had been wrongfully interfered with, these cases were never squarely based within property law.[463] As a result, Colavito enjoyed no common law right to possess the kidneys.[464]

The organ donation statutory scheme was then examined, which "allow[ed] donors to make a gift, effective upon death, to 'any specific donee, for therapy or transplantation needed by him'".[465] As discussed in Chapter 2, because the kidney was ultimately found not to be suitable for Colavito, it was not a kidney "needed by him".[466] The Court of Appeals found, "[u]nder the statutory scheme, gifts of a deceased donor are conditioned upon medical benefit to the intended recipient".[467] This case reflects an underlying conceptual tension in the organ, tissue, and blood donation framework, where transfer of these materials tends to be framed in terms of "donations" and "gifts" while simultaneously denying the property status of the materials. The effect of this in *Colavito* was to use property principles of conditional gifting to justify the absence of any entitlements by Colavito while denying the kidney was property that could be subject to a conversion claim.

The notion of the kidney being an imperfect gift invites consideration of who the donor of this gift is. With gifts subject to a condition precedent, "the donor retains title to the gift until the

[461] Hardcastle, *supra* note 26 at 77–78.
[462] *Colavito*, *supra* note 123.
[463] *Ibid* at 49–53.
[464] *Ibid* at 53.
[465] *Ibid* at 55.
[466] *Ibid* at 57.
[467] *Ibid*.

condition is satisfied".[468] It was the deceased man's spouse who made the decision to donate the kidneys to Colavito. She had legal authority under the Act to do so, and there would have been no authority for the organ donation organization to allocate the kidneys to Colavito or anyone else without her consent. Therefore, if she is the legal donor of the conditional gift, that would ordinarily mean title to the kidneys remained with her until the condition was satisfied. The fact that the donation organization gave away the kidney before waiting to see if the condition would be met could be seen as an interference with *her* rights to the kidney. She was not a party to the proceedings, however, and the Court in the case did not explore any of the ramifications of finding the kidney to be a conditional gift, being satisfied with their explanation of why Colavito did not have rights to the kidney.

The Canadian decision, *C(C) v W(A),* similarly involved a focus on property transfer. This case involved a dispute between a man and woman over the fate of embryos that had been created using each of their respective gametes.[469] The two parties had been friends and the respondent had agreed to provide his sperm so that the applicant could use it to create embryos and try to conceive through IVF. The applicant used the embryos and gave birth to twins, but there were four embryos left over. The parties engaged in custody and access disputes over the twins, and eventually a dispute arose as to what should be done with the remaining embryos.

The applicant attempted to obtain the embryos from the clinic where they were stored, but the clinic would not release them without the respondent's consent, which he refused to give. Despite this refusal, Sanderman J remarkably held that the embryos were the applicant's property.[470] With very little discussion or analysis, Sanderman J found that because the man had gifted his sperm to the woman so that she could have children, the embryos that were created were "chattels that can be used as she sees fit".[471] The lack of depth of the discussion and finding in *C(C)* that the embryos were property stands in contrast to the US case, *Davis v Davis,* addressed above, where Daughtrey J considered academic commentary, ethical guidelines, and the limited case law available in reaching a conclusion about the legal status of the embryos.[472] *C(C)* is

[468] Cameron Stewart et al, "The Problems of Biobanking and the Law of Gifts" in Goold et al, *supra* note 18, 25 at 33.
[469] *C(C)*, *supra* note 431.
[470] *Ibid* at para 21.
[471] *Ibid*.
[472] *Davis v Davis*, *supra* note 356.

remarkable for its failure to consider any case law, property theory, or legal or bioethical scholarship in reaching this conclusion. Instead, like *Greenberg* and *Catalona,* principles of property transfer were employed without first considering why or how the biomaterials came to be property.

Property transfer was also used in another Canadian decision, *Piljak Estate v Abraham,*[473] which involved a medical malpractice case brought on behalf of the estate of a deceased colorectal cancer patient against a doctor who performed a colonoscopy prior to the patient's diagnosis. The doctor did not detect the cancer during the initial colonoscopy, and the plaintiff claimed that the failure to detect was negligent. The defendants brought an application to have a liver tissue sample that had previously been taken from the deceased patient genetically tested. The test would help determine the cause of the cancer, which was relevant to whether the failure to detect the cancer met the standard of care. The tissue sample had been preserved and stored by the hospital at which it was taken. The defendants brought their application under a procedural rule that allows the court to order "the inspection of real or personal property where it appears to be necessary for the proper determination of an issue in a proceeding".[474] The Master therefore had to determine whether this tissue sample taken for diagnostic purposes was "personal property" within the meaning of this rule.

Master Dash adopted a line of reasoning from an academic article[475] asserting that tissue is originally owned by the patient, but once it is removed in the course of treatment and stored at the institution, it becomes part of the patient's medical record, which is owned by the institution that compiled it. This finding is an extrapolation of the Supreme Court of Canada's reasoning in *McInerney v MacDonald*.[476] In *McInerney*, the Court had to consider whether a patient had a right to access her complete medical record. The Court found that patients do have rights to access their medical records but noted that the physical record is owned by the physician or institution that compiled it.[477] Having found that the tissue sample was part of the patient's medical record, Master Dash concluded that the tissue sample was the property of the institution that owned the record:

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[473] *Piljak Estate v Abraham*, [2014] ONSC 2893 [*Piljak*].
[474] *Ibid* at para 17.
[475] Carol C Cheung, Bella R Martin & Sylvia L Asa, "Defining Diagnostic Tissue in the Era of Personalized Medicine" (2013) 185:2 CMAJ 135.
[476] *McInerney v MacDonald*, [1992] CarswellNB 247 (SCC) [*McInerney*].
[477] *Ibid* at paras 13–14.

> The authors state that it 'is unquestionably true that patients own their tissue before it is excised', and while it has never been squarely dealt with by a Canadian court, they conclude that diagnostic tissue, once excised becomes a 'component of the medical record'…As such, 'both possession and ownership are transferred to the institution' and 'by virtue of it being part of the medical record, diagnostic tissue is therefore owned by the institution or hospital.' At best a patient is entitled to 'reasonable access.'…While this is not binding on me I find the reasoning compellable and I adopt its conclusions.[478]

While this case at least recognizes the need to conceptually justify the creation of property rights and does not simply rest blindly on precedent or pragmatism, the line of reasoning adopted by the Master is fundamentally flawed. Despite proclaiming it to be "unquestionably true", the assertion that "patients own their tissue before it is excised" is contradicted by the historical common law maxim described above: *dominus membrorum suorum nemo videtur* ("no one is to be regarded as the owner of his own limbs")[479] and *R v Bentham,* where Lord Rodger reiterated that, not only are we not owners of our attached body parts, we do not even have a more limited right to possess them.[480]

While there are scholars advocating for an approach recognizing individuals as "owners" of their intact living bodies, even these scholars recognize this approach represents a departure from the common law.[481] The proposition that individuals own their materials prior to separation is far from "unquestionably true". As a result of this false premise, the authors' conclusion (and the Master's by adoption) is fundamentally flawed. The basis of their finding that excised tissue is owned by the institution is that "possession and ownership are transferred to the institution".[482] The transfer of ownership is not possible if one does not own the material to begin with.

It is also difficult to understand the role that *McInerney* plays in this reasoning. The authors contend that, "by virtue of it being part of the medical record, diagnostic tissue is therefore owned by the institution or hospital".[483] This statement suggests that it is the incorporation of the tissue into the medical record that gives rise to the institution's ownership interest. It is not clear, however, why tissue would have to be included in the medical record to create an ownership

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[478] *Piljak*, *supra* note 473 at para 26.
[479] *Yearworth*, *supra* note 93 at para 30.
[480] *Bentham*, *supra* note 361 at para 14.
[481] Quigley, "Property in Human Biomaterials", *supra* note 25 at 669; While Meredith Render argues that the seminal case of *Moore* can be understood as supporting a property interest to the entire, intact living body, she acknowledges that most interpretations of this case reflect the opposite view: Render, *supra* note 26 at 570.
[482] Cheung, Martin & Asa, *supra* note 475 at 139.
[483] *Ibid* at 137.

interest if the patients had already made a legal gift of their tissue, transferring ownership to the institution, as the authors simultaneously suggest.

The Supreme Court in *McInerney* accepted that the "the physician, institution or clinic compiling the medical records owns the physical records".[484] The Court did not elaborate on this finding, but it makes some sense in that the person or entity that procures, compiles, and controls the raw materials needed to create a medical record would own the physical record created. When applied to biomaterials, however, the analogy is not apt, as the biomaterials contributing to the medical record are not like the paper, ink, and folders, which are *already owned* by the institution. It is quite a stretch to interpret *McInerney* as an explanation for the creation of property rights over materials that are *res nullius.*

The explanation might make sense if the hospital already owned the biomaterials prior to compiling them in the medical record. Perhaps this is why the authors also explain that ownership is transferred from the individual source to the institution. The authors also allude to the work or skill exception, claiming that institutional ownership is especially persuasive "where the tissue ends up in a materially different form (e.g., slides, paraffin-embedded blocks)".[485] However, regardless of whether it is a transfer of ownership from source to hospital (which would represent a significant change to the common law position given individuals do not own their living bodies) or the application of work or skill that transforms the biomaterials into ownable property, there is no work for the medical record to do in the creation of property rights. On either account the biomaterials would already be ownable property. As a result, the *Piljak* medical record approach offers little conceptual guidance on the fundamental question of how biomaterials are transformed into things capable of being the subject of property rights.

iv. <u>*Pragmatism*</u>

Underlying many cases in this area are pragmatic and policy concerns. In the Australian case, *Roche v Douglas,* a plaintiff wanted to examine diagnostic tissue taken from a deceased man for the purpose of DNA testing to prove she was his biological child and therefore entitled to a portion of his estate.[486] Under a rule of civil procedure, the court could order the examination of

[484] *McInerney*, *supra* note 476 at para 14.
[485] Cheung, Martin & Asa, *supra* note 475 at 137.
[486] *Roche v Douglas*, [2000] 22 WAR 331 (WA Sup Ct) [*Roche*].

"property", and Master Sanderson therefore needed to determine whether the deceased's bodily samples, which had been preserved in paraffin wax, were "property" within the meaning of this rule. The Master explained some of the historical case law, including *Doodeward v Spence,* but concluded that this case was "not directly relevant to the matters at issue in this application".[487]

Instead, the Master noted the time and expense that would be saved in gathering evidence for the plaintiff's trial should she be allowed to perform DNA testing and found that this expediency provided good grounds for finding the material to be property for the purpose of the present facts.[488] The Master expounded further:

> In the wider sense, it defies reason to not regard tissue samples as property. Such samples have a real physical presence. They exist and will continue to exist until some step is taken to effect destruction. There is no purpose to be served in ignoring physical reality. To deny that the tissue samples are property, in contrast to the paraffin in which the samples are kept or the jar in which both the paraffin and the samples are stored, would be in my view to create a legal fiction. There is no rational or logical justification for such a result.[489]

This pragmatic approach to finding the samples to be property did not require the Master to determine who the property owner was, as it did not matter who owned the property for the procedural rule to be triggered.[490] While this approach certainly has an intuitive appeal, it does little to elucidate as a matter of property law and theory how or why the samples came to be objects of property. Nevertheless, it was cited with approval in subsequent Australian decisions of *Bazley* and *Re Edwards,*[491] although both cases used additional lines of authority (*Yearworth* and *Doodeward,* respectively) to ultimately reach their conclusions.

The overt pragmatism underlying Master Sanderson's decision is emblematic of considerations underlying many decisions in this area. It is clear that the development of the law in this area is imbued with influences beyond the strict need for coherent legal doctrine, evidenced by cases reflecting "property-adjacent" reasoning, rationalizations based on the need for the law to keep pace with science, and/or justifications grounded in unsubstantiated fears about the future of scientific research. In some respects, Master Sanderson has simply made explicit the driving forces behind the decision that often remain implicit in other cases.

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[487] *Ibid* at para 14.
[488] *Ibid* at para 23.
[489] *Ibid* at para 24.
[490] *Ibid* at para 25.
[491] *Bazley*, *supra* note 440 at paras 32–33; *Edwards*, *supra* note 391 at para 80.

C. Conclusion

Biomaterials have a long legal history that is currently being re-written in an *ad hoc* and conceptually confused manner, with many different interests to balance. The very fact that there are so many approaches to determining how biomaterials are transformed into ownable property indicates a lack of consistency in terms of how this fundamental question is addressed and a degree of malleability in terms of how it can be answered. As a result, despite the growing body of cases dealing with disputes over biomaterials, it remains difficult to predict when or how a particular biomaterial will be treated as property or who the property rightsholder will be.

For example, the current status of the work or skill exception is unclear. The Court in the influential *Yearworth* decision departed from the exception, yet it was upheld and formed the basis of the Australian *Re Edwards* decision and appears to have implicitly formed part of the Canadian *Piljak* decision. The scope of the exception, however, remains uncertain. Cases employing the exception have differed on key questions of (i) whether it merely gives rise to a possessory right or an expanded set of proprietary rights, (ii) who becomes the owner of the body or body parts upon their transformation into something capable of attracting property rights, and (iii) what degree of transformation is required and what level of work or skill is needed to trigger it.

Alternative explanations for how biomaterials become capable of attracting property rights have done little to clarify the picture. The *Roche* explanation based on pragmatism does little to elucidate such a complex area and the *Piljak* explanation based simultaneously on incorporation of tissue into the medical record as well as transfer from the individual to the institution is conceptually confused. While the Court in *Yearworth* made the greatest effort to explain the basis for their decision, it leaves much to be desired. The Court in *Yearworth* focused on control over the sperm yet did not explain why the men's (limited) ability to control how the sperm was used necessarily led to the creation of property rights. In contrast, Moore's lack of control proved fatal to his property claim. The presence or lack of individual control seems an important factor, yet the relevance and application of this factor is not yet clear.

One of the problems in making predictions in this area is that a lack of conceptual grounding and clarity has not prevented cases from becoming influential precedents. An obvious example is *C(C),* which lacked any meaningful analysis to support the finding that the embryos were property and yet has been cited and relied upon in future cases. Similarly, while the pragmatic

approach in *Roche* offers nothing in the way of principles to determine such thorny questions, it has been cited with approval in both *Edmonds* and *Bazley.* While *Yearworth* has been relied on internationally, subsequent cases have done little to expand upon or clarify its underlying rationale.

Further, the readiness with which courts have jumped to questions of property transfer to deny individual rights rather than grapple with how those transferred rights arose to begin with is problematic for individual claimants. It also presents an obstacle for the efforts described previously aimed at shifting away from terminology based on "donors" and "gifts" and toward a lexicon providing greater recognition of the ongoing interests individuals have in their biomaterials. While there is value in challenging the way we conceptualize the transfer of biomaterials and a change to more neutral terminology is potentially useful in this respect, the language of "donors" and "gifts" has become embedded in the law. These terms have specific legal meanings that have been endorsed in case law and entrenched in statute, and these terms have been employed specifically to deny individual rights as a matter of property law.

Despite the conceptual confusion underlying this body of case law, as property rights have now been allocated to individuals in some cases, there might be reason for optimism in terms of property law's ability to strengthen individual control over biomaterials. However, as the next chapter will demonstrate, there is a mismatch in values between those protected by property law and those that individuals have in their biomaterials. Conversely, the values institutions have in biomaterials are much more closely aligned with what property law is designed to protect. As a result, the next chapter will argue that where there are genuine contests of control between individuals and institutions, individuals will continue to struggle to have their interests recognized and protected under property law.

5. The Challenges for Individuals Asserting Property Rights Against Institutions

The previous chapter demonstrated that the legal status of biomaterials has been challenged in a range of different contexts. Sometimes the characterization of these materials is relevant to a procedural rule, sometimes to a family law dispute, and sometimes as a matter of tort or contract law. As a result, the parties to the disputes differ depending on the context. In disputes between individuals, property law has sometimes been used to determine competing claims of control. The *M (JC)* case and *C (C)* cases, for example, reflect situations where property rights have been recognized and allocated to individuals engulfed in family law disputes. Both cases involved disputes over the fate of reproductive material, and in both cases, the courts used property law to allocate control rights over the materials to individual litigants.

With respect to claims arising between individuals and institutions, *Yearworth* marked what many viewed to be a turning point, creating optimism that property law could benefit individuals and lead to greater individual control. Quigley, for example, remarked that a unifying feature of case law pre-*Yearworth* "was the fact that the only person who could *not* come to own human biomaterials was their source", with *Yearworth, Bazley,* and *Edwards* challenging this position.[492] This optimism is reflected in the views of many other scholars writing in this field who view property law as the best option for stronger protection for individual rights.[493]

However, this chapter will argue that the optimism created by the *Yearworth* line of cases should be tempered. The first part of this chapter will re-visit some of the cases and justifications for property rights highlighted in Chapter 4 to show that where control over biomaterials is genuinely contested, institutional interests have uniformly prevailed. The second part of this chapter will then offer an explanation for this asymmetrical recognition of property rights by looking at the underlying values of property law. Policy considerations have a strong influence in these decisions requiring a weighing of values and interests that property law is ill-equipped to do. This Chapter will argue that the values that property law is suited to consider are more closely aligned with institutional rather than individual interests, creating a rather pessimistic picture for individual claimants.

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[492] Quigley, "Property in Human Biomaterials", *supra* note 25 at 661 [emphasis in original].
[493] For example, see: Goold & Quigley, *supra* note 113; Nwabueze, *Biotechnology, supra* note 27; Mason & Laurie, *supra* note 114; and Render, *supra* note 26.

A. Lessons Learned from Case Law

As a starting point, it is notable that all the decisions directly involving research biomaterials have been decided in favour of institutions. *Moore* and *Greenberg* involved direct disputes between research participants, on one side, and researchers and research institutions on the other. While *Catalona* involved a dispute between a researcher and institution, the existence of property rights held by the individual participants was the key issue in the case. In all three cases, the limited rights and interests enjoyed by individual participants were outweighed by institutional interests.

Similar conclusions were reached in cases involving diagnostic tissue. In *Dobson,* the plaintiff's conversion claim failed. In *Piljak,* although the key question was whether the sample was property and not who owned the property, the Master nevertheless held that the institution was the owner. In *AB and Others,* Gage J denied the parents had any cause of action for wrongful interference with their children's bodies and, instead, found the work or skill applied by pathologists gave rise to property rights held by the *hospital*.[494] As a result, not only were the parents denied recognition of any legal rights to their deceased children's bodies, but the institutions responsible for removing and retaining the organs without valid consent were recognized as having superior rights to these biomaterials.

Similar to *AB and Others,* the Majority in *Moore* did not rest upon finding Moore lacked the necessary interest in his biomaterials but emphasized the superior rights allocated to the institution as one reason to deny his claim. They noted the inventive effort applied by the researchers and their subsequent patent as evidence the cell line was the product of the researchers' invention, "both factually and legally distinct from the cells taken from Moore's body".[495]

These cases have quite firmly denied claims based on individual property rights to separated biomaterials. While some of these cases implicitly (such as *Catalona* and *Greenberg*) or even explicitly (such as *Piljak*) recognize that individuals initially held property rights, the courts in these cases have readily found these rights to have been transferred as a justification for upholding the institutional interests at stake. The focus on property transfer is problematic both conceptually, in terms of failing to explain the origin of the rights that are transferred, and

[494] *AB and Others*, *supra* note 131 at para 257.
[495] *Moore*, *supra* note 241 at 141 (Panelli J, with Lucas CJ, Eagleson and Kennard JJ, concurring).

practically, as it deprives individuals of any ongoing control over biomaterials past the point of consent.

Even property scholars hailing the benefits of property law for individuals concede this point. Quigley, for example, advocates for a model of self-ownership whereby each person enjoys moral ownership and accompanying rights of control over their respective living bodies, which continue to exist in relation to biomaterials after separation.[496] In her view, consent should not be viewed as a distinct normative obligation, but "as an integral part of persons' property rights in their biomaterials".[497]

As an example, she discusses a person providing broad consent when donating biomaterials for research. In such a case, consent indicates an "inten[tion] to relinquish any further control over the samples", with the consequence of transferring the individual's property rights to the institution.[498] By doing so, the individual then takes on an obligation not to interfere with the samples going forward. In other words, "[b]y consenting you divest yourself of the corresponding powers from that point forward".[499]

On this basis, she views concerns expressed in *Moore* and *Greenberg* about the negative impact of individual property rights on the research environment as misplaced. She notes, "[t]here was a mistaken presumption that granting source property rights would somehow allow persons to exert control over their tissue samples beyond the point of donation".[500] However, from the discussion in Chapter 3 of this work, it is clear that consent in research is not properly viewed as a one-time occurrence or event. Consent to participate in research is a continuing state of affairs that must be maintained, giving rise to a corresponding right to withdraw, and there are legitimate calls for greater ongoing individual control in the biobank context. Yet even Quigley's account, which is among the strongest in terms of advocating for greater individual rights of control, acknowledges that individual rights are relinquished upon transfer of physical possession. This acknowledgement in scholarship and case law casts doubt on whether property law will be able to address the need for protection of ongoing interests identified in Chapters 2 and 3 of this work.

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[496] Quigley, *Self-Ownership, supra* note 5, c 8.
[497] *Ibid* at 271.
[498] *Ibid* at 269–70.
[499] *Ibid* at 270.
[500] *Ibid* at 273.

Further examples of the fixation on property transfer can be found in *Catalona* and *Colavito,* where conditional gifting was employed to deny individual rights. *Catalona* involved conditions subsequent imposed on the gifts of tissue samples for research.[501] Title to the tissue passed to the institution, but remained conditional upon the donors' continued consent, as they were found to have a surviving right to withdraw their samples from future study. *Colavito* involved a condition precedent, whereby "title" to the kidney would not pass to the intended donee unless the condition of compatibility was first satisfied. As the Court explicitly found the kidney not to be property under the common law, it is difficult to comprehend and pinpoint the rights and interests being transferred by "gift". Nevertheless, in both cases conditional gifting was used to justify institutional control. In *Catalona,* the finding of a conditional gift was used to conclude individual research participants transferred away their rights to the research institution while in *Colavito* it was used to deny any transfer of rights to the individual.

It is worth noting, though, that in *Catalona,* the law of gifts was not the only property-based option open to the court. The alternative conceptualization put forth by the researcher and participants was that the institution was a bailee of the biomaterials.[502] Such a finding would have meant that the biomaterial providers enjoyed broader continued rights and interests to the samples. The assertion of bailment was supported by the facts that participants enjoyed a right to withdraw (and in some cases a right to have the tissue destroyed) and the testimony of some participants who indicated that they donated their biomaterials specifically so Dr Catalona could use them in his research, not the university, leading some scholars to conclude that the better characterization of the participants' contributions was one of bailment as opposed to conditional gifts.[503] However, the Court relied on the wording of the consent forms and the practices of Dr Catalona (including that he would destroy samples from time to time and enter material transfer agreements pertaining to the samples which listed the University as the owner of the materials) to conclude the participants retained no ownership of the samples. Remarkably, the Court did not even find it

[501] See Cameron Stewart, Jennifer Fleming & Ian Kerridge, "The Law of Gifts, Conditional Donation and Biobanking" (2013) 21:2 J Law Med 351 at 354–55, who explore the different types of conditions that can be imposed on gifts in relation to the *Catalona* case.
[502] *Catalona*, *supra* note 455.
[503] Hardcastle, *supra* note 26 at 157; Goold & Quigley, *supra* note 113 at 253.

necessary to address the issue of bailment in their judgment, save for a brief mention in a footnote that they agreed with a lower court on this point.[504]

The cases dealing with research and diagnostic biomaterials paint a bleak picture for individual claimants. However, as Chapter 4 demonstrated, there are wide-ranging justifications for grounding property rights and cases where individuals have succeeded in claims against institutions. The following analysis will re-visit some of these cases and justifications and show why the optimism created by them should be regarded with caution.

i. Explanations based in Pragmatism

The pragmatic approach articulated in *Roche* (and approved of in *Bazley* and *Re Edwards*) does little to specify when such pragmatism and common sense should be employed to justify property rights. As there was no dispute in *Roche* over control of the biomaterial, the question simply being whether it amounted to property or not, overt reliance on pragmatic considerations is potentially understandable. Where serious contests of control over biomaterials arise, however, more detailed guidance is needed to justify granting or withholding property rights to particular parties. A pragmatic approach lacking clear conceptual grounding might be particularly susceptible to outside policy influences. Indeed, the overarching concern of the Master in *Roche* was the procedural efficiency that would be gained by finding the relevant material to be property. As discussed further below in the second Part of this chapter, where individuals take on institutions, policy considerations become particularly relevant and have been used to deny individual rights. As a result, this approach does not seem like a strong first line of argument for those seeking recognition of individual property rights to biomaterials in claims against institutions.

ii. The Work or Skill Exception

The work or skill exception also seems an unlikely candidate to offer stronger protection for individual rights. This is because (i) the relevance of the exception is in doubt in the wake of *Yearworth,* save for Australia where there is some conflicting authority as to its continued applicability, (ii) the parameters of the exception remain unclear and have been applied in ways that protect institutional interests, and (iii) relevant cases suggest that the resulting property rights

[504] *Catalona*, *supra* note 455, n 9.

would likely be allocated to the person or entity responsible for applying the work or skill rather than the individual source of the biomaterial.

The cases reviewed in the preceding chapter showed that the exception has not been consistently applied. One area of inconsistency pertains to the degree of work or skill and subsequent transformation needed to trigger the exception. While the removal and preservation of the brain in *Dobson* was insufficient to trigger the exception, preservation techniques were sufficient to give rise to property rights in *Kelly* and *AB and Others*. A common denominator in these cases is the protection of institutional interests. The denial of the exception in *Dobson* shielded the hospital from liability as did the application of the exception in *AB and Others.* In *Kelly* the exception protected the College's possessory interests against theft. As the parameters of the exception remain unclear, it is a very malleable principle that can seemingly be applied in different ways to protect institutional interests at stake.

Further, most cases applying the exception have recognized that the person or entity applying the work or skill is the one allocated the resulting property rights. In *AB and Others,* for example, it was the hospital where the pathologists removed and preserved the organs that was allocated property rights, notwithstanding that the removal and retention was done without the required consent. On the other hand, *Yearworth* and *Re Edwards* indicate some scope for expanding ownership to others.

However, *Yearworth* should be interpreted with some caution on this point. While Lord Judge CJ (on behalf of the Court) found he *could* have decided the case using the work or skill exception, he did not ultimately rest his conclusion on this basis. Nevertheless, he acknowledged that had he applied the work or skill exception, he "would have no difficulty in concluding that the unit's storage of the sperm in liquid nitrogen at minus 196°C was an application to the sperm of work and skill which conferred on it a substantially different attribute".[505] However, the conclusion that the exception could be used to uphold "the claims of the *men*" was not reconciled with the finding that the requisite work or skill was applied in "the *unit's* storage of the sperm".[506]

In contrast, the Australian decision, *Re Edwards,* more explicitly addressed this point. Hulme J found the sperm extracted from the body of the late Mr. Edwards was property on the

[505] *Yearworth*, *supra* note 93 at para 45(c).
[506] *Ibid* [emphasis added].

basis of the *Doodeward* work or skill exception. His Honour then had to determine the identity of the sperm's owner.[507] Unlike the other sperm cases (*Hecht, Yearworth, Lam,* and *Bazley*), the sperm was not extracted until after Mr. Edwards's death. As the work or skill exception was the basis for finding the sperm to be property, Hulme J noted that no work or skill had been applied while Mr. Edwards was alive. Mr. Edwards therefore did not have a property right to the sperm while he was alive, and it did not form part of his assets after death.[508]

Hulme J then considered whether the doctors and technicians who applied the requisite work or skill to the samples might be the owners. He rejected this possibility on the basis that the doctors were not applying work or skill to be able to use the sperm for their own purposes but were doing so as agents for Ms Ewards.[509] By process of elimination, Hulme J concluded:

> …in my view Ms Edwards is the only person in whom an entitlement to property in the deceased's sperm would lie. The deceased was her husband. The sperm was removed on her behalf and for her purposes. No-one else in the world has any interest in them. My conclusion is that, subject to what follows, it would be open to the Court to conclude that Ms Edwards is entitled to possession of the sperm.[510]

Essential to this finding is the fact that "no-one else in the world [had] any interest in [the sperm]". In fact, there was no respondent in the case. Ms Edwards simply sought a declaration that the sperm held at the IVF facility be released to her.[511] The Attorney General appeared as an *amicus curiae*, neither consenting to nor opposing the application.[512] The Attorney General's submissions, instead, appear aimed at ensuring a legally correct outcome, and it was counsel for the Attorney General that raised the possibility of deciding the case on property principles.[513]

While *Edwards* certainly indicates that the work or skill exception may be applied to generate property rights allocated to persons other than those applying the work or skill, the rationale underlying this finding would be of doubtful utility and relevance in situations where control over the biomaterials is seriously contested. If a research or medical institution were to claim a competing interest to sperm that it had applied work or skill to, it is doubtful that *Edwards*

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[507] *Edwards*, *supra* note 391 at para 86.
[508] *Ibid* at para 87.
[509] *Ibid* at para 88.
[510] *Ibid* at para 90.
[511] *Ibid* at paras 17–23.
[512] *Ibid* at paras 21–23.
[513] *Ibid* at para 42.

would be of much help to an individual claimant given the lack of any competing interests or claims in that case.

iii. *The* Yearworth *Focus on Control*

Prior to *Yearworth,* institutional interests were recognized and protected in *Dobson, Kelly, AB and Others, Moore, Greenberg, Catalona,* and *Colavito.* Against this backdrop, *Yearworth* and the other sperm cases that followed were welcomed and met with optimism by those seeking greater protection for individual rights.[514] Indeed, the *Yearworth* line of cases shows that individuals have enjoyed some success in claims against institutions. *Yearworth* and *Lam,* for example, both involved plaintiffs successfully suing institutions over the negligent destruction of their sperm, and in both cases, the sperm was found to be the plaintiffs' property. *Bazley* and *Re Edwards* involved women successfully gaining access to stored sperm from IVF facilities originating from the bodies of their deceased husbands. While this line of cases is certainly notable for recognizing individual property interests, these cases are different from the research and diagnostic biomaterial cases in an important respect: the institutional defendants in the *Yearworth* line of cases were not asserting superior rights to control and use the biomaterials for their own purposes.

In *Yearworth* and *Lam,* for example, the sperm had already been destroyed. The interest of the defendant institutions was simply to avoid liability by denying the men held any property rights. The defendants did not assert any superior right to control and use the biomaterials for their own purposes. It was clear that any use of the sperm was subject to the men's consent. Similarly, in *Bazley,* the IVF facility was not asserting that it had a property right to the sperm or that it had any ability to use the sperm for its own purposes. The objection of the facility to releasing the sperm to the applicant arose from a concern that it lacked the legal authority to comply with her request. The facility was bound by regulatory guidelines that prohibited clinics from facilitating pregnancy after a gamete provider's death and mandated the destruction of stored gametes unless the provider left clear, witnessed directions consenting to continued storage and use.[515]

[514] See Quigley, "Property in Human Biomaterials", *supra* note 25 at 661.
[515] *Bazley*, *supra* note 440 at para 5.

The facility in that case expressed to the applicant prior to the proceedings its willingness to comply with a court order directing it to continue storing the sperm,[516] indicating its interest in the case was primarily to ensure its actions regarding the deceased men's sperm were done with clear legal authority. In this respect, although the facility was preventing the claimant from accessing and using the sperm, the facility's position was not one based on a superior right to control and use the sperm for its own purposes. Instead, the facility viewed Ms Bazley and itself as sharing the same legal position in that neither of them had a right to store or use the sperm in the absence of clear written directions from Mr. Bazley.

In *Re Edwards,* although Ms Edwards was seeking an order allowing her to access the sperm held at an IVF facility, the facility was not even a party to the action. As discussed above, there were no respondents contesting her claim. Further, the fact that no one else had any interest in controlling the sperm was a significant point in Hulme J's determination that Ms Edwards was the owner.

In this respect, these cases stand in stark contrast to *Moore, Greenberg,* and *Catalona,* where the institutional defendants were using the biomaterials for their own research purposes. Similarly, in *AB and Others,* the hospital needed to defend its uses of the organs (removing, retaining, and destroying) in the absence of the plaintiffs' informed consent. In *Colavito,* the donation organization needed to defend its decision to allocate the kidney to a recipient of its choosing. These cases all involved competing claims to control and use the biomaterials and they were all decided in favour of the institutions.

The dividing line between these cases can be understood when examining the rationale offered by the Court in *Yearworth,* which focused strongly on control. The men in that case enjoyed a negative control right to direct how the sperm not be used. In particular, their ability to withdraw their consent for the continued storage of their materials and the fact that the sperm could not be used without their further consent led the Court to conclude that the incidents of ownership were strong enough to find they owned the material. No one else, including the institution, had any rights to the sperm. This makes sense, as the sperm was being held by the institution specifically

[516] *Ibid* at para 7.

for the men's benefit. In the research and diagnostic contexts, however, the situation is very different.

When biomaterials are taken during a diagnostic or therapeutic procedure, individuals have very little ongoing control. Indeed, the lack of ongoing individual control proved fatal to Moore's conversion claim. Despite the existence of a negative control right in *Moore* to direct that his biomaterials not be used in research, no property rights were allocated to him. Similarly, a negative control right allowing participants to withdraw from research in *Catalona* was insufficient to find the participants' property rights survived the transfer by way of gift. Further, in *AB and Others,* despite a negative control right the parents enjoyed to refuse consent to the removal and retention of organs in a post-mortem examination, the institutions' direct violation of that right resulted in property rights being allocated to the institutions.

In considering the research context, participants enjoy far less control than the claimants in *Yearworth,* making it doubtful the *Yearworth* reasoning will be of much use to ground ongoing rights. As discussed in Chapter 3, often participants do not even know their biomaterials are used, and where consent is sought, it is often in the form of broad consent for a wide array of unknown future biomaterial uses. As a result, while the *Yearworth* line of cases is certainly notable in terms of allocating property rights to individual sources of biomaterials, its ability to anchor future claims where institutional control is asserted should be met with some hesitation.

B. Policy Considerations and a Weighing of Values

When one considers the reasons institutions and individuals seek control over biomaterials, it becomes clearer why institutional claims of control are recognized in property law over those of individuals. The interests these respective parties have in biomaterials are very different. As a result, when they come in conflict, these competing interests must be weighed. In this weighing exercise, policy considerations become important, as can be seen in *Moore* and *Greenberg,* where the potential negative impact of individual rights on the research environment became an important issue. The interests of institutions align more closely with the interests property law is designed to protect. As a result, institutions have an advantage over individuals in framing their property claims.

Many institutions have economic interests in biomaterials. Universities, for example, are under pressure to commercialize research findings, and biomaterials are an essential resource fuelling many lucrative scientific discoveries. Biobanks are increasingly financed, at least in part, by the private sector and are financially motivated to collect, store, and share biomaterials. In addition, pathology clinics' entire existence depends on collecting and analyzing biomaterials; anatomy departments use biomaterials to help train the next generation of healthcare professionals entering the workforce; reproductive facilities store biomaterials and offer wide-ranging treatments using biomaterials in what has become a multi-billion dollar "fertility industry";[517] and DTC genetic testing companies directly profit from the information gathered from people's biomaterials. Biomaterials underpin the activities of these institutions, enabling them to operate within their respective industries.

The interests of individuals in biomaterials are different and, as discussed in Chapter 2, difficult to pinpoint with precision. Individuals have a clear informational privacy interest in biomaterials to the extent that they can reveal personal information, for example, through genetic testing. Beyond that, individual interests become a bit amorphous and difficult to define other than to say they reflect autonomy and dignity-based notions that can be deeply personal in nature.

So how does property law go about balancing, on the one hand, the economic and market-based interests of institutions, with the autonomy and dignity-based interests of individuals? Intellectual property scholar, Richard Gold, asserts that market values are the primary language of property law and discourse, which poses a problem for individuals who value their biomaterials in many different ways.[518] When competing values come into conflict, there is no overarching superscale in which to translate those values to see which comes out on top because they are not commensurate with one another.[519] While it is possible to nevertheless address and decide which values ought to be accorded greater weight in a particular dispute, property law is generally unable to accommodate such considerations as the value scale used to resolve property disputes is the market value.[520] The market value represents a type of superscale whereby the market price is

[517] Pasquale Patrizio et al, "The Changing World of IVF: The Pros and Cons of New Business Models Offering Assisted Reproductive Technologies" (2022) 39:2 J Assist Reprod Genet 305 at 307.
[518] See generally Richard Gold, "Owning Our Bodies: An Examination of Property Law and Biotechnology" (1995) 32:4 San Diego Law Review 1167.
[519] *Ibid* at 1215–31.
[520] *Ibid*.

assumed to reflect the various ways in which a good is valued.[521] However, an individual's asserted autonomy or dignity interests in their biomaterials do not translate well to this type of valuation given the myriad ways in which individuals value their biomaterials, which tend to be non-economic in nature.[522]

Gold analyzes US case law where the existence and/or allocation of property rights is in dispute and argues that claimants are unlikely to be awarded property rights where "their interest in the good is [not] principally economic or the court perceives that the allocation of property rights to one or the other of the parties will, in fact, hinder trade in the good".[523] In this respect, individuals are at a distinct disadvantage when claiming competing property rights against institutions. Gold uses the *Moore* case to highlight this line of reasoning, which was later echoed in *Greenberg.* In these cases, the economic rationale is explicit in their respective judgments.

The Majority in *Moore* was greatly concerned about the potential impact on the research environment should Moore be found to have a property right to his biomaterials. The Majority was concerned that "[t]he extension of conversion law into this area will hinder research by restricting access to the necessary raw material"[524] and "threat[en] to destroy the economic incentive to conduct important medical research".[525] The concern was essentially that researchers would be threatened by "disabling civil liability" if they were potentially liable in conversion for using cell lines and biomaterials without full knowledge of their origins and whether they were obtained from consenting individuals.[526] While the assumptions underlying the Majority's concerns have been criticized as lacking any empirical evidentiary support,[527] they are understandable against the backdrop of values property law is designed to evaluate and protect and have been echoed in subsequent cases.

In *Greenberg,* for example, the perceived negative economic consequences for the research environment were so great they were used not only to reject the plaintiffs' property claims, but even a more limited right for research participants to simply be informed of researchers'

[521] *Ibid*.
[522] *Ibid*.
[523] *Ibid* at 1173.
[524] *Moore*, *supra* note 241 at 144 (Panelli J, with Lucas CJ, Eagleson and Kennard JJ, concurring).
[525] *Ibid* at 146.
[526] *Ibid* at 143.
[527] Hardcastle, *supra* note 26 at 63; See also the dissenting judgment of Mosk J who strongly critiqued the Majority's view on this point: *Moore*, *supra* note 241 at 169–73.

commercial interests and intentions when providing biomaterials as part of the informed consent process.[528] In considering the competing interests of participants and researchers, Judge Moreno expressed great concern about the negative effect participant property rights would have on the research environment. His Honour stated that "the expansive theory championed by Plaintiffs would cripple medical research as it would bestow a continuing right for donors to possess the results of any research conducted by the hospital".[529]

Gold points to a case where ownership of a steel mill was contested to highlight that one of the functions of property law is to provide the rights-holder with "security that they, to the exclusion of all others, will be able to profit from the mills that they construct" because people will not build mills unless they will financially benefit from their creation.[530] The same logic could potentially be employed should a claim arise in the biobanking or research sector, which has become increasingly commercialized. If deciding between individuals or research facilities as holders of property rights, it might be compelling for an institution to argue that the infrastructure needed to facilitate research using biomaterials will not likely be created unless there is similar security provided through property law. As individuals are unlikely to be able to frame property claims in such strong economic terms, they will be at a disadvantage. This line of reasoning was persuasive in *Moore* and *Greenberg,* and in the decades since those cases were decided, the research sector has become commercialized to an even greater extent.

The traditional work or skill exception used to ground many of the property claims to biomaterials can similarly be understood in economic terms. Its Lokean roots reflect the notion that one should own the fruits of their labour. It is because one's "work or skill" is employed to transform a biomaterial into something different that the creation and allocation of property rights is justified. The case of *AB and Others* is quite astounding when one thinks about the decision in these terms. Despite the fact that these biomaterial collections were wrongly acquired and should only have been obtained with informed consent, the labour employed to remove and store the biomaterials was recognized and afforded stronger protection than the rights of the grieving parents that this application of labour infringed.

[528] *Greenberg*, *supra* note 448 at 1070.
[529] *Ibid* at 1076.
[530] Gold, *supra* note 518 at 1184.

The response to Gold's argument is that the application of property law *per se* does not necessarily mean that the object of property rights is alienable. As Quigley notes, "[w]hile it can be difficult to disentangle property from market transactions, these are not analytically and irrevocably bound up together" as "property does not necessarily entail the right to trade or enter into contractual agreements with other individuals or organizations".[531] Render similarly notes, "one of the most consensus-garnering and well-settled ideas in property theory is that the mere designation of 'ownership' (or the assignment of a 'property right') fails, in and of itself, to convey a set of known incidents", such as the ability to alienate.[532] Indeed, reproductive material has now been found to be property in a number of cases notwithstanding it is subject to legislative restrictions on buying and selling.

However, although these restrictions have not prevented reproductive materials from being characterized as property, there are nevertheless economic consequences relevant to property disputes in this area. The allocation of property rights to individuals in *C(C), M (JC), Bazley,* and *Edwards,* for example, enabled the individuals in question to store, transfer, and/or use the reproductive material in question. These activities are all part of a growing "fertility industry,"[533] which has "become big business around the world".[534] Greater individual access to gametes to pursue a wide range of reproductive treatment options enables this sector to continue growing, with projections the sector will be worth $41 billion globally by 2026.[535]

While the line of case law involving reproductive material does not tend to explicitly use market norms to justify granting individual property rights, the fact that these rights will potentially facilitate the reproductive health market arguably facilitated these findings. For example, the gamete storage facility in *Edwards* did not oppose Ms Edwards' application for possession of the sperm. Similarly, the facility in *Bazley* indicated it would comply with a court order for continued storage of the sperm if Ms Bazley were to obtain one. These facilities had an economic interest in continuing to store the sperm that aligned with a finding that the sperm was property owned by the individual applicants. In contrast, as *Moore* and *Greenberg* demonstrate, where the claimed

[531] Quigley, *Self-Ownership, supra* note 5 at 288.
[532] Render, *supra* note 26 at 598.
[533] Patrizio et al, *supra* note 517 at 307.
[534] *Ibid* at 305.
[535] *Ibid* at 307.

property rights by individuals conflict with the economic interests of institutions, property protection for institutional control is likely to be granted.

C. Conclusion

While Chapter 4 demonstrated a lack of consistency and conceptual coherence underlying the body of case law pertaining to property and human biomaterials, one of the unifying features of these cases is the lack of recognition of individual property rights when biomaterials are seriously contested by institutions. Given the malleability of approaches to property in this context and the strong overriding policy considerations reflected in relevant judgments, assertions that property law is the best tool to protect individual interests should be met with some skepticism.

Relevant case law demonstrates that where there are genuine contests of control over biomaterials between institutions and individuals, institutional claims have been recognized at the expense of individuals'. Although the *Yearworth* line of cases showed some success for individual plaintiffs taking on institutions, those cases did not involve competing claims by institutions to use the biomaterials for their own purposes. The cases that have involved such disputes have resoundingly been decided in favour of institutions. Similarly, cases based on the work or skill exception have also generally been decided in favour of institutional interests, with very limited authority suggesting anyone other than the applier of work or skill will be allocated property rights.

One of the underlying reasons institutional interests have prevailed is that they represent a much better fit with the interests property law is designed to protect. The market value is the scale by which competing property claims are evaluated. As individual interests tend to be non-economic in nature, individuals are disadvantaged. While Gold's work was published in 1995, almost 30 years later his analysis continues to ring true. Gold's conclusions that "[p]arties who cannot explain in economic terms why the court ought to grant property rights will not be granted such rights" and that "[p]arties who cannot found their opposition to the grant of property rights on market principles will fail to block the allocation of such rights"[536] are reflected in modern case law. It is only in the reproductive health setting where individuals have enjoyed success in claiming property rights to biomaterials. However, in this setting, greater individual access and control to

[536] Gold, *supra* note 518 at 1186.

biomaterials aligns with the economic interests of assisted reproduction institutions, thereby removing a potentially significant roadblock from asserted individual property rights.

In contrast, in the research and diagnostic biomaterial settings, institutional interests have prevailed. In *Moore* and *Greenberg,* for example, these economic policy considerations are overt. In other cases, the work or skill exception, which provides an economic incentive to engage in inventive activity, has been used to justify institutional control, as seen in *AB and Others* and *Kelly.* Ultimately these cases demonstrate that, because individuals will be more successful in property rights claims if they can be framed in economic terms, and because it is more difficult for individuals to do so than institutions given the value to the individual is not generally economic in nature, individuals are at a disadvantage in terms of claiming property rights against institutions.

As a result, it cannot be taken for granted that the application of property law will lead to greater protection for individual rights. In fact, the cases paint a rather pessimistic picture in this respect. Given the inherent conflict in values between property law and individuals' interests in biomaterials, legal frameworks better suited to addressing individual autonomy and dignity interests are worth considering as regulatory options. The next Part of this thesis will demonstrate that privacy law provides a much better alignment in this respect.

Part 2: Privacy Law as a New Regulatory Possibility

Part 1 of this thesis showed there are a range of contexts in which individuals need enforceable rights and remedies in relation to biomaterials, including, for example, biomaterials used in research, biomaterials taken from deceased bodies of loved ones, and biomaterials surreptitiously taken and genetically tested. This need arises because legislative governance frameworks and their consent paradigms do not fully recognize the autonomy interests at stake for individuals or provide remedies when these interests are infringed. This is particularly pronounced in the research context where the need to continue the supply of biomaterials has been increasingly prioritized at the expense of participant interests. While property law has dominated the discourse in terms of options to ground individual control rights, it appears unlikely to correct the power imbalance between individuals and institutions. This is because the values property law is designed to protect do not align well with the autonomy and dignity-based interests of individuals. As a result, new options are needed.

Property law has dominated the discourse in biomaterial regulation so thoroughly that literature on "alternatives" in the property/non-property dichotomy is comparatively meagre, with no single contender challenging its place. While there are many who disagree with and point to problems with property law in biomaterial regulation, there are few concrete options put forth as viable alternatives. Part 2 of this thesis will show why privacy law is an option worth considering in this respect.

Like property law, privacy law operates through an exclusionary boundary, giving control to the rights-holder. And through privacy torts, privacy law is now situated to offer claimants a wide range of remedies for privacy violations. A key advantage that privacy law offers is that it exists to protect the same kind of dignity and autonomy-based interests that individuals have in their biomaterials. These features and benefits of privacy law will therefore be explored in the remainder of this work to demonstrate why privacy law deserves greater attention as an option for biomaterial regulation.

Chapter 6 will examine the current state of privacy law across the common law world, including information privacy statutes and privacy torts. Chapters 7 and 8 will then consider these sources of privacy law in greater detail to highlight how they might apply to human biomaterials.

Chapter 7 will identify evidence in legislation and case law supporting an informatized approach to biomaterials and show how treating biomaterials as "personal information" could fill existing regulatory gaps. Chapter 8 will apply privacy torts to cases where individuals would otherwise be without a remedy to show the strengths and weaknesses of these causes of action in the biomaterial context. Chapter 9 will then conclude by comparing the features of privacy law highlighted in the preceding chapters with the property and statutory frameworks from Part 1. Overall, this Part will demonstrate that, although privacy law does not offer comprehensive protection for individual interests in biomaterials, there are distinct advantages of a privacy approach when compared to other legal frameworks and it is possible for these frameworks to co-exist. As a result, further attention to the potential role for privacy law in biomaterial regulation is warranted.

6. The Current State of Privacy Law

Privacy has traditionally been conceived of as "the right to be left alone"[537] or "a state of separateness from others".[538] Privacy encompasses different dimensions: spatial, personal, and informational[539] and provides individuals with control over aspects of one's individuality and personality that are shared with others.[540] Similar to property law, this individual control is enabled through the existence of an exclusionary boundary where the default position is that others have a duty of non-interference except with the rights-holder's consent.

The exclusionary boundary in privacy law is imposed through information privacy statutes and privacy torts. Both statutory privacy regulation and privacy torts are relatively recent legal developments in most jurisdictions. Privacy torts, in particular, have only just emerged in some common law jurisdictions (with the exception of the US and a few Canadian provinces), and have not yet emerged in others (such as Australia). Before privacy law can be meaningfully assessed in relation to biomaterial regulation, it is important to understand how privacy law operates. The remainder of this chapter will therefore out-line the current state of privacy law across various common law countries before moving on to discuss the feasibility and benefits of this approach to protect privacy interests in biomaterials through information privacy statutes (in Chapter 7) and privacy torts (in Chapter 8).

The following discussion will similarly begin by considering statutory frameworks governing personal information before moving on to discuss privacy torts. This discussion will highlight some initial observations about the privacy law landscape that may bode well for its application to human biomaterials. First, the fact that it is comprised of both statutes and torts, where the two frameworks can complement one another, makes privacy law uniquely suited to serve preventative and remedial purposes. Additionally, both courts and legislatures have shown a willingness to respond to new privacy challenges brought by developing technologies, expanding opportunities for legal redress for privacy wrongs. Further, the nascent nature of privacy torts means they remain malleable, with the potential to evolve to respond to new privacy concerns.

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[537] Bygrave, *Data Privacy Law, supra* note 59 at 24, quoting S Warren and L Brandeis, "The Right to Privacy" (1890) 4 Harvard L Rev 193 at 205.
[538] Laurie, *supra* note 313 at 6.
[539] *Dyment*, *supra* note 69 at para 30 (La Forest J).
[540] Wall, *Being and Owning, supra* note 26 at 186–87.

Unlike property law, privacy cases indicate that this malleability could be useful in claims by individuals against institutions. Finally, human rights law has strongly influenced the development of privacy torts, which is significant, as understandings of privacy in human rights law are robust enough to potentially encompass human biomaterials and the DNA they contain.

A. Statutory Frameworks

Informational privacy has been the subject of great debate and legal development as the advent of the internet and modern computing have produced and made available personal information in quantities never seen before. To regulate the collection, use, storage, and disclosure of this information, many jurisdictions have enacted information privacy statutes.[541] These statutes generally regulate personal information, defined generally to mean information about a reasonably identifiable person.

These statutes can exist at different jurisdictional levels (including federal statutes and those of individual states/provinces) and are sometimes aimed at different kinds of personal information (such as health information), or different actors (those in the public vs private sphere). The result can be a complex web of regulations. For this reason, the following discussion will highlight some general features of privacy statutes using a range of federal and provincial/state legislation from Canada and Australia. As it would be near impossible to catalogue the full range of relevant legislative provisions across the common law world, these statutes were chosen as they provide a representative picture of legislative privacy principles applicable to different entities in different sectors as well as different types of information.

In Canada, at the federal level, the *Privacy Act*[542] regulates personal information collected, stored, and used by federal government bodies, while the *Personal Information and Electronic Documents Act* (*PIPEDA*)[543] regulates personal information in the private sector. Individual provinces have also enacted privacy legislation to govern public entities,[544] private entities,[545] and

[541] See Bygrave, *Data Privacy Law, supra* note 59 at 8–15 for a historical account of data privacy law.
[542] *Privacy Act*, RSC 1985, c P-21 [*Privacy Act* (CAN)].
[543] *Personal Information Protection and Electronic Documents Act*, SC 2000, c 5 [*PIPEDA*].
[544] For example, many provinces have their own *Freedom of Information and Protection of Privacy Acts*: see RSBC 1996, c 165 (BC); RSO 1990, c F.31 (ON); RSA 2000, c F-25 (AB).
[545] *Personal Information Protection Act*, SBC 2003, c 63 (BC); *Personal Information Protection Act*, RSA 2000, c H-5 (Alberta).

personal health information.[546] For example, Alberta's *Health Information Act* regulates health information collected, used, and disclosed by "custodians", including various health service providers and government entities.[547] In Australia, the *Privacy Act 1988*[548] is the federal privacy statute that applies to both federal government and private sector entities. Like Canada, individual Australian states have also enacted their own privacy legislation that covers state-based public sector entities[549] and health information,[550] such as the *Health Records and Information Privacy Act* from New South Wales.[551] The Alberta and New South Wales legislation would be of particular relevance to the biomaterial research context, as they apply to public universities, while *PIPEDA* and the *Privacy Act (Cth)* would be relevant to DTC genetic testing and other commercial institutions (such as private laboratories or assisted reproduction facilities) that handle biomaterials.

There are similar principles and obligations that underly many information privacy frameworks. For example, consent generally must be obtained when collecting personal information, and the purposes for the collection must be disclosed.[552] Additional consent must then be obtained if the information is to be used for a new secondary purpose.[553] When personal information is transferred to a recipient in a different jurisdiction, the transferor must ensure that recipients are subject to similar legal obligations.[554] There are also obligations to protect and secure

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[546] *Health Information Act*, RSA 2000, c H-5 [*Health Information Act* (AB)] (Alberta); *Personal Health Information Act*, CCSM, c P335 (Manitoba).
[547] *Health Information Act* (AB), *supra* note 546, s 1(1).
[548] *Privacy Act 1988 (Cth)*, 1988/119 [*Privacy Act* (Cth)].
[549] See, for example, *Privacy and Data Protection Act 2014* (VIC), 2014/60; and *Personal Information and Protection Act 2004* (TAS).
[550] See, for example, *Health Records Act 2001* (VIC), 2001/2 [*Health Records Act* (VIC)]; and *Health Privacy Act* (NSW), *supra* note 66.
[551] *Health Privacy Act* (NSW), *supra* note 66.
[552] *PIPEDA*, *supra* note 543, s 6.1; *The Australian Privacy Principles*, Australian Government, Office of the Australian Information Commissioner (2014) , s 3.3, [Australian *Privacy Principles*]; The New South Wales and Alberta legislation do not explicitly require individual consent, but they do require that the individual be informed as to the purpose of the collection: See *Health Privacy Act* (NSW), *supra* note 66, s 4(1) of Sch 1; and *Health Information Act* (AB), *supra* note 546, s 22(3).
[553] *PIPEDA Schedule 1: Principles Set Out in the National Standard of Canada Entitled Model Code for the Protection of Personal Information*, CAN/CSA-Q30-96 , s 4.2.4 [Canadian *Privacy Principles*]; Australian *Privacy Principles*, *supra* note 552, ss 6.1 & 6.2; *Health Privacy Act* (NSW), *supra* note 66, ss 10(a) & 11(b) of Sch 1; Under the Alberta legislation, subsequent disclosures of health information must either be done with consent of the individual or for a specified purpose stipulated in the Act: *Health Information Act* (AB), *supra* note 546, ss 34–40.
[554] *Privacy Act* (Cth), *supra* note 548, s 16C; Australian *Privacy Principles*, *supra* note 552, ss 8.1 & 8.2; Canadian *Privacy Principles*, *supra* note 553, s 4.1.3; *Health Privacy Act* (NSW), *supra* note 66, s 14; The Alberta legislation requires a custodian to maintain safeguards to protect privacy and confidentiality of information disclosed to others outside of Alberta: *Health Information Act* (AB), *supra* note 546, s 60(1)(b).

personal information[555] under transparent and accessible data handling policies.[556] Individuals whose information has been collected must be provided access to the information held about them[557] and allowed to withdraw consent that was initially provided.[558]

When privacy principles and legislative requirements are violated, different statutory frameworks come with their own set of potential responses. For example, in Australia, the Office of the Australian Information Commissioner has a robust set of powers to receive, investigate, and determine allegations of privacy infringements, and to award damages to address privacy violations. The Commissioner can award general damages, taking into account hurt feelings and/or humiliation, as well as aggravated damages.[559] The quantum of such awards "should be restrained but not minimal".[560] The New South Wales Privacy Commissioner has similarly broad powers to investigate and award damages up to $40,000 for corporate respondents.[561]

In contrast, while the Canadian Privacy Commissioner can also investigate privacy complaints, it cannot, itself, award damages, but can refer matters to the Federal Court, which can award damages to complainants "including damages for any humiliation that the complainant has suffered".[562] The remedial prospects under the Alberta legislation are more limited, as the Act does not contemplate any damages awards for complainants through the Commissioner or the courts.[563] One explanation for the comparatively enhanced powers and remedies in Australia is that Australian courts and legislatures have not yet recognized privacy torts. As a result, the legislative

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[555] Australian *Privacy Principles*, *supra* note 552, s 11.1; Canadian *Privacy Principles*, *supra* note 553, s 4.7.1; *Health Privacy Act* (NSW), *supra* note 66, s 5 of Sch 1; *Health Information Act* (AB), *supra* note 546, s 60.
[556] Canadian *Privacy Principles*, *supra* note 553, ss 4.1.4 & 4.8.1; Australian *Privacy Principles*, *supra* note 552, ss 1.2 & 1.4-1.5; *Health Information Act* (AB), *supra* note 546, s 63. Note: the New South Wales legislation lacks an equivalent provision.
[557] Canadian *Privacy Principles*, *supra* note 553, s 4.9.1; *Australian Privacy Principles*, *supra* note 552, s 12.1; *Health Privacy Act* (NSW), *supra* note 66, s 7 of Sch 1; *Health Information Act* (AB), *supra* note 546, s 7.
[558] Canadian *Privacy Principles*, *supra* note 553, s 4.3.6; Office of the Australian Information Commissioner, "Consent to the Handling of Personal Information", (10 March 2023), online: *OAIC* <www.oaic.gov.au> [perma.cc/FM9H-FC67]; While the Alberta Act does not provide a general right to withdraw consent, it does provide a right to withdraw consent that had previously been given for disclosure of one's personal information: *Health Information Act* (AB), *supra* note 546, s 34(2).
[559] *Australian Privacy Principles Guidelines*, by Australian Government, Office of the Australian Information Commissioner (OAIC, 2022) at paras 5.18-5.21.
[560] *Ibid* at para 5.18.
[561] See *Health Records Act* (VIC), *supra* note 550, ss 42–47 & 54.
[562] *PIPEDA*, *supra* note 543, s 16.
[563] See *Health Information Act* (AB), *supra* note 546, ss 73–77, which set out the powers of the Commissioner. While complainants can seek judicial review of the Commissioner's decisions, there is nothing in the Act allowing for any damages awards.

scheme is crucial for remedying privacy wrongs in that country. That said, legislation currently before the Canadian House of Commons, if passed, will significantly enhance the powers of the Canadian Privacy Commissioner, and establish an administrative tribunal to hear appeals from the Commissioners' decisions.[564]

A benefit of statutory frameworks is that they provide a proactive set of rules and regulations pertaining to personal information. These statutes can guide organizational practices and policies and play an important preventative role in safeguarding privacy norms.[565] In theory, if everyone abides by the same set of established rules, then privacy infringements should be minimized. In practice, the picture is not quite so simple given sophisticated hacking and privacy breaching strategies (addressed in Chapter 2) and the complexity of the statutory landscape which can create loopholes for data collecting organizations to exploit.[566]

For example, while the exclusion framework is one where the default position requires individual consent for the collection, use, and disclosure of personal information, there are exceptions to this default requirement, including in the research context. These exceptions represent a balancing of individual interests in controlling their personal information with the interests of others in collecting, storing, disclosing, and using that information. The statutes are deliberately designed with these competing interests in mind. For example, the Australian *Privacy Act (Cth)* exists to "promote the protection of the privacy of individuals" and to balance individual privacy protection "with the interests of entities in carrying out their functions or activities".[567] The Purpose of Canada's *PIPEDA* is "to govern the collection, use and disclosure of personal information in a manner that recognizes the right of privacy of individuals with respect to their personal information and the need of organizations to collect, use or disclose personal information for purposes that a reasonable person would consider appropriate in the circumstances".[568]

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[564] Bill C-27, *An Act to enact the Consumer Privacy Protection Act, the Personal Information and Data Protection Tribunal Act and the Artificial Intelligence and Data Act and to make consequential and related amendments to other Acts*, 1st Sess, 44th Parl, 2021 (second reading 24 April 2023) [*Digital Charter Implementation Act*, 2022].
[565] Sarit K Mizrahi, "Ontario's New Invasion of Privacy Torts: Do they Offer Monetary Redress for Violations Suffered via the Internet of Things?" (2018) 8:1 W J Legal Stud 1 at 2–3.
[566] Nicholas Terry has described the statutory landscape as one of "regulatory arbitrage" in that savvy data traders have developed ways to avoid the more heavily regulated frameworks governing "health information" and operate, instead, in more lightly regulated sectors: Nicolas P Terry, "Big Data and Regulatory Arbitrage in Healthcare" in Vayena et al, *supra* note 47, 56 at 56.
[567] *Privacy Act* (Cth), *supra* note 548, s 2A.
[568] *PIPEDA*, *supra* note 543, s 3; See also *Health Records Act* (VIC), *supra* note 550, s 3(2).

While this balancing act reflects an inherent flexibility in information privacy law, there are some concerns that the exceptions to consent requirements have weakened the protection afforded by these statutes.[569] The next chapter will explore, in more detail, how these frameworks and their exceptions might apply to biomaterials. However, it is worth noting at this point that given the current lack of generalizable principles applicable to human biomaterials, imposing statutory rules regarding their collection, use, storage, and transfer, however weak, would nevertheless represent a significant step forward. Further, privacy statutes only comprise one half of the privacy law landscape and some of their limitations have been overcome by emerging privacy torts. These torts will therefore be considered next to gain a fuller picture of privacy law.

B. Privacy Torts

In the United States, renowned tort law scholar, William Prosser, identified four distinct privacy torts in his seminal article, "Privacy", published in 1960:

> 1. Intrusion upon the plaintiff's seclusion or solitude, or into [their] private affairs.
> 2. Public disclosure of embarrassing private facts about the plaintiff.
> 3. Publicity which places the plaintiff in a false light in the public eye.
> 4. Appropriation, for the defendant's advantage, of the plaintiff's name or likeness.[570]

This articulation has been highly influential in Canada and New Zealand, which have each now recognized their own versions of the first two torts from the list. In contrast, the approach in England has been to develop a tort of "misuse of private information" through an incremental approach originating in the historical equitable action for breach of confidence. Australia has thus far declined to follow either path, although the Australian Law Reform Commission has recommended the creation of statutory torts,[571] an approach that has been taken in some Canadian provinces.

The result is an inter-jurisdictional privacy tort landscape that is slightly uneven and still in flux. To better understand the various causes of action and jurisdictional differences, the following discussion will be broken down to address the following tort-based approaches: (i) intrusion upon seclusion; (ii) public disclosure of private facts; (iii) statutory torts in Canada; and

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[569] Bygrave, "The Body as Data?", *supra* note 31 at 23; Mizrahi also notes that *PIPEDA*'s consent requirements are contextual in that the form consent takes must be "reasonable" in relation to the sensitivity of the information, which is open to interpretation and exploitation: Mizrahi, *supra* note 565 at 18.
[570] Prosser, *supra* note 70 at 389.
[571] Australia, Australia Law Reform Commission, *Serious Invasions of Privacy in the Digital Era*, ALRC Rep 123 (Australian Law Reform Commission, 2014), art 2 [ALRC, *Privacy in the Digital Era*].

(iv) England's "misuse of private information" tort. This discussion will demonstrate the strong influence of human rights law and adaptability of privacy torts to respond to emerging privacy challenges, as well as the complementary nature of these torts to the statutory frameworks considered above.

i. Intrusion Upon Seclusion

According to US law stated in the *Restatement (Second) of Torts*:

> One who intentionally intrudes, physically or otherwise, upon the solitude or seclusion of another or [their] private affairs or concerns, is subject to liability to the other for invasion of [their] privacy, if the intrusion would be highly offensive to a reasonable person.[572]

This tort shares some similarities with the tort of intentional infliction of mental distress[573] and "includes physical intrusions into private places as well as listening or looking, with or without mechanical aids, into the plaintiff's private affairs".[574] It is actionable even without any "publication or other use of any kind" of the relevant information.[575]

Examples from US case law where intrusion upon seclusion has been established include cases where a doctor delivering a baby allowed a third party into the delivery room without the patient's consent[576] and police leaving a naked woman strapped to a restrainer board in a "spread eagle" position for three hours in the presence of male officers.[577] This tort also covers overseeing or overhearing another's private affairs, such as "looking into their bedroom window, opening their post, or gaining access to their banking information".[578]

US law has had a strong influence in the development of privacy torts in Canada and New Zealand.[579] The Ontario Court of Appeal decision, *Jones v Tsige,*[580] is the seminal decision in Canada establishing the common law intrusion upon seclusion tort. This case involved a bank employee who used her position at the bank to look at the plaintiff's banking records for personal

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[572] American Law Institute, *Restatement (Second) of Torts* (1977), §652B [*Restatement*], as reproduced in *Holland*, *supra* note 72 at para 14.
[573] Berryman, *supra* note 280 at 323.
[574] *Jones*, *supra* note 71 at para 20, citing the *Restatement*, *supra* note 572.
[575] *Ibid* at para 21, quoting the *Restatement*, *supra* note 572.
[576] *De May v Roberts*, 9 NW 146 (1881) [*De May*].
[577] *Hill v McKinley*, 311 F 3d 899 (8th Cir 2002) [*Hill*].
[578] John Hartshorne, "The Need for an Intrusion upon Seclusion Privacy Tort within English Law" (2017) 46:4 Comm L World Rev 287 at 289 [Hartshorne, "Intrusion Upon Seclusion"].
[579] Jason Varuhas & NA Moreham, "Remedies for Breach of Privacy" in Varuhas & Moreham, *supra* note 280, 1 at 23.
[580] *Jones*, *supra* note 71.

reasons 174 times over four years.[581] The defendant did not publish or distribute the plaintiff's information but accessed it for her own personal purposes, as she was in a common-law relationship with the plaintiff's former spouse.[582]

In determining that Ontario law recognized the tort of intrusion upon seclusion, Sharpe JA, on behalf of the Court, "accept[ed] Prosser's insight that the general right to privacy embraces four distinct torts, each with its own considerations and rules".[583] Sharpe JA reviewed lower court decisions from Ontario supporting the existence of the tort,[584] the existence of statutory privacy torts in four other Canadian provinces[585] (discussed below), international common law jurisprudence,[586] positions advocated by legal scholars,[587] and jurisprudence pertaining to the Canadian *Charter of Rights and Freedoms* (the "*Charter*"),[588] which has recognized privacy as a Constitutionally protected right.[589]

Shape JA noted the Supreme Court of Canada's recognition that section 8 of the *Charter,* providing a right against unreasonable search and seizure, is grounded in privacy and encompasses three different privacy interests: personal privacy, territorial privacy, and informational privacy.[590] Sharpe JA further noted the importance of privacy in the UN *Declaration of Human Rights* and the *International Covenant on Civil and Political Rights*.[591] Although the *Charter* does not apply to private disputes between individuals, Sharpe JA noted the Supreme Court's recognition that the common law should be developed consistently with *Charter* values.[592] Sharpe JA therefore concluded that "[t]he explicit recognition of a right to privacy as underlying specific *Charter* rights and freedoms, and the principle that the common law should be developed in a manner consistent with *Charter* values, supports the recognition of a civil action for damages for intrusion upon the

[581] *Ibid* at para 2.
[582] *Ibid* at para 4.
[583] *Ibid* at para 21.
[584] *Ibid* at paras 25–32.
[585] *Ibid* at paras 52–54.
[586] *Ibid* at paras 55–64.
[587] *Ibid* at para 66.
[588] *Canadian Charter of Rights and Freedoms,* Part I of the *Constitution Act, 1982,* being Schedule B to the *Canada Act 1982* (UK), 1982, c 11 [*Charter*].
[589] *Jones*, *supra* note 71 at paras 39–46.
[590] *Ibid* at paras 39–41.
[591] *Ibid* at para 44.
[592] *Ibid* at para 45.

plaintiff's seclusion".[593] In this way, the importance of privacy enshrined as a matter of human rights law played a key role in the recognition of this privacy tort.

Sharpe JA's judgment is also notable in recognizing the co-existence of personal information statutes and privacy torts. The defendant argued that the plaintiff should be precluded from recovering in tort law given the legislature's expressed intention to address informational privacy through various personal information statutes. In rejecting this argument, Sharpe JA pointed to gaps left by the statutory frameworks as a reason why the plaintiff's tort claim should be upheld.[594] In particular, Sharpe JA noted that under the federal *PIPEDA*, the plaintiff would not be able to sue the defendant directly but only the defendant's employer who could possibly escape any repercussions by showing the breach was the result of a rogue employee rather than a failure on its part to devise and implement privacy protections.[595] In addition, the plaintiff would not be able to secure damages under this framework.[596] In this way, the lack of comprehensive statutory coverage directly contributed to the creation of a privacy tort to fill regulatory gaps.

Drawing from US law articulated in the *Restatement,* Sharpe JA held that the tort is comprised of the following elements:

> first, that the defendant's conduct must be intentional, within which I would include reckless; second that the defendant must have invaded, without lawful justification, the plaintiff's private affairs or concerns; and third, that a reasonable person would regard the invasion as highly offensive causing distress, humiliation or anguish. However, proof of harm to a recognized economic interest is not an element of the cause of action.[597]

Given how the elements were construed, Sharpe JA was of the view that the tort would operate in a limited fashion without opening the floodgates, as "it is only intrusions into matters such as one's financial or health records, sexual practices and orientation, employment, diary or private correspondence that, viewed objectively on the reasonable person standard, can be described as highly offense".[598]

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[593] *Ibid* at para 46.
[594] *Ibid* at para 50.
[595] *Ibid*.
[596] *Ibid*.
[597] *Ibid* at para 71.
[598] *Ibid* at para 72.

In awarding damages, Sharpe JA noted that in the absence of pecuniary loss, damages are "moral" or "symbolic" and serve to "vindicate" the infringement of the plaintiff's rights.[599] In an effort to achieve consistency across judgments, Sharpe JA imposed a "conventional range" that he found to be capped at $20,000 after reviewing Canadian case law.[600] He also noted Manitoba legislation creating a statutory privacy tort, which contains principles to be considered in awarding damages, and incorporated these factors into his judgment.[601] Sharpe JA further noted that aggravated and punitive damages awards were neither encouraged nor excluded.[602] Subsequent case law has also suggested that an account of profits is potentially available in intrusion upon seclusion through a claim of "waiver of tort", meaning that "the plaintiffs give up the right to sue in tort and elect to base their claim in restitution", providing for a disgorgement of profits earned from the defendant's wrongful conduct.[603]

While *Jones* was an Ontario case and therefore not binding elsewhere in Canada, its influence has expanded past its borders. For example, in *Sweet v R,* a class action was certified by the Federal Court in a case against the federal government where it was alleged that the government's recklessness in protecting taxpayer data enabled third party hackers to gain access.[604] Similarly, the Nova Scotia Court of Appeal upheld a trial judge's certification of a class action based, in part, on intrusion to seclusion,[605] and in a New Brunswick decision on summary judgment, Grant J found there was a genuine issue for trial regarding a claim of intrusion upon seclusion.[606]

The uptake of this tort, however, has not been uniform across the country. In Alberta, for example, several cases have explicitly found there is no intrusion upon seclusion tort nor any general breach of privacy tort in that province,[607] despite recognizing a tort for public disclosure of private facts, discussed further below. In addition, in British Columbia, common law privacy

[599] *Ibid* at para 75.
[600] *Ibid* at paras 77–87.
[601] *Ibid* at para 87.
[602] *Ibid* at para 88.
[603] *Evans v The Bank of Nova Scotia*, [2014] ONSC 2135 at para 53.
[604] *Sweet v R*, [2022] FC 1228 [*Sweet*].
[605] *Capital District Health Authority v Murray*, [2017] NSCA 28 at paras 88–102 [*Capital District Health*].
[606] *Rancourt-Cairns v Saint Croix Printing and Publishing Co*, [2018] NBQB 19 at paras 66 & 75.
[607] *ES v Shillington*, [2021] ABQB 739 at para 36 [*Shillington*]; *Benison v McKinnon*, [2021] ABQB 843 at para 12; *Al-Ghamdi v College and Association of Registered Nurses of Alberta*, [2020] ABCA 81.

torts have not been recognized given the existence of a statutory cause of action.[608] In contrast, in Newfoundland, a class action was certified for parallel causes of action in intrusion upon seclusion and the province's statutory tort,[609] giving rise to a potentially wide variety of tort options in that province.

The fault element articulated by Sharpe JA as encompassing intentional and reckless conduct has given rise to some confusion and conflicting authority as to whether actions can be brought against corporate or government bodies that have failed to prevent third party hackers from gaining access to individuals' stored information. While some class actions for intrusion upon seclusion in these circumstances have been certified,[610] in a trilogy of Ontario Court of Appeal cases in 2022, the Court clarified that intrusion upon seclusion is not actionable in these situations.[611] On behalf of the Court, Doherty JA stated that the tort requires the defendant to have engaged in conduct that invades or intrudes upon the plaintiff's private affairs or concerns.[612] A defendant who carelessly allows another to access personal information they have compiled has not, themselves, engaged in "conduct" that invades anyone's privacy.[613] Doherty JA further clarified the meanings of "intention" and "recklessness" in this context, as follows: "[i]ntention is established if the defendant meant to intrude upon the privacy of the plaintiff or knew that it was a substantially certain consequence of the act which constitutes the intrusion" and "[r]ecklessness, also a subjective state of mind, refers to the realization at the time the prohibited conduct is being done that there is a risk that the conduct will intrude upon the privacy of the plaintiffs, coupled with a determination to nonetheless proceed with that conduct".[614]

Further interpretational questions arise when considering differences in how the tort has been framed in other jurisdictions. In New Zealand, for example, the seminal case recognizing intrusion upon seclusion is the High Court decision, *C v Holland.*[615] The case involved the plaintiff's housemate installing a recording device in the bathroom of their house and recording

[608] *Ladas v Apple Inc*, [2014] BCSC 1821 at para 76.
[609] *Hynes v Western Regional Integrated Health Authority*, [2014] NLTD(G) 137 at paras 13–26 [*Hynes*].
[610] *Sweet*, *supra* note 604 at para 132; *Kaplan v Casino Rama*, 2019 ONSC 2025 at para 29 [*Kaplan*].
[611] *Owsianik v Equifax*, [2022] ONCA 813; *Obodo v Trans Union of Canada Inc*, [2022] ONCA 814; *Winder v Marriott International Inc*, [2022] ONCA 815.
[612] *Owsianik v Equifax*, *supra* note 611 at para 54.
[613] *Ibid* at para 57.
[614] *Ibid* at para 60.
[615] *Holland*, *supra* note 72.

two video clips of the plaintiff while she showered.[616] In confirming the existence of the tort, Whata J referred to New Zealand privacy case law, international authorities, including Sharpe JA's judgment in *Jones,* privacy statutes, and the New Zealand *Bill of Rights Act* 1990.[617] After reviewing this wide breadth of authority, Whata J articulated the elements of the tort, as follows: "(a) An intentional and unauthorised intrusion; (b) Into seclusion (namely intimate personal activity, space or affairs); (c) Involving infringement of a reasonable expectation of privacy; (d) That is highly offensive to a reasonable person".[618]

There are some notable similarities and differences between *Holland* and *Jones*. Both cases relied on human rights protections for privacy as a justification for the tort. The New Zealand *Bill of Rights Act 1990* contains a similar right to be free against unreasonable search and seizure[619] as section 8 of the Canadian *Charter.* Similar to Sharpe JA's analysis, Whata J noted judicial interpretation of this section has given weight to privacy as a legal value.[620] Further, the judges in both cases rejected arguments that the existence of privacy statutes indicated courts should avoid developing the law in that field.[621]

The elements of the tort, however, reflect slight differences. On the fault element, Whata J's articulation requires "an intentional and unauthorized intrusion" whereas Sharpe JA in *Jones* noted that a standard of recklessness would suffice. It is not clear whether recklessness would also be encompassed in the New Zealand tort or, as indicated above, how far recklessness extends in this context.

Whata J's articulation also contains an additional element that there be a "reasonable expectation of privacy". Given that the other elements already require an intrusion into seclusion (intimate personal activity, space or affairs) that is highly offensive to a reasonable person, it is not immediately clear what impact the additional criterion for a "reasonable expectation of privacy" will have. Private law scholar, Samuel Beswick, and civil litigator, William Fotherby, defend the overlap between these principles, as "[t]he reasonable expectation of privacy inquiry focuses on the private nature of the matter in issue", identifying when a privacy interest has been

[616] *Ibid* at paras 1 & 2.
[617] *Ibid* at paras 11–64.
[618] *Ibid* at para 94.
[619] *New Zealand Bill of Rights Act 1990 (NZ)*, 1990/109, s 21.
[620] *Holland*, *supra* note 72 at paras 25–27.
[621] *Ibid* at paras 81–86.

engaged, whereas "[t]he offensiveness inquiry focuses on the seriousness of the interference with privacy", identifying when it is appropriate to remedy the violation in law.[622] Whata J justified the elements in terms of providing consistency between intrusion upon seclusion and the other key privacy tort recognized in New Zealand: public disclosure of private facts,[623] to which the discussion will now turn.

ii. Public Disclosure of Private Facts

In addition to intrusion upon seclusion, both New Zealand and Canada have recognized a common law tort of public disclosure of private facts. According to US law articulated in the *Restatement*:

> One who gives publicity to a matter concerning the private life of another is subject to liability to the other for invasion of [their] privacy, if the matter publicized is of a kind that
>
> (a) would be highly offensive to a reasonable person, and
>
> (b) is not of legitimate concern to the public.[624]

One of the key differences between the torts of intrusion upon seclusion and public disclosure of private facts is that the latter requires some form of publication (the extent of which may differ depending on the jurisdiction) of private *information.* Merely intruding upon an individual's private affairs is insufficient.[625]

There can be overlap between the two torts where private information is accessed through an intentional and unlawful intrusion and then published to others.[626] The focus on publication in the public disclosure tort in combination with the need for the disclosure to be "highly offensive" indicates that this tort exists to protect reputational interests and concerns about how one is perceived.[627] The tort is therefore similar to defamation.[628] However, whereas truth is a defence to defamation, public disclosure of private information inherently involves the publication of truthful

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[622] Samuel Beswick & William Fotherby, "The Divergent Paths of Commonwealth Privacy Torts" (2018) 84 Sup Ct L Rev 225 at 263.
[623] *Holland*, *supra* note 72 at para 96.
[624] *Hosking*, *supra* note 72 at para 68, quoting the *Restatement*, § 652D *supra* note 572.
[625] Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 290.
[626] *Ibid*.
[627] *Ibid*.
[628] *Ibid*.

information.[629] The wrong lays in the fact that this information is private, and the information subject therefore ought to be able to exercise control over it.

US law indicates that "publicity" means that there must be communication to the public at large or to enough people such that it is substantially certain to become public knowledge.[630] Disclosure to only one or two people will not suffice.[631] The disclosure must also be of private facts, not public ones[632] and the disclosure must be one that would cause a reasonable person to feel justifiably aggrieved.[633] Because the tort requires publication of information, the value of privacy can come into conflict with the value of freedom of expression. In US case law, freedom of expression often trumps the right to privacy.[634] As a result, although the US is the birthplace of this tort, the tort is viewed as having a relatively narrow application in that country.[635] In contrast, as discussed further below, in England, freedom of expression and the right to privacy are treated as being on equal footing, enabling the misuse of private information tort to provide more robust privacy protection. Canada and New Zealand arguably represent middle ground. Whereas freedom of expression is a constitutionally protected right in these jurisdictions, the right to privacy must be implicitly inferred from the right against unreasonable search and seizure. As a result, some commentators believe that case law from these jurisdictions aligns more closely with the US, with freedom of expression treated as a "right" and privacy as a mere "value".[636] The following discussion will highlight the key cases from these jurisdictions recognizing the public disclosure of private facts tort.

In *Hosking v Runting,* a majority of the New Zealand Federal Court of Appeal (New Zealand's highest court) recognized the tort of public disclosure of private facts. The facts involved a well-known New Zealand broadcaster, Mr. Hosking, and his wife and their twins. The couple had refused to give interviews about the twins or allow them to be photographed. After the couple separated, a magazine was planning to run an article about Mr. Hosking spending Christmas away from his family and commissioned a photographer to obtain photos of the twins, then 18-months

[629] Berryman, *supra* note 280 at 323.
[630] *Hosking*, *supra* note 72 at para 70.
[631] *Ibid*.
[632] *Ibid* at para 71.
[633] *Ibid* at para 72.
[634] *Ibid* at paras 73–75.
[635] *Ibid* at para 240 (Tipping J).
[636] Beswick & Fotherby, *supra* note 622 at 239–42.

old, to run with the story. The photographer successfully captured photographs of the twins while they were being pushed in a stroller by their mother on a public street. The couple brought proceedings seeking an injunction to prevent the publication of the photographs on the grounds that they violated the twins' rights to privacy.[637]

The plaintiffs' claim was unanimously rejected by the Court. However, in separate judgments by Gault P (Blanchard J concurring) and Tippings J, a Majority of the Court nevertheless recognized the existence of a tort for publication of private facts, with Keith J and Anderson J dissenting on this issue. Gault P reviewed international and domestic case law and privacy legislation in determining the tort should be recognized.[638] Similar to the intrusion upon seclusion cases, with respect to privacy legislation, Gault P noted the *Privacy Act* failed to confer positive, enforceable rights for a claimant,[639] and as a result, the common law should not be prevented from filling this gap.

Gault P articulated two elements comprising the tort: "1. The existence of facts in respect of which there is a reasonable expectation of privacy; and 2. Publicity given to those private facts that would be considered highly offensive to an objective reasonable person".[640] With respect to the first element, Gault P noted that "[p]rivate facts are those that may be known to some people, but not to the world at large".[641] With respect to the second element, Gault P noted the "highly offensive" criterion pertains not to the question of whether the information is private, but whether the *publicity* given to the information would be offensive.[642] Publicity in this sense refers to "wide-spread publicity of very personal and private matters", which Gault P clearly distinguished from the technical meaning of "publication" in defamation,[643] which imposes a much lower threshold that can be satisfied by disclosure to only a single other person.[644]

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[637] *Hosking*, *supra* note 72 at paras 1–13 (Gault P and Blanchard J).
[638] *Ibid* at paras 23–99.
[639] *Ibid* at para 99.
[640] *Ibid* at para 117.
[641] *Ibid* at para 119.
[642] *Ibid* at para 127.
[643] *Ibid* at para 125.
[644] Chris D L Hunt & Nikta Shirazian, "Canada's Statutory Privacy Torts in Commonwealth Perspective" (2016) Oxford U Comp L Forum, online: <ouclf.law.ox.ac.uk> [perma.cc/GH6V-Q8R7].

Gault P imposed no requirement for personal injury or economic loss.[645] Instead, what is being compensated for is humiliation and distress, and there is no requirement that the distress amount to a recognized psychiatric injury.[646] To balance the tort against the need to protect freedom of expression, Gault P imposed a defence where there is a "legitimate public concern in the information" that justifies its publication.[647] In terms of remedy, the tort will ordinarily give rise to an award for damages, although, similar to breach of confidence and defamation cases, in appropriate circumstances injunctive relief may be awarded.[648]

Although Gault P and Blanchard J recognized the existence of the tort, they found the elements had not been established in the case. The mere publication of photographs of the twins on a public street "would not publicise any fact in respect of which there could be a reasonable expectation of privacy", thus failing on the first element.[649] Further, the publication of the photographs would not be highly offensive to a reasonable person of ordinary sensibilities despite the fact that the children were very young.[650] As a result, there was no need to consider any public interest defence.[651]

Tipping J similarly agreed the tort should be recognized in New Zealand, albeit with a slightly different formulation. To Tipping J, "the fundamental ingredient" of the tort is "a reasonable expectation of privacy in respect of the information or material which the defendant has published or wishes to publish".[652] Additionally, rather than having a separate element regarding the publicity needing to be highly offensive, Tipping J thought this consideration should be brought into the "reasonable expectation of privacy" test and that the standard of "highly offensive" should be lowered to "substantially offensive".[653]

Similar to the cases establishing intrusion upon seclusion, both Gault P and Tipping J acknowledged in their judgments that the common law should develop consistently with

[645] *Hosking*, *supra* note 72 at para 128.
[646] *Ibid*.
[647] *Ibid* at para 129.
[648] *Ibid* at para 149.
[649] *Ibid* at para 164.
[650] *Ibid* at para 165.
[651] *Ibid* at para 170.
[652] *Ibid* at para 249.
[653] *Ibid* at para 256.

international human rights treaties and values.[654] Tipping J's judgment, in particular, was influenced by New Zealand's *Bill of Rights Act* and the underlying privacy protection afforded by the right against unreasonable search and seizure[655] as well as international human rights instruments which reflect privacy rights.[656]

In Canada, there has also been common law recognition of this tort. In the Ontario decision, *Jane Doe 464533 v DN* (*"Jane Doe 1"*),[657] the plaintiff obtained default judgment for public disclosure of private facts after her ex-boyfriend posted an intimate recording of her on a pornographic website. The elements of the tort were stated as follows: "[o]ne who gives publicity to a matter concerning the private life of another is subject to liability to the other for invasion of the other's privacy, if the matter publicized or the act of the publication (a) would be highly offensive to a reasonable person, and (b) is not of legitimate concern to the public".[658] Unlike the articulation in *Hosking,* there is no specific test for whether the facts are "public" or "private", and unlike Gault P's adherence to the US criteria for "publicity", an arguably narrower construction allowing for "an act of publication" has been incorporated.[659]

Stinson J found the elements had been established in the case.[660] In awarding damages, Stinson J departed from the "conventional range" capped at $20,000 in *Jones,* as the privacy interest at stake in *Jane Doe 1* involved much more serious consequences and the violation caused much greater offence.[661] Instead, general damages of $50,000 were awarded with punitive damages of $25,000 and aggravated damages of $25,000 for a total award of $100,000.[662] In addition, an injunction was ordered to permanently prohibit the defendant from publishing any intimate images or recordings of the plaintiff and to destroy all copies of the video or other intimate images of the plaintiff in his possession.[663]

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[654] *Ibid* at paras 6 & 229.
[655] *Ibid* at paras 224–26.
[656] *Ibid* at para 241.
[657] *Jane Doe 1*, *supra* note 72.
[658] *Ibid* at para 46.
[659] See discussion further below in this section.
[660] *Jane Doe 1*, *supra* note 72 at paras 47–48.
[661] *Ibid* at para 58.
[662] *Ibid* at paras 58–63.
[663] *Ibid* at para 64.

Although the defendant was subsequently successful in having Stinson J's default judgment set aside, as of the writing of this thesis, the matter does not appear to have been re-tried. The ruling and damages award ordered by Stinson J therefore remains instructive and has been influential in other cases, which have recognized that the default judgment being set aside "does not make Stinson J's analysis of invasion of privacy less important or persuasive".[664] In upholding Stinson J's recognition of the tort in *Jane Doe 72511 v Morgan* ("*Jane Doe 2*"), Gomery J echoed the rationale of the Court of Appeal in *Jones,* noting that adopting this new tort would be consistent with *Charter* values as articulated by the Supreme Court of Canada in relation to section 8 rights against unreasonable search and seizure.[665]

The facts of *Jane Doe 2* were very similar to *Jane Doe 1* and involved the plaintiff's ex-partner posting a sexually explicit video of her to the internet without her consent. As a result, Gomery J awarded damages in the exact same amounts and proportions as Stinson J[666] and similarly awarded injunctive relief.[667] Gomery J found the tort was actionable in the absence of any "visible and provable injury",[668] suggesting that emotional distress is compensable.

Gomery J adopted and elaborated upon the reason behind Stinson J's modification to the elements of the tort. The original articulation of the tort in the US *Restatement* requires the *matter* publicized to be "highly offensive". Gomery J acknowledged that an adult consensually taking and sharing explicit images of themselves is not "highly offensive". It is not the content of the information that needs to be highly offensive but the non-consensual *publication* of the content, which is why the Ontario formulation requires the plaintiff to prove "the matter publicized *or its publication* would be highly offensive to a reasonable person".[669]

However, neither Stinson J nor Gomery J discussed whether wide publicity to the world at large was required or whether "publication" in this context could be interpreted more narrowly. As both cases involved sexually explicit images and recordings being posted to the internet, there was no real need to address this point. Academic commentary has mixed views on this issue. For example, remedies expert, Jeff Berryman has suggested the Ontario articulation may "allow

[664] *Jane Doe 72511 v Morgan*, 2018 ONSC 6607 at para 74 [*Jane Doe 2*].
[665] *Ibid* at para 87.
[666] *Ibid* at paras 139–43.
[667] *Ibid* at paras 144–45.
[668] *Ibid* at para 106.
[669] *Ibid* at para 99 [emphasis added].

liability even where publication does not actually occur but where the defendant attempts to post the highly offensive material, or where the material is made available to a secured smaller group".[670] In contrast, privacy tort scholar, Chris Hunt, and civil litigator, Nikta Shirazian, have interpreted the focus on "publicity" and "the matter publicized" to mean that more widespread publication is required.[671]

The narrower view of "publication" in this respect was applied in the Ontario Small Claims Court by McGill Deputy J in *Halley v McCann.*[672] In that case, the defendant discovered the plaintiff (her sister) was staying as a patient in a crisis centre the defendant worked at, and disclosed the plaintiff's admission to the defendant's daughter, husband, and brother, who then informed other members of the family without the plaintiff's consent. McGill Deputy J held:

> Mass or bulk publication in the form of internet posting are not required elements of the tort. I accept that an act of publication is as simple as telling someone who is not entitled to know. The number of people told or limited manner in which the information is released to the public are factors that go to the quantum of damages.[673]

McGill Deputy J further elaborated that the "highly offensive" criterion was evaluated from the perspective of the plaintiff in terms of whether the disclosure would be highly offensive to a reasonable person *in the plaintiff's position*.[674] Further, the tort does not require proof of pecuniary loss or harm to an economic interest.[675] As a result, the elements were established and the plaintiff was awarded general damages of $7500 and punitive damages of $1500.[676]

In Alberta, *ES v Shillington*[677] involved similar facts to the *Jane Doe* cases, involving a defendant who physically and sexually assaulted the plaintiff in addition to posting intimate photos of her online. With respect to the photos, the plaintiff successfully alleged a claim for public disclosure of private facts, which Inglis J recognized for the first time in Alberta. Like McGill Deputy J in *Halley,* Inglis J noted that when speaking of what is "highly offensive to a reasonable person" it is important to clarify that the relevant perspective to consider is that of the person whose

[670] Berryman, *supra* note 280 at 333.
[671] Hunt & Shirazian, *supra* note 644.
[672] *Halley v McCann*, [2016] OJ No 4672 (Small Claims Ct) [*Halley*].
[673] *Ibid* at para 25.
[674] *Ibid* at para 31.
[675] *Ibid* at para 19.
[676] *Ibid* at para 50.
[677] *Shillington*, *supra* note 607.

information has been published, not the publisher or viewer of the publication. She therefore articulated the elements of the tort as follows:

> (a) the defendant publicized an aspect of the plaintiff's private life; (b) the plaintiff did not consent to the publication; (c) the matter publicized or its publication would be highly offensive to a reasonable person in the position of the plaintiff; and (d) the publication was not of legitimate concern to the public.[678]

Upon finding the elements satisfied, Inglis J issued an injunction ordering the defendant to return and remove the images of the plaintiff and prohibiting him from posting any images in the future.[679] She also awarded the plaintiff $80,000 in general damages, $50,000 in punitive damages, and $25,000 for aggravated damages.[680]

In relation to the elements, use of the term "publication" is, again, ambiguous, with the first element requiring an aspect of the plaintiff's private life to be "publicized" and the second element referring merely to a "publication". How widespread the publication needs to be therefore remains an open question. In terms of identifying matters of one's "private life", Inglis J suggested an approach similar to the English decision, *Campbell v MGN Limited* (discussed below), by considering what a reasonable person would "feel if they were placed in the same position as the claimant faced with the same publicity".[681] It is not clear, however, what the relevant distinction is between this test for "private life" and the third element of the tort, which also requires consideration of what a reasonable person in the plaintiff's position would feel with regard to the publication.

In Nova Scotia, the tort has been recognized with a slightly different articulation of the elements that aligns closer to *Hosking*: "(a) There must be publicity of the facts communicated to the public at large to become a matter of public knowledge; (b) The facts are those to which there is a reasonable expectation of privacy; and (c) The publicity given to those private facts must be considered, viewed objectively, as highly offensive to a reasonable person causing distress, humiliation or anguish".[682] In this respect, it is clear that publication must be widespread to satisfy the elements of the Nova Scotia tort. With respect to damages, "[g]iven the intangible nature of

[678] *Ibid* at para 68.
[679] *Ibid* at paras 80–81.
[680] *Ibid* at paras 97–102.
[681] *Ibid* at para 69, quoting from *Campbell v MGN Limited*, [2004] UKHL 22 at para 99 [*Campbell*].
[682] *Racki v Racki*, [2021] NSSC 46 at para 26 [*Racki*].

the interest protected by the privacy tort, general damages, as in claims in defamation, are presumed by the publicity of the private facts and are awarded at large".[683]

While this tort is growing across Canada, the above cases demonstrate that there remain slight differences between provinces and open questions, at least in Alberta and Ontario, as to the extent of publication required. There is also uncertainty surrounding the fault element for this tort. Whereas intrusion upon seclusion must be intentional (or reckless in some jurisdictions), it is not clear from the elements articulated in the above cases whether the public disclosure must be done with the intention of publishing private facts.

If the tort has roots in defamation, it is relevant to note that while the act of publication in defamation needs to be intentional, there is no requirement that the publisher know the material they are publishing is defamatory. Liability is generally regarded as strict in this respect.[684] It is understandable this point was not an issue in the revenge porn cases, as the publication in those scenarios would obviously involve the intentional publication of knowingly private information. Similarly, in *Hosking,* the claim failed as the information published was not sufficiently "private". The intention or knowledge of the defendant was not considered. It is conceivable, though, that someone could publish information about a person that would be highly offensive to a reasonable person in the plaintiff's position upon a reasonable belief or misunderstanding as to the private nature of that information. It is not yet clear from the case law above how such a situation would be handled, although academic commentary suggests that the absence of any fault element means "it is actionable *per se*, irrespective of the defendant's intent".[685]

iii. <u>*Statutory Torts*</u>

There are four Canadian provinces that have enacted statutory torts for general privacy violations: British Columbia, Saskatchewan, Manitoba, and Newfoundland and Labrador. In addition, Saskatchewan's Act contains a separate tort for distribution of an intimate image,[686] and similar legislation creating a specific privacy tort for intimate images has been passed in Alberta,[687]

[683] *Ibid* at para 28.
[684] ALRC, *Privacy in the Digital Era, supra* note 571 at para 5.64.
[685] Hunt & Shirazian, *supra* note 644.
[686] *Privacy Act* (SK), *supra* note 74, s 7.3.
[687] *Protecting Victims of Non-Consensual Distribution of Intimate Images Act*, SA 2017, c P-269.

Manitoba,[688] New Brunswick,[689] Nova Scotia,[690] and Newfoundland and Labrador.[691] The discussion in this section will focus on the four statutes creating a more general privacy tort, but it is worth noting the strong political will that existed to create entirely new statutory causes of action to address emerging societal harms brought by digital technologies.

With respect to the more general statutory privacy torts, there are slight differences between the statutes in terms of the relevant elements, defences, and remedies. British Columbia's, Saskatchewan's, and Newfoundland and Labrador's respective *Privacy Acts,* for example, provide, "[i]t is a tort, actionable without proof of damage, for a person, willfully and without a claim of right, to violate the privacy of an individual".[692] Different interpretations have been given to the term "willful" in this context.[693]

In Saskatchewan, this term has been interpreted to mean not merely that the act giving rise to the privacy violation was done intentionally, but that the defendant actually intended to violate the plaintiff's privacy.[694] To illustrate the difference, a person who accidentally walks into their neighbour's house thinking it is their own has violated their neighbour's privacy. While there was no intention to violate anyone's privacy, the act of entering the house was certainly done intentionally, notwithstanding that the privacy violation was the result of mere negligence.[695] Such a situation would not be actionable in Saskatchewan. Indeed, in a recent Saskatchewan case, the plaintiff's claim was struck for disclosing no valid cause of action, in part, because the plaintiff failed to plead any facts to support "that the defendant intended to violate his privacy".[696] By way of comparison, such a situation would also not be actionable under the Ontario intrusion upon seclusion tort, as the Ontario Court of Appeal recently clarified, as discussed above, that the conduct amounting to the intrusion must either have been with the intention of violating the

[688] *The Intimate Image Protection Act*, CCSM c I87.
[689] *Intimate Images Unlawful Distribution Act*, SNB 2022, c 1.
[690] *Intimate Images and Cyber-Protection Act*, SNS 2017, c 7.
[691] *Intimate Images Protection Act*, SNL 2018, c I-22.
[692] *Privacy Act* (Nfld), *supra* note 74, s 3(1); *Privacy Act* (BC), *supra* note 74, s 1(1); *Privacy Act* (SK), *supra* note 74, s 2; Note: rather than the word "individual", the Saskatchewan Act uses the term "another person".
[693] *Kumar v Korpan*, [2020] SKQB 256 ("It is fair to say that there is no firm agreement across the country as to what 'willfully' entails in the context of privacy legislation" at para 36); See also Hunt & Shirazian, *supra* note 644 for a discussion of this issue and relevant case law.
[694] *Peters-Brown v Regina District Health Board*, [1995] SJ No 609 (SKQB) at para 35.
[695] ALRC, *Privacy in the Digital Era*, *supra* note 571 at 115.
[696] *Kumar v Korpan*, *supra* note 693 at para 37.

plaintiff's privacy or with a subjective awareness of the risk that the plaintiff's privacy would be invaded.[697]

In contrast, the British Columbia Court of Appeal has indicated that "wilfully" requires "an intention to do an act which the person doing the act knew or should have known would violate the privacy of another person".[698] This represents a wider interpretation of the fault element compared to the Saskatchewan statutory tort or the Ontario action for intrusion upon seclusion, as constructive knowledge that one's actions will violate another's privacy would suffice. However, more recently, the Court of Appeal has questioned, in *obiter,* whether "the inclusion of the objective standard 'should have known'" adequately "capture[s] the deliberateness that is implicit in the word 'wilfully'",[699] but did not find it necessary to resolve this issue in the case.[700]

Assuming constructive knowledge remains the standard in British Columbia, if put on a spectrum, Saskatchewan's standard (specific intent to violate) and British Columbia's standard (constructive knowledge) would be at opposing ends, with the recklessness standard articulated in *Jones* for the intrusion upon seclusion tort falling somewhere in the middle.[701] That said, similar to Ontario case law, recent authority from British Columbia indicates a defendant must perform some action or conduct that violates the plaintiff's privacy.[702] A database defendant with poor security practices that enables a third-party hacker to violate personal information in the defendant's possession will not satisfy the requirement of "willful" conduct,[703] notwithstanding that previous authority from the same court left this question open.[704]

Manitoba's Act provides, "[a] person who substantially, unreasonably, and without claim of right, violates the privacy of another person, commits a tort against that other person", which is similarly actionable without proof of damage.[705] Rather than "willful" violations, the Manitoba statute merely requires "unreasonable" violations. The Act further provides a defence where "the defendant, having acted reasonably in that regard, neither knew [n]or should reasonably have

[697] *Owsianik v Equifax*, *supra* note 611 at para 59.
[698] *Hollinsworth v BCTV*, [1998] BCJ No 2451 (BCCA) at para 29.
[699] *Duncan v Lessing*, [2018] BCCA 9 at para 84.
[700] *Ibid* at para 86.
[701] Hunt & Shirazian, *supra* note 644.
[702] *GD v South Coast British Columbia Transportation Authority*, [2023] BCSC 958 at para 46.
[703] *Ibid*.
[704] *Campbell v Capital One Financial Corp*, [2022] BCSC 928 at paras 105–13.
[705] *Privacy Act* (MB), *supra* note 74, ss 2(1) & (2).

known" that their conduct would violate another's privacy.[706] The effect of this defence is to place the onus on the defendant to prove their lack of knowledge was reasonable rather than on the plaintiff to show they reasonably should have known more.[707]

All four torts require that the violation occur "without claim of right". While this term has been interpreted to mean "an honest belief in a state of facts which, if it existed, would be a legal justification or excuse",[708] case law has done little to clarify the precise scope and meaning of this test.[709] In particular, the question of whether the "honest belief" must be reasonably based is unclear from the authorities.[710] For example, in *St Pierre v Pacific Newspaper Group,* the defendant newspaper accidentally published a photo of the plaintiff that mis-identified him as a terrorist.[711] On the issue of "claim of right", Rice J held that although there is no express requirement in the Act that the claim of right be reasonable, an "honest belief" within the meaning of the test "must sensibly require a degree of reasonableness to meet the purpose of the Privacy Act".[712] It is difficult, however, to reconcile the judge's findings as to "willfulness" and "claim of right". This is because Rice J simultaneously held that the test for willfulness was met as the newspaper "*ought to have known* that they were using the wrong picture",[713] suggesting their lack of knowledge as to the plaintiff's identity was unreasonable. However, the newspaper was excused from liability by establishing a claim of right on the basis that their honest belief as to the plaintiff's identity was *not* unreasonable,[714] raising an important question as to how these standards can sensibly co-exist.

Unlike the common law torts, none of the Acts differentiate between privacy violations based on an intrusion upon seclusion versus public disclosure of private facts. However, they all appear broad enough to encompass both intrusions and disclosures.[715] The Saskatchewan, Manitoba, and Newfoundland and Labrador Acts specifically list examples of conduct that will

[706] *Ibid*, s 5(b).
[707] Hunt & Shirazian, *supra* note 644.
[708] *Hollinsworth v BCTV*, *supra* note 698 at para 30; *St Pierre v Pacific Newspaper Group Inc*, [2006] BCSC 241 at para 50 [*St Pierre*].
[709] Hunt & Shirazian, *supra* note 644.
[710] *Ibid*.
[711] *St Pierre*, *supra* note 708.
[712] *Ibid* at para 50.
[713] *Ibid* at para 49.
[714] *Ibid* at para 52.
[715] Hunt & Shirazian, *supra* note 644.

give rise to privacy violations, which include surveillance, harassment, following, eavesdropping, recording conversations, using people's names or likeliness for commercial purposes, and using letters, diaries or other personal documents.[716] The British Columbia Act simply indicates that "privacy may be violated by eavesdropping or surveillance whether or not accomplished by trespass".[717] Notably, none of these examples reflect a need to publish or disseminate private information. Similarly, where the alleged violation does pertain to disclosure, there is no requirement in the Acts that the disclosure be widespread.[718]

In terms of the relevant threshold of severity that a privacy violation must reach, the British Columbia, Newfoundland and Labrador, and Saskatchewan Acts provide that a person is entitled to the nature and degree of privacy that is reasonable in the circumstances, with regard given to the lawful interests of others.[719] In this respect, the plaintiff's privacy interest is balanced against the interests of others in determining whether there is a reasonable expectation of privacy. In addition, the Acts require that regard be given to the actions of the defendant, including "the nature, incidence and occasion of the act or conduct and to any domestic or other relationship between the parties".[720] In contrast, Manitoba's Act imposes a threshold that the violation be "substantial", which is absent in the Acts from the other jurisdictions.[721] And instead of taking into account the defendant's conduct and relationship of the parties in relation to whether there has been a privacy violation, the Manitoba Act stipulates that these factors, among others, be taken into account in making a damages award, discussed further below.[722]

Defences to the tort include consent, acts incidental to the exercise of a right to self-defence, acts authorized or required by law, acts by peace or public officers in the course of their

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[716] *Privacy Act* (Nfld), *supra* note 74, s 4; *Privacy Act* (SK), *supra* note 74, s 3; *Privacy Act* (MB), *supra* note 74, s 3.
[717] *Privacy Act* (BC), *supra* note 74, s 1(4).
[718] Hunt & Shirazian, *supra* note 644.
[719] *Privacy Act* (Nfld), *supra* note 74, s 3(2); *Privacy Act* (BC), *supra* note 74, s 1(2); *Privacy Act (SK)*, *supra* note 74, s 6(1).
[720] *Privacy Act* (Nfld), *supra* note 74, s 3(2); *Privacy Act* (BC), *supra* note 74, s 1(3); Note, the Saskatchewan Act additionally requires consideration of the effect of the defendant's act on the health or financial position of the plaintiff, and the conduct of both parties before and after the act, including any apology offered: *Privacy Act* (SK), *supra* note 74, s 6(2).
[721] *Privacy Act* (MB), *supra* note 74, s 2(1).
[722] *Ibid*, s 4(2).

duties, as well as defences for public interest, fair comment, and privilege.[723] In Saskatchewan, there is an additional defence where the act, conduct or publication is "that of a person engaged in a news gathering" for licensed broadcasters or newspapers containing public news.[724] And as mentioned above, Manitoba's Act has a defence where the defendant did not reasonably know their actions would violate the plaintiff's privacy.[725]

The British Columbia Act does not address potential remedies for privacy violations, but available remedies in the other jurisdictions include an award for damages, an injunction, an account to the plaintiff of profits, and/or delivery to the plaintiff of articles or documents.[726] Saskatchewan and Newfound and Labrador add to this list "other relief to the plaintiff that appears necessary under the circumstances".[727] As noted by Sharpe JA in *Jones,* Manitoba's Act is the only one that articulates factors that should be taken into account when making a damages award. These factors are:

> (a) the nature, incidence and occasion of the act, conduct or publication constituting the violation of privacy of that person;
> (b) the effect of the violation of privacy on the health, welfare, social, business or financial position of that person or [their] family;
> (c) any relationship, whether domestic or otherwise, between the parties to the action;
> (d) any distress, annoyance or embarrassment suffered by that person or [their] family arising from the violation of privacy; and
> (e) the conduct of that person and the defendant, both before and after the commission of the violation of privacy, including any apology or offer of amends made by the defendant.[728]

All the Acts except Manitoba's provide that the rights of action under the Acts are extinguished upon the death of the person whose privacy is alleged to be violated.[729]

In terms of the potential interaction between the statutory and common law torts, as mentioned above in the discussion on intrusion upon seclusion, different conclusions have been reached in British Columbia compared to Newfoundland and Labrador. Whereas Manitoba's, Saskatchewan's, and Newfoundland and Labrador's Acts provide that the remedies and actions

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[723] *Privacy Act* (Nfld), *supra* note 74, s 5(1) & (2); *Privacy Act* (SK), *supra* note 74, s 4(1) & (2); *Privacy Act* (MB), *supra* note 74, s 5; *Privacy Act* (BC), *supra* note 74, s 2(2) & (3); Note: the BC Act describes these as "exceptions" to what might otherwise be a privacy violation rather than "defences".
[724] *Privacy Act* (SK), *supra* note 74, s 4(1)(e).
[725] *Privacy Act* (MB), *supra* note 74, s 5(b).
[726] *Privacy Act* (Nfld), *supra* note 74, s 6(1); *Privacy Act* (SK), *supra* note 74, s 7; *Privacy Act* (MB), *supra* note 74, s 4(1).
[727] *Privacy Act* (Nfld), *supra* note 74, s 6(1); *Privacy Act* (SK), *supra* note 74, s 7.
[728] *Privacy Act* (MB), *supra* note 74, s 4(2).
[729] *Privacy Act* (Nfld), *supra* note 74, s 11; *Privacy Act* (SK), *supra* note 74, s 10; *Privacy Act* (BC), *supra* note 74, s 5.

available under their respective statutory torts are in addition to any others available in law,[730] the British Columbia Act contains no similar provision. The lack of a similar provision was the explanation given by Goodridge J in the Newfoundland and Labrador case, *Hynes,* for why parallel statutory and common law actions could be brought in Newfoundland when British Columbia courts had refused to recognize common law actions in light of their statutory tort.[731] Given the similarity of the Manitoba and Saskatchewan Acts to Newfoundland and Labrador's in this respect, it is possible parallel actions could arise in those provinces as well.

In Australia, the Australian Law Reform Commission (ALRC) recommended in 2014 that the Commonwealth introduce legislation to establish statutory privacy torts.[732] The recommendation was that the legislation establish two torts: intrusion upon seclusion and misuse of private information, the latter of which would include "collecting or disclosing private information about the plaintiff".[733] While Australia has not yet implemented these recommendations, the ALRC's recommendation to expand the public disclosure of private facts torts to include a wider range of potential "misuses" for private information is reflective of the English approach, which will be turned to next.

iv. English Tort of Misuse of Private Information

English courts have taken an incremental approach to develop the historical equitable breach of confidence action into a privacy tort. In the seminal case, *Campbell v Mirror Group Newspapers,*[734] supermodel Naomi Campbell sued Mirror Group Newspapers for photographs and an article exposing her at a Narcotics Anonymous meeting. In five separate judgments, a 3:2 Majority of the House of Lords found for Campbell. While the Lords and Baroness disagreed on the outcome, there was general agreement between them as to the test to apply.

Lord Nicholls of Birkenhead coined the name of the tort of "misuse of private information".[735] While he and Lord Hoffmann both found against Campbell, each of them

[730] *Privacy Act* (Nfld), *supra* note 74, s 7(1); *Privacy Act* (SK), *supra* note 74, s 8(1); *Privacy Act* (MB), *supra* note 74, s 6.
[731] *Hynes*, *supra* note 609 at para 25.
[732] ALRC, *Privacy in the Digital Era*, *supra* note 571, c 4.
[733] *Ibid* at 74; For a discussion of the ALRC recommendations, see Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 292.
[734] *Campbell*, *supra* note 681.
[735] *Ibid* at para 14.

nevertheless noted the importance of privacy in modern society and as a matter of human rights. Lord Nicholls, for example, cited La Forest J from the Supreme Court of Canada on this point[736] and Lord Hoffmann observed that human rights law has "idenf[ied] private information as something worth protecting as an aspect of human autonomy and dignity".[737]

Lord Nicholls similarly noted the influence of human rights obligations on the development of the law of confidence and privacy, observing that the *Human Rights Act 1998* (which implements the rights and obligations from the *ECHR*) had influenced the law of privacy.[738] He specifically noted that the values enshrined in Articles 8 (respect for private and family life) and 10 (freedom of expression) of the *ECHR* "are now part of the cause of action for breach of confidence", as the common law has developed in harmony with these Articles.[739] In the subsequent decision of *Ash v McKennitt,* Buxton LJ of the English Court of Appeal (Civil Division) (Latam and Longmore LJ agreeing) further confirmed that Articles 8 and 10 "are now not merely of persuasive or parallel effect but…the very content of the domestic tort that the English court has to enforce".[740]

Some commentators have critiqued the influence of human rights law on the development of privacy torts given that the former involves interactions between the state and individuals while the latter involves disputes between private individuals.[741] However, Lord Hoffmann in *Campbell* saw no problems in this respect. He saw "no logical ground for saying that a person should have less protection against a private individual than [they] would have against the state for the publication of personal information for which there is no justification".[742]

Lord Nicholls stated a two-stage test for determining whether this newly formulated breach of confidence could be established,[743] which has been followed in subsequent cases.[744] The test

[736] *Ibid* at para 12.
[737] *Ibid* at para 50.
[738] *Ibid* at para 11.
[739] *Ibid* at para 16.
[740] *Ash v McKennitt*, [2006] EWCA Civ 1714 at para 11 [*McKennitt*].
[741] For example, see Paula Giliker, "A Common Law Tort of Privacy? Thy Challenges of Developing a Human Rights Tort" (2015) 27 SAcLJ 761.
[742] *Campbell*, *supra* note 681 at para 50.
[743] *Ibid* at paras 23–28.
[744] See *McKennitt*, *supra* note 740 at para 11; and *Murray v Big Pictures (UK) Limited*, [2008] EWCA Civ 446 at para 27 [*Murray*].

considers "first whether the information whose disclosure is in dispute was private"[745] and secondly, "how the tension between privacy and freedom of expression should be resolved".[746] In determining whether the information is private, the test to employ is "whether in respect of the disclosed facts the person in question had a reasonable expectation of privacy".[747] He explicitly rejected the "highly offensive" test from the *Restatement,* which "is suggestive of a stricter test of private information than a reasonable expectation of privacy".[748]

Similar to the *Halley v McCann* and *Shillington* cases considered above regarding public disclosure of private facts, Lord Hope of Craighead specified that when considering a "reasonable expectation of privacy", the perspective to consider is that of the person whose information has been disclosed, not the mind of the reader.[749] To consider the latter perspective would be to "reduce[] the level of protection that is afforded to the right of privacy".[750] Instead, "[t]he question is what a reasonable person of ordinary sensitivities would feel if she was placed in the same position as the claimant and faced with the same publicity".[751]

The second step involves balancing competing interests. Article 8, itself, requires consideration of whether the interference with the plaintiff's right to private and family life is "necessary in a democratic society" to further the economic, health, safety, and security interests of the public.[752] In addition, this step requires balancing the Article 8 right to privacy against the defendant's Article 10 right to free expression. In this respect, these two values are to be given equal weight. Articles 8 and 10 of the Convention "are neither absolute no[r] in any hierarchical order, since they are of equal value in a democratic society".[753] Commentators have speculated that the equal footing of these respective values is part of what has led to the more permissive "reasonable expectation of privacy" test, compared with the US, Canada, and New Zealand where freedom of expression is paramount and the "highly offensive" test must be met.[754]

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[745] *Campbell*, *supra* note 681 at para 23.
[746] *Ibid* at para 28.
[747] *Ibid* at para 21.
[748] *Ibid* at para 22.
[749] *Ibid* at para 99.
[750] *Ibid*.
[751] *Ibid*.
[752] *Convention for the Protection of Human Rights and Fundamental Freedoms*, 4 Nov 1950, 213 UNTS 221, s 8(2) [*ECHR*].
[753] *Campbell*, *supra* note 681 at para 113.
[754] See generally Beswick & Fotherby, *supra* note 622.

By way of comparison, *Murray v Big Pictures (UK) Limited*[755] involved remarkably similar facts to the New Zealand case of *Hosking*. In *Murray,* famed author, JK Rowling, sued a photo agency on behalf of her small child for taking photos of him while out for a walk with his parents. While the New Zealand Court of Appeal unanimously rejected Hosking's claim involving almost identical circumstances, the English Court of Appeal found there was at least an arguable case that the claim on behalf of Rowling's child could succeed under the tort as formulated in England, which does not require the "highly offensive" criterion.[756]

Given the lower standard of "reasonable expectation of privacy" compared to a publication that would be "highly offensive" to a reasonable person, scholars have queried the potential breadth of the tort. Specifically, some are of the view that the tort may be broad enough to encompass situations like the intrusion upon seclusion cases where there has merely been wrongful access to information without any subsequent publication, or even cases involving physical intrusions without an informational component.[757] In this respect, the meanings of "misuse" and "information" in the tort of misuse of private information are open questions.

One reason these questions have arisen is because of the clear influence of Article 8 of the *ECHR* on the development of the English tort. It is clear that the rights protected by Article 8 are broader than simply informational privacy and encompass "physical privacy, and an 'intrusion' variant of the privacy action".[758] Case law from the European Court of Human Rights has found that Article 8 can be engaged merely by acquiring private information even where there is no subsequent publication.[759] Similarly, it can be engaged by physical intrusions, such as performing strip searches on visitors to a prison[760] or taking photographs of a newborn baby in hospital without parental consent even where there is no subsequent publication.[761]

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[755] *Murray*, *supra* note 744.
[756] *Ibid* at para 61.
[757] Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 295–98; Hunt & Shirazian, *supra* note 644; Beswick & Fotherby, *supra* note 622 at 225.
[758] Varuhas & Moreham, *supra* note 579 at 9.
[759] See *Halford v United Kingdom*, No 20605/92, [1997] ECHR 32 at para 52, where the Court noted that the applicant's allegation that police intercepted phone calls from her home engaged Article 8, as home phone calls were covered by the concept of "private life" within the meaning of the Convention; See also *Copland v United Kingdom*, No 62617/00, [2007] ECHR 253 at paras 42–43, where the Court confirmed that surreptitious monitoring of telephone calls, emails, and internet usage at work engaged Article 8; For a more detailed discussion of this point and these cases, see Hartshorne, "Intrusion Upon Seclusion", *supra* note 578.
[760] *Wainwright v The United Kingdom*, No 12350/04, [2006] ECHR 807 at para 43.
[761] *Reklos and Davourlis v Greece*, No 1234/05, [2009] EMLR 16 at paras 34–43.

There is also case law from England that suggests the tort is moving in this direction.[762] Statements in *obiter dicta* have emphasized "the modern law of privacy is not concerned solely with information or 'secretes': it is also concerned importantly with *intrusion*"[763] and that merely obtaining private information[764] or taking photographs, irrespective of the use to be made of them,[765] should, in some cases, be regarded as privacy violations. The cases of *Gulati v MGN*[766] and *Google v Vidal-Hall*[767] add further support to this contention.[768]

Gulati v MGN[769] involved claimants who were the victims of tabloid phone hacking. One of the claimants had worked at the BBC at the time, and, unlike the other victims who had larger public profiles, the publications resulting from the phone hacking did not reveal personal information about him, but rather entertainment-related news gleaned from his voicemails.[770] Despite the fact that his own personal information was never published, he was awarded damages of £85,000.[771] Arden LJ on behalf of the Court upheld this damages award, finding that damages in this context "compensate for the loss or diminution of a right to control formerly private information and for the distress that the respondents could justifiably have felt because their private information had been exploited".[772] With respect to the BBC employee, most of the damages award compensated for the intrusion and loss of control itself (£70,000), with a small additional amount for distress and aggravation.[773]

While this case certainly shows the possibility of recognizing a cause of action based on intrusion without any publication of personal information, torts and privacy scholar, John Hartshorne, points to the need to interpret the decision with caution in terms of its wider application on this point.[774] That is because liability was admitted by the defendant before trial, and the issues

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[762] For a discussion of relevant cases, see Hunt & Shirazian, *supra* note 644, n 23.
[763] *CTB v News Group Newspapers & Another*, [2011] EWHC 1326 (QB) at para 23 [emphasis in original].
[764] *Tchenguiz & Others v Imerman*, [2010] EWCA Civ 908 at para 68.
[765] *Wood v Commissioner of Police for the Metropolis*, [2009] EWCA Civ 414 at paras 29–34.
[766] *Gulati v MGN*, [2015] EWCA Civ 1291 [*Gulati*].
[767] *Vidal-Hall*, *supra* note 73.
[768] For a detailed discussion of these two cases on this point, see Hartshorne, "Intrusion Upon Seclusion", *supra* note 578.
[769] *Gulati*, *supra* note 766.
[770] *Ibid* at para 7.
[771] *Ibid* at para 70.
[772] *Ibid* at para 48.
[773] *Ibid* at para 70.
[774] Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 295.

before the courts were therefore confined to the assessments of damages.[775] The case of *Vidal-Hall,*[776] however, adds some support to the idea that the tort may be widening in this direction.

Vidal-Hall involved internet searches using the Safari browser on Apple products. The browser's default settings were set to block third party access from search information, however, the defendant, Google, found a "Safari workaround" enabling them to access this information without the users' knowledge or consent.[777] As a result, advertisements appeared on the users' devices related to their search results, potentially revealing private information about them.[778]

As Google is a registered corporation in the US, the plaintiffs had to apply to the court for permission to serve the proceedings in the US.[779] Two of the requirements they had to meet were to show there was a serious issue for trial and that their claim was made in tort.[780] Prior to this case, it was not entirely clear whether a new tort had developed or whether these new privacy cases had been decided on an expanded understanding of the equitable action for breach of confidence. Lord Hoffmann in *Campbell* noted that, while the former action for breach of confidence was based in equity and therefore grounded in the duty of good faith and conscience, the new action "focuses upon the protection of human autonomy and dignity – the right to control the dissemination of information about one's private life and the right to the esteem and respect of other people".[781] However, it was not until the 2015 decision, *Vidal-Hall,* that this became a central issue of importance.

The plaintiffs were granted permission for service and the Defendant unsuccessfully applied to set it aside.[782] On appeal from that decision, The Master of the Rolls and Sharp LJ (McFarlane LJ agreeing) noted that breach of confidence and misuse of private information "are now two separate and distinct causes of action" that protect different interests.[783] They further held that the plaintiffs' claims "raise[d] serious issues which merit a trial".[784]

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[775] *Ibid*.
[776] *Vidal-Hall*, *supra* note 73.
[777] *Ibid* at paras 2–3.
[778] *Ibid* at para 3.
[779] *Ibid* at para 6.
[780] *Ibid* at paras 7–9.
[781] *Campbell*, *supra* note 681 at para 51.
[782] *Vidal-Hall*, *supra* note 73 at para 12.
[783] *Ibid* at para 21.
[784] *Ibid* at para 137.

While the case ultimately settled prior to trial, it is nevertheless notable that even in the absence of any widespread publicity of the information obtained about the users' search results, the claim was upheld as potentially disclosing a valid cause of action.[785] While there was an aspect of the claim that involved publication in that other people may see advertisements on the users' devices and draw informational conclusions about the users, the Court of Appeal's judgment indicated that the claimants' complaints regarded "secret and blanket tracking and collation of information, often of an extremely private nature…and the subsequent use of that information for about nine months", which amounted to an "intrusion upon autonomy" causing anxiety and distress to the claimants.[786] While inconclusive, Hartshorne nevertheless considers that the case "offers additional support for the position that a claim in [misuse of private information] is now possible where private information has been misused in ways not involving publication".[787] Given the tide of decisions moving in this direction and the strong influence of Article 8 *ECHR* jurisprudence on the development of the English tort, Hunt and Shirazian have similarly speculated it is "probably inevitable that English courts will recognize a bare intrusion tort in the future".[788]

Like the other common law privacy torts explored above, the fault element in this tort remains unsettled.[789] In *Campbell,* there were conflicting articulations of the fault element, with the two-stage test articulated by Lord Nicholls failing to mention a fault element and Baroness Hale indicating that the defendant should reasonably know that their actions are infringing on the plaintiff's reasonable expectation of privacy.[790] In the subsequent decision of *Murray,* Sir Anthony Clarke MR, on behalf of the Court, provided a range of factors to be taken into account in determining whether a reasonable expectation of privacy exists.[791] Whether the defendant knew or ought to have known their actions would infringe the plaintiff's expectation of privacy was later incorporated into this list in *Weller v Associated Newspapers,* where Dingemans J noted that the

[785] Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 296.
[786] *Vidal-Hall*, *supra* note 73 at para 137; See Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 297 for a discussion of this point.
[787] Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 297.
[788] Hunt & Shirazian, *supra* note 644, n 23.
[789] John Hartshorne, "The Standard of Liability in Claims for Misuse of Private Information" (2021) 13:2 J Media L 211 [Hartshorne, "Standard of Liability"].
[790] *Campbell*, *supra* note 681 at paras 21 & 134; For a more detailed discussion of this point, see Hunt & Shirazian, *supra* note 644.
[791] *Murray*, *supra* note 744 at para 36.

court can take into account what the publisher knew or ought to have known in determining whether the plaintiff held a reasonable expectation of privacy.[792]

Further expanding on the fault element, the 2018 Court of Appeal decision, *Secretary of State for the Home Department v TLU and TLV,* suggests negligent misuses are actionable.[793] The case involved a spreadsheet that was published, which inadvertently contained a link to information identifying 1600 applicants for asylum. Although the publication of this information was not intentional, Gross LJ (McFarlane and Coulson LJ, concurring) had "no hesitation in concluding that the Home Office's publication of the spreadsheet misused [the claimants'] private and confidential information".[794] This case strongly suggests that mere negligent "misuses" of information are actionable under the tort.[795]

However, negligent acquiescence in allowing others to wrongfully misuse private information in one's possession may not be actionable. In *Warren v DSG Retail*, a retail company experienced a cyber-attack in which the attackers gained access to private customer information.[796] An affected customer brought an action for misuse of private information, among other things, against the retailer. In granting summary judgment in favour of the retailer, dismissing the plaintiff's claim, Saini J stated, "I accept that a 'misuse' may include unintentional use, but it still requires a 'use': that is, a positive action" amounting to some type of "interference" by the defendant.[797] Similar to intrusion upon seclusion, third-party hacking cases may, therefore, be difficult for plaintiffs to pursue under these torts.

C. Conclusion

In the above-canvassed jurisdictions, there are interpretational questions remaining as to how some of the elements of these emerging torts will be understood and applied in future cases. The fault element, for example, is unsettled in these torts. There are also differences between jurisdictions that could lead to significant divergences in outcomes. For example, the use of the "highly offensive" criterion in New Zealand, Canada, and the US is absent in England, which

[792] *Weller v Associated Newspapers*, [2014] EWHC 1163 (QB) at para 37.
[793] *Secretary of State for the Home Department v TLU and TLV*, [2018] EWCA Civ 2217 .
[794] *Ibid* at para 31.
[795] See Hartshorne, "Standard of Liability", *supra* note 789 at 222 for further discussion of the fault element in this case.
[796] *Warren v DSG Retail*, [2021] EWHC 2168 [*Warran*].
[797] *Ibid* at para 27.

imposes a lower "reasonable expectation of privacy" threshold. That said, the English tort is focused on "misuse" of "private information", leaving open questions as to whether "misuse" can encompass intrusions without publication and the extent to which physical violations of privacy can be cast in informational terms.

The role that the public interest plays also differs between torts. The British Columbia, Saskatchewan, and Newfoundland and Labrador statutory torts each require consideration of "the lawful interests of others" in determining whether there has been a privacy violation.[798] In England, the public interest must be balanced directly against the plaintiff's privacy right in determining the elements of the tort. In contrast, New Zealand and Canadian common law torts tend to encompass competing public interest concerns under a "legitimate public concern" defence,[799] recognized by Gault P in *Hosking.*[800] Given the high bar set by the "highly offensive" test in these torts, once a plaintiff meets this threshold, "it will only be a powerful public concern that could vindicate a serious interference with privacy" as a defence.[801] As a result, while public interests remain relevant as a defence, the bigger hurdle for plaintiffs in these jurisdictions will generally be proving the elements of the particular privacy tort.

While these interpretational questions certainly create a complex picture, the overarching point to take away is that these new torts remain malleable with different possibilities in terms of how they will evolve. Further, there appears to be a symbiotic relationship between common law torts and statutory privacy frameworks that can co-exist in the privacy law landscape. The fact that both legislatures and courts are willing to develop privacy law in new directions shows the increasing importance of privacy as a legal value and that there is the political and judicial will to address privacy challenges brought by advancing technologies. The influence of human rights law on judicial decisions is particularly important in this regard, as understandings of "privacy" under human rights law are robust and encompass dimensions of privacy beyond the purely informational, as will be explored further in Chapter 8.

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[798] *Privacy Act* (SK), *supra* note 74, s 6(1); *Privacy Act* (Nfld), *supra* note 74, s 3(1); *Privacy Act* (BC), *supra* note 74, s 1(2).
[799] Beswick & Fotherby, *supra* note 622 at 236 & 246.
[800] *Hosking*, *supra* note 72 at para 129.
[801] Beswick & Fotherby, *supra* note 622 at 247.

The current state of privacy law presented in this chapter reveals that privacy law can be used to address a range of privacy interests. Informational privacy interests are clearly engaged by statutes governing personal information. Further, the English misuse of private *information* and the tort of public disclosure of private facts have informational dimensions embedded within them. Intrusion upon seclusion, on the other hand, is broader in scope. In some cases, it also serves to protect informational privacy. For example, in *Jones v Tsige,* the complaint was that the plaintiff's banking records were wrongfully accessed by the defendant. Other cases, however, involve spatial and personal dimensions of privacy. *Holland,* for example, involved the defendant secretly spying on the plaintiff and recording her in the shower. Similarly, Canadian statutory torts have also been applied to situations involving non-consensual recordings.[802]

As individuals' autonomy and dignity-based interests in biomaterials encompass both informational and non-informational aspects, a comprehensive understanding of how privacy law can potentially safeguard these interests calls for consideration of the full range of privacy protections. The next chapter will therefore focus on the informational interests individuals have in biomaterials and how statutory frameworks governing "personal information" could be used to protect these interests. Chapter 8 will then consider how privacy torts could be used to remedy violations of individual interests in a range of situations identified from Part 1 of this work where additional protection is needed.

[802] See, for example *TKL v TMP*, [2016] BCSC 789.

7. Biomaterials as "Information" under Information Privacy Statutes

Given that biomaterials contain DNA, there is a clear informational connection between individuals and their biomaterials. While no one seriously doubts that there are privacy interests in one's recorded identifiable genetic information, it does not necessarily follow that, as a matter of privacy law, physical biomaterials, themselves, should be subject to the same rules as the recorded genetic information they can give rise to. Whether this informational interest in biomaterials can be protected under privacy law will depend on the meaning of "information" in this context and whether it is broad enough to encompass the physical DNA molecules within our cells.

The following discussion will therefore begin by considering what "information" means and how it can potentially be interpreted to include biomaterials. The chapter will then present the benefits of this approach in terms of providing consistency in regulation and closing regulatory gaps. Finally, the chapter will close by considering some lingering questions raised by this approach in terms of its scope of application and effectiveness as a regulatory tool. Overall, while this approach is not without its limitations, this chapter will demonstrate there is value in further exploring informational understandings of biomaterials as a matter of privacy law.

A. Defining "Information" to Include Biomaterials

The idea that the physical molecules making up our DNA should be regarded as information aligns well with common understandings and language regarding this material. DNA is often metaphorically referred to as "a genetic code" and "the genome as a 'book' or 'a blueprint'".[803] Base pairs are represented by letters (A,G,C,T) that convey meaning[804] and DNA is discussed and understood as "a medium through which information is transferred".[805] This is also reflected in the language of biology, with "transcription" and "translation" of "messenger RNA".[806]

Since the structure of DNA was discovered, information theory has significantly informed understandings of the molecule's function and structure in genetic sciences.[807] As a result,

[803] Hallinan & De Hert, *supra* note 65 at 131; Australia, Australia Law Reform Commission, *supra* note 68 at 268.
[804] ALRC, *Essentially Yours*, *supra* note 68 at 268.
[805] Hallinan & De Hert, *supra* note 65 at 131.
[806] ALRC, *Essentially Yours*, *supra* note 68 at 268.
[807] Hallinan & De Hert, *supra* note 65 at 132.

conceptual understandings of this molecule have changed from a focus on its physical structure to its role as an information carrier.[808] Evolutionary biologist, George Williams, proclaimed in 1992 that "[a] gene is not a DNA molecule; it is the transcribable information coded by the molecule", and traced scholarship from as early as the 1960s from others who advanced similar positions that "the gene is a package of information, not an object".[809]

Now, more than ever, the dividing line between the physical and informational is disappearing. Renowned geneticist, George Church, has gone so far as to encode an entire book he authored into a strand of synthetic DNA.[810] Hallinan and de Hert astutely question, "[i]f physical samples cannot be data or information, then does George Church's DNA book not constitute data or information either?"[811] However, the answer to this question is not straightforward. The below discussion will examine whether information privacy legislation can be interpreted to include physical biomaterials in definitions of "information" and then look to case law for additional support for this understanding.

i. Legislation

In most privacy statutes, "information" is not clearly defined. For example, Canada's *PIPEDA* defines "personal information" to mean "information about an identifiable individual".[812] Similarly, Australia's Commonwealth *Privacy Act* defines "personal information" to mean "information or an opinion about an identified individual, or an individual who is reasonably identifiable".[813] The European Union's *GDPR* is law directly applicable to member states. The *GDPR* defines "personal data" to mean "any information relating to an identified or identifiable natural person ('data subject')".[814] The focus in these definitions is on defining what it means for information or data to be "personal" (an issue that will be returned to further below), taking for granted that the meaning of "information" is obvious.[815]

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[808] *Ibid*.
[809] George C Williams, *Natural Selection: Domains, Levels, and Challenges* (New York: Oxford University Press, 1992) at 11.
[810] Wyss Institute, "Writing the Book in DNA", *Wyss Institute* (16 August 2012), online: <wyss.harvard.edu> [perma.cc/GVB3-NWTL]; Hallinan & De Hert, *supra* note 65 at 132.
[811] Hallinan & De Hert, *supra* note 65 at 132.
[812] *PIPEDA*, *supra* note 543, s 2(1).
[813] *Privacy Act* (Cth), *supra* note 548, s 6.
[814] *GDPR*, *supra* note 303, art 4(1).
[815] Bygrave, "The Body as Data?", *supra* note 31 at 13.

While most information privacy statutes do not directly address whether biological material constitutes information or data, the legislators behind these laws intended to give "personal information" or "personal data" a wide meaning.[816] Nevertheless, it is unclear and perhaps doubtful whether most legislators intended these terms to capture human biomaterials.[817] The Australian state of New South Wales is an outlier in this regard, as it has enacted three pieces of privacy legislation that explicitly include "body samples" within definitions of "personal information".[818]

There is also limited support in Canada for an expanded definition of "information". While Canada's *PIPEDA* does not explicitly include biomaterials within its definition of "personal information", Canada's Privacy Commissioner has indicated, in relation to *PIPEDA,* that, "[i]nformation need not be recorded for it to constitute personal information. It is sufficient that the information be about an identifiable individual even if the information is not in a recorded form, such as oral conversations, *biological samples* and real time video surveillance".[819]

Similarly, in a joint statement highlighting the privacy risks of DTC genetic testing, the Offices of the Information and Privacy Commissioners of Canada, Alberta, and British Columbia implicitly recognized that biological samples are a type of information.[820] Three times throughout the statement, the term "personal information" is used to refer to "biological samples and test results".[821] While these examples are far from statements of binding law, they are nevertheless significant in revealing the attitudes of Canadian Privacy Commissioners in terms of what they perceive to be part of their remit.

The domestic laws of several Eastern European countries also support a broad understanding of "personal data" as encompassing biological samples. In Estonia, for example, legislation "does not distinguish between data and the medium or carrier of data".[822] Similarly,

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[816] *Ibid* at 13–14.
[817] Bygrave, *Data Privacy Law, supra* note 59 at 127–28.
[818] *Privacy Act* (NSW), *supra* note 66; *Government Information Act* (NSW), *supra* note 66; *Health Privacy Act* (NSW), *supra* note 66.
[819] Office of the Privacy Commissioner of Canada, "Interpretation Bulletin: Personal Information", (11 October 2013), online: <www.priv.gc.ca> [perma.cc/72FJ-EV4M].
[820] Office of the Information and Privacy Commissioner of Alberta, Office of the Privacy Commissioner of Canada & Office of the Information and Privacy Commissioner for British Columbia, "Direct-to-consumer genetic testing and privacy", (4 December 2017), online: <www.priv.gc.ca> [perma.cc/V7PN-NRMQ].
[821] *Ibid*.
[822] Bygrave, "The Body as Data?", *supra* note 31 at 16, quoting Ants Nõmper, "Personal Data Protection Regulation in Estonia and Directive 95/46/EC" in Deryck Beyleveld et al (eds), *Implementation of the Data Protection*

privacy scholar, Lee Bygrave, notes that "Bulgaria, Latvia, Romania and Slovenia are also reported as treating bodily samples as data".[823]

As most privacy statutes are silent on this point, Bygrave suggests using definitions from the field of informatics to determine whether statutes can be similarly interpreted. In the field of informatics, the terms "data" and "information" are distinct. The term "data" can be understood as "a formalized representation of some entity (object, process, etc.) which is intended to communicate information about that entity"[824] or as "denot[ing] signs, patterns, characters or symbols which potentially represent some thing (a process or object) from the 'real world' and, through this representation, may communicate information about that thing".[825] The term "information" "denotes the semantic content of the data communicated to a person"[826] and can be understood as "compris[ing] a cognitive element involving comprehension of the representation".[827]

Under these definitions, Bygrave asserts human biomaterials would not be considered "information" as they lack the necessary cognitive element.[828] While it is unlikely that an entire human body would meet definitions of "data", he leaves room for the possibility that separated biomaterials that are "structured as a sample or set of samples with the intention of providing information" could be characterized in this way,[829] although he ultimately views this interpretation as doubtful.[830] However, Hallinan and De Hert point to two problems with applying informatics definitions to the field of privacy law.

The first is that "data" and "information" have distinct meanings in informatics yet are used almost interchangeably in privacy statutes.[831] Indeed, as stated above, the *GDPR* defines "personal data" as "*information* relating to an identified or identifiable natural person".[832] If definitions from

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Directive in Relation to Medical Research in Europe (Ashgate, 2004), 75–76; See also Hallinan & De Hert, *supra* note 65 at 125.

[823] Bygrave, "The Body as Data?", *supra* note 31 at 16.
[824] Bygrave, *Data Privacy Law, supra* note 59 at 127.
[825] Bygrave, "The Body as Data?", *supra* note 31 at 14.
[826] *Ibid*.
[827] Bygrave, *Data Privacy Law, supra* note 59 at 127.
[828] *Ibid*.
[829] Bygrave, "The Body as Data?", *supra* note 31 at 21.
[830] Bygrave, *Data Privacy Law, supra* note 59 at 127.
[831] Hallinan & De Hert, *supra* note 65 at 133.
[832] *GDPR*, *supra* note 303, art 4(1) [emphasis added].

informatics were intended to be incorporated into data privacy legislation, they would surely be used as distinct concepts.[833] For present purposes, it is also worth noting that the European *GDPR* is centred around the concept of "personal data", whereas legislation from common law countries tends to use the term "personal information" to mean essentially the same thing.

The second problem is that definitions of these terms in informatics are unsettled, and depending on which definitions are adopted, physical biomaterials may or may not be excluded.[834] Hallinan and De Hert point to the International Standards Organization's (ISO's) definition as an authoritative source on this issue. The ISO has defined "data" as "[a] reinterpretable representation of information in a formalized manner suitable for communication, interpretation, or processing…Data can be processed by humans or by automatic means".[835] Hallinan and De Hert argue that DNA can be encompassed by this definition:

> DNA are reinterpretable – otherwise they would be useless, both as a means to transfer biological specificity between generations, as well as for all forms of genetic analysis. DNA is a representation of information – information as to biological specificity. DNA is 'written' in a formalized language – comprised of four nucleotides. Finally, through the sequencing and analysis process, DNA is clearly capable of being processed by human and automatic means.[836]

Nevertheless, while it is certainly arguable that physical biomaterials can be incorporated into broader meanings of "data", it is perhaps unlikely that "personal data" under the *GDPR* encompasses these materials.

This is because the *GDPR* defines "genetic data" to mean "personal data relating to the inherited or acquired genetic characteristics of a natural person…and which result, in particular, from an analysis of a biological sample from the natural person in question".[837] In this respect, a "biological sample" is viewed as something different from the "genetic information" it gives rise to. Similarly, Canada's *PIPEDA* defines "personal health information" to include "information derived from the testing or examination of a body part or bodily substance of the individual",[838] suggesting that body parts and information derived from them are two distinct things, only the latter of which is "health information". Further, the Australian Law Reform Commission

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[833] Hallinan & De Hert, *supra* note 65 at 133.
[834] *Ibid* at 133–34.
[835] *Ibid* at 134, quoting International Standards Organisation, ISO 2382-1 (1993), Information Technology Vocabulary Part 1: Fundamental Terms, online: <www.iso.org> [perma.cc/UEA9-475R].
[836] *Ibid*.
[837] *GDPR*, *supra* note 303, art 4(13); Hallinan & De Hert, *supra* note 65 at 130.
[838] *PIPEDA*, *supra* note 543, s 2(1).

considered whether Australia's Commonwealth *Privacy Act* could be interpreted as encompassing physical biomaterials and found that it could not.[839] An initial concession to this approach is, therefore, that privacy legislation may need to be amended to bring physical biomaterials under its reach.

ii. Case Law

In the UK, the question of whether biomaterials are "information" arose in the *Marper* decision.[840] The case was brought by individuals who had been charged, but never convicted, of criminal offences. The claimants challenged UK law that allowed law enforcement agencies to indefinitely retain their fingerprints and biological samples. The case went to the House of Lords[841] before being heard by the Grand Chamber of the European Court of Human Rights.[842]

One of the questions was whether the retention of these samples violated Article 8 of the *ECHR*,[843] espousing the "right to respect for private and family life". In the House of Lords, in her dissenting judgment, Baroness Hale considered the question from the perspective of whether the biological samples were personal information attracting privacy protection. She stated:

> It could be said that the samples are not "information". But the only reason that they are taken or kept is for the information which they contain. They are not kept for their intrinsic value as mouth swabs, hairs or whatever. They are kept because they contain the individual's unique genetic code within them. They are kept as information about that person and nothing else. Fingerprints and profiles are undoubtedly information. The same privacy principles should apply to all three.[844]

What is notable about this reasoning is that Baroness Hale's characterization of the samples as "information" did not pertain to a particular privacy statute but appears to be derived and established as a common law principle. Her judgment was in dissent, and therefore does not create binding precedent, however, the other members of the House of Lords did not overtly disagree with this characterization. They did not directly address the question of whether the samples were "information", and instead, they found Article 8 was not violated on other grounds.

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[839] ALRC, *Essentially Yours*, *supra* note 68 at 262–67.
[840] *Marper,* UKHL, *supra* note 67; *Marper,* ECtHR, *supra* note 67.
[841] *Marper,* UKHL, *supra* note 67.
[842] *Marper,* ECtHR, *supra* note 67.
[843] *ECHR*, *supra* note 752.
[844] *Marper* UKHL, *supra* note 67 at para 70 [citations omitted].

The case was then appealed to the European Court of Human Rights, where the Grand Chamber unanimously held:

> … all three categories of the personal information retained by the authorities in the present cases, namely fingerprints, DNA profiles and *cellular samples*, constitute personal data within the meaning of the Data Protection Convention as they relate to identified or identifiable individuals.[845]

This decision specifically interpreted the *Data Protection Convention*, which is a Convention applicable to all EU member states. The understanding of "personal information" to specifically include cellular samples, alongside other types of information, is therefore significant with potentially far-ranging application. The Court, however, failed to support this pronouncement with any analysis as to the legal meaning of "personal information". This could be because, as the Court noted, "[t]he [UK] Government accepted that fingerprints, DNA profiles and samples were 'personal data' within the meaning of the Data Protection Act".[846] The Government's position was not based on the definition of "personal information" but whether their retention policy engaged Article 8 of the *ECHR*.[847]

While it would be useful to have a clearer picture upon which the Court based its pronouncement about cellular samples constituting "information" within the meaning of the *Data Protection Convention*, the decision "seems to signal a degree of judicial acceptance" of the view that human biomaterials constitute information.[848] The unanimity of the Court in its judgment adds further support to this proposition.[849] Further, the fact that this understanding was uncontested by the UK Government is also notable and reflective of Baroness Hale's interpretation of this point as a matter of UK law.

Additionally, the dearth of analysis provided by the Grand Chamber to support its interpretation of "personal data" has not proved problematic in terms of the precedential value of the decision. In the more recent 2020 decision of the European Court of Human Rights, *Gaughran v United Kingdom,*[850] the Court had to consider whether the indefinite retention of biometric data of individuals convicted of certain offences in Northern Ireland was an impermissible violation of

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[845] *Marper,* ECtHR, *supra* note 67 at para 68 [emphasis added].
[846] *Ibid* at para 63 (see also para 68).
[847] *Ibid*.
[848] Bygrave, "The Body as Data?", *supra* note 31 at 10.
[849] *Ibid* at 10–11.
[850] *Gaughran*, *supra* note 67.

Article 8 of the *ECHR*. The Applicant in *Gaughran* was fingerprinted, photographed, and had a buccal swap taken after his arrest for a drunk driving offence. A DNA profile was created from the buccal swab, after which the physical sample was destroyed. As a result, the retention (and informational status) of the physical biomaterial was not an issue in the case. Nevertheless, the Court noted:

> … *it is not disputed by the Government that DNA material is personal data* and that in the present cases there was an interference with the applicant's right to respect for his private life. The Court, having regard to its case-law, according to which DNA profiles clearly constitute data pertaining to one's "private life" and their retention amounts to an interference with the right to respect for one's private life within the meaning of Article 8 § 1 of the Convention (see S. and Marper, cited above, §§ 67-77), finds no reason to hold otherwise.[851]

Although the status of the physical material itself was not an issue in the case, it seems to be taken for granted, following *Marper,* that it is, in fact, "personal data".[852]

It is also significant that the pronouncement in *Marper* by the European Court of Human Rights was tied specifically to the *Data Protection Convention*, whereas in *Gaughran,* the inclusion of physical biomaterials within the meaning of "data" has been articulated as a generalizable principle. While this aspect of *Gaughran* may not be binding given that this was not a disputed issue in the case, it nevertheless adds support to the idea that biomaterials can, at least in some circumstances, be characterized as "personal data", which could potentially be applied to a wider array of contexts in the future.

The *Marper* decision and its treatment of biomaterials as "personal data" attracted attention in privacy scholarship. Bygrave analyzed the case and noted some of the benefits of taking a data privacy approach to regulating human biomaterials.[853] While he ultimately reached a lukewarm conclusion as to whether the law should move further in this direction, he provided evidence, arguments, and benefits of this approach,[854] which influenced subsequent work by privacy scholars, Dara Hallinan and Paul de Hert, who argue the European Union's *GDPR* should be interpreted in this manner.[855]

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[851] *Ibid* at para 63 [emphasis added].
[852] This point is reinforced by a heading used in the judgment, which states, "Retention of biometric data (DNA samples and profiles, fingerprints)", suggesting that DNA samples are a form of "biometric data".
[853] Bygrave, "The Body as Data?", *supra* note 31.
[854] *Ibid*.
[855] Hallinan & De Hert, *supra* note 65.

While the above examples illustrate some support for this interpretation in Australian legislation and European case law, there is also limited support in Canada reflected in the *Piljak* decision[856] (discussed in Chapter 4) and the Supreme Court of Canada decision, *R v Dyment*.[857] *Dyment* involved a man, Dyment, who was brought to hospital after being involved in a motor vehicle accident. While he was unconscious, a doctor filled a vial of free-flowing blood coming from an open wound in Dyment's head.[858] The doctor filled the vial solely for medical testing but then later handed it to a police officer investigating the collision. The police officer did not have a warrant, nor did he obtain Dyment's consent. Subsequent testing of the sample revealed Dyment's blood alcohol level exceeded what was permitted under the *Criminal Code*.

Dyment was convicted of driving while intoxicated and successfully appealed his conviction to the Supreme Court of Prince Edward Island on the grounds that the taking of his blood violated his *Charter* rights, including his section 8 rights to be secure against unreasonable search or seizure. Mitchell J found that the blood sample formed part of Dyment's medical record, which was confidential, and the transfer and receipt of the sample by the police amounted to "a gross violation of the sanctity, integrity and privacy of the appellant's bodily substances and *medical records*".[859] The Crown then appealed to the Appeal Division of the Supreme Court of Prince Edward Island, where MacDonald J, on behalf of the Court, agreed there had been an unlawful search and seizure. MacDonald J held it was unlawful because (i) there was no evidence the police officer held a reasonable belief that Dyment had committed an offence, and (ii) because it violated PEI's *Hospital Act,* which prohibited hospitals from removing *information* from a *medical record* except under certain conditions which were not met in the case.[860] Similar to Mitchell J, MacDonald J believed the blood sample formed part of Dyment's medical record. The purpose behind the statutory obligation to compile the medical records was to keep patients' information confidential, and the blood sample would reveal information when analyzed.[861]

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[856] *Piljak*, *supra* note 473.
[857] *Dyment*, *supra* note 69.
[858] *Ibid* at para 12.
[859] *Ibid* at para 17 (La Forest J), quoting from the Supreme Court of PEI judgment: 47 Nfld & PEIR 350 at 355 [emphasis added].
[860] *Ibid* at para 18 (La Forest J), citing the Supreme Court of PEI Appeal Division decision: 57 Nfld & PEIR 210.
[861] *Ibid*.

The case was then appealed to the Supreme Court, and while none of the Supreme Court Justices directly considered the question of whether the blood sample formed part of Dyment's medical record, and, instead, upheld the finding that Dyment's *Charter* rights had been violated on other grounds (to be returned to in Chapter 8), La Forest J noted that Michell J from the Supreme Court of PEI was "substantially right" in finding there had been "a gross violation to the sanctity, integrity and privacy of the appellant's bodily substances *and medical records*".[862] Further, La Forest J's judgment uses informational language to refer to the blood sample, indicating that it was "*confided*" for medical purposes,[863] providing tacit support for an informatized view of biomaterials.

The *Piljak* case, discussed in Chapter 4, further supports the idea of biomaterials forming part of a patient's medical record. In that case, the Master found a diagnostic tissue sample to be "property" on the bases that (i) individuals own their tissue while attached and transfer ownership upon excision; and (ii) the tissue becomes part of the medical record, which, according to *McInerney,* is owned by the institution. By solely focusing on the property implications of this characterization, however, the Master failed to grapple with the significant privacy law implications of this pronouncement.

Characterizing a physical biomaterial sample as a "record" begs the question as to what it is a record of. Is it possible for it to be a record of anything other than *information*? The concepts of "record" and "information" are inextricably tied. Canada's *Privacy Act,* for example, defines "personal information" to mean "information about an identifiable individual that is *recorded* in any form".[864] The connection between "information" and "record" was explained by Alberta's Information Privacy Commissioner as follow: "it is clear that 'information' is part of a record and is contained in a record, and that *there would not be a record without information*".[865]

If Master Dash is correct that Mrs. Piljak's biomaterial formed part of her medical record, it logically follows that the biomaterial is a record of *information*. Indeed, on the facts of the case,

[862] *Ibid* at para 49 [emphasis added].
[863] *Ibid* at para 45 [emphasis added].
[864] *Privacy Act* (CAN), *supra* note 542, s 3 [emphasis added].
[865] *Re Alberta (Human Rights and Citizenship Commission), Order 97-020*, [1998] CarswellAlta 2086 at para 56 (Robert C Clark, Commissioner) [emphasis added].

the defendants were seeking access to the sample to understand whether her cancer should have been detected earlier. In other words, it was being sought for its informational value.

The Master's view accords with some Canadian scholarship. The decision was heavily influenced by an article published by Cheung et al,[866] which also advocated for an understanding of biomaterial samples forming part of the "medical record" for *property law* purposes without considering the *privacy* implications involved. In contrast, while health law scholars, Ubaka Ogbogu, Sarah Burningham and Timothy Caulfield, also advocate for an understanding of biomaterials as forming part of the "medical record", their analysis is not directed at justifying institutional property rights but grounding individual control and access rights.[867] The authors in neither article, however, address the more fundamental question of whether physical DNA molecules are capable of being understood as "information" or "data" from which to constitute a "record". Instead, this appears to simply be assumed.[868] If this assumption proves true, though, then as Ogbogu et al point out, there are important implications in terms of individual access to and control of biomaterials. These and other advantages to an informatized approach will now be considered in more detail.

B. Identifying the Benefits of an Informational Approach

In 2003, the ALRC published its seminal report addressing how Australia should regulate and protect genetic information.[869] The Report contained a chapter examining human samples, which acknowledged the New South Wales legislation (which applies to body samples) and queried whether the Commonwealth *Privacy Act* could be similarly interpreted to include physical samples within the meaning of "personal information". While the ALRC concluded the *Privacy Act*, as it currently stood, could not be so interpreted, it nevertheless recommended, with broad support from many privacy bodies, that the Commonwealth legislation should be amended to reflect the New South Wales approach.[870]

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[866] Cheung, Martin & Asa, *supra* note 475.
[867] Ogbogu, Burningham & Caulfield, *supra* note 12.
[868] For example, Ogbogu et al make statements such as "...the health information is contained within a cell or a tissue sample" and query whether biomaterials are "analogous to physical medical records" given they "contain[] 'personal and private' genetic information about an individual": *Ibid* at 282–83.
[869] ALRC, *Essentially Yours*, *supra* note 68.
[870] *Ibid* at 277–78 & 285–87.

This recommendation arose from concerns that biomaterials, particularly those stored in the research context, were not adequately protected.[871] While the ALRC's recommendation on this issue was ultimately not adopted by the Australian Commonwealth government, its report is nevertheless significant in demonstrating the utility of such an approach to enhance consistency and fill regulatory gaps. The following discussion will elaborate upon the benefits of this approach. It will show how an understanding of biomaterials as "personal information" could (i) provide needed regulatory consistency; (ii) close regulatory gaps; (iii) ground individual rights of access and withdrawal of consent; (iv) promote policy creation; (v) utilize a ready-made regulatory framework; and (vi) complement privacy torts.

i. Consistency in Regulation

While a distinction between physical samples and information is often taken for granted, the logic behind this regulatory categorization needs consideration in light of technological advancements in genetics and information technology. Privacy scholar, Mark Taylor, has gone so far as to assert the burden should be on those seeking to impose a distinction rather than the other way around given that both recorded genetic information and physical biomaterials are the same in terms of their interpretive potential.[872] For example, if a sample has been collected for the purpose of being sequenced and used in research, due to the increased speed and decreased cost of sequencing, "[a]nything that can be done with sequenced genetic information, can also be done with the original sample and a sequencing machine".[873]

Given that both physical biomaterials and recorded genetic information can reveal the same information about an individual, "there is no clear distinction between biological sample and recorded information from a privacy perspective".[874] A justification is therefore needed for treating them differently.[875] In some respects, physical samples are actually more vulnerable than digitized information, the latter of which can be encrypted and subjected to other digital security measures

[871] *Ibid* at 268–77.
[872] Taylor, *supra* note 65 at 158.
[873] Hallinan & De Hert, *supra* note 65 at 124.
[874] Taylor, *supra* note 65 at 158–59.
[875] *Ibid* at 158.

to prevent unauthorized access.[876] In contrast, so long as biomaterials continue to exist in their physical form, the genetic information within them can be accessed.[877]

The ALRC's Report similarly noted the need for consistency between the regulation of physical samples and the information they contain, particularly as physical samples are increasingly being used for the purpose of extracting their genetic information.[878] Instead, as genetic information is subject to privacy legislation while physical samples are not (with the exception of New South Wales), genetic information is more heavily regulated than the physical samples it is derived from. The logic of this distinction is questionable[879] and gives rise to regulatory inconsistencies and gaps that become apparent when considering requirements for consent and disclosure.

ii. Filling Regulatory Gaps

The ALRC noted differences in consent requirements between the collection of genetic information and physical biomaterials. Under the *Privacy Act (Cth),* there is an obligation to obtain consent when collecting genetic information and to disclose to the individual how the information will be handled.[880] Both Canada and Australia have "Privacy Principles"[881] that must be complied with as a matter of privacy law.[882] Australia's *Privacy Principles* provide that sensitive information cannot be collected unless the individual consents and the information is reasonably necessary for the entity's functions or activities.[883] Canada's *Privacy Principles* similarly require "knowledge and consent" for collection, use, and disclosure of personal information, subject to certain exceptions, considered further below.[884]

Consent in this respect needs to be sufficiently informed. Under Alberta's *Health Information Act,* for example, individuals must be informed as to the purpose for which their personal information is being collected.[885] Under Canada's *PIPEDA*, "the consent is only valid if

[876] Gedefa Urgessa, *supra* note 65 at 105.
[877] *Ibid*.
[878] ALRC, *Essentially Yours*, *supra* note 68 at 269.
[879] Taylor points out the unjustified and arbitrary nature of the exclusion of biomaterials from privacy frameworks in this respect: Taylor, *supra* note 65 at 159; see also Hallinan & De Hert, *supra* note 65 at 124.
[880] ALRC, *Essentially Yours*, *supra* note 68 at 269.
[881] Canadian *Privacy Principles*, *supra* note 553; Australian *Privacy Principles*, *supra* note 552.
[882] *PIPEDA*, *supra* note 543, s 5(1); *Privacy Act* (Cth), *supra* note 548, s 15.
[883] Australian *Privacy Principles*, *supra* note 552, s 3.3.
[884] Canadian *Privacy Principles*, *supra* note 553, s 4.3.
[885] *Health Information Act* (AB), *supra* note 546, s 22(3).

it is reasonable to expect that an individual to whom the organization's activities are directed would understand the nature, purpose and consequences of the collection, use or disclosure of the personal information to which they are consenting".[886] Further, consent is also required when personal information is to be used for a different secondary purpose from what it was originally collected for.[887] Similarly, Australian *Privacy Principles* provide that information collected for a primary purpose cannot be used or disclosed for a different purpose unless the individual consents or exceptions apply,[888] including if the individual would reasonably expect the secondary use or disclosure and the secondary purpose is directly related to the primary purpose (if dealing with sensitive information).[889]

There are no similar legal provisions for physical samples.[890] While the law of battery imposes a consent requirement for the removal of tissue, this consent does not need to be fully informed.[891] Where biomaterials are removed specifically for a primary research purpose, consent must be given under the relevant tissue donation statutes, but the statutes similarly fail to impose any disclosure obligations in terms of what participants need to be told.[892] In contrast, New South Wales legislation, which applies to bodily samples, imposes a requirement that the individual be informed as to "the purposes for which the information is collected" as well as "the persons to whom (or the types of persons to whom) the organisation usually discloses information of that kind".[893] A significant gap in the law exists in jurisdictions that lack this protection, particularly in the research context where many research biomaterials were initially collected for a different primary purpose (as discussed in Chapter 3).

The UK regulatory landscape contains a potential conflict in this regard. As pointed out in Chapter 3, broad consent for the collection of physical biomaterials in biobanking is common. While the UK's *Human Tissue Act* allows for this approach,[894] it does not necessarily follow that such consent encompasses the processing and use of genetic information within the sample.

[886] *PIPEDA*, *supra* note 543, s 6.1.
[887] Canadian *Privacy Principles*, *supra* note 553, s 4.2.4.
[888] Australian *Privacy Principles*, *supra* note 552, s 6.1.
[889] *Ibid*, s 6.2.
[890] ALRC, *Essentially Yours*, *supra* note 68 at 269.
[891] *Ibid*.
[892] *Ibid* at 270.
[893] *Health Privacy Act* (NSW), *supra* note 66, s 4(1) of Sch 1.
[894] Human Tissue Authority, *supra* note 220 at 13–14.

Regardless of what is permitted with respect to the physical tissue by the *Human Tissue Act*, as soon as the sample is sequenced, the UK's *Data Protection Act* applies, where, as Hallinan and De Hert point out, "[i]t is far from clear" whether broad consent is legally permitted.[895]

The Office of the Australian Information Commissioner has also interpreted consent requirements under the *Privacy Act (Cth)* to require specific consent, requiring organizations to "explain the reason for their request and be as specific as possible" without "ask[ing] for a broader consent than is necessary". The OAIC specifically notes that individuals "shouldn't be asked to consent to undefined future uses".[896] Given the interpretive potential is the same as between physical biomaterials and the recorded genetic information obtained from them, there should be consistency in terms of disclosure obligations and consent requirements. Where biomaterials are used for a secondary purpose, in particular, there is a regulatory vacuum. This is problematic not only in terms of individuals potentially not knowing their biomaterials can be collected and used for other purposes, but also in terms of where those biomaterials might end up.

Personal information is subject to rules governing disclosure, whereas no similar equivalent exists for physical biomaterials.[897] Australia's *Privacy Act (Cth),* for example, imposes restrictions on the disclosure of personal information for purposes other than the primary purpose for which the information was collected unless the information subject has given consent.[898] Alberta's *Health Information Act* provides that disclosure should be done with consent or within the confines of a finite list of specified purposes in the Act.[899] The lack of similar regulations regarding "disclosure" (which, in this context, is better understood as a "transfer" of biomaterials),[900] creates regulatory gaps ripe for exploitation.

To illustrate this problem, the ALRC used an example of a personal investigator seeking access to a newborn screening card for a private paternity investigation. Under existing law, the public health authority storing the newborn screening cards could not disclose the card itself to the investigator, as the card is a record of information coming under the ambit of privacy legislation.[901]

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[895] Hallinan & De Hert, *supra* note 65 at 127.
[896] Office of the Australian Information Commissioner, *supra* note 558.
[897] ALRC, *Essentially Yours*, *supra* note 68 at 271.
[898] *Ibid*.
[899] *Health Information Act* (AB), *supra* note 546, ss 34–40.
[900] ALRC, *Essentially Yours*, *supra* note 68 at 271.
[901] *Ibid*.

However, there would be no legal obstacles to the public health authority punching a hole from the blood spot on the card and transferring a piece of the blood sample to the investigator.[902] This action would not amount to a privacy breach under legislation or a violation of any other law. In contrast, in New South Wales, health information (including bodily samples) collected for one purpose cannot be disclosed for a different purpose unless the individual consented or other relevant exceptions allow for the disclosure,[903] none of which would apply to this circumstance.

Further, the *Privacy Act (Cth)* prohibits transferring personal information overseas unless the receiving country has laws similar in substance to those in Australia or the transferor otherwise ensures that the information will be treated to the same standards imposed by Australian law.[904] Similarly, Canada's *Privacy Principles* provide that an organization remains responsible for personal information it possesses "including information that has been transferred to a third party for processing" and that organizations must "use contractual or other means to provide a comparable level of protection while the information is being processed by a third party".[905] Alberta's *Health Information Act* imposes a similar requirement to maintain safeguards to protect privacy and confidentiality of information to be disclosed to others outside Alberta.[906] The same obligation does not apply to physical biomaterials, except in New South Wales,[907] meaning they could be transferred elsewhere without any restrictions on how they could be subsequently used or further transferred.[908]

iii. Rights of Access and Withdrawal of Consent

Bringing biomaterials within definitions of "personal information" would not only fill these gaps regarding the collection and transfer of biomaterials but also create important rights of access and withdrawal of consent. Privacy legislation gives individuals rights of access to the information about them that is stored by others.[909] For example, the Canadian *Privacy Principles* provide that, upon request, organizations must inform individuals if they hold personal information about the individual and "shall allow the individual access to this information" and "shall provide

[902] *Ibid*.
[903] *Health Privacy Act* (NSW), *supra* note 66, s 11 of Sch 1.
[904] *Privacy Act* (Cth), *supra* note 548, s 16C; Australian *Privacy Principles*, *supra* note 552, ss 8.1 & 8.2.
[905] Canadian *Privacy Principles*, *supra* note 553, s 4.1.3.
[906] *Health Information Act* (AB), *supra* note 546, s 60(1)(b).
[907] *Health Privacy Act* (NSW), *supra* note 66, s 14 of Sch 1.
[908] ALRC, *Essentially Yours*, *supra* note 68 at 271.
[909] *Ibid*.

an account of the use that has been made or is being made of this information and an account of the third parties to which it has been disclosed".[910] Similar provisions exist under the Alberta legislation[911] and Australian *Privacy Principles*.[912]

No similar right of access exists for biomaterials.[913] This is a problem for individuals who could have legitimate reasons for accessing stored biomaterials. To return to Goold and Quigley's example of "Anne's biopsy" from Chapter 2, there are any number of reasons why Anne may wish to re-gain control over her donated sample, including moving it to a different research study, subjecting it to further testing, perhaps to avoid a new procedure or gain information about the state of her health at the time it was taken, for health or legal purposes.[914]

The *Roche, Piljak,* and *Dobson* cases each involved situations where litigants were seeking access to stored pathology samples. In each case, the question of whether the respective samples were "property" was central to resolving the claims. However, focusing on the physical properties of the samples and whether they are objects of personal property ignores the strong informational interest individuals have in their separated biomaterials. As the physical samples have the same interpretive potential as any data recorded once the sample is analyzed, the same rationale for allowing individuals access to their personal information exists in relation to their physical biomaterials. Whether a sample is "property" and if so, who the property rights-holder is, are not questions that should be relevant to whether an individual can gain access to their own sample. And the benefits of this approach would go both ways. A plaintiff who puts their health at issue in civil litigation must disclose relevant health information to the defence that would otherwise be private. An understanding of biomaterials as information would similarly enable their discovery by the defence without needing to prove their status as "property". This would have been particularly helpful in *Piljak,* where it was the defence seeking access to the sample.

This right of access could therefore be grounded by extending information privacy law to physical biomaterials. The right may need to be tailored or limited given public health concerns in handling bodily material,[915] but "access" in this sense could be understood to mean access by a

[910] Canadian *Privacy Principles*, *supra* note 553, s 4.9.1.
[911] *Health Information Act* (AB), *supra* note 546, s 7.
[912] Australian *Privacy Principles*, *supra* note 552, s 12.1.
[913] ALRC, *Essentially Yours*, *supra* note 68 at 273.
[914] Goold & Quigley, *supra* note 113 at 247.
[915] ALRC, *Essentially Yours*, *supra* note 68 at 273–74.

registered pathologist to perform testing on behalf of an individual. For example, the New South Wales legislation provides a right of access, which includes a right to authorize another's access to one's information[916] (which could include a pathologist), and the form of access includes an "inspection"[917] (which could conceivably include a pathologist's examination). Information custodians are permitted to deny access requests where the requested form of access would be "detrimental to the preservation of the information or…would otherwise not be appropriate",[918] which could apply if inspection would destroy the sample, or the applicant made an inappropriate request to have biological material returned personally to them. Further, the Privacy Commissioner can issue Guidelines regarding certain forms of access.[919] While Guidelines specific to bodily samples have yet to be issued, if necessary, it is possible this could be done to clarify the scope and application of these provisions in this context.

Some contend that rights of access could be extrapolated one step further as giving rise to a correlated duty to conserve.[920] In New South Wales, for example, there is a statutory obligation to retain health information for seven years.[921] This could be useful in *Dobson*-type situations where the allegation is one of wrongful destruction.

In addition to rights of access, information privacy law also provides a right to withdraw consent. For example, Canada's *Privacy Principles* provide that "[a]n individual may withdraw consent at any time, subject to legal or contractual restrictions and reasonable notice".[922] The Office of the Australian Information Commissioner has similarly interpreted consent requirements under the *Privacy Act (Cth)* as including a right to withdraw consent at any time,[923] and the Alberta legislation provides a right to withdraw prior consent to third-party disclosures.[924]

As discussed in Chapter 3, a right to withdraw consent in research using biomaterials, particularly in the biobanking context, has given rise to debate. One of the major problems with employing a property law approach is the reduction of consent to a one-time transfer of rights over

[916] *Health Privacy Act* (NSW), *supra* note 66, ss 26–27.
[917] *Ibid*, s 28(1)(b).
[918] *Ibid*, s 28(3).
[919] *Ibid*, s 28(2).
[920] Taylor, *supra* note 65 at 178.
[921] *Health Privacy Act* (NSW), *supra* note 66, s 25.
[922] Canadian *Privacy Principles*, *supra* note 553, s 4.3.6.
[923] Office of the Australian Information Commissioner, *supra* note 558.
[924] *Health Information Act* (AB), *supra* note 546, s 34(2).

biomaterials. As mentioned in Chapter 5, even Quigley, who is among those most strongly advocating for individual property rights, sees no problems with this understanding of property law and consent.[925] However, Chapter 3 demonstrated the need for *ongoing* control and a more robust understanding of autonomy staying true to the notion that consent is an ongoing state of affairs that must continue to exist.

By recognizing individual legal rights to withdraw consent, privacy law can accommodate this more robust understanding of consent. Treating biomaterials as personal information in this respect avoids the strain of needing to conceptualize the transfer of biomaterials as either a conditional gift or bailment, which was the issue in *Catalona,* and instead, understands the right to withdraw as an inherent part of the privacy protection afforded to individuals over their personal information. This requirement also fits nicely with the consent requirements above, which require additional consent for secondary uses of personal information. A right to withdraw can be more meaningfully exercised when an individual is made aware of the purposes for which their biomaterials are used.

The ongoing nature of individuals' interests in biomaterials aligns better with a privacy approach than the application of property law. This is because once property rights are given away, the former rights-holder incurs a new legal obligation to refrain from interfering with the object of property. In contrast, privacy rights are non-transferrable.[926] As Radhika Rao, legal expert in biomaterial regulation, notes, "the idea that one individual may assert another's privacy right is incoherent."[927] The informational privacy interests that an individual has in relation to their biomaterials remain with the individual regardless of physical possession. Rights of access and withdrawal would better recognize the ongoing nature of individuals' interests in biomaterials than configurations of property rights, which are inherently transferrable.

iv. Incentivize Policy Creation

In addition to filling regulatory gaps and grounding individual rights of access and withdrawal of consent, extending the application of information privacy law to biomaterials will also play a preventive role in privacy protection. This is because privacy statutes legally obligate

[925] Quigley, *supra* note 5 at 269–71.
[926] Radhika Rao, "Property, Privacy, and the Human Body" (2000) 80 BU L Rev 359 at 434–37; Wall, *Being and Owning, supra* note 26 at 203.
[927] Rao, *supra* note 926 at 437.

organizations collecting personal information to articulate clear and transparent policies as to how they use, store, and transfer personal information.[928] For example, the Canadian *Privacy Principles* require organizations to implement publicly accessible policies and procedures for the management of personal information, including how personal information is protected and how the organization will receive and respond to privacy complaints.[929] Similarly, the Australian *Privacy Principles* require relevant entities to implement "practices, procedures and systems" to ensure compliance[930] and to create publicly available policies, which must contain specific information about the uses and disclosures of personal information and the ability of individuals to access their information and lodge complaints.[931] The Alberta *Health Information Act* also requires custodians to establish policies and procedures to implement the requirements of the Act.[932]

By requiring organizations to articulate clear and transparent policies and practices for handling biomaterials, entities using biomaterials will be forced to directly confront and acknowledge the individual privacy interests at stake. Explicit policy creation in this respect can play an important role in preventing unauthorized access and misuse of biomaterials in one's possession. While the creation of policy does not necessarily mean it will be enforced, it certainly places an onus on organizations to justify their practices in handling biomaterials, and underlying privacy legislation provides standardization in terms of the minimum requirements that must be fulfilled.

Instead, under the current legal environment, from the point that biomaterials are collected to the point they are sequenced (or otherwise analyzed in a manner giving rise to recorded personal information), they are in a regulatory limbo. While the recorded genetic information obtained through the sequencing process would be subject to information privacy law, the biomaterials themselves are not. As discussed above, the lack of rules regarding disclosure, consent for secondary uses, and transfer to others means that any number of things can be done to one's biomaterials by any number of actors without the need for the individual to know or consent. By bringing biomaterials within the ambit of privacy law and institutional policy, regulation begins

[928] ALRC, *Essentially Yours*, *supra* note 68 at 275; see also Mizrahi, *supra* note 565 at 2–3.
[929] Canadian *Privacy Principles*, *supra* note 553, ss 4.1.4 & 4.8.1.
[930] Australian *Privacy Principles*, *supra* note 552, s 1.2.
[931] *Ibid*, ss 1.4-1.5.
[932] *Health Information Act* (AB), *supra* note 546, s 63.

"closer to the point of collection", thereby increasing the effectiveness of existing rules and "the capacity to keep track of the use and transfer of genetic samples from the source to the end user of genetic information".[933]

v. Ready-made Regulation

Extending information privacy law to encompass biomaterials also means that aspirations to fill regulatory gaps and enhance regulatory consistency can be achieved without having to reinvent the wheel. Privacy principles, for example, are designed to be flexible and are generally articulated with a high level of abstraction, allowing them to be generalizable and adaptable to a changing technological landscape.[934] In terms of their content, while some principles might require modification to apply to physical biomaterials (for example, requirements for access, as noted above, would need to be subject to certain public health limitations, and "disclosure" of information might be better understood in terms of a "transfer" of biomaterials),[935] most privacy principles are capable of being applied to physical biomaterials.[936]

This generalizability of privacy principles could be beneficial in terms of spurring greater standardization and best practices in biobank regulation, which is a field that remains highly fragmented.[937] In fact, privacy principles are already reflected in some biobank governance codes.[938] And when suspected privacy violations occur, investigative and regulatory bodies and procedures already exist to receive, investigate, and determine complaints.[939]

To the extent that there are already statutory frameworks governing biomaterials in specific contexts, such as organ donation or assisted reproductive treatments, the ALRC was unbothered by the potential overlap or conflict of legal provisions. This is because privacy legislation generally allows for information collection, use, storage, and disclosure that are "required or authorized by or under law".[940] And should such an expansion open the floodgates to an unacceptably high volume of material, the ALRC acknowledged that the scope could be potentially reduced by

[933] ALRC, *Essentially Yours*, *supra* note 68 at 276.
[934] Bygrave, "The Body as Data?", *supra* note 31 at 14; ALRC, *Essentially Yours*, *supra* note 68 at 282.
[935] ALRC, *Essentially Yours, supra* note 68 at 270–71 & 273–74.
[936] Bygrave, "The Body as Data?", *supra* note 31 at 21; ALRC, *Essentially Yours*, *supra* note 68 at 276–77.
[937] Bygrave, *Data Privacy Law, supra* note 59 at 128; Hallinan & De Hert, *supra* note 65 at 126.
[938] Bygrave, "The Body as Data?", *supra* note 31 at 21.
[939] ALRC, *Essentially Yours*, *supra* note 68 at 276.
[940] *Ibid* at 281.

specifically excluding certain activities or actors from the application of information privacy law where a robust set of regulations already exists, such as for post-mortem examinations or coronial inquests.[941]

Expanded definitions of "personal information" to include biomaterials would, however, come with some practical burdens. Most information privacy statutes are governed by an administrative oversight body or office, which may not have expertise in matters pertaining to physical biological samples.[942] The expansion of a privacy commissioner's competence to include physical biomaterials would therefore come with concomitant needs for training and additional resources to handle investigations involving a new type of subject matter.[943] In addition, as noted above, while general principles underlying data privacy law can be applied to physical biomaterials, there would nevertheless be a need to adjust certain provisions (like access and "transfer") for the sake of coherency.[944] As the privacy legislative landscape is complex, this could require amendments to many different legislative instruments.[945]

While the practical concerns raised by this approach are important to consider, they are surmountable. Whether it is worthwhile to embark on this course essentially depends on whether the value to be realized outweighs the associated limitations. Taylor argues that, given the incredible value biomaterials bring to research and other institutions, the practical burden of adequate regulation is justifiable.[946] Further, advances in information technology already mean that privacy commissioners and government departments are continuously needing to expand their expertise. The need to stay current in a rapidly changing technological environment is simply a requirement of the job. Additionally, the statements of various Canadian privacy commissioners, highlighted above, reveal that they might already view biomaterial regulation as part of their jurisdictional reach. Given the many advantages such an approach could yield, it is at least a regulatory path worth considering.

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[941] *Ibid* at 282.
[942] Bygrave, "The Body as Data?", *supra* note 31 at 22.
[943] ALRC, *Essentially Yours*, *supra* note 68 at 285; Bygrave, "The Body as Data?", *supra* note 31 at 22.
[944] Bygrave, "The Body as Data?", *supra* note 31 at 22.
[945] *Ibid*.
[946] Taylor, *supra* note 65 at 178.

vi. Supplement to Privacy Torts

The discussion thus far has focused on how understandings of "information" as encompassing biomaterials could give rise to new regulation under statutory privacy frameworks. In this respect, greater consistency can be achieved between the regulation of physical biomaterials and the genetic information within them, justified by the fact that the interpretive potential of the two is the same. Further, regulatory gaps surrounding consent, disclosure, and transfer could be filled and new rights of access and withdrawal of consent could be recognized. This shift could facilitate both a preventative approach by incentivizing policy creation and provide a system of accountability using the complaints procedures and investigative powers bestowed upon Privacy Commissioners through these statutes. While this, alone, would represent a significant evolution in terms of recognizing individual interests in biomaterials, as discussed in the previous chapter, these statutory frameworks represent only one half of the privacy landscape. Tort law protection has also emerged to enhance the remedial potential of privacy law.

The interaction between information privacy statutes and privacy torts is therefore important to consider. While the content of privacy torts and how they might apply to biomaterials will be elaborated upon in the next chapter, an initial point to note is that, at a minimum, treating biomaterials as "information" is unlikely to hinder the development of privacy torts in relation to biomaterials, and could actually facilitate this progression. As discussed in the previous chapter, defendants in privacy tort cases have sometimes argued that where there is overlap between the alleged privacy violation and the subject-matter governed by information privacy statutes, the statutory frameworks should apply to the exclusion of privacy torts. However, these arguments have been unsuccessful, with courts ready to conclude that the two frameworks can co-exist.[947] Treating biomaterials as personal information within the meaning of information privacy statutes would therefore be unlikely to adversely affect their incorporation into privacy torts.

To the contrary, treating these materials as personal information could be beneficial. This is because judges deciding privacy tort claims often have recourse to information privacy statutes to help guide their analyses. For example, in *Jones v Tsige*, Sharpe JA explicitly referred to the principles articulated in the Manitoba legislation for awarding damages,[948] and in *Halley v*

[947] *Hopkins v Kay*, [2015] ONCA 112; *Romana v Canadian Broadcasting Corp*, [2016] MBQB 33 [*Romana*].
[948] *Jones*, *supra* note 71 at para 81.

McCann, the statutory meaning of "personal information" formed the starting point of the judge's analysis.[949] If "personal information" was explicitly defined in statute to include biomaterials, this could be similarly influential in cases involving allegations that informational privacy interests in biomaterials have been infringed.

In addition, statutory requirements and institutional policies could be relevant in determining privacy tort claims alleged on standards of recklessness. As discussed in Chapter 6, there is doubt across several jurisdictions as to whether an institution could be liable under privacy torts for carelessly or recklessly allowing a third party to violate the plaintiff's privacy. However, there is some authority in Canadian federal courts that leaves the possibility open.[950] Further, where plaintiffs have suffered economic loss or other compensable harm, it is also possible to pursue ordinary negligence claims against institutional defendants. In either case, by bringing biomaterials within information privacy frameworks, these frameworks and institutional policies, which would establish relevant obligations and best practices for safeguarding biomaterials, would be useful to determine the standard of care should a third-party damage or destroy biomaterials stored by an institution.[951]

C. Realizing the Benefits of an Informational Approach

The preceding discussion outlined legal and scholarly support for the inclusion of biomaterials in definitions of "personal information", and resulting benefits that this interpretational approach could yield. However, the realization of these benefits depends on the scope of this expanded understanding and ability to overcome some of the known limitations of information privacy statutes. The following discussion will therefore consider these issues, in turn.

i. Scope of Application

As most biomaterials contain DNA, the question arises as to whether all biomaterials containing DNA should be treated as records of "information", or whether there ought to be limits in this regard. An additional interpretational issue arises with respect to the meaning of "personal" in the context of "personal information". Information privacy statutes are not concerned with all

[949] *Halley*, *supra* note 672 at para 27.
[950] *Sweet*, *supra* note 604 at para 132.
[951] While not discussing biomaterials, Mizrahi makes this point, more generally, in relation to database defendants: Mizrahi, *supra* note 565 at 28.

forms of information and data, but only those that are "personal", denoting a connection between the information and an identifiable individual to whom it pertains. Whether a particular biomaterial is "personal information" therefore depends, both, on how far "information" extends and how strong of a connection is needed to an identifiable person.

Thresholds of identifiability, however, are not always clear or easy to apply. Often, criteria based on reasonableness of identification are used, encompassing considerations of the likelihood that the individual would be identified and difficulty with which identification can be made.[952] Australia's Commonwealth *Privacy Act,* for example, defines "personal information" to mean "information or an opinion about an identified individual, or an individual who is reasonably identifiable".[953] Canada's *Privacy Act* defines "personal information" to mean "information about an identifiable individual that is recorded in any form".[954] This term has been judicially interpreted to mean that "[i]nformation will be about an identifiable individual where there is a serious possibility that an individual could be identified through the use of that information, alone or in combination with other available information".[955]

As discussed in Chapter 3, tests for identifiability reflect the notion that identifiability is a spectrum that can range from easy to very difficult.[956] While it can be difficult to pinpoint exactly where on the spectrum notions of "reasonableness" or "serious possibility" fall, the benefit of this approach is its flexibility and contextual nature that can adapt to changing identification techniques. For example, twenty years ago, an individual's raw genetic sequencing data would have carried a very low possibility of identification absent any other associated informational details. Now, however, there is an ever increasingly "serious possibility" of identification given the vast amounts of genetic data that have been collected from people around the world. As a result, there are calls to regard genetic information as inherently identifiable.[957]

Whether a similarly flexible approach should be applied to the question of whether all biomaterials should be regarded as "information" also needs to be considered, especially as there remain many uses for biomaterials that are non-informational in nature. The ALRC envisioned a

[952] Bygrave, *Data Privacy Law, supra* note 59 at 131.
[953] *Privacy Act* (Cth), *supra* note 548, s 6.
[954] *Privacy Act* (CAN), *supra* note 542, s 3.
[955] *Gordon v Canada (Health)*, [2008] FC 258 at para 34.
[956] Hull et al, *supra* note 258 at 63.
[957] Kulynych & Greely, *supra* note 269 at 111–12.

wide ambit to the meaning of "information" in this regard, whereby all biomaterials would be regulated under the *Privacy Act,* subject to any other relevant pieces of legislation (such as that governing organ and tissue donation).[958] To the ALRC, whether or not a particular biomaterial is *personal* information, however, would depend on whether the "bodily sample" is "from an individual whose identity is apparent or can reasonably be ascertained from the sample".[959]

While this approach is advantageous in terms of its clarity of application, it may be overbroad and impose rules and obligations in situations where it is undesirable to do so. Particularly as identifiability becomes easier and we move closer to an understanding of biomaterials and genetic information as being inherently identifiable, there would be almost no limit to biomaterials coming within personal information frameworks. From the hairdresser sweeping up discarded hair to the garbage collector who takes it away, a wide array of entities could be subject to new legal obligations regarding the collection, use, storage, and transfer of these materials and the need for compliant policies and security measures in terms of how they are handled. Indeed, the need for nuance is one reason Bygrave ultimately concluded that while both biomaterials and data should be regulated within the same overarching scheme, a conceptual distinction should nevertheless be maintained between them.[960]

An alternative option would be to take a more contextual approach. Just as notions of likelihood and difficulty of identification are relevant to the proper characterization as to whether information is "personal", these same notions can play a role in characterizing biomaterials as "information". Taylor's focus on the interpretive potential of biomaterials is a useful starting place, as the primary justification for treating biomaterials as information is the fact that both sequenced genetic data and biomaterials awaiting sequencing have the potential to yield the same information.

The likelihood and difficulty of realizing a biomaterial's interpretive potential will depend on the purpose for which the biomaterials are collected and availability of the relevant "interpretive framework",[961] such as a genetic sequencing machine. Similar to identifiability, interpretability of biomaterials will range from very easy (for example, where biomaterials in a genomic research study are collected, prepared, and awaiting sequencing) to very hard (for example, discarded hair

[958] ALRC, *Essentially Yours*, *supra* note 68 at 280–81.
[959] *Ibid* at 286.
[960] Bygrave, "The Body as Data?", *supra* note 31 at 24.
[961] Taylor, *supra* note 65 at 164.

on a hairdresser's floor). Were the hairdresser to send some of the hair to a DTC genetic testing company, however, the calculation changes, as suddenly the purpose for the collection is to interpret the DNA within the hair and this is achieved by accessing the necessary interpretive framework. As a result, there is a stronger argument to regard biomaterials as personal information the closer they are to being genetically sequenced.

This type of contextual approach is reflected in some of the authorities reviewed above. Baroness Hale in *Marper,* for example, emphasized the purpose for collecting and storing the samples from suspects of crime was not "for their intrinsic value as mouth swabs, hairs or whatever".[962] Instead, they were "kept as information about the person and nothing else".[963] Returning to definitions of "information" and "data" in informatics, a contextual approach also makes sense. Bygrave, for example, acknowledged that biomaterials could be treated at least analogously to "data" where they are "structured as a sample or set of samples with the intention of providing information".[964]

Collections held by pathology departments, research biobanks, and DTC testing companies would appear contenders for biomaterials that could be regarded as records of the DNA "information" within them. These types of biomaterials are stored for their informational potential and are interpretable given the "interpretative frameworks" these institutional collectors have at their disposal. In contrast, where biomaterials are not structured in this way and there is no intention for them to provide information, it makes less conceptual sense to treat them as such.

While this approach could potentially be criticized as imposing additional shades of grey on already murky interpretive questions, a contextual approach is beneficial given the myriad ways biomaterials are valued and represents a significant advantage over the "one-size-fits-all" approach of property law.[965] While Herring advocates for a *sui generis* statutory approach to biomaterial regulation rather than privacy law, he nevertheless makes a point about the limitations of property law that is salient to the present analysis. As a matter of property law, "the urine flushed down the toilet and the egg frozen for reproductive purposes" are treated the same,[966] which could lead to

[962] *Marper,* UKHL, *supra* note 67 at para 70.
[963] *Ibid*.
[964] Bygrave, "The Body as Data?", *supra* note 31 at 21.
[965] Herring, *supra* note 29 at 216. Note, while Herring points to limitations of property law, he does not advocate for a privacy approach but *sui generis* statutory frameworks.
[966] *Ibid*.

absurd consequences, such as being fined for littering when your hair falls to the pavement or being asked to return and remove the dandruff you left at a restaurant.[967] While Herring admits the likelihood of these examples giving rise to actual legal claims is low,[968] they nevertheless represent a conceptual shortcoming of subjecting all biomaterials to the same framework and the bluntness of property law as a regulatory tool in this regard. In contrast, privacy law already has built-in flexibility where privacy norms only apply to reasonably identifiable information. A similarly flexible approach to determining when biomaterials should be regarded as records of information would provide much needed nuance in regulating this complex subject matter.

ii. Overcoming the Limitations of Information Privacy Statutes

While the discussion above highlighted some of the benefits to treating biomaterials as records of information in terms of closing regulatory gaps, it is also important to consider which gaps might be left open. Consent plays a strong role in privacy law. The default position is one in which the person to whom the information pertains is the one who gets to control the information. In this respect, consent is the gatekeeping mechanism through which an individual can choose who has access to their information and what uses, and further disclosures, can be made of that information. As a result, "[c]onsent has…been central to normative discourse on privacy and data protection".[969] There is a concern, however, as to whether information privacy statutes, alone, are sufficient to protect individuals' interests in their biomaterials given the wide-ranging exceptions that exist to consent requirements.[970]

This might be particularly important in the research context, where there are often exceptions to the need for consent to collect, use, and disclose personal information. For example, Alberta's *Health Information Act* allows information custodians to use and disclose identifying health information for the purpose of conducting research that is approved by a research ethics board.[971] Further, the identifiability threshold applied by the Act is very high, where "individually identifying" information is limited to information where "the identity of the individual who is the subject of the information can be *readily ascertained* from the information".[972] So long as identity

[967] *Ibid* at 224.
[968] *Ibid*.
[969] Bygrave, "The Body as Data?", *supra* note 31 at 23.
[970] *Ibid*.
[971] *Health Information Act* (AB), *supra* note 546, ss 27(1), 35(1) & 50(1).
[972] *Ibid*, s 1(1) [emphasis added].

cannot be "readily ascertained", the information is regarded as "non-identifying" and custodians are free to collect, use, and disclose the information without consent.[973]

As discussed in Chapter 3, the idea that privacy is protected through anonymization represents an overly narrow view of privacy interests. To return to Beyleveld's example of a devotedly Catholic woman whose de-identified health information is passed along to researchers studying hormonal contraception, she has an interest in controlling who accesses her information and for what purposes. Extrapolating from Wendler, the closer the potential use strikes to the values she views as fundamental, the greater her say should be in the contributions she makes. Wide exceptions to the need for consent in the research context fail to provide the level of nuance needed to give full respect to participant autonomy.

However, statutory exceptions to consent requirements are not all equally wide. In New South Wales, a research exception applies to the use and disclosure of health information without consent for secondary research purposes that are in the public interest.[974] However, the NSW legislation (i) imposes a lower threshold for identifiability based on whether the information subject's identity can be "*reasonably* ascertained"[975] and (ii) requires researchers and research ethics boards to comply with statutory guidelines produced by the Information and Privacy Commissioner.[976]

The statutory guidelines impose additional requirements in terms of the information researchers must consider and address in their research proposals. For example, researcher must articulate, with reference to the legislation, the specific exception for consent the proposal is being made under and why they believe the requirements for the exception have been fulfilled. This includes an explanation as to "why the public interest in the research substantially outweighs the public interest in the protection of privacy".[977] In addition, research ethics committees must keep a record of the data items researchers are seeking to use or disclose and report this information annually to the Privacy Commissioner.[978]

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[973] *Ibid*, ss 19, 26 & 32(1).
[974] *Health Privacy Act* (NSW), *supra* note 66, Sch 1, ss 10(1)(f) & 11(1)(f).
[975] *Ibid*, Sch 1, ss 10(1)(f)(i)(A) & 11(1)(f)(i)(A) [emphasis added].
[976] *Ibid*, Sch 1, ss 10(1)(f)(iii) & 11(1)(f)(iii).
[977] Information and Privacy Commission, NSW, "Statutory Guidelines on Research", (2004), online (pdf): <www.ipc.nsw.gov.au/sites/default/files/2019-01/statutory_guidelines_on_research.pdf> , s 2.9.
[978] *Ibid*, ss 4.5 & 4.8.

In addition to imposing more stringent requirements, a benefit of this approach is its inherent flexibility, allowing the Privacy Commissioner to alter or add to the requirements through the Guidelines without having to amend legislation. Rather than complete deference shown to research ethics boards, as with in the Alberta legislation, the New South Wales framework reflects more direct regulation in terms of what researchers must demonstrate and what ethics boards must consider when determining whether consent should be obtained. It further mandates record keeping and reporting to be able to trace the datapoints being accessed in this manner. This framework could therefore prove a useful model to other jurisdictions in terms of balancing the competing interests of researchers and participants.

Another consideration in terms of the strength of regulatory protection offered by statutory frameworks is the type of personal information biomaterials would come within. For example, consent mechanisms are generally stronger for health information than other types of personal information. Often, health information is regulated by specific statutes providing more stringent regulations (although the above example from Alberta shows that exceptions to consent requirements can still be wide). If biomaterials are regarded as "health information" or "sensitive information", they would therefore be subject to ostensibly stronger regulatory provisions.

An alternative approach would be to create a new category of personal information that is subject to a comparable level of protection to health information.[979] This approach was taken in Denmark where, although privacy statutes apply to physical biomaterials, it was determined that this framework did not adequately protect individual self-determination in terms of collecting and using biomaterial samples in research.[980] As a result, stronger and more tailored mechanisms were proposed to grant individuals greater control over the collection and use of biomaterials in research and the ability to access and demand the destruction of their biomaterials.[981] Treating biomaterials as a *sui generis* type of personal information could be beneficial. While the interpretive potential of biomaterials awaiting sequencing and recorded genetic information post-sequencing is the same and therefore justifies similar levels of protection, there may, nevertheless be justifications in some contexts to treat the two differently. For example, as mentioned above, rights of access may need

[979] Bygrave, "The Body as Data?", *supra* note 31 at 23.
[980] *Ibid* at 24.
[981] *Ibid*.

different parameters than with recorded information given the hygienic concerns arising from handling bodily substances.

The idea that different types of personal information can attract different regulatory provisions is already imbedded in privacy statutes. For example, Australia's *Privacy Act* contains specific provisions tailored to various types of personal information, such as credit information, financial hardship information, identification information, sensitive information, and health information (which includes genetic information).[982] Should there be lingering regulatory gaps needing to be filled regarding biomaterials, a similarly tailored approach could be applied.

Lastly, a significant shortcoming of information privacy statutes is that the remedial options they offer tend to be limited. While these statutes generally provide Privacy Commissioners with investigative powers to receive and respond to complaints, they do not usually have the power to make damages awards. As a result, even where there are clear violations in terms of how personal information is collected, used, and disclosed, the individual information subjects are left without compensation. The exception is the Australian Privacy Commissioner who is vested with broader powers, including the power to make damages awards. Similarly, legislation is currently before the Canadian House of Commons that, if passed, would create a statutory cause of action for individuals to sue for damages where a commercial entity has infringed the individual's interests through a violation of the Act.[983] However, as the cause of action would only apply to defendant organizations engaged in commercial activities, it is not comprehensive in scope. As a result, the privacy torts discussed in Chapter 6 will remain an important supplement to privacy statutes to overcome this remedial problem. The next chapter will therefore be devoted to considering how privacy torts could be used to further strengthen privacy protection over biomaterials.

D. Conclusion

Given that the interpretive potential of biomaterials is on par with recorded genetic information, the justification for legal differentiations between them is disappearing. In recognition of this fact, the application of information privacy statutes to biomaterials is a regulatory possibility requiring consideration. As this chapter has demonstrated, this regulatory approach offers many

[982] *Privacy Act* (Cth), *supra* note 548, ss 6 & 6FA.
[983] *Digital Charter Implementation Act*, *supra* note 564, s 107.

potential benefits. It can provide greater consistency between rules governing the informational and the physical dimensions of biomaterials, close regulatory gaps, and ground rights of access and withdrawal of consent.

This approach, however, would not be without practical and interpretational hurdles. Although statutory interpretations of "information" might arguably encompass physical DNA, it is possible, and perhaps likely, that legislative amendments would be needed to make this explicit. Whether all biomaterials should be treated as "information" is a further question needing to be determined. This chapter has argued for a flexible approach in this respect that is similar to the concept of identifiability, such that where a biomaterial has been collected for interpretational purposes and where interpretational frameworks are accessible, a stronger case can be made for treating the biomaterial as information.

Whether this "information" will be "personal" and therefore fall within the ambit of information privacy statutes, however, depends on the concept of identifiability. High thresholds of identifiability, such as Alberta's "readily ascertainable" standard, may mean that the benefits of bringing biomaterials within definitions of "information" will be tempered, as many biomaterials may fall outside of this definition. An information statutory approach to biomaterial regulation will therefore be most effective if accomplished in tandem with a reconsideration of what "readily" or "reasonably" ascertainable identification means in the context of genetic information. A recognition that genetic information is inherently identifiable would close or at least narrow some of the remaining gaps in this approach.

While clearly not a panacea for the complex problem of biomaterial regulation, this regulatory avenue shows one way in which privacy law could play a regulatory role. Privacy torts represent the other half of the privacy law landscape that also require consideration in this context. The next chapter will therefore look at how the range of privacy torts could potentially apply to biomaterials.

8. The Application of Privacy Torts to Biomaterials

Privacy is not a unitary concept in law. It has different dimensions and gives rise to different causes of action that protect different interests. The previous chapter highlighted the informational interests individuals have in biomaterials and how these could be protected through information privacy statutes. While this regulatory option presents some advantages, one key limitation is its failure to offer meaningful recourse to individuals whose biomaterials have been misused. Privacy torts provide an important supplement to these statutory frameworks in this regard.

This chapter will therefore consider the privacy interests individuals have in biomaterials and how privacy torts might be used to address them. Part 1 of this work identified a range of situations where individuals lack legal protection for their interests in biomaterials. This chapter will therefore return to some of these situations to evaluate whether privacy torts may offer a viable path forward. Specifically, this chapter will examine the contexts of (i) non-consensual genetic testing; (ii) research uses of biomaterials without adequate (or any) consent; and (iii) wrongful interferences with deceased bodies (or biomaterials taken from them). While this selection of examples is not comprehensive in covering all the scenarios in which control over biomaterials could be contested, it will illustrate, more concretely, how these torts might operate in cases involving a representative range of potential privacy interests. Non-consensual genetic testing, for example, will engage informational privacy interests, whereas research uses of biomaterials and interferences with biomaterials from deceased bodies engage privacy interests that are more personal in nature.

This examination will demonstrate that there can be different privacy interests at stake for individuals depending on the circumstances of the case. Further, privacy torts are suited to protect these various types of privacy interests and provide remedies when they are violated. However, given the range of different privacy tort options, jurisdictional differences to privacy torts, and remaining interpretational questions about how some of these torts operate, the resulting picture is complex. For ease of reference, Table 1 therefore summarizes, in general terms, the elements of each of the torts considered from Chapter 6. While the table does not capture all the jurisdictional nuances of these torts, which are covered more extensively in Chapter 6, it provides a rough guide to assist in the analysis and application of these torts to the scenarios below. This analysis will

ultimately demonstrate that, although there is significant variation in terms of the likely level of protection privacy torts will provide, depending on the factual context and jurisdiction in which the claim arises, privacy torts offer promising legal avenues for individual litigants, at least in some circumstances. As a result, there is merit to developing and elaborating upon this analysis further as a matter of privacy law and biomaterial scholarship.

Table 1: Privacy Torts and their Respective Elements

Tort	**Definition/Elements**	**Key Sources of Legal Authority**
Intrusion Upon Seclusion	• An intrusion upon the plaintiff's private affairs; • Involving an infringement of a reasonable expectation of privacy (in New Zealand); • That is highly offensive to a reasonable person in the plaintiff's position; • That is done intentionally (or in Canada, recklessly)	*Jones v Tsige* (Ontario) *C v Holland* (New Zealand)
Public Disclosure of Private Facts	• Publicity (or publication in Ontario); • Given to private facts; • Where the publicity/publication is highly offensive to a reasonable person in the plaintiff's position	*Hosking v Runting* (New Zealand) *Jane Doe 1, Jane Doe 2,* and *Halley v McCann* (Ontario) *ES v Shillington* (Alberta) *Racki v Racki* (Nova Scotia)
Misuse of Private Information	• Step 1: Determining the plaintiff's reasonable expectation of privacy (including consideration of a range of factors such as the degree of fault of the defendant and whether they knew the plaintiff failed to provide consent); • Step 2: Resolving the tension between privacy and freedom of expression	*Campell v MGN Limited* *Murray v Big Pictures (UK) Limited* *Gulati v MGN* *Google v Vidal-Hall*
Saskatchewan, British Columbia, and Newfoundland and Labrador Statutory Torts	• A violation of privacy (including consideration of the lawful interests of others, circumstances of the case, and the parties' conduct); • That is willful (in SK: specific intent; BC: constructive knowledge); and • Without claim of right	*Privacy Act* (British Columbia) *The Privacy Act* (Saskatchewan) *Privacy Act* (Newfoundland and Labrador)
Manitoba Statutory Tort	• A violation of privacy; • That is substantial; • Unreasonable; and • Without claim of right.	*The Privacy Act* (Manitoba)

A. Non-Consensual Genetic Testing

As discussed in Chapter 2, surreptitious genetic testing, where one person has biomaterials from another genetically tested without consent, is a growing problem in the wake of the DTC

genetic testing phenomenon. Unlike some of the other contexts that will be considered in this section, the privacy interest at stake in this context is clear and uncontroversial. This is because genetic information has been recognized at the highest judicial levels as being deeply personal and private. For example, Canadian Supreme Court Justices have found "[t]here is undoubtedly the highest level of personal and private information contained in an individual's DNA",[984] and that "[w]ithout constraints on the type of information that can be extracted from bodily substances, the potential intrusiveness of a DNA analysis is virtually infinite".[985] Further, "[t]he taking and retention of a DNA sample is not a trivial matter and, absent a compelling public interest, would *inherently constitute a grave intrusion* on the subject's right to personal and informational privacy".[986] Similarly, Justices from the highest court in New Zealand have noted "[t]he highest expectation of privacy relates to searches of the person and particularly intimate searches, such as strip-searchers…, or invasive procedures, such as DNA testing".[987]

There is a clear informational privacy interest at stake for individuals in their DNA, and as Greely maintains, "there seems no good justification for unconsented, surreptitious DNA collection and analysis".[988] The question is how the law can best address this growing problem. Nwabueze, for example, advocates strongly for a property law approach. However, even he acknowledges the potential role for privacy torts in his hypothetical example (raised in Chapter 2) involving a person's biomaterials being tested for HIV/AIDS where the person only gave consent to a test for diabetes.[989] Greely rejects a property law approach as apt to cause confusion, and instead, proposes a "require[ment] that whoever analyzes a DNA sample must have good evidence that it was either collected consensually or under an applicable exception".[990] The following discussion will illustrate how the application of privacy torts could impose such a requirement.

The discussion below will therefore consider a hypothetical scenario where Alfred collects hair from Beatrice's hairbrush without her knowledge or consent and submits the hair to a laboratory for genetic testing to satisfy his own personal curiosity about Beatrice's genetic make-

[984] *R v SAB*, [2003] SCC 60 at para 48 (Arbour J, on behalf of a unanimous court).
[985] *R v RC*, [2005] SCC 61 at para 28 (Fish J, with McLachlin CJ, Major, Binnie and Deschamp JJ concurring).
[986] *Ibid* at para 39 [emphasis added].
[987] *R v Williams*, [2007] NZCA 52 at para 113 (Glazebrook J, William Young P concurring).
[988] Greely, *supra* note 22 at 157.
[989] Nwabueze, "Donated Organs", *supra* note 121 at 216.
[990] Greely, *supra* note 22 at 157.

up. In the scenario, the laboratory tests the hair samples without requiring "good evidence" of Beatrice's consent and discloses the genetic test results to Alfred. To illustrate how privacy torts might apply, the discussion will first consider potential actions against Alfred before considering potential liability for the laboratory.

i. Liability of Alfred for the Non-Consensual Collection of Biomaterials and Access to the Genetic Information they Yield

The person who surreptitiously collects biomaterials and accesses the genetic information within them could be liable for intrusion upon seclusion, privacy violations under Canadian statutory privacy torts, and/or the English misuse of private information tort. Intrusion upon seclusion requires that there be an invasion upon the plaintiff's private affairs or concerns, and that the invasion be highly offensive to a reasonable person in the plaintiff's position. Manitoba's statutory tort similarly requires the violation to be "substantial". In contrast, the other statutory torts and the English misuse of private information tort simply require that there be a reasonable expectation of privacy. Given the strong judicial recognition of the private nature of one's DNA, highlighted above, it is likely that Beatrice's genetic information would be regarded as a matter of her private affairs over which she enjoys a reasonable expectation of privacy.

This assessment is supported by the range of applicable factors that are used to determine whether a reasonable expectation of privacy exists. Hunt and Shirazian have catalogued these factors from privacy tort statutes and case law, which include the nature of the activity or information, the form of the material (e.g., letters, diaries, personal documents), the location of the activity, attributes of the plaintiff (e.g., if the plaintiff has a particular vulnerability), conduct of the plaintiff, whether the information is in the public domain, the effect on the plaintiff, and the conduct of the defendant, including whether the defendant engaged in harassment and surveillance, whether the defendant knew that the plaintiff did not consent, and the defendant's motive and purpose.[991] Applied to our scenario, the nature of the information (i.e., one's DNA) is regarded, judicially and by the public, as amongst the most sensitive types of personal information in existence. Further, Alfred had full knowledge that Beatrice did not consent and engaged in this activity for his own personal purposes and benefit. Other factors may also weigh in Beatrice's favour, for example, if the hair was collected from within her own home or if the discovery of this

[991] Hunt & Shirazian, *supra* note 644.

violation has had a significant impact on her. Overall, there is a very strong case that Beatrice has a reasonable expectation of privacy in her genetic information, wrongfully accessed by Alfred.

Further, there is a strong argument that the violation of Beatrice's privacy interests would be "substantial" (required by the Manitoba tort) and "highly offensive" to a reasonable person (required by intrusion upon seclusion). In discussing the "highly offensive" criterion, Sharpe JA noted that its purpose is to eliminate claims by "individuals who are sensitive or unusually concerned about their privacy" by limiting the tort to "intrusions into matters such as one's financial or *health records*, sexual practices and orientation, employment, diary or private correspondence" that are objectively highly offensive.[992]

Similarly, in the US case, *Doe v High-Tech Institute,* the plaintiff's college collected his blood sample for the purpose of rubella testing, but then had it tested for HIV without the plaintiff's knowledge or consent.[993] In that case, Judge Davidson remarked, on behalf of the Court, "[w]e see little difference between a person's objectively reasonable expectation to keep in seclusion the medical information that may be obtained from a blood sample and his or her expectation to keep in seclusion information in medical files."[994] Further, the highly personal nature of information revealed through an HIV test, which can carry significant social stigma, supported the satisfaction of the highly offensive test[995] and led to the Court's conclusion that the plaintiff's intrusion upon seclusion claim should not have been dismissed.[996] Given that genetic information is regarded as being a deeply personal form of health information that could also give rise to stigma and/or discrimination, it is likely that surreptitiously accessing another's genetic information would be on the same level as the banking records accessed in *Jones* and HIV status accessed in *High-Tech Institute,* and satisfy the highly offensive test.

While Beatrice likely enjoys a reasonable expectation of privacy in her genetic information, whether the English misuse of private information tort would be satisfied will also depend on whether "misuse" encompasses a mere intrusion versus a publication. As discussed in Chapter 6, there is growing authority from case law, including the *Gulati* and *Vidal-Hall* cases,

[992] *Jones*, *supra* note 71 at para 72 [emphasis added].
[993] *Doe v High-Tech Institute*, *supra* note 184 at 1069.
[994] *Ibid*.
[995] *Ibid* at 1070.
[996] *Ibid* at 1071–72.

that wrongful access without publication could be actionable, and many commentators agree the tort is moving in this direction.[997] Under this line of authority, it is therefore certainly arguable that Alfred's invasion of Beatrice's genetic privacy could be an actionable misuse of private information in England.

With respect to the fault element of these torts, in this hypothetical scenario, there would be little doubt that Alfred's conduct would be regarded an intentional violation of Beatrice's privacy, as he deliberately collected Beatrice's biomaterials, submitted them for genetic testing, and then accessed the test results without Beatrice's knowledge or consent. On any standard of fault, from mere negligence to specific intent, the fault element would likely be met.

In terms of balancing the interests at stake, as discussed in Chapter 6, the misuse of private information tort requires balancing freedom of expression interests, and the British Columbia, Saskatchewan, and Newfoundland and Labrador torts require consideration of the lawful interests of others. In addition, a defence of public concern also applies to intrusion upon seclusion. In our scenario, regardless of whether this balancing occurs as part of the elements of the tort or as a defence, it is unlikely to be compelling given that there is no public interest served by Alfred's non-consensual access to Beatrice's genetic information. The equation might be different, for example, if Alfred was a member of law enforcement collecting biomaterials in the course of a criminal investigation, which raises its own set of ethical and legal questions.[998] For the present analysis, however, there are no compelling public interests to consider, and as a result, Beatrice would have strong privacy tort claims against Alfred across many common law jurisdictions.

ii. Liability of the Laboratory for Accessing and Disclosing Genetic Information without Good Evidence of Consent

The Laboratory in our example could be liable in intrusion upon seclusion for accessing Beatrice's genetic information as well as public disclosure of private facts for the disclosure of test results to Alfred. In addition, these actions could amount to privacy violations under the statutory torts as well as a misuse of private information under the English tort.

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[997] Hartshorne, "Intrusion Upon Seclusion", *supra* note 578 at 295–98; Hunt & Shirazian, *supra* note 644; Beswick & Fotherby, *supra* note 622 at 225.
[998] James W Hazel & Ellen Wright Clayton, "Law Enforcement and Genetic Data", (20 January 2021), online: *The Hastings Center* <www.thehastingscenter.org/> [perma.cc/GC7L-KA4R].

With respect to the fault element of these torts, the fault element in Saskatchewan, requiring specific intent to violate the plaintiff's privacy, may prove problematic. This is because the laboratory is not necessarily undertaking the genetic test and disclosure with the aim of violating Beatrice's privacy. Such a violation would merely be incidental to the laboratory's business operations. Whether the fault element in the other torts is met will largely depend on what the lab knew (or perhaps, should have known) about whether Beatrice consented. In our scenario, the lab lacks "good evidence" of consent. While this could encompass a range of consent practices from not requiring consent at all to not having appropriate identification verification procedures, the below discussion will demonstrate that, the weaker the consent practices, the more likely it is Beatrice will succeed in meeting the fault elements.

A standard of recklessness (for intrusion upon seclusion) could arguably be satisfied if Beatrice can show that the lab subjectively knew there was a risk that testing the hair would violate her privacy (for example, if the lab did not require individual consent or identification) but proceeded with the testing in the face of that risk. A standard of constructive knowledge (reflected in the elements of the British Columbia and Manitoba statutory torts) would be easier to establish, as a lab performing genetic testing on a sample without good evidence of consent should be aware that the testing and disclosure would violate the sample provider's privacy. In England, while negligent misuses can be actionable, there is no standalone fault element, as the defendant's conduct is but one factor to consider in determining whether there has been a violation of the plaintiff's reasonable expectation of privacy. Therefore, the more knowledge the lab had or should have had, the heavier the fault factor will weigh in favour of the plaintiff. The satisfaction of the fault element across these various torts will, then, ultimately depend on the particular consent practices of the lab in question and what they knew or should have known based on the evidence of consent that they require. In contrast, as discussed further below, public disclosure of private facts lacks a specific fault element, and the lab's knowledge of Beatrice's lack of consent may, therefore, not be relevant to liability under that tort.

With respect to the testing itself and whether this could amount to a privacy violation (whether through intrusion upon seclusion, misuse of private information, or a statutory tort), this might also depend on the information provided to the lab. If Beatrice's name, for example, is included with the sample, then, for the same reasons discussed in relation to claims against Alfred,

there would be a strong argument that an intrusion has been made into Beatrice's private affairs that violates a reasonable expectation of privacy in a manner that is highly offensive to a reasonable person. However, if the lab merely received a sample without any associated information about the provider, it is conceivable the lab could argue that no privacy violation has taken place. This is because, as discussed in Chapters 3 and 7, there is continued debate about whether genetic information should be regarded as inherently identifiable. The lab could argue that Beatrice has no privacy interest in her raw genetic sequence data and that no intrusion into her private sphere has occurred.

However, it would be more difficult for the lab to justify disclosing the information to Alfred, who is clearly able to identify the person to whom the information relates. With respect to the public disclosure of private facts tort, while the elements have been articulated slightly differently across jurisdictions, there must generally be publicity given to private facts, which is highly offensive to a reasonable person in the plaintiff's position. There is no fault element explicitly associated with this tort, so regardless of whether the lab specifically intended to violate Beatrice's privacy, they could be liable provided the elements are satisfied.

In this regard, the publication of Beatrice's genetic information to Alfred would almost certainly amount to a disclosure of "private facts". The disclosure would also likely be highly offensive to a reasonable person in Beatrice's position, for the same reasons already discussed. However, whether disclosure to a single person would satisfy the "publicity" requirement is unsettled across jurisdictions. As discussed in Chapter 6, the Ontario decision, *Halley v McCann,* indicates that disclosure to one other person will suffice,[999] and the statutory torts similarly do not require any widespread publicity. In contrast, Nova Scotia[1000] and New Zealand[1001] authorities suggest widespread publicity is required, while the law in Alberta is unclear.[1002]

In jurisdictions where the publicity requirement can be overcome, the onus would then shift to the lab to prove they had consent. This could be problematic for a lab with poor consent practices that lacks good evidence of consent. While the public disclosure of private facts tort and the statutory torts are similar in that consent is regarded as a defence, the statutory torts also have a

[999] *Halley*, *supra* note 672 at para 25.
[1000] *Racki*, *supra* note 682 at para 26.
[1001] *Hosking*, *supra* note 72 at para 125.
[1002] See *Shillington*, *supra* note 607.

requirement that the violation be done "without claim of right". As discussed in Chapter 6, where there is an "honest mistake" as to the lawfulness of the violation, the claim could fail, and it is not entirely clear whether such a mistake must be reasonable. It was relevant in *St Pierre,* where the Sun published a photograph of the plaintiff misidentifying him as a terrorist, that "there was no evidence that would indicate that the Sun's system of checking was previously so sloppy that confidence in it by the editors was unjustified".[1003] As a result, where a lab routinely implements "sloppy" consent procedures, it may be more difficult to establish a claim of right, versus a one-off error arising from an honest mistake.

With respect to the English misuse of private information tort, the *Vidal-Hall* case suggests that disclosure need not be widespread. In that case, any "disclosures" of private information pertained to targeted advertisements on the plaintiffs' respective screens that may have been seen by others in the vicinity of the plaintiffs.[1004] As a result, the disclosure to a single person may not be a problem for Beatrice's success in this tort. Further, rather than operating as a defence, English jurisprudence has indicated that "the absence of consent and whether it was known or could be inferred" is one factor to be taken into account in determining whether a reasonable expectation of privacy has been violated, as are "the circumstances in which and the purposes for which the information came into the hand of the publisher".[1005] The fact that the lab accepted biomaterials for genetic testing for financial gain without good evidence of consent would likely weigh in favour of recognizing a violation of Beatrice's reasonable expectation of privacy. Further, it would be difficult for a lab in such circumstances to claim a countervailing freedom of expression right to justify this conduct.

In sum, privacy torts are likely to provide strong avenues for legal redress against the person surreptitiously collecting and submitting biomaterials for genetic testing and accessing the test results. With respect to actions against the lab, there will be greater difficulties for plaintiffs and variance between jurisdictions. For example, statutory tort actions in Saskatchewan may be difficult because of the heightened fault element. Actions for intrusion upon seclusion may depend on the identifiability of the biomaterials received by the lab and whether the lab was reckless in

[1003] *St Pierre*, *supra* note 708 at para 52.
[1004] *Vidal-Hall*, *supra* note 73.
[1005] *Murray*, *supra* note 744 at para 36.

their consent practices. While fault is not required for public disclosure of private facts, New Zealand and Nova Scotia explicitly require widespread publicity.

In contrast, Ontario seems a promising jurisdiction for this type of claim. Similarly, Manitoba, British Columbia, and Newfoundland and Labrador offer possibilities with their statutory torts given the lower fault element compared to Saskatchewan and the lack of any requirement that publication be widespread. There is, however, uncertainty about the "claim of right" requirement and how that might operate in a case of mistaken belief of consent. The English misuse of private information tort also appears promising, as many of the relevant factors (nature of the information, knowledge of consent, purpose for disclosure) would weigh in favour of finding there has been a violation of a reasonable expectation of privacy. Further, with respect to all the torts, there is unlikely to be compelling public interest concerns to consider, at least with respect to the hypothetical situation considered in the analysis. In contrast, the public interest will likely weigh much heavier in the biomedical research context, to which the discussion will now turn.

B. Using Biomaterials in Research without Informed (or Any) Consent

Chapter 3 identified two situations in the research context where greater individual control over biomaterials is needed. The first pertains to situations where an individual's biomaterials are used for a secondary research purpose without consent on the grounds that the sample is non-identifiable. The second pertains to the use of biomaterials for a primary research purpose where broad consent is obtained. Each of these contexts will be addressed, in turn, below to show the role privacy torts could potentially play in grounding individual rights and remedies.

i. Use of Biomaterials Without Consent

As discussed in Chapter 3, biomaterials are sometimes used in research without participant knowledge or consent. This can occur in situations, for example, where a clinician removes a biomaterial sample for medical purposes, and then either uses it themselves for a research purpose or transfers it to others for use in research in de-identified form. Chapter 3 argued that this practice is problematic in that even where biomaterials are de-identified, there are informational privacy risks to participants justifying a consent requirement, especially where biomaterials are genetically sequenced. Further, regardless of informational privacy risks, robust respect for participant autonomy requires recognition that participants should have a say in the contributions they make.

This section will therefore consider a hypothetical scenario of a patient, Carlie, whose spleen was unknowingly transferred by her doctor, Dr Davis, to a researcher, Dr Ellis, following a splenectomy procedure. Dr Ellis has genetically sequenced the spleen as part of her research protocol. Although Carlie's spleen was de-identified, a subsequent data breach has re-identified her as a participant and published her genetic sequence data on the dark web. As a result of this data breach, Dr Ellis has contacted Carlie to inform her that her spleen was used in research and her genetic sequence data has been published online.

In this scenario, Carlie has a clear informational privacy interest at stake in that her identity and genetic information has been accessed and published without her knowledge or consent. Additionally, this section will demonstrate that she also has a *personal* privacy interest that was violated when Dr Davis transferred her spleen, and Dr Ellis correspondingly received it, without her knowledge or consent. The violation of both types of privacy interests could give rise to potential tort claims. The discussion will therefore first consider her informational privacy interests before considering her personal privacy interests.

a) Informational Privacy Breaches through Re-identification and/or Hacking

The private nature of genetic information has been considered above in the Beatrice scenario, and from that discussion, we can begin from a starting point that recognizes that Carlie's genetic information will likely fall within her sphere of private affairs or concerns and represent information over which she enjoys a reasonable expectation of privacy. The actions available to Carlie and the potential defendants bearing liability regarding the access and disclosure of her genetic information will, however, depend on how the privacy breach transpired. With respect to the rogue who re-identified Carlie and published her information, liability could arise for the full range of privacy torts. By re-identifying Carlie, the rogue gained access to her genetic information, potentially attracting liability in intrusion upon seclusion. By publishing her genetic information online, the rogue could be liable for publication of private facts and misuse of private information. As the Canadian statutory torts do not differentiate between access and disclosures, liability encompassing both these dimensions could arise as actionable privacy violations under these torts as well. The problem for Carlie in this respect will be identifying the rogue.

If the rogue is revealed to be an employee of the research institution, the employee could be personally liable, and the institution could potentially be vicariously liable for these torts.

However, if the rogue is an unidentified third-party hacker who surreptitiously gained access to Dr Ellis's database, Carlie's ability to advance a claim will depend on whether the institution or Dr Ellis can be held liable. As discussed in Chapter 6, institutional liability for third-party hacking cases is unavailable in Ontario's intrusion upon seclusion tort, England's misuse of private information tort, and British Columbia's statutory privacy violation tort, although there is limited Canadian federal case law on intrusion upon seclusion to suggest the test for recklessness could potentially be satisfied. It would also likely fail to meet the Saskatchewan interpretation of "willfulness", which requires a specific intent to violate the plaintiff's privacy. Overall, the prospects for successfully recovering against the institution with respect to the wrongful access and disclosure of Carlie's genetic information are grim. However, it might be the case that the non-consensual transfer and use of Carlie's spleen, itself, is a violation of Carlie's privacy interests. The following discussion will therefore consider this possibility.

b) Personal Privacy Violations for the Collection and Transfer of Biomaterials without Consent

Wendler's argument that individuals should have a say in the contributions they make reflects a robust understanding of patient and participant autonomy. It also finds support in privacy case law in the Supreme Court of Canada decision, *R v Dyment,*[1006] discussed in Chapter 7. The Majority found that Dyment's section 8 *Charter* right to be free against unreasonable search or seizure was violated when the police obtained the blood sample, without Dyment's consent, from Dyment's treating doctor. La Forest J (Dickson CJC concurring and Lamer, Beetz and Wilson JJ concurring, in part) explored the historical development of the interests this right protects. He noted that although the origin of the right against unreasonable search and seizure was grounded in property law (to protect against invasions of one's house, for example), it is now recognized as primarily protecting privacy interests, and "should be interpreted broadly to achieve that end, uninhibited by the historical accoutrements that gave it birth".[1007]

La Forest J recognized three "zones" of privacy: "those involving territorial or spatial aspects, those related to the person, and those that arise in the information context" and found "[a]ll three…are directly implicated in the present case".[1008] With respect to the "spatial" aspect, La

[1006] *Dyment*, *supra* note 69.
[1007] *Ibid* at para 27.
[1008] *Ibid* at para 30.

Forest J found that this was not limited to a particular place or property; instead, "what is protected is people, not places".[1009] In terms of privacy related to the person, La Forest noted that it is not the physical person that is protected, as there is legal protection for bodily integrity elsewhere, but "the dignity of the human person".[1010] Personal privacy concerns the "invasion of the person in a moral sense".[1011] Finally, La Forest J noted that informational privacy is also grounded in notions of human dignity and integrity, with personal information about a person remaining "in a fundamental way [their] own" to do with what they like.[1012]

Applied to the facts of the case, La Forest J found that Dyment's personal privacy had been violated by taking and testing the blood without Dyment's consent.[1013] La Forest J noted that a blood sample taken solely for medical purposes is "subject to a well-founded expectation that it was to be kept private"[1014] and that Dyment "retained an expectation that his privacy interest in the sample would continue past the time of its taking".[1015] Having taken the blood for medical purposes, the doctor "was charged with a duty to use the blood only for medical purposes".[1016] La Forest J found this violation was not minimal, as the use of "an individual's blood or other bodily substance confided to others for medical purposes for purposes other than these seriously violates the personal autonomy of the individual".[1017]

While the facts of *Dyment* pertained to unauthorized access to bodily materials by law enforcement, the underlying principle that individuals have informational, spatial, and personal privacy interests in their separated biomaterials is of potentially broader application in the current environment where biomaterials are highly valued and sought-after resources. And although *Dyment* involved a *Charter* question and not a question of privacy torts, it is not a massive leap to see how one could extend to the other. Although Canada has not taken the same "horizontal integration" approach as in England, where human rights jurisprudence forms "the very content" of the misuse of private information tort,[1018] human rights law is, nevertheless, highly influential

[1009] *Ibid* at para 31.
[1010] *Ibid* at para 32.
[1011] *Ibid*.
[1012] *Ibid* at para 33.
[1013] *Ibid* at para 38.
[1014] *Ibid* at para 41.
[1015] *Ibid* at para 42.
[1016] *Ibid*.
[1017] *Ibid* at para 45.
[1018] Beswick & Fotherby, *supra* note 622 at 235.

in this regard. Canadian cases have consistently espoused the need for the common law to develop consistently with *Charter* values.[1019] Further, La Forest J proclaimed the importance of privacy, going to "the heart of liberty in a modern state" and being "essential for the well-being of the individual" with "profound significance for the public order".[1020] These comments from *Dyment* have been influential in recognizing both intrusion upon seclusion[1021] and public disclosure of private facts[1022] in Canada, and have been cited with approval overseas by some of the highest judicial authorities across the common law world.[1023]

The *Dyment* case therefore holds a particular level of significance, domestically and internationally, in privacy tort case law. And the recognition from five Supreme Court justices that a serious privacy invasion occurred when an individual's biomaterials were transferred and used without consent would, therefore, presumably be influential were a tort-based privacy action to arise in a future case involving an alleged misuse of biomaterials. The following discussion will therefore explore how *Dyment* could be used to ground Carlie's tort claims against Drs Davis and Ellis.

A few preliminary points from *Dyment* are useful to concretize Carlie's privacy interest in her spleen. In rejecting the Crown's argument that the police officer was simply "given" the sample and did not "take" or "seize" it, La Forest J stated, "the most important flaw [in the Crown's argument], and the matter that has compelling weight, is that when the officer took the sample from the doctor he took something that the doctor held for medical purposes only, subject to a well-founded expectation that it was to be kept private".[1024] La Forest J further held that this privacy interest in the extracted biomaterial "continue[s] past the time of its taking" and "the doctor, in extracting the blood, placed himself in a situation where, pursuant to professional ethics and likely to hospital management regulations as well, he was charged with a duty to use the blood only for medical purposes".[1025]

[1019] *Jones*, *supra* note 71 at para 46; *Jane Doe 2*, *supra* note 664 at para 87; See also *Hosking*, *supra* note 72 at paras 6 & 229, where New Zealand Court of Appeal Justices made the same point with respect to international human rights treaties and values.
[1020] *Dyment*, *supra* note 69 at para 28.
[1021] *Jones*, *supra* note 71 at paras 40–41.
[1022] See *Shillington*, *supra* note 607 at para 59; *Jane Doe 2*, *supra* note 664 at para 87.
[1023] In the UK, see *Campbell*, *supra* note 681; in New Zealand, see *Hosking*, *supra* note 72.
[1024] *Dyment*, *supra* note 69 at para 41.
[1025] *Ibid* at para 42.

The importance of the doctor-patient relationship underpinned La Forest J's reasoning, as he noted the vulnerability of patients who are required to "permit invasions of [their] bod[ies]", and the "dehumanization" of patients in a healthcare system increasingly focused on a team approach to medical treatment rather than individualized doctor-patient relationships.[1026] It is against this backdrop that the case was decided and that La Forest J underscored the primacy of the doctor's obligations to their patients, stating, "[w]hat I wish to emphasize…is that I cannot conceive that the doctor here had any right to take Mr. Dyment's blood and give it to a stranger for purposes other than medical purposes *unless the law otherwise required*, and any such law, too, would be subject to Charter scrutiny".[1027] As a result, the police officer breached Dyment's *Charter* right by taking the blood sample.[1028] While the lawfulness of the doctor's conduct in transferring the sample to the officer was not directly at issue in the case, La Forest J's comments strongly suggest the doctor violated his obligations to Dyment as well.

Three important principles can therefore be taken from this judgment. The first is that when a medical professional removes biomaterials from a patient for medical purposes only, those biomaterials are subject to an expectation that they be kept private. The second is that transferring biomaterials to a third party without patient consent could put a doctor in breach of a duty to only use the biomaterials for medical purposes. The third is that taking biomaterials from a medical professional knowing that they were obtained for medical purposes only also infringes the patient's privacy interests.

Applied to Carlie's scenario, there could, therefore, be liability against both the doctor and researcher for intrusion upon seclusion or Canadian statutory torts. In terms of whether there has been an invasion into Carlie's private affairs or concerns, *Dyment* is clear that there is an expectation that biomaterials removed for medical purposes only are to be kept private. Both Dr Davis who gave the spleen without consent, and Dr Ellis who took the spleen without consent, are intruding on Carlie's personal privacy. And whether the intrusion or violation would be "substantial" (required in Manitoba) or "highly offensive" to a reasonable person in Carlie's position (required in intrusion upon seclusion) is certainly arguable.

[1026] *Ibid* at para 40.
[1027] *Ibid* at para 39 [emphasis added].
[1028] *Ibid* at para 43.

In this respect, the facts of our hypothetical scenario may be less compelling than the facts of *Dyment,* where the sample was transferred to law enforcement to the detriment of the patient. In contrast, Dr Ellis's taking of the spleen was not done for the purpose of using it against Carlie. Nevertheless, as discussed in Chapter 3, empirical studies indicate that most people believe they should be asked for consent when their biomaterials are used, supporting the view that a reasonable person in Carlie's position may very well find what happened to Carlie offensive. Additionally, as discussed in Chapter 3, even where biomaterials are de-identified, there are informational privacy risks that remain (which, in our hypothetical scenario, actually eventuated). The existence of both personal and informational privacy interests might heighten the degree of offence the scenario elicits. Further, medical doctors are charged with a fiduciary duty to place patient interests above all else, and it was in the context of this relationship that Carlie's spleen was taken, transferred, and used without so much as a discussion with her.

Commenting on the nature of the privacy infringement in *Dyment,* La Forest J explicitly recognized the seriousness of the violations of Dyment's autonomy and dignity interests, stating that one "*seriously* violates the personal autonomy of the individual" when one uses biomaterials obtained solely for medical purposes for ulterior purposes.[1029] Further, La Forest J found the infringement to be on par with infringements to one's bodily integrity, which is typically regarded as the most serious of personal violations. In his view, when compared to infringements of bodily integrity, "[t]he dignity of the human being is *equally seriously violated* when use is made of bodily substances taken by others for medical purposes in a manner that does not respect that limitation".[1030] These comments strongly suggest the nature of the privacy violation at stake for Carlie falls at the more significant end of the spectrum.

The fault element would, however, give rise to the same issues as in Alfred's action against the lab, considered above, in that neither the doctor nor the researcher was specifically intending to violate Carlie's privacy. This could prove problematic for a statutory action in Saskatchewan. However, if Carlie can prove recklessness (that Drs Davis and Ellis subjectively knew that transferring the spleen without consent would risk violating Carlie's privacy interests) or

[1029] *Ibid* at para 45 [emphasis added].
[1030] *Ibid* at para 49 [emphasis added].

constructive knowledge (that they should have known of this risk), Carlie could potentially succeed in intrusion upon seclusion or the other Canadian statutory torts, respectively.

Unlike Alfred and Beatrice's scenario above, Carlie's scenario raises important issues of public concern to be weighed against Carlie's privacy claim. Assuming Dr Ellis had obtained research ethics approval for her study protocol, she may argue she has a "lawful interest" in taking the spleen notwithstanding Carlie's lack of knowledge or consent, which must be considered in the statutory privacy torts in British Columbia, Saskatchewan, and Newfoundland and Labrador in determining whether there has been a violation. Additionally, the public interest served through scientific advancement could be raised as a defence to Carlie's intrusion upon seclusion claim.

While *Dyment* did not involve privacy torts, there was a countervailing public interest in investigating crime that was relevant to whether the *Charter* violation was justified. This public interest, however, was severely undermined by the fact that the police officer could have obtained a warrant if he had had probable cause to suspect Dyment had committed an offence. La Forest J quoted prior Supreme Court authority for the proposition that "where it is feasible to obtain prior authorization…such authorization is a precondition for a [constitutionally] valid search and seizure".[1031] While the validity of a search and seizure would not be at issue in Carlie's case, the underlying principle that prior authorization should be obtained where it is feasible to do so, is certainly relevant. Practical difficulties in obtaining consent are often raised in the research context as a reason why it should not be required.[1032] In granting consent waivers, research ethics guidelines contemplate a weighing of different factors, including the difficulty of obtaining consent and the public interest to be served by the study against the risks of harm to participants.[1033] As mentioned in Chapter 3, however, where biomaterials are de-identified, the default position is that no consent is required regardless of how feasible it would be to obtain it. By recognizing the autonomy interests of biomaterial providers through privacy torts, the public interest served by a research protocol and feasibility issues surrounding consent would come into play in cases like Carlie's

[1031] *Ibid* at para 46, quoting *Hunter v Southam Inc*, [1984] 2 SCR 145 at 161.
[1032] Canada's Tri-Council Policy Statement, for example, provides that it must be "impossible or impracticable to seek consent from individuals from whom the materials were collected" as one factor to consider, along with, inter alia, the necessity of using identifiable biomaterials in the protocol and the unlikelihood of adversely affecting the individual's welfare: *TCPS2*, *supra* note 216, art 12.A; See also NHMRC Guidelines, *supra* note 296, s 2.3.10, which contains similar requirements.
[1033] *TCPS2*, *supra* note 216 art 12.3A; NHMRC Guidelines, *supra* note 296, s 2.3.10.

where biomaterials are de-identified. And in some cases, these competing interests might be compelling. But at a minimum, they would at least have to be weighed directly against the serious privacy interests of individual biomaterial providers, which represents a significant change to current practice and greater recognition of the individual rights at stake. Further, in intrusion upon seclusion where "public concern" is a defence, the burden of proof would fall on researchers to explicitly justify why obtaining consent was not feasible in a particular case and how the public will be served by the research being undertaken.

If Carlie's claim succeeds, in terms of remedies, if her case was similar to that of Henrietta Lacks or John Moore, whose biomaterials were used to create highly lucrative cell lines, Carlie could seek an account of profits under the Saskatchewan, Manitoba, and Newfoundland and Labrador statutory torts and a "waiver of tort" under the common law intrusion upon seclusion tort. Additionally, the conduct of the doctor and researcher would be relevant to whether awards for aggravated and/or punitive damages are appropriate. At the other end of the spectrum, where there is no direct financial benefit traceable to any individual provider's biomaterials and nothing malicious about the defendants' conduct, given that Carlie has not suffered any tangible harm, her damages award might be at the smaller end of the scale, within the conventional range imposed in *Jones.* Were Carlie to be among a group of providers who collectively learned as a result of the data breach that their biomaterials had been taken by Dr Davis and transferred to Dr Ellis without consent, it is also possible for a class action to be brought, enabling claims to proceed where it might not be economical for any individual plaintiff to sue on their own. Further, it is possible for claimants to seek injunctive relief, in which Drs Davis and Ellis could be ordered to stop collecting biomaterials without consent and potentially destroy biomaterials already collected. The flexibility of the remedial response through privacy torts is adaptive and responsive to the issues and interests at stake in particular cases, making them an appealing option for future claimants.

The discussion of Carlie's claim has focused on the common law intrusion upon seclusion tort and the statutory privacy torts, as these are the most obviously applicable. Whether the English misuse of private information tort would be of use to Carlie is less certain. This is because the tort pertains to misuses of private *information.* However, as discussed in Chapter 6, there is case law and academic commentary suggesting that the tort is moving in the direction of recognizing physical intrusions. It is also possible for a creative argument to be crafted using the *Marper* and

Gaughran authorities to argue that Carlie's spleen is a form of "personal information", although the success of this argument would be far from certain. As a result, while it is presently unclear whether the misuse of private information tort would be of assistance to Carlie, it is certainly possible that future developments will see it moving in this direction.

ii. Use of Biomaterials Obtained through Broad Consent

The discussion in this section has focused, thus far, on situations where biomaterials removed in medical treatment are provided to researchers without patient knowledge or consent. Chapter 3 of this thesis also identified a need for greater ongoing control over biomaterials by knowing participants, particularly in the biobanking context. While willing participants who consensually provide biomaterials for research might be unlikely to sue the biobanks and researchers making use of their materials, where the scope of their consent is exceeded, it is conceivable that such claims could arise. This discussion will therefore consider a hypothetical scenario involving Fran, who provided biomaterials to a biobank under a broad consent that they be used in the study of disease, with the explicit condition that her biomaterials were not to be used in research related to pregnancy termination. Fifteen years later, she discovered that induced pluripotent stem cells, derived from her biomaterials, were being used in a study attempting to create whole embryo models (sometimes referred to as "synthetic embryos") from these cells.[1034] The study, itself, does not pertain to termination of pregnancy, but Fran is deeply troubled as she believes that synthetic embryos are "alive" and being created solely to be experimented on and "killed".

The first issue to consider as to whether Fran can bring privacy tort claims against the biobank is whether she has an actionable privacy interest in her biomaterials. *Dyment* is certainly helpful in this respect, demonstrating that personal, informational, and spatial privacy interests can exist in biomaterials. However, the analogy between *Dyment* and Fran's scenario is not as close as with Carlie's scenario, above. That is because both Dyment's and Carlie's biomaterials were obtained in the context of a doctor-patient relationship, giving rise to confidentiality obligations and a fiduciary duty to always put the patient's interests first. In contrast, Fran provided her

[1034] Note: Kim et al have recently summarized the current state of stem cell and developmental biology, indicating that early human embryo models, including blastoids and gastruloids have been used from reprogrammed somatic and induced pluripotent stem cells, respectively: Yunhee Kim, Inha Kim & Kunyoo Shin, "A New Era of Stem Cell and Developmental Biology: From Blastoids to Synthetic Embryos and Beyond" (2023) Exp Mol Med 1 at 4 & 7.

biomaterials directly to a research biobank. Unlike medical treatment, research is not undertaken for the benefit of individual participants, and while there is a debate about whether clinician-researchers owe fiduciary obligations to participants enrolled in clinical trials,[1035] it is doubtful that this heightened duty exists in the biobanking realm where there is no ongoing relationship between the parties. Nevertheless, there are some shared features between the biobanking and clinical contexts in that obligations of privacy and confidentiality arise in both contexts, and both situations involve a more vulnerable party needing to trust and rely on the other. As biobank participants lack ongoing control over their biomaterials post-separation, they depend on the biobank to exercise its control in an ethical manner and place a great deal of trust in the biobank to make appropriate use of their biomaterials.

Further, one of the key issues grounding the privacy interest in *Dyment* was that the blood sample was collected for a medical purpose and then transferred, without consent, to another person for a different purpose. While the biobank-participant relationship is not identical to the underlying doctor-patient relationship in *Dyment*, Fran's concern is not dissimilar to Dyment's in that her biomaterials were transferred to a researcher for a purpose that arguably contravened the purposes for which her biomaterials were provided. The sense of violation she feels upon learning her biomaterials were used in synthetic embryo research is of the same kind as the dignitary violation suffered by Dyment, as well as Carlie, in our example above. As a result, while the line to be drawn between *Dyment* and Fran's case is, perhaps, not as straight as with Carlie's, there is nevertheless an argument to be made that Fran has a personal privacy interest in her biomaterials.

The arguable nature of Fran's privacy interest is also reflected by the relevant factors in establishing a "reasonable expectation of privacy", out-lined above in the Beatrice example. These factors include the form of the material, the conduct of both parties, and the defendant's motive or purpose. On the one hand, the purpose of the transfer was to facilitate socially beneficial, cutting-edge biomedical research. On the other hand, however, Fran's biomaterials, in which she enjoys a personal, dignity-based interest, were transferred to be used in a highly controversial area of biomedical research without confirming her consent, despite knowing she had reservations about research in the reproductive context. As a result, it is certainly possible that Fran could be found

[1035] See generally E Haavi Morreim, "The Clinical Investigator as Fiduciary: Discarding a Misguided Idea" (2005) 33:3 JL Med & Ethics 586.

to have suffered a violation of her reasonable expectation of privacy for the purpose of the Canadian statutory torts (in British Columbia, Saskatchewan, and Newfoundland and Labrador) and the English misuse of private information tort. However, whether, for the purpose of the English tort, there has been a misuse of "information" may depend on whether the tort expands to include non-informational intrusions or, perhaps, whether any associated personal information was disclosed along with her sample to the synthetic embryo researcher.

In terms of an action for intrusion upon seclusion, the intrusion into Fran's privacy would have to be highly offensive to a reasonable person in Fran's position (and the Manitoba statutory tort would similarly require the violation to be "substantial"). To return to Wendler's argument from contribution, while there is little normative difference between contributing to Alzheimer's research versus Parkinson's, there is a normative difference where biomaterials are used contrary to interests and values the individual views as fundamental. In this respect, since Fran's objection to abortion research is a product of deeply held religious convictions, it is conceivable that a reasonable person in her circumstances would view synthetic embryo research as highly offensive and substantial.[1036]

With respect to the fault element, unlike the third-party hacker cases where institutional liability would be very difficult to establish, in this scenario, the biobank, through the positive act of transferring Fran's biomaterials, engaged in conduct that arguably violates Fran's privacy. The question will therefore be whether the violation meets the standards of fault in the respective torts. As in the examples above, the fault element in Saskatchewan would continue to prove problematic, as Fran will likely be unable to prove that the biobank specifically intended to violate her privacy. However, it is possible Fran could claim recklessness in intrusion upon seclusion if she can prove the biobank was subjectively aware of her objection and the possibility that she would object to using her biomaterials in synthetic embryo research but transferred her biomaterials anyway. Alternatively, if the biobank lacked subjective awareness but the transfer occurred in circumstances where they should have had this awareness, it is possible the lower constructive knowledge standard (employed in British Columbia and Manitoba) could be met. Whether the biobank had a "claim of right" in the context of these statutory torts will depend on whether the

[1036] For example, for a Catholic perspective on the ethical problems with synthetic embryos, see Tad Pacholczyk, "What about synthetic embryos?", (10 August 2023), online: *The Catholic Times* <catholictimescolumbus.org> [perma.cc/8NZX-C3EA].

biobank had an honestly held belief that the research would not infringe Fran's interests, and, potentially whether such a belief was reasonably based.

If Fran is able to establish the elements of the statutory torts and/or intrusion upon seclusion tort, then the biobank would likely raise consent as a defence. In this respect, a court would have to consider whether broad consent meets the legal requirements for consent in research, with the burden of proof falling on the biobank to establish the validity of Fran's consent. As discussed in Chapter 3, the legality of broad consent remains unsettled despite the pervasiveness of the practice. As a result, judicial consideration of this issue would be a significant matter for the entire biomedical research community, and one they may wish to avoid. While success for Fran is far from certain, her case is at least arguable. And if she were to succeed, the implications could be far-reaching. Injunctive relief, for example, is a possibility. If the broad consent mechanism used by the biobank is invalid, then there could potentially be significant consequences, the most serious of which could include the mandated destruction of biomaterial samples. If nothing else, the possibility of this outcome adds to the list of reasons provided in Chapter 3 for a more meaningful application of the principle of autonomy that recognizes the need for informed and ongoing decision-making over one's biomaterials.

Overall, the use of privacy torts in the research context reveals some possibilities for plaintiffs who discover their biomaterials have been used without consent or beyond the scope of what they consented to. In a third-party hacking situation where participant information is accessed and leaked, recovery against research institutions under privacy torts will be doubtful in most jurisdictions, although the prospect of recovery against the hacker, if they can be identified, is strong. The *Dyment* case represents fertile ground for arguments establishing personal privacy interests in biomaterials. The closer the facts of a particular case align with *Dyment* (where biomaterials were transferred from a medical doctor to another for non-medical purposes) the stronger the arguments will be. As a result, where doctors transfer patient biomaterials without consent to be used in research, there is a strong argument that both the doctor and researchers are violating patient privacy. This violation could potentially be actionable under intrusion upon seclusion or the Canadian statutory torts, except for in Saskatchewan, where there is a heightened fault element. Misuse of private information is less likely to succeed given the need for

"information", although the tort appears to be evolving in the direction of recognizing bare intrusions.

With respect to biobanking and broad consent practices, where the scope of a participant's consent is arguably exceeded, tort liability could arise. Difficulties for plaintiffs in this respect will include establishing a privacy interest in their biomaterials and meeting the fault element, which would be almost impossible in Saskatchewan but at least arguable under the recklessness standard in intrusion upon seclusion and the constructive knowledge standard in other statutory torts. Difficulties for biobanks will include proving they had valid consent and that the public interest in research should outweigh the expressed parameters of consent provided by participants.

C. Deceased Bodies and Biomaterials Taken from Them

In addition to surreptitious genetic testing and biomaterials used in research, the discussion of *AB and Others* in Part 1 of this work demonstrates a need to better ground the claims of bereaved next-of-kin when the bodies of their loved ones are wrongfully interfered with. Like the research context, discussed above, before considering the application of privacy torts, it is necessary to first identify the privacy interest at stake. In this respect, an initial difficulty for privacy law in this context is the fact that privacy rights generally do not survive death.[1037] Therefore, successful privacy tort claims will depend on surviving family members grounding their *own* interests in the bodies that have been infringed.

For example, there was a US case involving similar facts to *Dyment* except that the blood taken and tested following the car accident was taken from a patient who had already died.[1038] Contrary to the finding in *Dyment,* there was no "seizure" or privacy violation from the non-consensual taking of the blood as privacy rights do not survive death.[1039] This has also presented some challenges in other cases involving publication of photographs[1040] and television broadcasts[1041] of the bodies of murdered children without parental consent. While the actions of the defendants in these cases were offensive and grotesque, there was no infringement of parental

[1037] Nwabueze, "Cadavers", *supra* note 178 at 166; Three of the Canadian statutory privacy torts similarly provide that rights of action are extinguished upon death: *Privacy Act* (BC), *supra* note 74, s 5; *Privacy Act* (Nfld), *supra* note 74, s 11; *Privacy Act* (SK), *supra* note 74, s 10.
[1038] *Hubenschmidt v Shears*, [1978] 270 NW 2d 2 [*Hubenschmidt*].
[1039] *Ibid* at 4.
[1040] *Waters v Fleetwood*, [1956] 212 Ga 161 [*Waters*].
[1041] *Armstrong v H & C Communications*, 575 So 2d 280 (Dist Ct App 199) [*Armstrong*].

privacy rights. It is important, then, to consider what rights an individual might have over the deceased body of another.

Jurisprudence from the European Court of Human Rights is helpful in this regard. *Petrova v Latvia* involved the mother of a man who died in an accident and whose kidney and spleen were donated for transplantation without her knowledge or consent.[1042] Latvian law reflected a consent framework whereby donation could occur if the donor had not expressed an objection during their lifetime, provided no objection was expressed by the donor's closest relatives.[1043] The government argued that there was no requirement to seek out the donor's relatives to confirm their lack of objection, however, the mother successfully argued that her right to object under the framework could not be meaningfully exercised if she was not notified of the prospective donation.

The Court clarified that the rights alleged to have been violated were the mother's own rights rather than those of her deceased son.[1044] This is because "Article 8 rights are eminently personal and non-transferrable".[1045] The applicant must therefore be "personally affected" by the alleged violation.[1046] The Court concluded that failing to give the applicant the opportunity to express her consent or objection to the donation of her son's organs was sufficient to conclude there was an interference with her Article 8 right to respect for her private life[1047] and that this interference was not justified under Article 8(2) (which requires balancing the infringement against social interests necessary to a democratic society).[1048]

Similarly, a case against France succeeded in which the failure to return the deceased body of the applicants' young child within a reasonable timeframe following an autopsy was found to be an unjustified infringement of the parents' Article 8 rights.[1049] Cases against Russia have also succeeded where the government has refused to return the bodies of alleged terrorists to their

[1042] *Petrova v Latvia*, No 4605/05, [2014] Eur Ct HR (4th Sec), online: <hudoc.echr.coe.int/?i=001-144997> [perma.cc/8P5G-66UY].
[1043] *Ibid* at paras 35–36.
[1044] *Ibid* at paras 54–55.
[1045] *Ibid* at para 55.
[1046] *Ibid*.
[1047] *Ibid* at paras 87–89.
[1048] *Ibid* at para 98.
[1049] *Pannullo and Forte v France*, No 37794/97, [2001] ECHR 741.

families.[1050] In all of these cases, the individual applicants were found to have Article 8 privacy rights to the bodies that were violated by the state.

While the European Court of Human Rights jurisprudence provides some grounding for individual rights to deceased bodies, the existence of such rights raises difficult conceptual questions. Wojtyczek J in a concurring judgment in *Petrova v Latvia* expressed the idea that the rights of the family members and the rights formerly vesting in the deceased are intertwined, in that "the relatives do not act as autonomous rights-holders, but as depositaries of a right which belonged to the deceased", which "[t]hey should exercise…according to the wishes of the deceased".[1051] In this respect, the Article 8 right "encompasses the right to respect for the dignity of a deceased close relative".[1052]

Wall's work can assist in explaining, from a theoretical perspective, why the undignified treatment of a deceased body could amount to an infringement of the next-of-kin's rights. Wall maintains that our social experience of the world is mediated through the bodies of others.[1053] When someone dies, although the person no longer exists, the physical body through which others interacted with them does.[1054] The deceased body therefore retains a significance to those through which it mediated social experience, as the "manifestation" of the formerly living person.[1055] The surviving people who enjoyed close relationships with the deceased person therefore have an interest in preserving the dignity of that person's body.

As a result, if the justification for rights to a deceased body is the need to preserve the deceased person's dignity, where the wishes of the deceased person conflict with those of the next-of-kin, the next-of-kin's claim weakens. In Wojtyczek J's view, with respect to organ donation, the relatives "act as guardians of the deceased person's rights" to ensure the deceased person's prior wishes are carried out.[1056] This point was also recognized in the English decision, *Borrows v HM Coroner for Preston*, where Cranston J held it is "no longer good law" to hold that the wishes

[1050] *Sabanchiyeva and Others v Russia*, No 38450/05, [2013] Eur Ct HR (1st Sec), online: <hudoc.echr.coe.int/?i=001-120070> [perma.cc/Z5WH-J5H5]; *Maskhadova and Others v Russia*, No 18071/05, [2013] Eur Ct HR (1st Sec), online: <hudoc.echr.coe.int/?i=001-120068> [perma.cc/ZN6Y-8JQP].
[1051] *Petrova v Latvia*, *supra* note 1043 at 31.
[1052] *Ibid*.
[1053] Wall, *Being and Owning, supra* note 26 at 63–64.
[1054] *Ibid*.
[1055] *Ibid* at 64.
[1056] *Petrova v Latvia*, *supra* note 1043 at 30.

of a deceased person can be ignored as "[i]t is quite clear from the jurisprudence of the European Court of Human Rights that the views of a deceased person as to funeral arrangements and the disposal of his or her body must be taken into account".[1057]

A potential tension therefore exists where, on the one hand, the parents from *AB and Others* should have an actionable claim to protect their ability to act as guardians of their children's dignity interests, which were interfered with when their children's organs were taken and retained without their knowledge or consent. On the other hand, the right should not be able to completely override the known wishes of the individual where those wishes can reasonably be carried out. In *Borrows,* a dispute arose between the biological mother and uncle of a deceased teenager as to who should arrange the funeral and disposal of the body. The mother's intention to disregard the boy's previously stated wishes about cremation was one, among several, factors considered in Cranston J's decision to charge the uncle with these responsibilities.[1058] Organ donation legislation in common law countries similarly tends to give preference to the individual's wishes, whether for or against organ and tissue donation, and only requires next-of-kin agreement where the individual's wishes were unknown.[1059]

With respect to privacy tort protection, it is worth considering whether these torts would have provided the parents in *AB and Others* with any additional remedial avenues. The discussion above demonstrated strong support from the European Court of Human Rights that there are privacy rights to deceased bodies and that these rights are protected by Article 8 of the *ECHR*. While none of these cases involved privacy tort claims, just as with *Dyment,* the fact that they were decided using human rights law is significant and could be influential in future privacy tort cases involving similar facts. That said, these decisions are not binding outside Europe, and as a result, although arguable, it is far from certain that a privacy interest would be recognized as a matter of privacy tort law. Even in England where Article 8 *ECHR* jurisprudence forms "the very content"

[1057] *Borrows v HM Coroner for Preston*, [2008] EWHC 1387 (QB) at para 20 [*Borrows*].
[1058] *Ibid* at paras 26–27.
[1059] Maeghan Toews & Timothy Caulfield, "Evaluating the 'Family Veto' of Consent for Organ Donation" (2016) 188:17–18 CMAJ DOI: <10.1503/cmaj.160752>; Maeghan Toews, "Organ and Tissue Donation" in Ben White, Fiona McDonald & Lindy Willmott, eds, *Health Law in Australia*, 3rd ed (Pyrmont NSW: Lawbook, 2018) 773 at 794–96.

of the right engaged by the misuse of private information tort,[1060] success in that jurisdiction would depend, once again, on an expanded understanding of "information".

However, if, outside England, a privacy interest of this nature was recognized, the parents would have strong claims for intrusion upon seclusion and/or violations of privacy under the Canadian statutory torts. Given the public outcry following the organ retention scandal, it would not be difficult to demonstrate that such an intrusion is substantial (required in Manitoba) or highly offensive to a reasonable person in the family's position (required in intrusion upon seclusion). In terms of fault, the hospitals were not intentionally trying to infringe the parents' privacy rights, and therefore the specific intent threshold in Saskatchewan is, again, unlikely to be established. However, there is an argument that the recklessness standard for intrusion upon seclusion would be met, as it would be hard for the hospital to argue they were not aware of the risk that the parents would feel violated. This is because the rationale for not seeking consent was a desire to avoid upsetting the parents, which clearly demonstrates knowledge that retaining organs in this manner carried a risk of emotional harm. Despite direct knowledge of this risk, organs were nevertheless removed and retained. For the same reason, a constructive knowledge standard (for the British Columbia and Manitoba torts) would likely be met as well.

While there are public interest concerns to balance, they are unlikely to be persuasive given the ease with which parental consent could have been obtained. Further, while some of the retained organs were used in research and anatomical instruction, others were merely kept as part of a collection and/or subsequently destroyed, undermining the necessity of this practice to advance the public interest.

If the parents in *AB and Others* were to succeed in intrusion upon seclusion or the Canadian statutory torts, the strong remedial potential of privacy torts becomes evident. All three claimants suffered from psychiatric illnesses arising from discovering their children's bodies had not been returned to them whole. However, only one of the claimant's illnesses was a foreseeable consequence of failing to inform her at the time of the post-mortem examination that organs might be retained, as she was deemed to be an emotionally fragile person. As an intentional tort, intrusion upon seclusion would not attract the same foreseeability requirements imposed by negligence

[1060] *McKennitt*, *supra* note 740 at para 11 (Buxton LJ, Latam and Longmore LJ, agreeing).

law.[1061] As a result, there is no bar to recovery for emotionally robust people whose subsequent distress is unlikely or unforeseeable. Further, there is no threshold in terms of emotional harm that must be satisfied. This is because privacy torts protect personal autonomy and dignitary interests where emotional harm is the expected consequence of their infringements.

While privacy torts, particularly intrusion upon seclusion and the Canadian statutory torts (excluding Saskatchewan), could prove useful to claimants in similar circumstances as the parents in *AB and Others,* the greatest hurdle would likely be establishing a recognized privacy interest. In this respect, while relevant case law from the European Court of Human Rights that recognizes this type of privacy interest would not be binding, human rights jurisprudence has had a significant impact on the development of privacy torts. Further, these torts came into existence because the facts before the courts "cried out" for a remedy.[1062] Misuses of deceased bodies and bodily materials taken from them are situations that have similarly cried out for a remedy for centuries. This is an area that, due to the historical no-property rule, the common law has failed to address. On the right set of facts, it is therefore at least conceivable that the law could move in this direction through privacy law.

D. Conclusion

This chapter has demonstrated the potential utility of privacy torts in specific contexts where biomaterials are alleged to have been misused. While these torts hold some promise for individual litigants, the applicability and likelihood of success under the different torts is variable. The context of non-consensual genetic testing has the strongest potential in terms of privacy tort protection and redress. There are strong arguments that a full range of privacy torts could impose liability on those who collect biomaterials without consent for this purpose, and possibly also laboratories and DTC companies that test biomaterials and disclose the results without good evidence of consent.

[1061] See *Shillington*, *supra* note 607 at para 85, where, in relation to public disclosure of private facts, among other intentional torts, Inglis J cited *Norberg v Wynrib*, [1992] 2 SCR 226 at para 54 for the proposition that "the Defendant's liability is not restricted to foreseeable consequences". While this statement pertained to public disclosure of private facts, as intrusion upon seclusion is also regarded as an intentional tort, the same principle would likely apply. .

[1062] *Jones*, *supra* note 71 at para 69; *Shillington*, *supra* note 607 at para 40.

There are two potential reasons for the comparative strength of claims in this context. The first pertains to the fault element. Whereas an individual who deliberately collects and submits another's biomaterials for genetic testing without consent will satisfy even the strictest fault requirement, institutional fault will rarely reach this level. The lack of utility of the Saskatchewan tort, for example, shows the need for a lower standard of fault than one of specific intent for all but the most egregious of cases. Further, where biomaterials are negligently mishandled, for example, in a *Yearworth* type of situation, privacy torts may be of limited utility. Although the English misuse of private information tort can apply to negligent privacy violations, it would need to expand to encompass physical privacy violations to apply to that context.

The second reason why surreptitious genetic testing provides a strong base for privacy claims is that it raises informational privacy interests, which are well-established in relation to genetic information. Where alleged privacy infringements involve misuse of physical biomaterials without an informational component, the first hurdle claimants will need to overcome is having their *personal* privacy interests judicially recognized. The *Dyment* case provides strong authority for the notion that such interests exist in biomaterials. In the research context where medical practitioners transfer patient biomaterials without consent, *Dyment* may be particularly useful to ground privacy-based arguments. An argument by analogy to *Dyment* could also be made where biomaterials are provided knowingly by participants to researchers for certain research purposes, where the limits of those purposes are then exceeded. With respect to privacy interests in deceased bodies, however, additional rationale is needed to justify the interests at stake.

In terms of a jurisdictional comparison, Canada appears most promising for the application of privacy torts to biomaterials. This is because of the range of privacy torts that exist across the country, including public disclosure of private facts, intrusion upon seclusion, and statutory privacy torts. Further, as the Canadian intrusion upon seclusion tort has explicitly been defined as including the standard of recklessness, the door has been opened for recovery beyond what is possible under a standard of specific intent, as required in the Saskatchewan statutory tort. The constructive knowledge standard employed in the other statutory torts opens that door wider, although the statutory torts require consideration of the defendant's "claim of right" (required in all four jurisdictions) and "lawful interests" of others (required in British Columbia, Saskatchewan,

and Newfoundland and Labrador) as elements of the tort, allowing for arguments grounded in mistaken belief and/or public interest to be considered alongside the interests of the plaintiff.

In contrast, except with respect to surreptitious genetic testing, the English misuse of private information tort seems unlikely, in its current form, to offer much assistance. In some respects, this is surprising given that the tort has imposed a lower threshold through the "reasonable expectation of privacy" test than other jurisdictions that require violations to be "highly offensive" or "substantial", and the English tort also encompasses negligent as opposed to intentional or reckless violations. Further, it reflects Article 8 of the *ECHR*, which is wide in scope, and it gives equal weight to privacy and freedom of expression in balancing competing interests in these claims. However, its utility in biomaterial cases may remain limited unless definitions of "misuse" and "information" expand, more explicitly, to encompass physical intrusions.

While the discussion in this chapter is far from comprehensive in terms of exploring all the situations in which biomaterials could be misused, it does, at least, illustrate how privacy torts could operate in cases of this nature. And given the possibility of redress these torts provide, at least in some circumstances, the discussion also shows the value of further scholarly elaboration as to the potential application of privacy torts to a broader range of contexts where control over biomaterials is disputed. Whether the law is likely to move in this direction and, if so, how it ought to interact with the other legal frameworks considered in this work are also important questions to consider. This thesis will therefore close in the following chapter by considering the future legal directions for biomaterial regulation.

9. Privacy and the Future of Biomaterial Regulation

The regulation of biomaterials is a complex problem. As demonstrated in Part 1 of this work, its legal complexity stems, in part, from the historical no-property rule, excluding bodies and biomaterials from the legal realm that typically deals with tangible things. As a result, when new technological advances and applications for these materials have called for legal rules, the law has responded through piecemeal legislative frameworks and context-specific guidelines. While serving an important function, these governance frameworks have proven insufficient in providing enforceable rights and remedies for individuals experiencing infringements of their interests, and as a result, litigants, courts, and scholars have increasingly turned to property law as the answer. However, the increasing value of biomaterials has meant that institutions are claiming control in a widening array of contexts. To adequately address the remedial vacuum for individuals, property law needs to protect individual autonomy and dignity interests in the face of competing economic and market-based institutional interests, a balancing act it is ill-suited to do.

Part 2 of this work therefore explored the potential role for privacy law to supplement existing legal frameworks and ground individual rights and claims to biomaterials. Chapter 7 explored existing law and scholarship reflecting a truly informatized view of the human body, where biomaterials are treated as a form of personal information. While this approach would represent a legal advancement in creating new rules, rights, and duties pertaining to biomaterials, given the myriad information privacy statutes that exist, reform in this direction would not be simple. Further, given the many exceptions to consent requirements embedded in these frameworks, this approach would not be comprehensive in terms of protecting individual interests. That said, as the interpretive potential of biomaterials and recorded genetic information is the same, and as many of the modern uses for biomaterials are informational in nature, it makes sense to subject biomaterials to legal rules that are consistent with those pertaining to recorded genetic information, at least in situations where biomaterials are collected or stored for the purpose of genetic sequencing.

To provide individuals with meaningful recourse when their biomaterials are misused, tort protection is the more promising option. In this respect, there is a range of privacy torts as potential tools to address the growing problem of surreptitious genetic testing and, arguably, non-consensual

uses of biomaterials in research and biomaterials taken from bodies of deceased loved ones. The utility of these torts, particularly in the latter two contexts, will, however, depend on where the claim arises, as there is considerable jurisdictional variability in the privacy tort landscape. Further, successful tort claims in these contexts will require a robust understanding of personal privacy interests that encompasses the autonomy and dignity-based interests individuals have in biomaterials. Both privacy statutes and privacy torts may, therefore, require further evolutions to squarely bring biomaterials within their ambit.

By taking a macro perspective of relevant legal frameworks, insights can be gained into future directions that biomaterial regulation might take. This concluding chapter will therefore attempt to consider the full regulatory picture to comment on the potential ways in which the law may evolve. The first part of the chapter will compare the conceptual coherence of privacy law and property law to demonstrate the conceptual advantages a privacy approach provides. The second part of this chapter will then explore the likelihood of privacy law evolving to encompass biomaterials and what the resulting regulatory picture might look like, ultimately concluding that, while uncertain, legal regulation of biomaterials through privacy law is possible. And given the advantages this legal framework holds, it is a possibility worth greater consideration.

A. Property Law as a Transitional Phase in the Recognition of Privacy Rights

In evaluating the possible directions of future legal evolutions in biomaterial regulation, it is useful to begin by looking back in time to consider how property and privacy law came to be recognized as distinct legal fields. While property law has deep roots in the common law, it was not until new legal challenges arose from the printing press and photography that privacy law was born.[1063] These technological developments raised new legal issues about what could lawfully be published that had not previously needed to be grappled with. And at that time in England, there was no legal concept of privacy, so claims regarding the non-consensual publication of personal correspondence, for example, had to be framed in terms of property law.[1064]

Initially, property rights were found in relation to private works and correspondence to protect the author's ability to determine whether to publish or disclose their "thoughts and

[1063] Patrick O'Callaghan, *Refining Privacy in Tort Law* (Berlin, Heidelberg: Springer, 2013) at 78–79.
[1064] *Ibid*.

sentiments".[1065] This extension of property law, however, reflected an underlying conceptual strain and artificiality: "[t]hat a thing belongs to a [person] constitutes property; that another [person] should or should not see it is not property".[1066] Further, the "wounded feelings" these cases tended to give rise to were not generally regarded as within the purview of the courts.[1067] The attempt to shoehorn what were in essence privacy rights into the realm of property eventually gave way to new actions in breach of confidence and defamation,[1068] from which the more modern misuse of private information tort has emerged.

There are strong parallels between this historical account and the current state of the law regarding biomaterials. The discussion of property law in Chapters 4 and 5 demonstrated the importance of a close alignment between the legal interests at stake for individuals and the regulatory frameworks to purportedly protect them. In this respect, Chapter 5 argued property law was a poor fit as the interests property law is best suited to protect are more closely aligned with institutional interests in biomaterials rather than those of individuals. Further, biomaterial cases similarly give rise to "wounded feelings", which fall outside the type of harm that is typically addressed through property law. Given the obstacles to claimants and conceptual disconnect underlying the property law cases, it is possible to see these cases as being "shoehorned" into a property framework in the same way as cases arising in the wake of the printing press. In this respect, property case law may represent merely a transitional phase in a much broader legal evolution in biomaterial regulation. This section will explore whether it makes sense for privacy law to form the next evolutionary phase.

The primary reasons for this conceptual shoehorning are that property law provides an exclusionary boundary, leaving the rights-holder with open-ended control powers, and offers remedies when property rights are violated. However, the discussion in this work has noted that (i) privacy law also provides an exclusionary boundary, with embedded flexibility needed for biomaterial regulation that property law lacks, (ii) privacy law provides a stronger alignment, when compared to property law, between the interests it is designed to protect and the interests at stake for individuals, which suggests it could provide firmer ground for individual claimants against

[1065] *Ibid* at 80, discussing *Prince Albert v Strange* (1949) 2 De Gex & Smale 652 at 695.
[1066] *Ibid* at 79, quoting *Prince Albert v Strange, ibid.*
[1067] *Ibid* at 79–80.
[1068] *Ibid* at 80–81.

institutions, and (iii) this close alignment means that the remedies offered by privacy law correspond directly to the interests at stake for individuals. The following discussion will elaborate on these points to demonstrate that privacy law provides a plausible framework for the next step in the continued evolution of biomaterial regulation.

i. The Exclusionary Boundaries of Property and Privacy Law

There are structural similarities between property and privacy law that make privacy a relevant tool to consider in biomaterial regulation. Both operate through an exclusionary boundary, enabling individual control by imposing obligations on the rest of the world to refrain from interfering with the relevant subject matter.[1069] However, the exclusionary boundary under property law is more rigid than privacy law, which has an embedded flexibility. As a matter of property law, the exclusionary boundary is strong, although not inviolable, as it can be crossed with the consent of the rights-holder or as a matter of statutory or common law principles enabling non-consensual interferences. However, it nevertheless represents a strong form of protection as the tangibility of personal property is what signals to the rest of the world the obligation of non-interference.[1070] There is no room for personal judgment or discretion nor any need for calculation when determining whether one is obligated to refrain from interfering with another's property. The ease with which one can identify their duty of non-interference is what justifies the strong protection for the rights-holder.[1071]

In contrast, the exclusionary boundary imposed by privacy law is more flexible. It is not all information about a person, for example, that imposes a duty of non-disclosure as a matter of privacy law.[1072] Nor do all spaces or aspects of one's person that are subjectively viewed as being personal call for protection under privacy law. As discussed in the preceding chapters, notions of "reasonableness" are embedded in determining whether a particular subject matter is "private". This notion of reasonableness means the concept of privacy is malleable and capable of evolving in new directions. This point was recognized by Tipping J in *Hosking,* who observed that the "expectations of privacy [that] are reasonable will be a reflection of contemporary social values

[1069] Rao, *supra* note 926 at 418–25.
[1070] Render notes, "The 'thingness' of property rights is significant in that we know things about our legal duties with respect to a thing that is owned even if we do not know who the owner is": Render, *supra* note 26 at 563.
[1071] Wall, *Being and Owning, supra* note 26 at 193.
[1072] See *ibid* at 195.

and the content of the law will in this respect be capable of accommodating changes in those values".[1073]

While the embedded criterion of reasonableness renders privacy law malleable, it also means the exclusionary boundary is more permeable than in property law. This apparent weakness, however, may provide a useful compromise and balancing point between the many conflicting interests in biomaterials held by different actors. For example, one of the primary objections to Moore's conversion claim was the indeterminate liability that would follow for researchers who could never be certain, when using biomaterials transferred by someone else, whether appropriate consent was obtained.[1074] As conversion does not require knowledge of wrongdoing, the concern was that exposure to liability could be vast and hinder valuable scientific research. In contrast, as discussed in the previous chapter, intrusion upon seclusion generally requires intentional or reckless conduct; statutory torts generally require "willful" conduct; and the English tort protects "reasonable" expectations of privacy. These standards suggest that a researcher who reasonably believes appropriate consent has been obtained for the biomaterials in their possession is unlikely to be liable should privacy torts be extended to this context.

Similarly, as discussed in Chapter 7, a potential problem for property law is the fact that human bodies are "leaky",[1075] shedding skin cells, hairs, saliva, and bodily waste all the time. If, as many property scholars in this field advocate, individuals each own their separated biomaterials, then we are constantly depositing our property everywhere we go, potentially littering or creating involuntary bailments. In contrast, privacy law has the concept of reasonableness embedded in it. Recovery for wrongful infringements is only possible over subject matter to which a reasonable expectation of privacy exists. In some cases, those infringements must rise to the level of being "highly offensive" to a reasonable person.

Further, a loss of physical possession of biomaterials does not compromise the exclusionary boundary of privacy law, as privacy rights are non-transferrable. This is an important point in an era where high quality human DNA can be recovered from air, water, and sand.[1076]

[1073] *Hosking*, *supra* note 72 at para 250.
[1074] *Moore*, *supra* note 241 at 143.
[1075] Herring, *supra* note 29 at 220–23.
[1076] Osborne, *supra* note 97.

Whereas some would view our shed hair, skin, and saliva as abandoned property,[1077] when these materials are genetically sequenced, there are clear informational privacy interests that continue to exist regardless of who is in possession of them. Privacy law is therefore better equipped to address the problems that remain for property law in dealing with our leaky bodies. Rather than a weakness, the flexibility of the privacy law exclusionary boundary enables it to provide the necessary nuance for dealing with individuals' interests in biomaterials. And as the following discussion will show, it is also designed to protect the very interests at stake for individuals in biomaterial cases, further solidifying its suitability as a regulatory framework.

ii. Conceptual Alignment to Ground Claims Against Institutions

Chapter 2 of this work discussed the autonomy and dignity-based personal interests that exist in biomaterials. In this discussion, it was conceded that the amorphous concept of "dignity" presents a challenge in precisely identifying the interests at stake for individuals in biomaterials. Nevertheless, there is some concept of "dignity", however that term might be defined, operating in the background of these cases that is reflected in the deeply personal interests individuals can have in biomaterials, justifying individual autonomy and control.

Privacy law is similarly understood as protecting autonomy and dignity interests. Just as with individual interests in biomaterials, the exact content of these interests is difficult to pinpoint, rendering the concept of privacy imprecise.[1078] As privacy scholar, Stephen Penk, has put it, "[t]hat privacy is a large, unwieldy and elusive concept is axiomatic",[1079] with autonomy and dignity-based justifications for privacy ubiquitous in case law and scholarship. For example, Tipping J in *Hosking* stated, "[i]t is of the essence of the dignity and personal autonomy and well-being of all human beings that some aspects of their lives should be able to remain private if they so wish".[1080] Similarly, La Forest J, in *Dyment,* noted that "privacy is essential for the well-being of the

[1077] See the discussion of "abandonment" further below.
[1078] Giliker, *supra* note 741 at 762; See also Robert Stevens, "Damages for Wrongdoing in the Absence of Loss" in Varuhas & Moreham, *supra* note 280, 97 at 112–13, who questions whether "dignity" is a convincing justification for privacy interests.
[1079] Stephen Penk, "Thinking about Privacy" in Stephen Penk & Rosemary Tobin, eds, *Privacy Law in New Zealand* (Wellington: Brookers, 2010) at 1; See also Chris D L Hunt, "The Common Law's Hodgepodge Protection of Privacy" (2015) 66 UNBLJ 161 at 162, who notes that "privacy remains a deeply - arguably an essentially - contested concept".
[1080] *Hosking*, *supra* note 72 at para 239.

individual", being "[g]rounded in [a person's] physical and moral autonomy",[1081] the violation of which amounts to an "affront to human dignity".[1082]

Media and privacy law scholar, NA Moreham, traces how the concepts of autonomy and dignity have been used to underpin the development of the English misuse of private information tort.[1083] With respect to the concept of dignity, Moreham points to prominent privacy scholars who regard privacy as a "dignity tort",[1084] such as Edward Bloustein who argues that, in privacy violations, "[t]he injury is to our individuality, to our dignity as individuals, and the legal remedy represents a social vindication of the human spirit thus threatened rather than a recompense for the loss suffered".[1085] Moreham explains that the understanding of "dignity" in this respect is often associated with Immanuel Kant's argument that respect for persons requires that we treat one another as an "end" as opposed to a "mere means".[1086] To concretize this principle in the privacy context, Moreham provides some examples of how privacy violations infringe dignitary interests:

> To use another person's private experience to further one's research, to make money, to titillate, to entertain or to make a point is to treat that person as a means to your ends rather than to respect that individual's inherent value as a person.[1087]

Respect for autonomy is also at the centre of privacy law.[1088] Privacy enables autonomy in that "it protects a claimant's ability to determine whether, when and to whom he or she is accessible" and "whether and in what circumstances others have access to his or her physical self and private affairs".[1089] In this respect, privacy encompasses different dimensions: spatial, personal, and informational[1090] and "enables us to exercise our preferences and choices as to which aspects of our individuality we share or relinquish with others, control which aspects of our personality

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[1081] *Dyment*, *supra* note 69 at para 28.
[1082] *Ibid* at para 32.
[1083] NA Moreham, "Compensating for Loss of Dignity and Autonomy" in Varuhas & Moreham, *supra* note 280, 125 at 134–35.
[1084] *Ibid* at 134, citing P Cane, *The Anatomy of Tort Law* (Oxford, Hart Publishing, 1997), 71-74, and Edward Bloustein, "Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser" (1964) 39 NYUL Rev 962 at 1002-1003.
[1085] Moreham, *supra* note 1083 at 134, quoting Bloustein, *supra* note 1084 at 1002-1003.
[1086] Moreham, *supra* note 1083 at 135.
[1087] *Ibid* at 136.
[1088] Bygrave, *Data Privacy Law, supra* note 59 at 120; Aisling de Paor, "Regulating Genetic Information-Exploring the Options in Legal Theory" (2014) 21 Eur J Health L 425 at 438.
[1089] Moreham, *supra* note 1083 at 137.
[1090] *Dyment*, *supra* note 69 at para 30 (La Forest J).

that we make available for public judgment and criticism, and determine how we construct a public personae that may be distinct from the realities of our own personhood".[1091]

Despite a lack of precision, these autonomy and dignity-based interests align more closely with the individual interests at stake in relation to separated biomaterials than those protected by property law. As discussed in Chapter 5, property law is better suited to evaluate competing interests by translating them into the language of market value.[1092] Property claims therefore tend to be resolved in favour of the party whose interests will better serve the market.[1093] Without needing to pinpoint a common understanding of human dignity, it is clear that the individual interests in biomaterials that this thesis has identified as being in need of protection are deeply personal, as opposed to economic or tangible, in nature. As Herring has argued, "at the very least what supporters of dignity are identifying is the sense of value many people recognise in body parts which is beyond the physical type captured by a property analysis." [1094]

The alignment between protected interests in privacy law and the interests individuals have in biomaterials may provide strong grounding for individuals in claims against institutions. Chapter 5 demonstrated that misalignment in this regard is a possible explanation for why individuals have difficulty claiming property rights where control over biomaterials is seriously contested by institutions. In contrast, the values at stake for individuals in biomaterial cases are of the same nature as the values underlying privacy law.

As seen in the previous chapter, privacy torts involve an inherent weighing of individual interests against public interests, and this is done in different ways depending on the jurisdiction.[1095] For example, the statutory privacy torts in BC, Saskatchewan, and Newfoundland and Labrador each require consideration of "the lawful interests of others" in determining whether there has been a privacy violation.[1096] Similarly, the Article 8 *ECHR* right to privacy requires consideration of competing public interest concerns and the resulting English misuse of private information tort requires direct balancing of an individual's Article 8 right with the defendant's Article 10 right to

[1091] Wall, *Being and Owning, supra* note 26 at 186–87.
[1092] See Gold, *supra* note 518.
[1093] *Ibid*.
[1094] Herring, *supra* note 29 at 218.
[1095] Beswick & Fotherby, *supra* note 622 at 245–47.
[1096] *Privacy Act* (SK), *supra* note 74, s 6(1); *Privacy Act* (Nfld), *supra* note 74, s 3(1); *Privacy Act* (BC), *supra* note 74, s 1(2).

free expression, with these rights viewed as being of equal importance. The equal footing of these values and expansive protection afforded by Article 8 has enabled the English tort to evolve into a robust mechanism for protection of informational privacy.[1097] In contrast, competing public interest concerns have played less of a role in Canadian and New Zealand case law, as these concerns are more relevant to a defence of "legitimate public concern" rather than forming part of the elements of the torts.[1098] For example, in *Hosking,* Gault P imposed a defence where there is a "legitimate public concern in the information" that justifies its publication.[1099] As discussed in Chapter 6, the biggest challenge for plaintiffs in these jurisdictions tends to be overcoming the high bar set by the "highly offensive" test, and once this is done, it would have to be a very compelling public interest to justify a highly offensive violation of individual privacy.[1100]

While it is impossible to predict with certainty how a court would view the privacy interests of individuals in their biomaterials when considered against the various countervailing public interests to be served through institutional uses of biomaterials, some initial observations can be made. Firstly, from the case law examined in Chapter 6, there are cases from a range of jurisdictions where individuals have succeeded against institutional defendants. The English cases often involve individuals bringing claims against large media corporations.[1101] In Canada, numerous class actions have been certified against both corporate and government defendants.[1102] While these cases must be understood in relation to their own facts, and the English cases, in particular, need to be contextualized within the rampant tabloid culture in the English media,[1103] they at least provide for the possibility that individuals can succeed against institutions in privacy torts.

Secondly, in biomaterial cases, the significance of the public interests at stake will vary depending on the facts. The analysis in Chapter 8, for example, demonstrated that in cases of surreptitious genetic testing, there will not be compelling public interest concerns to consider. In contrast, in the biomedical research context, the public interest will likely be more compelling.

[1097] See generally Beswick & Fotherby, *supra* note 622.
[1098] *Ibid* at 236 & 246.
[1099] *Hosking*, *supra* note 72 at para 129.
[1100] Beswick & Fotherby, *supra* note 622 at 247.
[1101] For example, see: *Campbell*, *supra* note 681; *Murray*, *supra* note 744; *Gulati*, *supra* note 766; and *Vidal-Hall*, *supra* note 73.
[1102] *Sweet*, *supra* note 604; *Capital District Health*, *supra* note 605; *Kaplan*, *supra* note 610.
[1103] See generally Beswick & Fotherby, *supra* note 622.

However, the public interest concern that has played the largest role in shaping these torts is the need to preserve free expression. The paramount importance of this right, enshrined in federal human rights law in Canada and New Zealand, is one reason commentators have formed the view that these jurisdictions offer a more restrained approach to privacy torts compared to England, where these values are on equal footing.[1104] However, the type of public interests at stake in biomaterial cases will rarely engage this paramount concern. Instead, public interests are more likely to involve the advancement of scientific knowledge and understanding of human health and disease. Although these interests are also very important, as discussed in Chapter 8, the burden will be on researchers to demonstrate that privacy violations were necessary and proportionate to achieving these aims, which could be difficult in cases where participant consent could feasibly have been obtained. Further, given the significance of the privacy interest recognized in *Dyment* as being on par with infringements to bodily integrity, it would have to be a very compelling public interest to prevail over this individual right.

While it is possible institutional interests will continue to prevail against individuals', privacy torts at least recognize and respond to the dignity and autonomy interest that individual have in their biomaterials, providing a greater chance of achieving legal protection. This alignment provides advantages not only in terms of grounding claims against institutions, but, as the following discussion will show, also in terms of securing meaningful remedies.

iii. Remedial Nexus with Individual Interests

The previous chapters in this thesis highlighted the remedial shortcomings of the consent paradigm imposed through statutory instruments, which do not provide individuals with any positive enforceable rights. The need for remedies when biomaterials are misused is one of the key reasons property law is viewed as a strong tool. However, property law is not well-suited to provide remedies for the type of harm that individuals suffer.

For example, as discussed in Chapter 2, in *Yearworth,* the Court's finding that the sperm was the men's property did not, itself, answer the question of whether they could recover damages for mental harm. It was only because the sperm was property *under a bailment* that the Court of Appeal was happy to allow damages to be awarded using contract law principles, which are slightly

[1104] *Ibid*.

more accommodating regarding compensation for mental harm than negligence. The Court was less certain as to whether damages for mental harm could otherwise be awarded for the negligent destruction of property the claimants suffered.[1105]

The reason for this uncertainty is that compensable mental harm is not typically associated with property loss or damage. The primary harm ordinarily suffered from property damage is economic loss (i.e., the diminution in value or cost of repair). This type of remedy makes sense in the context of the values property law is designed to protect, which are economic in nature. In contrast, the interests individuals have in their biomaterials are autonomy and dignity-based, and when they are infringed, it is intangible mental and dignitary harm that occurs rather than financial loss.

Privacy torts, on the other hand, are designed to remedy the exact type of harm individuals suffer when biomaterials are misused. In *Gulati,* where the plaintiffs' phones had been hacked by a tabloid publisher, Arden LJ on behalf of the English Court of Appeal indicated that "damages are an award to compensate for the loss or diminution of a right to control formerly private information and for the distress that the respondents could justifiably have felt because their private information had been exploited".[1106] Loss of a right to control and associated distress precisely describe the wrong at the heart of biomaterial cases needing to be remedied. Further, unlike claims in negligence,[1107] there is no threshold of severity the mental harm must meet to be compensable.[1108]

Even without proof of harm, Canadian statutory privacy torts are actionable *per se,*[1109] and there is case law in Canada and England to suggest common law privacy torts are as well. Unlike negligence, which requires proof of harm or loss, privacy torts address violations of one's fundamental dignity and autonomy interests, which are, themselves, actionable. In *Jones v Tsige,* for example, Sharpe JA made it clear that "proof of actual loss is not an element of the cause of

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[1105] *Yearworth*, *supra* note 93 at para 55.
[1106] *Gulati*, *supra* note 766 at para 48.
[1107] Most common law countries require proof of a recognized psychiatric illness, with the exception of Canada, which requires proof of "serious and prolonged" mental harm, which does not depend on a particular psychiatric diagnosis: *Saadati*, *supra* note 151 at paras 28 & 37.
[1108] See *Jones*, *supra* note 71 at para 90, where the plaintiff was awarded $10,000 despite suffering no harm to her health; See also *Gulati*, *supra* note 766, where the plaintiffs' significant damages awards were upheld without requiring proof of psychiatric illness.
[1109] *Privacy Act* (BC), *supra* note 74, s 1(1); *Privacy Act* (MB), *supra* note 74, s 2(2); *Privacy Act* (SK), *supra* note 74, s 2; *Privacy Act* (Nfld), *supra* note 74, s 3(1).

action for intrusion upon seclusion".[1110] In *Racki v Racki,* Coughlan J indicated that, similar to defamation, in a public disclosure of private facts case, "general damages…are presumed by the publicity of the private facts and are awarded at large".[1111] Similarly, in the English case, *AAA v Associated Newspapers*, a young child was awarded damages for a newspaper article featuring her picture and speculating about her paternity.[1112] She was too young to suffer any mental harm or distress but was nevertheless awarded damages for the infringement of her privacy rights.[1113] Because the interests at stake are dignity and autonomy-based, a damages award must "demonstrate, both to the victim and to the wider community, the vindication of these fundamental, although intangible, rights which have been violated by the wrongdoer".[1114] As a result, these torts could remain useful tools in biomaterial cases where plaintiffs have not suffered financial loss or physical harm.

In addition, while the quantum of damages awards in several jurisdictions started off modestly, as the torts have developed, courts have become more comfortable awarding sizeable sums. For example, in the groundbreaking *Campbell* case in England in 2002, Naomi Campbell's success in proving her claim was significant, however, she was awarded a mere £2500 in general damages plus £1000 in aggravated damages.[1115] In contrast, in 2008, the plaintiff in *Mosley v News Group Newspaper* was awarded £60,000 for the wrongful publication of information that he participated in a sado-masochistic orgy,[1116] marking the beginning of a trend in English privacy cases of larger damages awards.[1117]

Similarly, while Sharpe JA imposed a "conventional range" for damages in *Jones v Tsige,* with $20,000 as the upper end of the range for intrusion upon seclusion, judges in subsequent decisions involving public disclosure of private facts did not feel compelled to adhere to this range. For example, general damages of $50,000 were awarded in both *Jane Doe 1* and *Jane Doe 2,* and $80,000 in *Shillington,* with similarly high awards being made under the statutory privacy torts.[1118]

[1110] *Jones*, *supra* note 71 at para 74.
[1111] *Racki*, *supra* note 682 at para 28.
[1112] *AAA v Associated Newspapers*, [2012] EWHC 2013.
[1113] *Ibid* at para 127.
[1114] *Jane Doe 2*, *supra* note 664 at para 132, quoting Justice Cromwell in *G (BM) v Nova Scotia* (Attorney General), 2007 NSCA 120 at para 130.
[1115] *Campbell*, *supra* note 681 at para 10.
[1116] *Mosley v News Group Newspaper*, [2008] EWHC 1777 at para 236.
[1117] Moreham, *supra* note 1083 at 126.
[1118] For example, $85,000 was awarded to the plaintiff in *TKL v TMP*, *supra* note 802.

However, not all cases will attract such large awards, and in biomaterial cases without significant psychological or financial harm, large awards may not be warranted. Nevertheless, these cases demonstrate flexibility and a judicial willingness to make awards that are appropriate on the facts before them.

The availability of aggravated and punitive damages awards further strengthens the remedial potential of privacy torts. English courts have awarded aggravated damages for misuse of private information,[1119] and even the Privacy Commissioner under Australia's *Privacy Act (Cth)* has the power to award aggravated damages.[1120] While punitive damages are unavailable in Australia[1121] and unsettled in England,[1122] the Canadian revenge porn cases are examples where these types of damages have been awarded, forming a substantial part of the plaintiffs' total damages award. In *Jane Doe 1 and 2* each of the plaintiffs was awarded $25,000 for aggravated damages and an additional $25,000 in punitive damages. Similarly, the plaintiff in *Shillington* was awarded $25,000 in aggravated and $50,000 in punitive damages.[1123] In cases like *Moore,* where Moore was exploited by his treating doctor as a source of lucrative biomaterials, these additional forms of damages add an important dimension to the remedial offerings of these torts.

In addition, injunctive relief is also possible to prevent publication of personal information. This form of relief has readily been granted in English misuse of private information cases, whereas Canadian and New Zealand courts have taken a more restrained approach.[1124] This is arguably due to greater emphasis placed on freedom of expression in the latter jurisdictions, which courts are more reluctant to limit.[1125] That said, in appropriate cases, such as the Canadian revenge porn decisions, courts have ordered defendants not to further publish intimate images or recordings and to destroy or return to the plaintiff any such material in their possession.[1126] This form of relief

[1119] *Gulati*, *supra* note 766 at para 70.
[1120] Normann Witzleb, "Determinations under the Privacy Act 1988 (Cth) as a Privacy Remedy" in Varuhas & Moreham, *supra* note 280, 377 at 401.
[1121] *Ibid* at 405–406.
[1122] While there has been some doubt about the availability of punitive damages, Lord Toulson, in dissent, indicated that punitive damages should be available "to deter flagrant breaches of privacy and provide adequate protection for the person concerned": *PJS v News Group Newspapers*, [2016] UKSC 26 at para 92.
[1123] *Shillington*, *supra* note 607 at paras 98–102.
[1124] Beswick & Fotherby, *supra* note 622 at 248–51.
[1125] *Ibid* at 250–51.
[1126] *Jane Doe 1*, *supra* note 72 at para 64; *Jane Doe 2*, *supra* note 664 at paras 144–45.

is also explicitly available under three of the Canadian statutory privacy torts.[1127] Further, in New Zealand, while the plaintiffs in *Hosking* were unsuccessful in obtaining an injunction to prevent the publication of the photos of their children, Gault P nevertheless recognized that injunctive relief may be appropriate in other cases.[1128] As discussed in the previous chapter, this type of remedy could have very significant consequences in the research context, where the legality of biobanks' collections of biomaterials is questionable given the broad consent paradigm employed in that sector.

In addition to injunctive relief and general, aggravated, and punitive damages, it is also theoretically possible for privacy torts to be remedied through an account of profits. An account of profits is an equitable remedy that, "in the field of torts,…is highly controversial given the traditional focus upon compensation and the historical separation of law and equity".[1129] That said, the Canadian statutory privacy torts in Manitoba, Saskatchewan, and Newfoundland explicitly include an account of profits in their respective lists of available remedies.[1130] Similarly, as mentioned in Chapter 6, in an Ontario class action certification decision where plaintiffs alleged that a bank employee improperly accessed and disclosed their financial records for fraudulent purposes, their cause of action against both the rogue employee and the bank for intrusion upon seclusion was certified as was their claim for "waiver of tort".[1131] Waiver of tort means that "the plaintiffs give up the right to sue in tort and elect to base their claim in restitution", providing for a disgorgement of profits earned from the defendant's wrongful conduct.[1132]

Further, given that the English misuse of private information tort originated in the equitable breach of confidence action, there remains the possibility that equitable relief could be granted in that jurisdiction as well. On behalf of the Majority in *PJS,* Lord Mance of the Supreme Court stated that the question of whether an account of profits is available under this tort is an open question.[1133] Remedies expert, Katy Barnett, notes the unsettled nature of this issue and advocates in favour of

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[1127] *Privacy Act* (Nfld), *supra* note 74, s 6(1)(b); *Privacy Act* (MB), *supra* note 74, s 4(1); *Privacy Act* (SK), *supra* note 74, s 7(b).
[1128] *Hosking*, *supra* note 72 at para 149.
[1129] Varuhas & Moreham, *supra* note 579 at 10.
[1130] *Privacy Act* (Nfld), *supra* note 74, s 6(1)(c); *Privacy Act* (SK), *supra* note 74, s 7(c); *Privacy Act* (MB), *supra* note 74, s 4(1)(c).
[1131] *Evans v The Bank of Nova Scotia*, *supra* note 603 at para 62.
[1132] *Ibid* at para 53.
[1133] *PJS v News Group Newspapers*, *supra* note 1123 at para 42.

an account of profits "where compensatory damages are inadequate, an injunction is unavailable, the defendant's breach was advertent and the defendant made a profit".[1134] This form of damages could be particularly relevant in cases like *Moore,* where the plaintiff was seeking a share of the profits earned through the non-consensual creation of a highly lucrative cell-line using his biomaterials, and represents a significant advantage of privacy torts over other tort-based options.

The resulting remedial picture for privacy torts is one that is flexible and varied, with a full range of potential remedies to address the specific wrongs of a particular case. Further, the remedies offered directly correspond to the individual interests infringed when biomaterials are misused. While it is possible that privacy law could also be accused of conceptual shoehorning in that expanded definitions of "information" or "personal privacy" may be needed to fully encompass biomaterials, on this more fundamental level examining the basic nature of the wrongs and remedies that legal frameworks are designed to address, it becomes clear that privacy law provides a neater conceptual fit. For this reason, it is possible that the current dominance of property law in biomaterial discourse will fade as privacy law emerges as the stronger regulatory option.

B. The Future of Privacy Rights to Biomaterials

While it cannot be predicted with certainty whether privacy law will take hold as a new tool for biomaterial regulation, there are lessons to be learned from the property law context that suggest that consideration of this evolutionary possibility is not without merit. Although there are many factors that could influence future developments of the law, the following discussion provides some general insights arising from the comparative work undertaken in this thesis. The thesis will then close by considering how these different legal frameworks might interact, demonstrating the possibility for a harmonious co-existence.

i. Lessons Learned from Property Law

Several lessons can be learned from the field of property law in terms of considering the potential for privacy law to extend to human biomaterials. The first lesson is that the precedential value of case law is strong, despite the poorly reasoned and conceptually confused nature of the

[1134] Katy Barnett, "Gain-Based Relief for Breach of Privacy" in Varuhas & Moreham, *supra* note 280, 183 at 184.

decisions being relied on. For example, in the property context, Sanderman J in *C(C)* determined that the embryos in question were the applicant's property with no discussion of the legal or ethical ramifications of such a significant pronouncement. Despite these conceptual shortcomings, the case has been recognized as establishing important precedent, being relied on in subsequent decisions.[1135] Early evidence of the same trend can be seen in privacy case law. The *Marper* decision of the European Court of Human Rights is reminiscent of *C(C)* in the sweeping pronouncement that the biological samples in the case were "information", without analysis or consideration of any broader implications. And like *C(C),* the lack of analysis did not prevent the decision from being relied on for this principle in the subsequent decision of *Gaughren.* What this trend demonstrates is that, for better or worse, the myriad conceptual questions raised in biomaterial regulation cases do not need to be fully resolved (or even addressed) for a decision to gain traction and influence the development of the law.

Further, courts considering privacy and biomaterial property claims heavily borrow principles and precedents from one another across common law jurisdictions. For example, the Australian *Doodeward* case establishing the work or skill exception has been widely relied upon as establishing a common law principle. The US decision of *Moore* has had tremendous influence throughout common law countries. And the UK's *Yearworth* marked a departure from the no-property rule regarding sperm that has been followed, and expanded upon, in other jurisdictions as well. In the privacy context, Prosser's articulation of four privacy torts as a matter of US law has had enormous significance in Canada and New Zealand. And the Ontario decision, *Jones,* has been influential not only in other Canadian provinces but also in New Zealand's recognition of intrusion upon seclusion, just as New Zealand's recognition of public disclosure of private facts in *Hosking* has been influential in Canada. And underpinning these legal developments is the importance of privacy as a matter of human rights, where La Forest J's views on privacy in *Dyment* have been repeated in jurisprudence around the world. As a result, it is conceivable that the informational characterization of biomaterials from *Marper* and *Gaughren,* or a future case that recognizes personal privacy interests in biomaterials in a privacy tort claim, could have profound significance internationally, despite any lingering conceptual questions.

[1135] *M (JC)*, *supra* note 429 at paras 20–21; *Lam*, *supra* note 437 at para 39; *KLW v Genesis Fertility Centre*, [2016] BCSC 1621 at paras 60–62.

The impetus behind legal developments in both the property and privacy realms is the need for the law to respond to new technologies. The Court's pronouncement in *Yearworth* that "developments in medical science now require a re-analysis of the common law's treatment of and approach to the issue of ownership of parts or products of a living human body"[1136] was echoed in *M (JC)* and formed the basis of Russell J's justification for extending the common law past the boundaries of *Yearworth*.[1137] Similarly, while not pertaining to biomaterials, privacy tort case law has relied heavily on this desire for the common law to keep pace with technology.

Sharpe JA in *Jones,* for example, noted that, "[f]or over one hundred years, technological change has motivated the legal protection of the individual's right to privacy…".[1138] Similarly, in *Jane Doe 2,* there was a similar recognition of the need for a new cause of action, "[r]epresent[ing] a constructive, incremental modification of existing law to address a challenge posed by new technology".[1139] Inglis J in *Shillington* noted, "the increased use of new technologies has created rapid societal change that has created new possibilities for privacy breaches that require adequate legal protection".[1140] While recognizing privacy rights to biomaterials would, in some circumstances, represent a novel application of privacy principles, there is a clear willingness by the judiciary to push the boundaries of existing legal frameworks in response to new issues arising from technological change. Just as this rationale has been influential in property jurisprudence involving biomaterials and in early cases recognizing privacy torts, it could also prove persuasive on the right set of facts involving biomaterials where a claimant would otherwise be left without a remedy.

Although property law was once thought to be inapplicable and inappropriate as a legal framework in which to adjudicate disputes over human bodies and biomaterials, as technology has made these materials more useful and valuable, in-roads to the no-property rule have been made, notwithstanding the conceptual difficulties these exceptions create. The similarities between the property and privacy law experiences demonstrate that privacy law is equally capable of moving in new directions to address new and emerging privacy wrongs. While it is far from certain that the law will move in this direction, this thesis has argued that it is a possibility worthy of

[1136] *Yearworth*, *supra* note 93 at para 45(a).
[1137] *M (JC)*, *supra* note 429 at para 63.
[1138] *Jones*, *supra* note 71 at para 67.
[1139] *Jane Doe 2*, *supra* note 664 at para 93.
[1140] *Shillington*, *supra* note 607 at para 55.

consideration. The next section will consider the implications of this potential evolution in terms of the interactions between the full complement of regulatory options.

ii. The Interactions between Privacy Law, Property Law, and Statutory Governance Frameworks

While the above discussion has argued the plausibility of a legal evolution recognizing privacy rights to biomaterials, this is not to say that such an evolution would leave property law or statutory governance frameworks without work to do. It is possible for these frameworks to operate in tandem. As Laurie has noted, "the two concepts of privacy and property are treated as either/or options when there is no sound reason to do so".[1141] Indeed, while privacy law has certain advantages in terms of grounding individual rights and remedies, there remain cogent reasons for property law and legislative instruments to play their own roles as well.

One of the major concerns in biomaterial regulation is that because these materials are so valuable, in the absence of property protection, they are vulnerable to being taken.[1142] As discussed in Chapter 8, privacy law could potentially play a role where biomaterials are wrongfully taken and used without individual consent, for example, in research. However, if biomaterials are wrongfully taken from an institution that validly possesses them, privacy law will not be of much assistance to the institution, as privacy rights are non-transferrable, and institutions lack the autonomy and dignity-based interests that privacy law protects. In *Kelly,* for example, body parts were taken from a school of anatomy. Similarly, it was recently revealed that the Harvard Medical School's morgue manager has allegedly been stealing body parts and selling them in a black market.[1143] These cases illustrate that property law has an important role to play. In *Kelly,* the rogue employee was charged and convicted of theft, and in the Harvard morgue case, the morgue manager, his wife, and two of their customers have been accused of conspiracy and interstate transport of stolen goods.[1144]

[1141] Graeme Laurie, "Privacy and Property? Multi-Level Strategies for Protecting Personal Interests in Genetic Material" in Bartha Knoppers & Charles Scriver, eds, *Genomics, Health and Society: Emerging Issues for Public Policy* (Ottawa, Canada: Government of Canada: The Policy Research Initiative, 2003) 83 at 84.
[1142] See Douglas, *supra* note 18.
[1143] David K Li, "Harvard Morgue Theft Ring Stole Body Parts, Sold Brains and Turned Human Flesh into Leather", *NBC News* (15 June 2023), online: <www.nbcnews.com> [perma.cc/L9SL-JLJ7].
[1144] *Ibid*.

How the two frameworks coincide is therefore an important issue to consider. Wall advocates for a hybrid property/privacy approach to biomaterial regulation.[1145] In his work, *Being and Owning,* Wall considers the justifications for granting individual rights of control over separated biomaterials and whether property or privacy frameworks are best suited to protect them. In his view, individuals have unique and non-transferrable interests in "functionally unified" biomaterials (such as stored gametes, which continue to serve the same function despite physical separation from the body) and the bodies and biomaterials of deceased loved ones.[1146] In Wall's view, these biomaterials should be governed by a new category of confidentiality rights and protections, whereas other biomaterials should be left to the realm of property, whereby institutions can gain property rights through some combination of the work or skill exception and statutory provisions enabling institutional possession, use, control, transfer, and profit.[1147] Wall allows for the possibility that the two frameworks will overlap, stating that "in most instances where progenitors or family members retain entitlements in bodily material, healthcare institutions who possess the items of bodily material may obtain property rights in bodily material *that are nonetheless subject to duties of confidentiality owed to progenitors or family members*".[1148]

The position taken in this work has not adopted Wall's distinction between functionally unified and non-unified biomaterials. The previous two chapters have, instead, explored a potential role for privacy law that is much wider in scope than that envisaged by Wall, encompassing informational privacy interests and personal privacy interests in these materials. However, the interaction between property and privacy law imagined by Wall is relevant to the present analysis. This thesis has not attempted to resolve questions of whether or how property rights arise in biomaterials or to whom these rights are initially allocated, but instead, has pointed out how vast, complex, and unsettled these questions are. The point to be emphasized here, though, is that, however these questions end up being resolved, the resulting property rights should be "*subject to*" the underlying privacy rights and entitlements to biomaterials enjoyed by individuals.

This hierarchy of legal norms mirrors existing privacy and property relationships. To illustrate, imagine someone finding another's misplaced personal diary containing the author's

[1145] Wall, *Being and Owning, supra* note 26, c 6.
[1146] See generally *ibid,* c 2.
[1147] *Ibid* at 208.
[1148] *Ibid* [emphasis added].

most intimate thoughts. The finder has certain property rights to the diary, including a right of possession good against everyone but the diary's true owner. But this does not mean the finder can do whatever they wish with the diary. Relevant to the present discussion, the finder cannot publish the contents of the diary in a manner allowing the author to be reasonably identified. To do so would risk liability under a range of privacy torts, including public disclosure of private facts, misuse of private information, and Canadian statutory privacy torts. This limitation is not grounded in the author's ownership interest in the diary, but that the diary contains personal information about the author over which the author enjoys a reasonable expectation of privacy that continues to exist past the point of being de-possessed of the physical diary. If privacy rights apply to biomaterials, these rights should therefore be paramount. Whatever property rights that exist should not allow the rights-holder to violate the ongoing privacy interests in the biomaterials.

In relation to existing statutory frameworks, both privacy and property rights would be subordinate to biomaterial legislation. As discussed in Chapter 2, there are legitimate reasons to impose statutory rules for certain biomaterial uses that should continue to be respected regardless of what the exclusionary boundaries of property or privacy law would otherwise allow. In fact, these instruments could provide important contours to the privacy interests at stake. The previous chapter, for example, explained how personal privacy rights could be recognized to preserve the dignity of a person's deceased relative, but noted that this recognition could give rise to difficulties where the rights-holder attempts to exercise the right in contravention of the deceased person's known wishes. Statutory frameworks regarding deceased biomaterial donation provide legal hierarchies of decision-making in this respect that generally give primacy to the previously expressed wishes of the deceased person,[1149] thus cementing an important limitation to any of the next-of-kin's asserted privacy rights. What privacy torts can add to this picture is the potential for remedies where deceased bodies are wrongfully interfered with by others in contravention of these rights, thus filing a legal gap that has persisted for centuries.

Recognizing privacy rights to biomaterials may also strengthen individual property claims. As discussed in Chapters 4 and 5, property cases denying individual claims where institutions genuinely contest control over biomaterials are often resolved using concepts of property transfer, where individual rights "evaporate" or are "gifted" upon transfer of physical possession. Similarly,

[1149] Toews & Caulfield, *supra* note 1059; Toews, *supra* note 1059 at 794–96.

some scholarship reflects the notion that individuals "abandon" their property interests in biomaterials excised during medical procedures, making them fair game for researchers to take possession of, without the need for consent.[1150] While the legal concept of "abandonment" is unsettled outside of US law,[1151] to the extent that it exists elsewhere in the common law, it, along with concepts of "gifting", requires a subjective intention to relinquish any ongoing interests or claims to the thing being transferred.[1152] As Goold notes, given the informational interests individuals have in their biomaterials, which contain DNA, it may be unlikely, in most cases, that individuals intend to relinquish all claims to their separated biomaterials.[1153] Solidifying these interests through privacy law would cast further doubt on the presumptions underlying assertions of property transfer.

Further, *Yearworth, Moore,* and *Catalona* raised the importance of "control" in determining whether property rights exist. While in *Yearworth,* the men had a negative control right to the sperm that was sufficient to ground their property claims, similar negative control rights did not ground any property rights in *Moore* or any ongoing property rights in *Catalona.* By bringing biomaterials within the exclusionary boundary of privacy law, individual control will be enhanced. Limits will be placed on biomaterial uses that do not respect the autonomy and dignity interests of the biomaterial provider. This may assist individual litigants seeking to establish additional property rights, should the need arise. For example, in situations of negligent interferences with biomaterials, individuals will struggle to succeed under most privacy torts. However, the existence of privacy control rights to biomaterials may strengthen an individual's property claim in this context, compounding the level of protection beyond what either framework could do on its own. As a result, those advocating for a property law approach may benefit from understanding the potential privacy interests at stake, as the advancement of one could strengthen the other.

[1150] See Simon Douglas & Imogen Goold, "Property in Human Biomaterials: A New Methodology" (2016) 75:3 Cambridge LJ 478 at 488 for a critique of "the common academic view that tissue [can] be presumed abandoned where the source of tissue has no further interest in it".
[1151] *Ibid*.
[1152] In relation to abandonment, Goold notes that "a clear, unequivocal intention on the part of the owner to divest herself of all rights in relation to the tissue" is required: Goold, *supra* note 189 at 149; In relation to gifting, Stewart et al notes one of the required elements of a legal gift is that "the property is intended to pass to the donee": Stewart, Fleming & Kerridge, *supra* note 501 at 353.
[1153] Goold, *supra* note 189 at 148.

At a minimum, the two frameworks are not mutually exclusive. The key to this relationship, though, is recognizing the paramountcy of privacy rights as an important and legitimate parameter on the exclusionary boundary created through property law. While it is far from a foregone conclusion that the law will develop in this manner, this path forward offers a conceptually clearer and more comprehensive regulatory picture than the current landscape, making it worthy of continued consideration.

C. Conclusion: Privacy Law and the Law of the Body

The above discussion shows there is room for multiple regulatory frameworks for different purposes. This multiplicity of regulatory functions reveals the fact that no single regulatory framework currently in existence can provide comprehensive protection and redress for the myriad situations in which individual biomaterials could be misused. The limitations of these frameworks speak to the uniqueness of the human body and biomaterials, which do not fit neatly within any one framework. In this respect, Render has pointed to similarities between human bodies and the internet, in that the internet is unlike anything else in the world and, when it emerged, did not fit neatly into existing legal frameworks.[1154] As a result, the field of "cyberlaw" was born, with new legal rules and principles tailored to the unique features of the online world.[1155]

Just as the printing press and photography delivered privacy law, and the internet delivered cyberlaw, human biomaterials may be in the midst of delivering a "Law of the Body".[1156] Thomas Kuhn introduced the notion of "paradigm shift" in his seminal work, *The Structure of Scientific Revolutions*, to describe the revolutionary process through which one foundational scientific theory gives way to another.[1157] A Kuhnian paradigm shift occurs after enough anomalies arise under an existing paradigm that a new model of understanding is required.[1158] Applied to the present discussion, it is conceivable that the ways in which biomaterials are conceptually shoehorned into established legal frameworks are legal "anomalies", signaling that we are on the cusp of developing something new.

[1154] Render, *supra* note 26 at 602–604.
[1155] *Ibid* at 602–4.
[1156] Render, *supra* note 26.
[1157] TS Kuhn, *The Structure of Scientific Revolutions*, 4th ed (Chicago, IL: University of Chicago Press, 2012) at 1096.
[1158] Kuhn, *supra* note 1157.

Indeed, as technology continues to evolve, legal challenges are only going to become more complex. This work has highlighted the need to account for the informational dimension of human biomaterials, which is likely to continue to grow in importance as more information and data continue to be gathered, analyzed, and shared. For example, in Iceland, using the population-based deCODE biobank, researchers have been able to "impute" genotypes about the entire Icelandic population in discoveries about everything from diabetes to cancer to gallstones,[1159] regardless of whether consent was provided to participate in relevant studies. Currently, deCODE claims to have recruited approximately 160,000 participants who have provided genotypic and medical data,[1160] representing slightly less than half the Icelandic population. The failure to obtain consent from remaining Icelanders, however, has not proven a barrier to analyzing their genomes, with deCODE founder, Kári Stefánsson, claiming to be able to identify every Icelandic carrier of the BRCA2 gene mutation at the "push of a button".[1161]

Similarly, concerns about "predictive"[1162] and "derived" data[1163] are giving rise to new privacy challenges. Even where physical samples have not been analyzed to reveal genetic information, other data points can serve as proxies for this information to nevertheless predict, with increasing accuracy, one's genetic make-up. As algorithmic decision-making is increasingly relied upon, the potential for "proxy discrimination" exists, which is difficult to identify, much less address, given the sophistication of the artificial intelligence models used for these analyses.[1164]

Addressing issues of individual control over physical biomaterials is therefore only one piece of a broader regulatory puzzle brought by advancing technologies in fields of informatics, artificial intelligence, and biotechnology. And from this broader perspective, the importance of the informational dimension of the body and associated privacy law protections become apparent. As

[1159] Carl Zimmer, "In Iceland's DNA, New Clues to Disease-Causing Genes", *The New York Times* (25 March 2015), online: <www.nytimes.com> [perma.cc/Y5AF-QY36]; Jocelyn Kaiser, "Agency Nixes deCODE's New Data-Mining Plan" (2013) 340:6139 Science 1388 at 1389.
[1160] deCODE genetics, "SCIENCE", (undated), online: *deCODE genetics* <www.decode.com> [perma.cc/6K79-5T2N].
[1161] Antonio Regalado, "Genome Study Predicts DNA of the Whole of Iceland", (25 March 2015), online: *MIT Technology Review* <www.technologyreview.com> [perma.cc/H5CL-ZEVZ].
[1162] Sharona Hoffman, "Big Data's New Discrimination Threats" in Vayena et al, *supra* note 47, 85.
[1163] Alda Yuan, "Derived Data: A Novel Privacy Concern in the Age of Advanced Biotechnology and Genome Sequencing" (2018) 37 Yale L & Pol'y Rev Inter Alia 1.
[1164] Anya Prince & Daniel Schwarcz, "Proxy Discrimination in the Age of Artificial Intelligence and Big Data" (2020) 105 Iowa LR 1257.

a result, rather than assigning physical biomaterials to the realm of property and information to the realm of privacy, it makes sense to consider them together as part of a bigger picture.

This work has shown that bringing privacy law into the regulatory discussion offers new regulatory pathways for individuals seeking greater control over their biomaterials. It has shown the importance of synchronicity between the interests a particular legal framework is designed to protect and the dignity and autonomy-based interests at stake for individuals. And it has shown the need for causes of action to ground individual claims when these interests are infringed, and a full range of remedies that respond to the dignitary wrongs and emotional harm individuals suffer when biomaterials are misused.

Should a new legal paradigm emerge, these lessons will be informative in terms of structuring an effective set of rights, duties, and remedies. Alternatively, should the law continue developing incrementally through existing and distinct legal fields, privacy law could provide an important supplement to better ground and protect individual rights. Either way, the Law of the Body, in whatever form it takes, will benefit from greater consideration of privacy law in the regulation of human biomaterials.

What is clear is that contests of control over biomaterials are likely to continue given how valuable these materials have become. And as long as existing regulatory tools remain incomplete, litigants and courts will be required to exercise ingenuity to find new solutions. Privacy law offers a creative approach in this regard, deserving greater scholarly attention as the quest to solve the complex problem of biomaterial regulation continues.

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