Is Consent Required for Genetic Research in a Death Investigation System in Canada?

by

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Abstract

A two-step consent process is required for genetic research performed on decedents that fall within the jurisdiction of a statutory death investigation system in Canada. Removal of tissue and organs necessary to fulfill the mandate of a death investigation does not require consent from the decedent's legal next of kin, which if mandatory, would undermine the death investigation process. Consent is needed from either the decedent in life, or his biological next of kin after death for the use of the body, organs and tissue for subsequent genetic research purposes. Informed consent, including the risks associated with breach of the decedent's genetic privacy, should also be obtained as part of the consent process. The need for consent is grounded in the principle of personal autonomy, and the dignity of the individual in life and death, supported by academic literature and Canadian jurisprudence. Vital to the integrity and function of both death investigation systems and genetic research is public trust, which can be achieved by balancing the need for genetic research with the individual's right to informational privacy in their genetic information, both in life and death, through policy and governance.

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Introduction

This paper will argue that a two-step consent process is required for research use of cadaveric genetic data recovered under the authority of a death investigation system in Canada. As the specific details of a genetic research project may not be known at the time of a diagnostic forensic autopsy, consent (authorization) for potential future use of organs and tissue in genetic research should be obtained from the deceased's legal next of kin at the time of recovery, that is, the forensic autopsy. Further, informed consent should also be sought from biological relatives of the deceased who share genomic information when it is known that their genetic data will be included in research. Canadian jurisprudence, with one exception, has not clarified if a body is a research subject after death.[1] This paper will argue that a body is a potential research subject, including when under the authority of a death investigation. As consent for removal of tissue is not required to fulfill the mandate of death investigation legislation,[2] it will be argued that subsequent genetic research use of cadaveric tissue derived from a forensic autopsy absent consent cannot be legally justified in Canada.

The necessity of a two-step consent process rests with the issue that the legal next of kin[3] who by law are granted control of the body, may or may not be the biological next of kin, i.e. those relatives who share a genetic relationship with the deceased,[4] a distinction that has taken on

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[1] *Health Research Ethics Authority Act,* SNL 2006, c H-1.2, as amended by 2011 c22; 2012 c33 s 1, 2(e).

[2] That is, the purpose of tissue removal in a forensic autopsy is evidentiary support of cause and manner of death determination: see P D G Skegg, The Use of Corpses for Medical Education and research: The Legal Requirements, 1991, Med Sci Law 31(4) 345 at 350 notes that "… the removal and processing of samples for histological study is now regarded as a proper part of a post-mortem examination…, [and] … [a]uthorization of a post-mortem examination can therefore be taken to include authorization for the removal and retention of some tissue. But the tissue must be retained for purposes implicit in the authorization of the post-mortem examination itself, such as the confirmation of the cause of death or the investigation of an abnormal condition."

[3] The legal next of kin refers to who the deceased chose to have control of his body after death, as authorized through provincial Wills Acts, Anatomy Acts, and organ donation legislation.

[4] For example, organ and tissue donation legislation gives priority to a spouse over biological relatives in consenting to donation in the absence of valid antemortem consent from the cadaveric donor: *Human Tissue Gift Act,* RSBC 1996, c 211, s 5(10); *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, s 4(2); *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 6(1); *The Human Tissue Gift Act*, CCSM c H-180 s 1 "nearest relative" and s 3(1); *Trillium Gift of Life Network Act*, RSO 1990, c H, ss 5(1) and 2; *Human Tissue Gift Act,* SNB 2014, c 113 s 5(1); *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 12(1); *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 5(1); *Human Tissue Act*, RSNL 1990, c H-15s, 7(1); *Human Tissue Act*, RSNWT 2014, c 30s, s 5; *Human Tissue Gift Act*, RSY 2002, c 117s 5(1). The Québec legislation does not address the issue (*An Act to Facilitate Organ and Tissue Donation,* SQ 2010, c 38.)

significance with the advent of genetic research, including in the field of forensic science.[5] Canadian law currently recognizes a right of the legal next of kin[6] to control the body only for the purpose of disposition,[7] grounded in ensuring that the body is treated with dignity,[8] and often centered on issues of 'body wholeness'[9] at body disposition.

Post mortem interest in a body includes not only the duty of the living to ensure that the body is treated with dignity,[10] but also the autonomy-based right of the individual while alive to choose if one's body is to be used in research post mortem.[11] The argument for the necessity of consent for genetic research in this context will be grounded in the dignity of the individual, both in life and death, and respect for the personal autonomy of the individual, expressed in the protection of privacy of the genetic information[12] of both the deceased and his genetic relatives. Consent acknowledges the right of an individual to make a choice concerning his body, a principle established in Canadian jurisprudence.[13] Although distinct principles, both privacy and consent are grounded in the concept of individual autonomy, that is, the right to self-determination, and

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[5] See for example, Jamie Ducharme, "Millions of Americans Could Be Identified Using Consumer Genetic Databases—Even If They've Never Taken a DNA Test", *Time*, (13 October 13, 2018) online: http://time.com/5423170/dna-test-identify-millions/; Megan Molteni, "The Future of Crime-Fighting Is Family Tree Forensics" *Science*, (26 December 2018), online https://www.wired.com/story/the-future-of-crime-fighting-is-family-tree-forensics/; Nathan Collins, "Stanford Researchers Discover a New Way to Find Relatives from Forensic DNA", *Stanford News*, (17 October 2018), online: https://news.stanford.edu/2018/10/17/new-way-find-relatives-forensic-dna/.

[6] In Canada, the duty of disposition may also fall to the executor of the deceased's estate, who may or may not be the deceased's biological next of kin: see *Hunter v. Hunter*, [1930] O.J. No. 147, 65 O.L.R. 586. See below at 40.

[7] *Saleh v. Reichert,* [1993] O.J. No. 1394, 104 D.L.R. (4th) 384; *Miner. v. Canadian Pacific Railway Co.*, 1910, 15 W.L.R, 1911 Carswell 23, 18 W.L.R. 476; *Mason v. Westside Cemeteries Ltd*., [1996] O.J. 1387; *Hunter v. Hunter*, [1930] O.J. No. 147, 65 O.L.R. 586.

[8] *Abeziz v Harris Estate,* [1992] O.J. No. 1271. Farley J states at 7 that the right to a body, here to an executor, is a "…fundamental obligation … that the body be appropriately dealt with – that is disposed of in a dignified fashion."

[9] Valerie M Sheach Leith "Consent and Nothing but Consent? The Organ Retention Scandal" (2007) 29:7 Sociology of Health and Illness 1023 at 1026-1031. The author refers to the term 'body wholeness', that is, a cadaver whose organs are within the body at final disposition. Although not a legal definition, the concept of 'body wholeness' will be demonstrated to be a concept that influences Canadian jurisprudence relating to cadavers.

[10] *Criminal Code*, RSC 1985, c C-46, s 182(b).

[11] See discussion of organ donation below at 69.

[12] This paper will not differentiate paediatric and adult genetic research, although it has been argued that the paediatric population "… may be deserving of enhanced privacy protection:" see Edward S Dove *et al*, "Charting the Privacy Landscape in Canadian Pediatric Biobanks" (2013) 20 Health L J 12 at ¶ 3, citing *AB v Bragg Communications Inc.,*2012 SCC 46.

[13] *R v Morgentaler*, [1988] 1 SCR 30; *Carter v Canada (Attorney-General)*, 2015 SCC 5; [2015] 1 SCR 331; *R v Dyment*, [1988] 2 S.C.R. 417; *R v Colarusso,* [1994] 1 S.C.R. 20.

respect for that individual's dignity.[14] Specifically, consent respects the autonomy of the individual, and informed consent mitigates risks to privacy in genetic research.[15]

Studies have shown the importance participants place on their personal autonomy in research.[16] Respect for personal autonomy is a core principle expressed in the *Tri-Council Policy Statement Ethical Conduct for Research Involving Humans.*[17] Personal autonomy has also been held by the Supreme Court of Canada to be the basis of an individual's unique personal health information protection,[18] information today which may include genetic information.[19]

Genetic data (within organs and tissues) is routinely collected in the course of a forensic autopsy for diagnostic purposes absent consent under the authority of death investigation legislation.[20] Since the personal genetic health information of the living biological relatives may be obtained from cadaveric genetic research,[21] a two-step consent process allows for respect for and protection of the privacy of both the deceased's and living relatives' genetic personal health

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[14] It will be argued that a cadaver itself no longer has autonomy, dignity through respect is owed the body after death, and privacy of personal health information is protected after death.

[15] The degree of risk associated with genetic research is controversial: see David S Wendler & Annette Rid, "Genetic Research on Biospecimens Poses Minimal Risk" (2015) 31:1 Trends in Genetics 11 at 11. For the purpose of this paper, the degree of risk to breach of privacy will not be accepted, only that there is a risk to breach of privacy in genetic research.

[16] Imogen Goold, "Property or Not Property? The Spectrum of Approaches to Regulating the Use of Human Bodily Material" (2013) 21 JLM 299; Nina Hallowell *et al*, "Lay and Professional Understandings of Research and Clinical Activities in Cancer Genetics and their Implications for Informed Consent" (2010) 1:2 American J of Bioethics Primary Research 25; Ubaka Ogbogu & Sarah Burningham, "Privacy Protection and Genetic Research: Where Does the Public Interest Lie?" (2014) 51:3 Alta L Rev 471.

[17] Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2014 at 6. This policy document will be subsequently be referred to as TCPS2.

[18] In the federal *Personal Information Protection and Electronic Documents Act*, SC 2000, c 5, s 2(1)(a)(c), 'personal health information' is defined "…with respect to an individual, whether living or deceased, means … information concerning the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of the individual." In *McInerney v MacDonald,* [1992] 2 RCS 138, 93 DLR (4th) 415 at 148*,* the Court stated that "… the [medical] records consist of information that is highly private and personal to the individual. It is information that goes to the personal integrity and autonomy of the patient."

[19] The federal *Digital Privacy Act*, SC 2015, c 3, s 2(1), which amends the *Personal Information Protection and Electronic Documents Act,* defines 'personal information' as "…information about an identifiable individual."

[20] *Supra* note 2.

[21] Quianta L Moore *et al*, "Ethical and Legal Challenges Associated with Public Molecular Autopsies" (2016) 44 JL Med & Ethics 309 at 309.

information, both legally protected in Canada,[22] when forensically derived genetic information may subsequently be used in research.

This paper is divided into sections reflecting the law's historic consideration of the deceased individual (decedent). Each section will be framed in reference to how, and to whom the law grants control of the body when under the authority of a death investigation system, and specifically in reference to genetic research. The first section will consider the intact body, that is, how the law historically first considered who had control of a cadaver. A brief description of death investigation systems in Canada will demonstrate that the death investigator's role is generally limited to the statutorily defined purpose of the death investigation and does not extend to authorizing the use of a body for genetic research.[23]

Examination of Canadian jurisprudence will illustrate how and why the law gives purpose-based control of the body to the legal next of kin, specifically associated with body disposition, grounded in the concept of dignity owed the body by the living.[24] The subsequent sections will consider control of separate cadaveric organs, in the context of organ donation[25] and organ retention.[26] Organ donation legislation will briefly be reviewed as another example of respect for the dignity of an individual extending to his cadaveric organs, and respect for the autonomy of the organ donor while alive, through the statutory requirement for consent for use of donated organs in research.

A discussion of the law relating to organ retention in reference to purpose–based control of organs by death investigators and legal next of kin will argue that the legal next of kin's control of organs in this context reflects protection of 'body wholeness'[27] in the final disposition of the

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[22] See below at 93.
[23] The exception is in relation to unidentified and unclaimed bodies: see below at 57.
[24] See discussion below at 50.
[25] Organ donation, here specifically cadaveric organ donation, refers to an organ that has been donated obtained by legally valid consent (authorization) of either the decedent or his legal next of kin: see Maeghan Toews & Timothy Caulfield, "Evaluating the 'Family Veto' of Consent for Organ Donation" (2016) 188 CMAJ 17.
[26] Organ retention refers to whole cadaveric organs collected and retained at a forensic autopsy for diagnostic purposes relating to the death investigation, that is without the necessity of consent from either the deceased or his next of kin: see Clarissa S Krinsky, Sarah L Lathrop & Robert R Reichard, "A Policy for the Retention and Extended Examination of Organs at Autopsy" (2010) 55:2 J Forensic Sciences 418 at 418.
[27] *Supra* note 9.

deceased. Although specified in only three provinces,[28] this death investigation legislation gives authority for organ retention only for diagnostic purposes, and not for subsequent use in research.[29] In the other provinces' and territories' statutes that do not specifically address organ retention, retained organs could potentially be deemed available for subsequent use in research without consent from the donor, if viewed as diagnostic tissue,[30] for example. However, other authors argue that the individual source of tissue maintains a "limited right of control", particularly when use of the tissue may "… violate or injure the donor's privacy or autonomy-based rights,"[31] as may occur if used for research, absent consent.

Thus, in Canada, use of a cadaveric organ in research under organ donation legislation requires valid consent, whereas organ retention under death investigation legislation generally has no such legal requirement.[32] This legal discrepancy leads to a consideration of the authority, if any, for the genetic research use of forensically derived cadaveric tissue.

Tissue samples obtained from a forensic autopsy for diagnostic purposes, and from which the individual's unique genetic information may be recovered, will then be considered. Having argued that a cadaver is a research subject in Canada, three questions will be asked: is consent from research participants required for use of the tissue or use of the genetic information; if consent is required for use of genetic information, does genetic data fall under the legal umbrella of personal health information; and finally, if genetic data is personal health information, is consent for use of the body and its components sufficient for use of the individual's genetic information in genetic research? In the specific context of genetic research, the individually

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[28] *Fatality Inquiries Act*, RSA 2000, c F-9, ss 25(2)(a)(b), The *Coroners Act*, SS 1999, c C-38.01, s 14(4) and *Coroners Act*, RSPEI 1988, c C-25, s 10(4).

[29] In this context, diagnostic purpose refers to the determination of cause and manner of death by the death investigator: see below for discussion of death investigator's legislated control of the body at 24.

[30] Carol C Cheung, Bella R Martin & Sylvia L Asa, "Defining Diagnostic Tissue in the Era of Personalized Medicine" (2013) 185:2 CMAJ 135. What is tissue and what is an organ is not clear in the context of a forensic investigation: see discussion below at 6. This differentiation may not be necessary in the context of organ donation legislation but takes on significance in organ retention in the course of a forensic autopsy: see discussion at 74.

[31] 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 at 284-285. See also R Alta Charo, "Body of Research – Ownership and Use of Human Tissue" (2006) 355:15 New England J of Medicine 1517 at 1518, who suggests the right to control one's tissue may be viewed in the context of personal health information privacy.

[32] Except for Ontario: see below at 80. Further, retained organs could be secondary use tissue sources – see below at 14 for discussion of secondary use of tissues.

unique nature of genomic information, the increasing challenges of ensuring privacy of genetic information,[33] and the statutory post-mortem privacy protection of personal information indicate the need for research participant consent, that is, consent from genetic next of kin, rather than consent from the legal next of kin.

Definitions of the cadaver and its constituent parts – the grey zone

What legally differentiates a 'body', an 'organ' and 'tissue'? Definitions relating to the human body and its parts in inter- and intraprovincial legislation are confusing and inconsistent. The definition of a 'body' in the context of this paper seems obvious: a body is synonymous with a corpse, a deceased human being.[34] However, in the context of the relationship between a body and its organs and tissues, it is useful to consider alternate common usages of the term 'body'. A body may be defined as "… the material part or nature of a human being."[35] This broad definition is not clear: is a body the *complete* body or its constituent parts? This very issue arises in death investigation legislation.

Death investigation systems in Canada are disparate in their definition and use of the word "body." For example, Newfoundland, Nova Scotia and Alberta define a "body" as "a dead human body or the remains of a dead human body.[36] None of these three provinces' legislation define "remains". A dictionary definition of "remains" is "… a part or the parts of a person's body after death; a corpse", and "… a piece or fragment of a dead body.[37] Using this definition, the term body may include a part of a body, such as an organ. This view is specifically incorporated in the death investigation legislation of Manitoba, for example, which defines a "body" as "… a dead human body and includes a part of a dead human body and the remains of a

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[33] Canada, Office of the Privacy Commissioner of Canada, *Health, Genetic and Body Information,* (Ottawa: Office of the Privacy Commissioner, 1 November 2016), online: https://www.priv.gc.ca/en/privacy-topics/health-genetic-and-other-body-information/.

[34] *Merriam-Webster Dictionary* online: <http://www.merriam-webster.com/dictionary/body 1a (2) *sub verbo* 'body'.

[35] *Ibid* at 1a(1) and b.

[36] *Fatality Inquiries Act*, RSA 2000, c F-9, s 1(c); *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 2(b);*Fatality Investigations Act*, SNS 2001, c 31, s 2(b).

[37] *Oxford English Dictionary* online: www.oed.com 3b *sub verbo* 'remains'.

dead human body."[38] Here, the cadaver and its constituent parts should be dealt with identically under the purpose of the legislation.

The attempt to legally differentiate what is a body and what its components are becomes easier when the terms 'organ' and 'tissue' are employed, rather than the vague term 'remains'.[39] An 'organ' generically refers to "… a fully differentiated structural and functional unit of an organism … that performs a specific function."[40] 'Tissue' may be defined as "[t]he substance, structure, or texture of which an animal or plant body, or any part or organ of it, is composed; *esp.* any one of the various structures, each consisting of an aggregation of similar cells or modifications of cells, which make up the organism."[41] In short, using these definitions, organs are composed of tissues, and organs are parts of a body.

A specific definition of 'tissue' in provincial human tissue donor legislation is surprisingly rarely included in the respective statutes.[42] Most provinces' tissue donation statutes consider tissue as analogous to organs for the purpose of the legislation.[43] However, blood is not considered 'tissue' in any provinces' human tissue donor legislation,[44] potentially allowing, for example, use of blood recovered for toxicology purposes in a death investigation to be subsequently used in genetic research[45] absent consent under donor legislation.

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[38] *The Fatality Inquiries Act*, CCSM 1990, c F52, s 1(1).

[39] The definition of "remains" became a key issue in the ruling of *Shipley v. New York* N.E.3d - 2015 N.Y. Slip Op. 04791: see below at 82.

[40] *Supra* note 34 at 2a *sub verso* 'organ'.

[41] *Supra* note 37 at 5 *sub verso* 'tissue'.

[42] The *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 1 defines tissue as "any part of a living or dead human body" and thus would include organs. Similar definitions are used in the Manitoba, Northwest Territories and Ontario statutes: *The Human Tissue Gift Act*, CCSM c H-180, s 1; *Human Tissue Act*, RSNWT 2014, c 30, s 1; *Trillium Gift of Life Network Act*, RSO 1990, c H, s 1. The *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 2(y) definition describes tissue as "a functional group of human cells."

[43] *Human Tissue Gift Act,* RSBC 1996, c 211; s 1, *The Human Tissue Gift Act*, CCSM c H-180, s 1; *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 2; *Trillium Gift of Life Network Act*, RSO 1990, c H s 1; *Human Tissue Gift Act,* SNB 2014, c 113; s 1, *Human Tissue Act*, RSNL 1990, c H-15, s 2; *Human Tissue Gift Act*, RSY 2002, c 117 s 1; *Human Tissue Act*, RSNWT 2014, c 30, s 1; *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, s 1, 4(1);*Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 2, 11(2) differentiate tissue from organs.

[44] *Human Tissue Gift Act,* RSBC 1996, c 211, s 1; *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, s 2; *The Human Tissue Gift Act*, CCSM c H-180, s 1; *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 2; *Trillium Gift of Life Network Act*, RSO 1990, c H s 1; *Human Tissue Gift Act,* SNB 2014, c 113, s 1; *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 1; *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 3(a); *Human Tissue Act*, RSNL 1990, c H-15, s 2; *Human Tissue Gift Act*, RSY 2002, c 117, s 1; *Human Tissue Act*, RSNWT 2014, c 30, s 1.

[45] See for example Jessica Lam *et al*, "Codeine-Related Deaths: The Role of Pharmacogenetics and Drug Interactions" (2014) 239 Forensic Science International 50, and Antti Levo *et al*, "Post-Mortem SNP Analysis of

Although the definitions of ‘organ’ and ‘tissue’ above attempt to differentiate the two terms, what constitutes an organ versus tissue may be a grey area practically in death investigation systems. For example, do collected samples represent “… large pieces of tissue (or) small pieces of organ?”[46] In the practice of forensic pathology, “[r]etention of entire organs is distinct from tissue samples kept in ‘stock jars’, paraffin blocks and laboratory specimens.”[47]

The significance of differentiating a ‘body’ from its ‘organs’ and its ‘tissue’ becomes relevant when genetic information derived from these body parts is used in research after mandated use authorized under the death investigation is completed, as law and policy varies depending on which descriptive term is employed. However, a ‘body’, ‘organs’ and ‘tissue’ all potentially come under the jurisdiction of a death investigation system. To add further complexity, the nature of death investigation systems also varies between provinces and territories.

Background – Death Investigation Systems

A medico legal or forensic autopsy[48] is completed primarily to determine the cause of death. The forensic autopsy differs from the hospital autopsy[49] in that consent of the legal next of kin is not required for the post mortem examination,[50] and the findings may be made public, as in a coroner’s inquest.[51] The absence of consent for primary removal of tissue at autopsy for

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CYP2D6 Gene Reveals Correlation Between Genotype and Opioid Drug (Tramadol) Metabolite Ratios in Blood” (2003) 135 Forensic Science International 9. However, see the Court’s reasoning in *R v Dyment* below at 24.

[46] Kathryn Haden-Pinneri & Victor W Weedn, “Organ and Tissue Retention” (2013) 3:3 Academic Forensic Pathology 294 at 294.

[47] *Supra* note 26 at 418.

[48] A forensic autopsy is defined as a post mortem examination by “… a medical examiner, coroner or justice of the peace [who] has [legal] jurisdiction…” to order the autopsy (See Elizabeth C Burton & Kim A Collins (eds), “Autopsy Rate and Physician Attitudes Toward Autopsy”, *Medscape*, (11 February 2014), online: http://emedicine.medscape.com/article/1705948. “Forensics … refers to the application of various fields of science and medicine in the resolution of legal proceedings”. Ann Bucholz, History of Death Investigation in *Death Investigation: An Introduction to Forensic Pathology*, (New York: Taylor and Francis, 2015) at 1.

[49] Burton, supra note 48: A hospital or clinical autopsy refers to a post mortem examination of a body requiring the “…granting of permission…” i.e. consent of the decedent’s next of kin.

[50] Belinda Carpenter *et al*, “The Role of Coronial Autopsies in a Context of Decreasing Hospital Autopsies: An Investigation of the Issues” (2010) 18 JLM 402 at 402; Canadian provincial death investigation legislation does not require consent for an autopsy.

[51] “An inquest is a public hearing conducted by a coroner before a jury of … community members. Inquests are held for the purpose of informing the public about the circumstances of a death. Although the jury’s conclusions are not binding, it is hoped that any recommendations suggested, if implemented, will prevent deaths in similar circumstances:” see Ontario, Ontario Ministry of Community Safety and Correctional Services, *Death*

diagnostic purposes[52] becomes relevant when the scope of the forensic autopsy is potentially expanded beyond diagnosis to include use of collected cadaveric tissue for subsequent research.[53]

Canadian death investigation systems are governed by provincial and territorial legislation,[54] and are broadly categorized as either a medical examiner or coroner system.[55] Canadian coroner systems are modeled on the English coroner system, historically referred to as the crowner.[56] Medical examiners were first introduced in Massachusetts in 1877, and the first medical examiner system was established in New York City in 1918.[57] The key mandate of both a coroner and medical examiner system is to determine cause[58] and manner[59] of death, and as part of a death investigation, a coroner or medical examiner may require a forensic autopsy,[60] a

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Investigations: About Inquests, online: http://www.mcscs.jus.gov.on.ca/english/DeathInvestigations/Inquests/AidToInquests.html.
See also Québec, Bureau du Coroner Québec, *Coroner's Investigation and Inquest,* online: https://www.coroner.gouv.qc.ca/fileadmin/Organisation/Depliant_anglais.pdf: "A public inquest may deal with one death, or several that occurred in similar circumstances. Like the investigation, it concludes with the preparation of a report that is a public document available to anyone who submits a request."

[52] Small tissue samples are routinely retained during the course of a forensic autopsy in order to make pathological diagnoses relating to the death under investigation: see *supra* note 2 at 350 : " … the removal and processing of samples for histological study is now regarded as a proper part of a post-mortem examination…, [and] … [a]uthorization of a post-mortem examination can therefore be taken to include authorization for the removal and retention of some tissue. But the tissue must be retained for purposes implicit in the authorization of the post-mortem examination itself, such as the confirmation of the cause of death or the investigation of an abnormal condition."

[53] Supra note 50 at 403.

[54] *Coroners Act*, SBC 2007, c 15; *Fatality Inquiries Act*, RSA 2000, c F-9; *The Coroners Act*, SS 1999, c C-38.01; *The Fatality Inquiries Act*, CCSM 1990, c F52; *Coroners Act*, RSO 1990, c C.37, *Coroner's Act*, RSQ, c. C-68; *Coroners Act*, RSNB 1973, c C-23; *Fatality Investigations Act*, SNS 2001, c 31; *Coroners Act*, RSPEI 1988, c C-25; *Fatalities Investigations Act*, SNL, 1995, c F-6.1; *Coroners Act*, RSY 2002, c 44; *Coroners Act*, RSNWT (Nu) 1988, c C-20.

[55] Gregory J Davis & Stephen J Cina (eds), "The Medical Examiner and Coroner Systems", *Medscape*, (29 March 29 2011), online: http://emedicine.medscape.com/article/1785357-overview.

[56] Werner U. Spitz, ed, *Spitz and Fisher's Medicolegal Investigation of Death*, 3d ed (Springfield, Ill: Charles C. Thomas, 1993) at 4.

[57] Randy Hanzlick & Debra Combs, "Medical Examiner and Coroner Systems History and Trends" (1998) 279:11 JAMA 870 at 872; *supra* note at 55.

[58] Richard C Froede, ed, *Handbook of Forensic Pathology*, (Northfield, Ill: College of American Pathologists, 1990) at 9 defines 'cause of death' as "the disease, injury, or abnormality that alone or in combination is responsible for initiating the sequence of functional disturbances, whether brief or prolonged, that eventually ends in death."

[59] *Ibid.* Manner of death is defined as "a classification of the way in which the cause of death came about with special reference to social relationships and personal causation."

[60] Not all bodies that are investigated by a death investigation system undergo an autopsy. Forensic autopsy rates in Canada range from approximately 20-35% of total cases investigated by coroners and medical examiners: see Natalie Clancy, "Low Autopsy Rate in B.C. Alarms Experts" *CBC News* (3 February 2013) online: https://www.cbc.ca/news/canada/british-columbia/low-autopsy-rate-in-b-c-alarms-experts-1.1335613.

medical procedure[61] that remains the gold standard for accurate determination of cause of death.[62] The performance of a forensic autopsy is authorized by provincial death investigation legislation in Canada, and importantly, unlike other medical procedures, does not require the consent of the legal next of kin.[63] As Matshes *et al* note: "One critical philosophical underpinning of medicolegal autopsies is their unique nature – they are a medical procedure performed without family consent, and sometimes against families' wishes."[64] The ability to perform an autopsy in this circumstance without the permission of the legal next of kin is reasonable, as the legal next of kin may, for example, be alleged suspects in the death, and may decline consent for an autopsy to prevent the collection of potentially valuable but incriminating evidence by the death investigator.[65]

A dead body or cadaver will fall within the jurisdiction of a death investigation system in Canada only under specific circumstances, determined by how one has been deemed to have died. For example, if the deceased is under the care of a physician, and a doctor is willing to sign his death certificate, and if death is the result of a natural disease process, such as cancer or a heart attack, then a death will not be subject to investigation by a coroner or medical examiner.[66] Death by suspected accident, suicide, homicide or otherwise unknown circumstances will require the death investigator to sign the death certificate, and identify the body.[67] Importantly, one cannot control during life whether or not one's body will come under the authority of a death investigation system.

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[61] Randy Hanzlick *et al*, "Case of the Month: History Repeats Itself (Sometimes)" (1999) 159 Archives of Internal Medicine 1837 at 1838. The authors refer to the autopsy as a "medical procedure." See also Evan W Matshes *et al*, "What is a Complete Autopsy?" (2011) 1:1 Academic Forensic Pathology 2 at 2.

[62] Elizabeth C Burton & Mahmud Mossa-Basha, "To Image or to Autopsy?" (2012) 156:2 Annals of Internal Medicine 158; Marcus Nashelsky B & Christopher H Lawrence, "Accuracy of Cause of Death Determination Without Forensic Autopsy Examination" (2003) 24:4 American J of Forensic Medicine and Pathology 313.

[63] *Supra* note 50.

[64] Matshes, *supra* note 61 at 2.

[65] Pekka Saukko & Bernard Knight, *Knight's Forensic Pathology*, 4th ed (Boca Raton, FL, CRC Press, 2016) at 2. See also, for example, R. *v. Polimac* below at 33.

[66] *Coroners Act*, SBC 2007, c 15, s 2 (1)(c); *Fatality Inquiries Act*, RSA 2000, c F-9, s 10(2)(h); *Coroners Act*, RSO 1990, c C.37, s 10(1)(e); *The Fatality Inquiries Act*, CCSM 1990, c F52, s 7(9)(b)(i); *Fatality Investigations Act*, SNS 2001, c 31, s 9(c); *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 5(c); *Coroners Act*, RSY 2002, c 44, s 6(3).

[67] Committee for the Workshop on the Medicolegal Death Investigation System, *Medicolegal Death Investigation System: Workshop Summary* (Washington, DC: National Academies Press, 2003) at 7.

Why Question the Necessity of Consent for Research in Death Investigation Systems?

Public trust in both death investigation systems and in scientific research is vital. Death investigation systems have faced public scrutiny when public trust has been deemed to be compromised, with resulting modification of practice guidelines.[68] In Canada, the Supreme Court has found that the standard to which a death investigator, specifically a coroner, is held in reference to the collection of evidentiary cadaveric biomaterial in an investigation "… is only the good faith belief that the evidence is necessary for the purposes of his or her non-criminal investigation."[69] In effect, ensuring public trust in the use of cadaveric biomaterials (organs and tissue) is limited to the legislated mandate of the provincial death investigation system. Equally, in reference to public trust in research, Bach notes that "…[r]esearch ethicists and regulators ought to pay more attention to the practices of cadaver research because it is a topic of concern for the public. A primary goal of human subjects' research ethics and regulations is to preserve and, at times, restore public trust in the research enterprise."[70] As genomics technology moves rapidly forward, the need for ethical guidelines is an important component of public trust.[71] Establishing an ethical framework that ensures the autonomy of research participants goes beyond that of avoiding negative media attention:

> … careful attention to ethics often goes hand in hand with … [] … a higher degree of public trust and acceptance of clinical research … If a population loses trust in medical research and opts out, (or a high proportion do), then their ability to benefit from research tailored to their needs is diminished and everyone loses out.[72]

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[68] See for example, the retention of organs at Alder Hey Children's Hospital: "Organ Scandal Background", *BBC News*, (29 January 2001), online: http://news.bbc.co.uk/2/hi/1136723.stm.

[69] *R v Colarusso*, [1994] 1 S.C.R. 20 at 23. The appellant consented to collection of blood and urine for medical purposes following a motor vehicle accident in which he was the impaired driver resulting in the death of another individual. The Court held that the coroner's seizure of the samples was reasonable under section 8 of the *Charter* for the non-criminal purpose of the death investigation, but the subsequent seizure by police was an unreasonable seizure.

[70] Michelle C Bach, "Still Human: A Call for Increased Focus on Ethical Standards in Cadaver Research", (December 2016) 28:4 HEC Forum 355 at 363, citing Resnick. The issue of whether a cadaver is a human research subject in Canada is discussed below at 62.

[71] S Cunningham-Burley, "Public Knowledge and Public Trust" (2006) 9:3 Community Genetics 204.

[72] R Ashcroft, "The Ethics of Reusing Archived Tissue for Research" (2000) 26 Neuropathology and Applied Neurobiology 408 at 410.

In the context of cadaveric genetic research, control of one's body may be reflected in simple black and white terms: Nelkin and Andrews note that "[s]ome individuals do not want research done on their bodies after death."[73] In a recent study, genomic research participants have expressed the importance of controlling their personal genetic information, a majority of respondents stating that "… data sharing standards in research are not a matter of consensus."[74] The authors noted that "… [t]he notion that one's views on data sharing can vary depending on personal attributes and contextual variables was a common reason why participants desired at least some individual control over the use of their information."[75] However, no clear legal or policy requirement for consent for use of forensically derived cadaveric genetic information in genetic research currently exists in Canada.

It is uncertain how frequently cadaveric tissue derived from a forensic autopsy is used in genetic research in Canada. However, the declining rate of the hospital autopsy suggests that the forensic autopsy will be a significant on-going source of cadaveric tissue collected at autopsy that is potentially available for genetic research. [76] Equally, the amount of stored or archived tissue[77]

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[73] Dorothy Nelkin and Lori Andrews, "Do the Dead Have Interests? Policy Issues for Research after Life" (1998) 24 Am J Law and Med 261 at 277.

[74] Leila Jamal *et al*, "Research Participants' Attitudes Towards the Confidentiality of Genomic Sequence Information" (2014) 22 Eur J Human Genetics 964 at 966. Study findings also included that de-identification of genetic data and maintained contact with participants by researchers increased the level of participant trust and maintaining confidentiality of the data reflected respect for the individual participants. See also Lee *et al*, whose "…study found that many participants did not distinguish between biospecimens and EHR data" (at 107).

[75] *Ibid.*

[76] Ann Bucholz, History of Death Investigation in *Death Investigation: An Introduction to Forensic Pathology*, (New York: Taylor and Francis, 2015 at 2; Marnie Wood J & Ashim K Guha, "Declining Clinical Autopsy Rates Versus Increasing Medicolegal Autopsy Rates in Halifax, Nova Scotia" (2001) 125 Arch Pathol Lab Med 924; Laura Weiss Roberts *et al*, "Perceptions of the Ethical Acceptability of Using Medical Examiner Autopsies for Research and Education" (2000) 124 Arch Pathol Lab Med 1485 at 1485; Burton, *supra* note 48 at 1; Jaimie Henry and Nick Nicholas, "Dead in the Water – Are We Killing the Hospital Autopsy with Poor Consent Practices?" (2012) 105 Journal of the Royal Society of Medicine 288 at 288; Jacqui Wise, "Hospital Autopsies Are on the Verge of Extinction, Study Finds" (2015) 350 BMJ h3236; David Harrington and Edward Sayre, "Managed Care and Measuring Medical Outcomes: Did the Rise of HMOs Contribute to the Fall of the Autopsy Rate?" (2009) 70 Social Science and Medicine 191 at 191; Angus Turnbull, Michael Osborn and Nick Nicholas, "Hospital Autopsy: Endangered or Extinct?" (2015) 68 Journal of Clinical Pathology 601 at 601; Belinda Carpenter *et al*, "The Role of Coronial Autopsies in a Context of Decreasing Hospital Autopsies: An Investigation of the Issues" (2010) 18 JLM 402 at 402.

[77] Here, the term "archived tissue" refers to tissue preserved and stored in formalin, as well as paraffin embedded tissue and microscopic sections of tissue stored on slides: see Ubaka Ogbogu & Michael Mengel, "Who Owns Diagnostic Specimens in the Era of Personalized Medicine" (2013) 5:3 Can J Pathology 86 at 87. Tissue collected at a post-mortem examination is preserved and may be stored in this stable form for an indefinite period in paraffin blocks, or as stained tissue on microscopic slides: See Rohan Hardcastle, *Law and the Human Body: Property Rights, Ownership and Control*, (Portland: Hart Publishing, 2009) at 8-9. The frequency of retention of tissue at forensic post mortem examinations in Canada is unknown, and the necessity of routine collection of forensic

collected from forensic autopsies in Canada is unknown.[78] These stored tissue samples exist in both stand-alone death investigation facilities, and in hospitals,[79] each organization having its own policies governing storage and use guided by national standards.[80] After an allotted period

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cadaveric tissue for diagnostic purposes is controversial in the academic literature: see Geoffroy Lorin De la Grandmaison, Phillippe Charlier & Michel Durigon, "Usefulness of Systematic Histological Examination in Routine forensic Autopsy" (2010) 55:1 Journal of Forensic Sciences 85; Roger Byard W & Calle Winskog, "Histology in Forensic Practice: Required or Redundant?" (2012) 8 Forensic Science, Medicine and Pathology 56; D Kimberly Molina, Leisha E Wood & Randall E Frost, "Is Routine Histopathological Examination Beneficial in All Medicolegal Autopsies?" (2007) 28:1 The American Journal of Forensic Medicine and Pathology 1; Judith Fronczek *et al*, "The Role of Histology in Forensic Autopsies: is Histological Examination Always Necessary to Determine a Cause of Death?" (2014) Forensic Science, Medicine and Pathology 39.
Lorin de la Grandmaison *et al* at 87 note that the controversy may reflect variability in preponderance of types of cases autopsied between death investigation systems, specifically that "[n]atural deaths more often require the use of microscopy to establish cause of death than violent deaths." The Ontario Forensic Pathology Service Annual Report July 27, 2013-July 26, 2014 at 24 notes that "[h]istology services are provided through laboratories at community hospitals and on-site at the Forensic Pathology Units. At the Provincial Forensic Pathology Unit, two full-time histotechnologists are employed to process approximately 1,600 tissue specimens each month." Harold Sanchez & Kim Collins (eds), "Rates of Autopsy", *Medscape*, (28 April 2017), online: https://emedicine.medscape.com/article/1705948-overview#a2 note an increase in medicolegal autopsies (from 43.6% to 55.4%), and a decrease in hospital autopsies, from 16.9% per annum to 4.3%.

[78] The Canadian Association of Pathologists guidelines for the retention and use of human biologic material suggests the retention of coroner/medical examiner wet tissue for "3 months after the final report", paraffin blocks for 10 years and microscopic slides for 10 years, "as per general autopsy, or by Autopsy Records discretion of the Coroner's/Medical Office/forensic pathologist": see Canadian Association of Pathologists, "The Retention and Use of Human Biologic Material", (approved November 2005), online: https://www.cap-acp.org/guide_retention-human-biologic-material.php. The College of American Pathologists recommends that slides and tissue blocks be retained "indefinitely", and that formalin fixed tissue be retained for 1 year College of American Pathologists, "College of American Pathologists (CAP) Retention of Laboratory Records and Materials", online http://www.ncleg.net/documentsites/committees/PMC-LRC2011/December%205,%202012/College%20of%20American%20Pathologist%20Retention%20Policy.pdf. The UK Royal College of Pathologists recommend that tissue blocks, and microscopic slides be retained for "at least 10 years" see The Retention and Storage of Pathological Records and Specimens (5th edition), Guidance from The Royal College of Pathologists and the Institute of Biomedical Science, April 2015, ss 136 and 158. Shawn E Yost *et al*, "Identification of High-confidence Somatic Mutations in Whole Genome Sequence of Formalin-fixed Breast Cancer Specimens" (2012) 40:14 Nucleic Acids Research e107 note in general that "… formalin fixation and paraffin embedding has been the standard sample preparation for pathologists for decades, resulting in large archived tumor specimen collections."

[79] For example, in Canada, the medical examiners offices of Alberta (https://justice.alberta.ca/programs_services/fatality/ocme/Pages/default.aspx), and the coroner's office in Ontario (https://www.mcscs.jus.gov.on.ca/english/centre_forensic/CFS_intro.html) are stand-alone facilities. A stand-alone death investigation facility could be considered a biobank, that is, "… an organized collection of human biological material and associated information for one or more research purposes" see: Katie M Saulnier and Yann Joly, Locating Biobanks in the Canadian Privacy Maze, 2016, The J of Law, Medicine and Ethics, 44, 7 at 8. The TCPS2 defines a 'biobank' defined as "… [a] collection of human biological materials. It may also include associated information about individuals from whom biological materials were collected (*supra* note 17 at 202 'biobank'.)

[79] *Supra* note 17 at 3. The TCPS2 is a policy "…to guide Canadian researchers, in Canada and abroad, in the conduct of research involving humans."

[80] CAP (Canada) guidelines supra note 78, and Supriya Nikita Kapila, Karen Boaz & Srikant Natarajan, "The Post-Analytical Phase of Histopathology Practice: Storage, Retention and Use of Human Tissue Specimens" (2016) 6:1 International Journal of Applied and Basic Medical Research 3.

of storage, these samples may be discarded as hospital waste, or used for research, [81] and although it has been suggested that "stained histological sections" are "true derivatives,"[82] native DNA has been recovered from stained cytological smears,[83] archived tissue samples,[84] and dried blood samples.[85] Therefore, both decades old archived cadaveric tissue materials, and tissue continuously collected on a daily basis during the course of forensic autopsies in Canada are potentially available for secondary use[86] in genetic research.

Currently, there are no international standards in academic research journals requiring the cadaveric tissue source be included in genetic research publications.[87] Great Britain and Switzerland, for example, require consent from legal next of kin for use of forensically derived cadaveric tissue in research.[88] It is difficult to identify the frequency of secondary use of cadaveric tissue obtained under death investigation legislation in Canada for genetic research.[89]

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[81] Carol C Cheung, Bella R Martin & Sylvia L Asa, "Defining Diagnostic Tissue in the Era of Personalized Medicine" (2013) 185:2 CMAJ 135 at 135.

[82] True derivatives refer to samples that are "fundamentally alter(ed) from the original histological specimen", and are thus deemed data, and not tissue: Ubaka Ogbogu & Michael Mengel, "Who Owns Diagnostic Specimens in the Era of Personalized Medicine" (2013) 5:3 Can J Pathology 86 at 87. See also Heather R Bemmels, Susan M Wolf & Brain Van Ness, "Mapping the Inputs, Analyses, and Outputs of Biobank Research Systems to Identify Sources of Incidental Findings and Individual Research Results for Potential Return to Participants" (2012) 14:4 Genetics in Medicine 385 at 387 (Table 1) for examples of derived materials and derived data.

[83] Joanne L Simons & Sue K Viniter, "Effects of Histological Staining on the Analysis of Human DNA from Archived Slides" (2011) 56: S1 J Forensic Science S223 at S223. Cytological smears represent cell samples applied directly to a glass slide for subsequent microscopic examination.

[84] Robert A Stephenson *et al*, "Effect of Section Thickness on Quality of Flow Cytometric DNA Content Determinations in Paraffin-Embedded Tissues" (1985) 7 Cytometry 41. See also Hardcastle *supra* note 77 regarding stability of DNA in histological blocks and Slides. Hardcastle at 9 suggests that tissue stained and stored on microscopic slides "… does not alter the physical composition of the biological materials, but instead makes the DNA structure in the materials more easily identifiable."

[85] Anna-Liina Rahikainen *et al*, "DNA Quality and Quantity from UP to 16 Years Old Post-Mortem Blood Stored on FTA Cards" (2016) 261 Forensic Science International 148.

[86] *Supra* note 17 at 209 defines 'secondary use' as "[t]e use in research of information or human biological materials originally collected for a purpose other than the current research purpose."

[87] A requirement for the source of tissue would be useful, but controversial: See for example, the role of 'body brokers' in America who sell donated cadavers and organs internationally for purposes including international research: Brian Grow and John Shiffman, "A Reuters journalist bought human body parts, then learned a donor's heart-wrenching story" The Body Trade, Reuters online: https://www.reuters.com/investigates/special-report/usa-bodies-brokers/. The article describes a US medical examiner office referring "pauper cases" to an American "body broker" company. These "pauper cases" are assumed to be unclaimed and unidentified bodies (see below at 61).

[88] Bernice S Elger, Marie-Claude Hofner & Patrice Mangan, "Research Involving Biological Material from Forensic Autopsies: Legal and Ethical Issues" (2009) 76 Pathobiology 1 at 1. The authors at 5 note that "[t]he Council of Europe do not contain an explicit section on research on cadaveric material obtained in a forensic context. Therefore, forensic pathologists must refer to recommendations on the use of cadaveric material in general."

[89] Recent data from Ontario indicate that 5-10 % of requests for post mortem tissue are requested for research purposes, although the paper does not specify how many of those requests are for tissue from forensic autopsies, nor

However, Moore *et al* note that, in America, "[t]here is a national movement supporting the retention and use of bio-specimens from deceased individuals for the purpose of genetic testing,"[90] and Bach suggests that "[t]here is a big business booming in the United States around the use of cadavers for research, education, and commercial purposes."[91] The value of archived tissue, including autopsy tissue for genetic research is "unquestionable."[92] There are specific benefits of using cadaveric tissue in genetic research that include the ability to study several organs from one body, the examination of whole organs, most commonly the heart and the brain, less risk of infectious disease,[93] and the ability to determine the metastatic distribution of malignant tumours.[94]

Despite the potential value of forensic cadaveric genetic information in research, a recent parliamentary paper addressed potential harm relating to clinical genetic testing and genetic information that can be applied in the context of forensically derived genetic research:

> Genetic testing is a potential Pandora's box, as it could be used for less than altruistic purposes. In the wrong hands, genetic science could be used to cause more harm than good. As genetic testing becomes more commonplace, Canadians will be challenged to determine the role they wish genetic information to play in their lives.[95]

In the context of genetic research, this reference to 'harm' specifically relates to risk of breach of informational privacy, where the genetic information is the personal health information[96] of

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if the requests are for genetic research: see Samantha Crombie *et al*, "The Pathology Tissue and Archive Committee: Its Role in Human Tissue Research" (2015) 7:3 Canadian Journal of Pathology 15 at 18.

[90] *Supra* note 21 at 309. Moore *et al* cite numerous medicolegal papers and note that genetic testing may be performed for the purpose of research (at 311).

[91] *Supra* note 70 at 355.

[92] Caterina Giannini *et al*, "Maintaining Clinical Tissue Archives and Supporting Human Research" (2010) 135 Arch Path Lab Med 347 at 347. The authors note their study included autopsy derived tissue, but do not specify if the tissue was collected under a death investigation system. See also Crombie, *supra* note 89 at 17, and Jessica Wright *et al*, "Regulating Tissue Research: Do We Need Additional Rules to Protect Research Participants?" (2010) 17 European Journal of Health Law 455 at 455.

[93] Amy L McGuire *et al*, "Taking DNA from the Dead" (2010) 11:5 Nature Review Genetics 318 at 318.

[94] Kristof Van Assche *et al*, "Governing the Postmortem Procurement of Human Body Material for Research" (2015) 25:1 Kennedy Institute of Ethics Journal 67 at 67-68.

[95] Canada, Library of Parliament, Legal and Social Affairs Division, Parliamentary Information and Research Service, *Genetic Discrimination and Canadian Law,* (background paper), by Julian Walker, no. 2014-90-E, 16 September 2014 at 10.

[96] Timothy Caulfield and Blake Murdoch, "Genes, Consent and Biobanks: Yes, There's Still a Consent Problem" *PLOS Biology,* (25 July 2017), online: http://journals.plos.org/plosbiology/article?id=10.1371/journal.pbio.2002654. The authors at 5 note: "… the ability to pull information from cells, tissue and genetic material has advanced rapidly

the individual research subject.[97] In the use of information derived from death investigation systems, if the genetic information is included in research without prior consent (having been collected without consent as mandated in provincial death investigation legislation), the personal autonomy of those individuals who share the genetic information is not respected. This process is inconsistent with both policy and law in relation to research in Canada.

Informed Consent and Risk to Privacy in Research in Canada

In order to protect the personal autonomy of individual Canadians' in relation to their genetic information, the role of consent in mitigating informational risk[98] in genetic research plays a key role, a principle expressed in both policy and law in Canada.

Picard and Robertson consider the basis for the necessity of consent in medical research:

> Though modern medical research tends to be associated with cures and benefits rather than perversity and suffering, we dare not forget the lessons of past abuses … [t]he concept of consent, therefore, plays as vital a role in medical research as it does in therapeutic treatment (perhaps even more so), as a means of promoting personal autonomy and protecting the bodily integrity and human dignity of the subject.[99]

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over the past few decades. Indeed, the sequencing of entire genomes has become increasingly inexpensive and routine. This digitization of tissue, cells and genetic data means that the line between health information (or health records) and tissue has largely disappeared." See also Amy L McGuire *et al*, "Confidentiality, Privacy, and Security of Genetic and Genomic Test Information in Electronic Health Records: Points to Consider" (2008) 10:7 Genetics in Medicine 495; 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 Journal of Law and the Biosciences 94 at 97, who note that, in America, under a regulation implementing the federal *Genetic Information Non-Discrimination Act* , the Privacy Rule (falling under the federal *Health Information Privacy and Accountability Act of 1996*) was amended whereby genetic information is deemed to be health information. A Canadian Court has found that human biological materials are synonymous with medical health records. In *L.D. (Guardian ad litem of) v Provincial Health Services Authority*, 2011 BCSC 628 at ¶ 55, the Court stated that "…there seems to be no real distinction between the blood sample cards and any other medical record retained by health professionals for medical purposes."

[97] William Grizzle *et al*, "Recommended Policies for Uses of Human Tissue in Research, Education, and Quality Control" (1999) 123 Archives of Pathology and Laboratory Medicine 296 at 297; Crombie *et al*, *supra* note 89 at 16.

[98] Flavio D'Abramo, "Biobank Research, Informed Consent, and Society. Towards a New Alliance?" (2015) 69 J Epidemiol Community Health 1125 at 1125.

[99] Ellen I Picard and Gerald B Robinson, *Legal Liability of Doctors and Hospitals in Canada*, 4th ed, Toronto: Thomson Carswell, 2007) at 100. Here, the authors refer to consent as informed consent, not authorization. They note in their discussion of consent in research at 100 that "… the requirement of voluntary informed consent is entrenched in the many international and ethical codes which regulate human experimentation…".

History has shown that infringement of personal autonomy and dignity in the medical research context, regardless of intent, may have dire consequences.[100] The *Nuremburg Code* of 1948 arising from the well-known abuse of concentration camp prisoners as research subjects by the National Socialist Party (Nazis), and the *Declaration of Helsinki* of 1964 are key international guidelines that have been the basis of preserving research subject autonomy and dignity worldwide, including in Canada.[101] Both documents unambiguously indicate the need for the informed consent of the individual research subject.[102] The *Tri-Council Policy Statement Ethical Conduct for Research Involving Humans* (TCPS2)[103] likewise is predicated on informed consent for primary collection of tissue or data from a research participant.[104] However, whether a cadaver is a human "research subject" in Canada is not clear, as will be discussed below.

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[100] Paul Weindling *et al*, "The Victims of Unethical Human Experiments and Coerced Research under National Socialism" (2016) 40:1 Endeavor 1*; Havasupai Tribe of Havasupai Reservation v. Arizona Board of Regents*, nos. 1 CA-CV 07-0454, 1 CA-CV 07-0801 decided November 28, 2008; *supra* note 73 at 269-273; Charles A Walker "Lest We Forget: the Tuskegee Experiment" (2009) 13:1 The J of Theory Construction and Testing 5; Trudo Lemmens, "In the Name of National Security: Lessons from the Final Report on the Human Radiation Experiments" (1999) 6 European J of Health Law 7;and *Muir v. Alberta*, 132 D.L.R. (4th) 695, [1996] 4 WWR 177.
Social Darwinism theory was an accepted norm prior to World War II, and was supported by views of respected scientists throughout the West, including America, that "… qualities such as intelligence, mental illness, work ethic, criminality and poverty were inherited": see Dónal P O'Mathuna, "Human Dignity in the Nazi Era: Implications for Contemporary Bioethics" (2006) 7 BMC Medical Ethics 7:2 at 5.

[101] Jocelyn Downie, Timothy Caulfield, and Colleen M Flood, eds, *Canadian Health Law and Policy*, 4th ed, (Markham, Ontario: LexisNexis, 2011) at 448, 449. Although drafted for living research subjects, these legal instruments may be applied to research performed on deceased individuals, as the ethical principles of these instruments have been adopted by the World Archaeological Congress' Vermillion Accord, which ethically guides the archaeological study of the dead: see Thomas D Holland, "'Since I Must Please Those Below': Human Skeletal Remains Research and the Law" (2015) 41 Am J L & Med 617 at 648.

[102] *The Nuremberg Code*, article 1 online: https://history.nih.gov/research/downloads/nuremberg.pdf and WMA Declaration of Helsinki, *Ethical Principles for Medical Research Involving Human Subjects*, 64th WMA General Assembly, adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964 and amended by the Fortaleza, Brazil, October 2013 at 25-32, the latter document at 32 stating: "For medical research using identifiable human material or data, such as research on material or data contained in biobanks or similar repositories, physicians must seek informed consent for its collection, storage and/or reuse. There may be exceptional situations where consent would be impossible or impracticable to obtain for such research. In such situations the research may be done only after consideration and approval of a research ethics committee." See below at 103. The TCPS2 at 209 defines a "research ethics board (REB)" as "[a] body researchers, community members, and others with specific expertise… [] …established by an institution to review the ethical acceptability of all research involving humans conducted within the institution's jurisdiction or under it's auspices."

[103] *Supra* note 17 at 3. The TCPS2 is a policy "…to guide Canadian researchers, in Canada and abroad, in the conduct of research involving humans."

[104] *Ibid* at 7. The TCPS2 defines a participant as "[a]n individual whose data, or responses to interventions, stimuli, or questions by a researcher are relevant to answering a research question; also referred to as "human participant," and in other policies/guidance as "subject" or "research subject.""

As the field of genomics advances, potential secondary uses[105] of genetic information make the question of informed consent more relevant. For example, scientific advancements have arguably made “anonymous data” a fallacy.[106] Ogbogu and Burningham note that: “Even when genetic information is de-identified, it remains unique to an individual and could potentially be linked to that person (or his or her genetic relatives) if used in conjunction with other personal health information or publicly available information.”[107]

Privacy concerns in genetic research unanticipated by research organizations [108] have resulted in an increased perception of privacy risks associated with genetic research. In short, technology in genetic research has reached a point where “… the guarantee of absolute privacy and confidentiality is not a promise that medical and scientific researchers can deliver any longer.”[109] Provincial and federal privacy legislation provides limited temporal protection of the personal health information of the deceased.[110] The genetic information recoverable from the cadaver is the personal health information of not only the cadaver, but also his biological relatives who share his genetic data. Both are protected under established health information privacy legislation in Canada.[111]

The Office of the Privacy Commissioner of Canada has stated that “[o]ne of the fundamental principles of data protection and privacy laws is the concept of purpose specification and the expectation that personal information should only be used for the purpose for which it was

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[105] *Ibid* at 209. ‘Secondary use’ is defined in the TCPS2 as “[t]he use in research of information or human biological materials originally collected for a purpose other than the current research purpose.”

[106] Jeantine E Lunshof *et al*, “From Genetic Privacy to Open Consent” (2008) 9 Nature Reviews Genetics 406.

[107] *Supra* note 16 at 475.

[108] Dan He *et al*, “Identifying Genetic Relatives without Compromising Privacy” (2014) 24:4 Genome Research 664 at 664. See also Amy L McGuire & Laura M Beskow, “Informed Consent in Genomics and Genetic Research” (2010) 11 Annual Review of Genomics and Human Genetics 361 at 367, who refer to the risks associated with linking individuals to biomaterials through DNA.

[109] *Supra* note 106 at 409. The authors cite the American Society of Human Genetics statement regarding genome-wide association studies, which concludes that the combination of repository genotypes and demographic data “… is an accurate and unique identifier.” See also Kathy L Hudson & Francis S Collins, “Family Matters” (2013) 500 Nature 141. The authors discuss the impact on the family of Henrietta Lacks following the release of the genome of the HeLa cell line to the public domain. Proposed revisions to the TCPS2 acknowledges the risk associated with re-identification of anonymized data (Government of Canada, Panel on Research Ethics Proposed Revisions to TCPS 2 (2014) – Research Involving Human Cells and Cell Lines, October 2017 online: http://www.pre.ethics.gc.ca/consultations/2017/CLAS_en.pdf at 6).

[110] Below at 93.

[111] See below at 20 for exceptions in research.

collected."[112] Thus, the use of cadaveric genetic information in research when recovered for the purpose of determining cause and manner of death under death investigation legislation, absent valid consent to donate, would not be consistent with this policy. Further, in Canada, research policy is consolidated in a transprovincial document[113] grounded in the need for consent in human research, including informed consent in genetic research.

Canadian Human Research Policy – The TCPS2

The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans[114] (TCPS2) is a policy guide of ethical standards in human research in Canada.[115] The document carries significant weight, in that, in order to receive federal funding from the Agencies,[116] researchers and the institutions in which they carry out their research are required to follow the guidelines outlined in the TCPS2.[117] Other organizations not funded by the Agencies, including those operating within the private and public sector, have adopted the TCPS2 as an ethical research standard.[118] Although no legal requirement exists for its use, the Canadian federal government's Panel on Research Ethics notes that: "Even if not subject to TCPS2, researchers conducting research in Canada would be subject to the applicable laws, regulations and policies in effect, including, but not limited to those concerning the protection of privacy of participants, confidentiality, and the capacity of participants to consent."[119]

The TCPS2 dedicates much of its 210 pages to the principle of consent. The core principle of "Respect for Persons" is deemed to be at the heart of the consent process, grounded in the

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[112] Office of the Privacy Commissioner of Canada, *Policy Statement on the Use of Genetic Test Results by Life and Health Insurance Companies,* (Ottawa: OPCC, July 10, 2014) at 1.
[113] *Supra* note 17.
[114] *Ibid.*
[115] Michael McDonald, "From Code to Policy Statement: Creating Canadian Policy for Ethical Research Involving Humans" (2009) 17:2-3 Health L Rev 12 at 12.
[116] *Supra* note 17 at 3. The Agencies include the Canadian Institute of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada.
[117] *Ibid.*
[118] Government of Canada, Panel on Research Ethics, TCPS2 Interpretations: Scope online: http://www.pre.ethics.gc.ca/eng/policy-politique/interpretations/scope-portee/ at 1.
[119] *Ibid* at 3.

autonomy of the individual.[120] The need for "free, informed and on-going consent" given by the research subject is expressed clearly:

> Respect for Persons implies that individuals who participate in research should do so voluntarily, understanding the purpose of the research, and its risks and potential benefits, as fully as reasonably possible. When a person has the capacity to understand this information, and the ability to act on it voluntarily, the decision to participate is generally seen as an expression of autonomy.…This [consent] process is meant to emphasize Respect for Persons. Under no circumstances may researchers proceed to conduct research with anyone who has refused to participate. Subject to exceptions set out in this Policy, consent must be obtained from participants prior to the conduct of research.[121]

Clearly "voluntary" consent cannot apply to a dead body, when cadaveric tissue is recovered in a forensic autopsy. Equally, a cadaver cannot offer "on-going" consent, suggesting that valid consent for organ or tissue donation, for example, must be informed and expressed. However, consent from genetic next of kin would meet these criteria when their genetic information is subsequently included in research, to be discussed below.

In practice, the TCPS2 requires research ethics review, and consent for research use of cadaveric tissue.[122] Absent consent through antemortem donation, that is, consent from the cadaveric donor, the TCPS2 allows for consent to be made by an "authorized third party."[123] What is important from this directive is that the legal authority granting consent may not necessarily be a genetic relative whose shared genetic information may be used in the genetic research. However, Article 13.5 of the TCPS2[124] states that consent from individual family members in genetic research is mandatory.[125] This suggests that, in practice, a two-stage process is required, where

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[120] *Supra* note 17 at 6-7.

[121] *Ibid* at 25.

[122] *Supra* note 17 at Article 12.1. In practice in death investigation systems, relying on this section of the TCPS2, consent is required from the donor in life (Article 12.1(a)(c)).

[123] *Ibid* at 201. This term is defined as "[a]ny person with the necessary legal authority to make decisions on behalf of a prospective participant who lacks the capacity to decide whether or not to participate, or to continue to participate, in a particular research project."

[124] *Ibid* at 196.

[125] *Ibid*. Article 13.5 states that "[r]esearchers who seek to recruit members of a family to participate in genetic research *shall* ... seek consent from individual family members (emphasis added), where 'shall' is defined as "…a mandatory provision" at 210.

the legal authority granting use of cadaveric organs and tissue is not deemed a 'family member"[126] in the context of the specific proposed genetic research.

Thus, relying solely on TCPS2 policy, absent valid consent for donation, cadaveric organs and tissues may be used in genetic research, including when recovered under death investigation legislation. Since an individual cannot control if he will be subject to a forensic investigation in death, control of genetic information can only be made prior to death, specifically by choosing (or not choosing) to donate one's body or body parts for genetic research.

If an individual has died in circumstances governed by a death investigation system, the shared genetic information of his living biological relatives may also be included in research without their knowledge or consent. In America, it has been stated that

> … current medical research norms permit a scientist who has access to previously collected samples of a patient's blood or tissue to sequence that patient's genome without asking the patient to consent to sequencing… The scientist then may, and in some cases … *must*, share the resulting genomic data with others, including sending the dataset for inclusion in federal government databases used by researchers and companies worldwide, usually without any additional notice to the patient.[127]

The international sharing of research, including genetic information means this American policy, and other international research practices allowing sharing of research subject data without consent, impacts the personal autonomy of Canadian genetic research subjects.

Consent in Human Research in Canada - Case Law

As noted previously, genetic information is personal health information, including its use in genetic research.[128] The Supreme Court of Canada has made it clear that personal health information "… remains in a fundamental sense, one's own, for the individual to communicate or retain as he or she sees fit,"[129] reflecting the personal autonomy of the individual and

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[126] *Ibid* at Article 13.5.
[127] *Supra* note 96, Kulynych at 98.
[128] *Supra* note 31 at ¶ 12.
[129] *Supra* note 18 at 148.

supporting the requirement for consent for its use. In the context of genetic research performed on forensically derived cadaveric genetic data, consent law is also relevant to biological relatives who share genetic data with the deceased.

Although case law in Canada is sparse in relation to consent for research, the principle of informed consent in clinical medicine is well established.[130] As well, Charter challenges[131] have addressed the issue of consent in relation to collection of biomaterials. For example, the Supreme Court of Canada has held that " … the use of a person's body without his consent to obtain information about him, invade[s] an area of personal privacy essential to the maintenance of his dignity."[132] As will be argued below, dignity of the body transcends death, and thus genetic research performed without consent could be judicially deemed an invasion of "… personal privacy essential to the maintenance of his dignity."[133]

Consent of genetic relatives in reference to collection of human biomaterials was considered in *L.D. (Guardian ad litem of) v. Provincial Health Services Authority.*[134] In British Columbia, parents opposed to newborn blood sample storage without their consent (beyond their consent for the blood collection for the treatment of their child) sought a class action in 2011, arguing the collections … "amount to a legally unauthorized fully functional DNA database for every child and his or her parents." [135] The Court adopted a reasonableness standard using the modified objective test in determining that consent was not required for the subsequent storage of the samples, finding that "… a reasonable person in the objective position of the plaintiffs would have consented to such storage if they had been informed that the samples were being

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[130] *Supra* note 101 at 469.

[131] The *Canadian Charter of Rights and Freedoms,* The Constitution Act, 1982, Schedule B to the Canada Act 1982 (UK), 1982, c 11 applies only to "… any governmental activity": see Canada, Parliamentary Research Branch, Law and Government Division, *Human Right Legislation and the Charter: A Comparative Guide*, by Nancy Holmes, no. MR-102E, 18 September 1997 (revised). However, in *Hill v Church of Scientology*, [1995] 2 SCR 1130 at 1132, the Supreme Court of Canada stated that "…[t]he common law must be interpreted in a manner which is consistent with *Charter* principles. This obligation is simply a manifestation of the inherent jurisdiction of the courts to modify or extend the common law in order to comply with prevailing social conditions and values." See also *Jones v Tsige*, 108 O.R. (3d), 2012 ONCA 32 at ¶ 45.

[132] *Dyment,* supra note 13 at 431-432.

[133] *Ibid.*

[134] *L.D. (Guardian ad litem of) v. Provincial Health Services Authority*, 2011 BCSC 628.

[135] *Ibid* at ¶ 6.

stored for medical purposes related to the health of the infants."[136] However, in *Halushka v. University of Saskatchewan*,[137] and the more recent *Weiss c. Solomon,*[138] the respective Courts concluded that a "higher level of disclosure of information is required…" in human research, relative to that of informed consent in clinical medical practice.[139] Further, "… the duty to inform is the most exacting possible."[140]

Although Canadian Courts have not to date considered if a cadaver is a research subject,[141] research use of the shared genetic information of the body's biological next of kin is human genetic research. However, there is no requirement for the consent of next of kin to perform a forensic autopsy in a death investigation in Canada,[142] and the statutory requirement for consent for research using forensically derived genetic information varies among provinces.[143] Thus, the status of the need for consent in research of genetic information collected post mortem under death investigation systems in Canada is a complex issue. This does not, however, preclude the necessity of considering the need for consent in this context.

Wicclair and DeVita propose that the protection owed a cadaver in research includes: "… (1) protection from being used for research that is incompatible with the deceased's …[]… premortem preferences and values; (2) protection against unwarranted disclosure of confidential information; and (3) protection from having their bodies treated disrespectfully."[144] In other words, postmortem privacy, respect for personal autonomy while alive through acknowledging ante-mortem consent (or not consent), and dignity of the body are the duties owed by researchers in cadaveric research. Thus, as "… it is widely recognized that the information which may be contained in a person's medical records is among the most sensitive kinds of personal data,…

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[136] *Ibid* at ¶ 55.
[137] *Halushka v University of Saskatchewan,* 53 DLR (2d) 436, 1965 CanLII 439 (SK CA).
[138] *Weiss c Solomon*, [1989] J.Q. no. 312, 48 C.C.L.T. 280.
[139] *Supra* note 99 at 176.
[140] *Ibid* in reference to *Weiss c Solomon*. It has also been suggested that a higher standard of care for researchers was implied in *Zimmer v. Ringrose*, (1981), 124 D.L.R. (3d) 215 (Alta C.A.): see Timothy M Banks, "Misusing Informed Consent: A Critique of Limitations on Research Subjects' Access to Genetic Research Results" (2000) 63 Sask L Rev 539 at 555.
[141] See below at 62 for discussion of a cadaver as a research subject in Canada.
[142] *Supra* note 50. Consent is not required for either legal or genetic next of kin.
[143] See discussion below at 93.
[144] Mark R Wicclair & Michael DeVita, "Oversight of Research Involving the Dead" (2004) 14:2 Kennedy Institute of Ethics Journal 143 at 144.

[and] … the privacy of health information is a universal concern which … affects every member of society[,]"[145] then the post mortem protection of genetic informational privacy may be justified through autonomy based choice while alive, and sustained dignity in death, specifically in relation to cadaveric genetic information. This may be ensured in practice by requiring consent for use of cadaveric genetic data obtained in the course of a death investigation. Historically, Canadian courts' consideration of the post-mortem individual[146] began initially with the cadaver, determining specifically who, if anyone, may have control of the body for the purpose of final disposition of the body. As science progressed, legal issues arose concerning who has control of the cadaver's organs, and most recently in the age of genomic research, human tissue has received judicial review in reference to who may have legal interests in both the tissue itself, and its genetic data.[147] This paper will first consider who may have legal control of a cadaver in Canada.

The Law and the Cadaver – Who Has Control?

In determining if consent is required for cadaveric genetic research in death investigation systems, and if so, from whom, the analysis will begin by considering those individuals and groups who may be granted legal control of the body. It will be argued that legal control of a deceased individual is predicated on the purpose of control by the living.

Death Investigator's Control of the Body

Provincial legislation governing death investigation varies between provinces, but each statute gives some degree of control of the body to the death investigator in order to investigate the death, including the primary task of identifying the deceased. This is not absolute control but is effectively legislated authority limited to the deemed purposes arising from the investigation of

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[145] Barbara von Tigerstrom, "Protection of Health Information Privacy: The Challenges and Possibilities of Technology" (1998) 4 Appeal 44 at 3.

[146] The word 'decedent' will be used interchangeably with deceased individual. See *Meriam-Webster Dictionary,* www.merriam-webster.com sub *verso* 'decedent.'

[147] *Piljak Estate v Abraham*, 2014 ONSC 2893.

the death.[148] Currently, no provincial death investigation legislation gives a death investigator control of an identified body for the purpose of research in Canada.[149]

Next of Kin and the Forensic Autopsy

With this right to take control of a body without the consent of the next of kin,[150] there is a concomitant obligation of the death investigator to perform his duty in such a way that he maintains public trust.[151] The conceptual interpretation of public trust will be temporally and geographically contextual, and will reflect what is considered appropriate treatment of a body after death, the circumstances of which will vary among cultures, religions and philosophies.[152] Thus, despite having statutory authority to order or perform a forensic autopsy, coroners and medical examiners generally attempt to consider the wishes of the deceased's legal next of kin in deciding not if, but how the forensic autopsy is performed, recognizing and respecting religious and personal objections when possible.[153] Thus, despite a death investigator's legislated authority to order a forensic autopsy, the objections of the deceased's next of kin may result in modifications as to how the autopsy is performed, that is, a limited autopsy may be requested.[154]

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[148] *Coroners Act*, SBC 2007, c 15, s 13; *Fatality Inquiries Act*, RSA 2000, c F-9, s 25; *The Coroners Act*, SS 1999, c C-38.01, s 14; *The Fatality Inquiries Act*, CCSM 1990, c F52, s 12(1); *Coroners Act*, RSO 1990, c C.37, s 28; *An Act Respecting the Determination of the Causes and Circumstances of Death*, CQLR c R-0.2 , s 12; *Coroners Act*, RSNB 1973, c C-23, s 32; *Fatality Investigations Act*, SNS 2001, c 31, s 13; *Coroners Act*, RSPEI 1988, c C-25, s 10; *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 14; *Coroners Act*, RSY 2002, c 44, s 15; *Coroners Act*, RSNWT 1988, c C-20, s 14(1).

[149] Unidentified and unclaimed bodies are the exception: see below at 57.

[150] *Coroners Act*, SBC 2007, c 15, s 14(2) specifically includes that an autopsy may be performed under the authority of a coroner against the wishes of the legal next of kin.

[151] Stephen Cordner & Fiona Leahy, "Ethics and Research on Bodies in the Jurisdiction of Coroners or Medical Examiners" (2013) 3:3 Academic Forensic Pathology 301 at 301; see also *supra* note 69.

[152] Elizabeth Burton, "Religions and the Autopsy," Medscape, 20 March 2012 (updated) online: http://emedicine.medscape.com/article/1705993-overview; , Norman R Goodman, Jeffrey L Goodman, & Walter I Hofman, "Autopsy: Jewish Laws and Customs 'Halacha'" (2011) 32:3 Am J Forensic Med and Pathology 300 at 300; Richard M Conran & Kim A. Collins, (eds), "Medicolegal Issues and the Autopsy" Medscape Reference, 25 July 2013. online: http://emedicine.medscape.com/article/1975045-overview, citing NY Public Health sec. 4210-c.

[153] Bucholz, *supra* note 48 at 3-4; Burton, supra note 152; , Lauren R Boglioli & Mark L Taff, "Religious Objection to Autopsy" (1990) 11:1 Am J Forensic Med and Pathology 1. A formalized relationship between First Nations and the coroners service exists in British Columbia: First Nations Health Authority, online: http://www.fnha.ca/about/news-and-events/news/first-nations-health-authority-and-bc-coroners-service-partnership;

[154] Limiting the autopsy refers to the performance of a partial autopsy. For example, a family may request that the brain, eyes or other organs of the body not to be removed for examination. If a death investigation is not hindered by limiting the autopsy, the request may be granted. See Belinda Carpenter *et al*, "Communicating with the Coroner: How Religion, Culture and Family Concerns May Influence Autopsy Decision Making" (2011) 35 Death Studies 316; Randy Hanzlick & Mario I Mosunjac, "Case of the Month – the Rest of the Story" (1999) 159 Arch Intern Med 1173 at 1174.

Individuals will have their own beliefs that will guide their perception of what is appropriate respect for the body, which underlies the requirement for consent for hospital non-forensic autopsies from next of kin having legal control of the body.[155] Unlike a forensic autopsy, however, a hospital autopsy is performed without the need to fulfill the legislated mandate of a death investigation system.[156]

Where objections by the legal next of kin have conflicted with the death investigator's authority, judicial determination of the limits of control of a body have been necessary. To date, a court in Canada has not addressed if the legal next of kin have a legal claim to control the way the autopsy is performed when under the authority of a death investigation system. Other countries have judicially delineated the criteria under which next of kin may have the authority to control the post mortem examination of the body. American case law has held that the consent of next of kin for performance of a forensic autopsy may be required when the objection to autopsy is on religious grounds,[157] predicated on the doctrine of informed consent, and based on "… the right of the next of kin to bury a deceased family member in the condition that the body was in at the time of death, that is, without mutilation."[158] Potential objections necessitating consent from legal next of kin may not, however, be limited to those based on religion, but may also include "…ethical or philosophical objections of a decedent's family…"[159]

In Australia, legislation in all jurisdictions except South Australia[160] gives the Australian Supreme Court discretion to override the performance of a forensic autopsy if the deceased's next of kin oppose, some statutes referring to religious or cultural objections.[161] However,

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[155] See Province of British Columbia Healthlink BC, Autopsy: *Should I Have an Autopsy Done on My Loved One*? online: http://www.healthlinkbc.ca/healthtopics/content.asp?hwid=uz2102#zx3684. The decision-making process for consent to autopsy is outlined, and considers the consenting individual's religious, ethnic and cultural beliefs.

[156] *Supra* note 50.

[157] Jack R Bierig, "Informed Consent in the Practice of Pathology" (2001) 125 Arch Pathol Lab Med 1425 at 1425.

[158] *Ibid* at 1426.

[159] *Ibid* at 1426, citing *Weberman v Zugibe* s Ct NY 1977. The use of the word "decedent" implies the Court considered the deceased not simply as a cadaver, or source biological material, but as a deceased person. See *Kohn v United States*, 591 F. Supp.568 (E.D.N.Y. 1984) below at 82.

[160] The website of the South Australia Coroners Court states: "…Because the State Coroner has to bring down a finding as to the specific cause of death, it is his decision as to whether a post-mortem is conducted. However, the State Coroner will seriously consider objections raised by next of kin." see Australia, Courts Administration Authority of South Australia, Coroners Court, "Post Mortems", online: http://www.courts.sa.gov.au/OurCourts/CoronersCourt/Pages/Post-Mortems.aspx#stopping.

[161] Prue Vines, "The Sacred and the Profane: The Role of Property Concepts in Disputes about Pot-mortem Examination" (2007) 29:2 Sydney L Rev 235 at 252.

"…[w]here there is either scientific advantage or some suspicion about the death, the court will not allow religious, cultural or psychological objections to interfere with the process,"[162] thus balancing the family's concerns with the primary goal of determining cause of death in the forensic context.

Next of Kin's Control of the Body

Legal authority justifying the legal next of kin's control of a body not under the authority of a death investigation system is complex in Canada, both in the academic literature and in Canadian jurisprudence. Relevant legislation varies between provinces, and case law to date has not followed a principled approach. The argument in academic literature generally hinges on two primary concepts: the right to a body, or a proprietary right, or a right of a body, that is, inherent rights of the body itself, in practice the duty of the living to ensure that the decedent is treated with dignity.

Control as a Right **to** a Body

Cantor describes the historical basis of the legal next of kin's control of or right to a body:

> Stemming from the legal duty of the next of kin to dispose of a corpse, the common law found concomitant rights of the next of kin to determine the place and mode of a corpse's disposition…The control rights lodged in the next of kin included the rights to hold and protect the body, … and assure the undisturbed repose of the human remains.[163]

However, no absolute property interest in a dead body is said to exist in common law.[164] This maxim arose historically: " The basis for the rule is that a corpse is *nullius in bonis* (i.e. in the

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[162] *Ibid* at 254. The assumption is that "scientific advantage" is in reference to determining the cause of death, not scientific research.

[163] Norman L Cantor, *After We Die: The Life and Times of the Human Cadaver* (Washington, DC: Georgetown University Press, 2010) at 61-62. Hardcastle, supra note 77 at 47 indicates that there a duty to bury a body recognized in English common law. Canadian case law, including *Edmonds* and *Miner* refer to the next of kin's duty to bury infra at XX. The *Criminal Code of Canada* s. 182(a) states that it is "…an indictable offence and liable to imprisonment for a term not exceeding five years" if one "…neglects, without lawful excuse, to perform any duty that is imposed on him by law or that he undertakes with reference to the burial of dead human body or human remains."

[164] Taylor suggests that the 'no property' rule arose in opposition to slavery-based property rights in the human body: See Richard Taylor, "Human Property: Threat or Savior?" (2002) 9:4 Murdoch University Electronic J of Law

legal ownership of nobody) – a dead body belonged exclusively to the ecclesiastical jurisdiction until the nineteenth century, … (this) exclusive domain over the dead … based on the simple fact that burial grounds all belonged to the churches."[165]

When the common law absorbed ecclesiastic jurisdiction, "… the principle that there was no property in a body was maintained, the person who was charged with the duty of disposing of the body …[having]… the limited right to possess it until burial."[166]

Case Law - Canada

In Canada, case law addresses the issue of a proprietary interest in a body, if any, by the next of kin. In general, Courts have not established a legal principle, instead each case turning on the facts. In the first Canadian case on point, the Court in *Davidson v Garrett*[167] followed the "no property in a body" rule, relying on English jurisprudence.[168]

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at ¶ 4; see also Mark Pawlowski, "Property in Body Parts and Products of the Human Body" (2009) 30 Liverpool Law Rev 35 at 35; Wendy Bonython & Bruce B Arnold, "Privacy, Personhood, and Property in the Age of Genomics" (2015) 4 Laws 377 at 378; , Minia E Bremenstul, "Victims in Life, Victims in Death –Keeping Burial Rights out of the Hands of Slayers" (2013) 74 La L Rev 213 at 222; , Muireann Quigley, "Property in Human Biomaterials – Separating Persons and Things?" (2012) 32:4 Oxford J of Legal Studies 659; Thomas L Muinzer , "Law of the Dead – A Critical Review of the Burial Law, With a View to its Development" (2014) 34(4) Oxford J of Legal Studies 791 at 792; Remigius N Nwabueze , "Biotechnology and the New Property Regime in Human Bodies and Body Parts" (2002) 24 Loyola of Los Angeles International and Comparative Law Review 19 at 22; Roger S Magnusson, "The Recognition of Proprietary Rights in Human Tissue in Common Law Jurisdictions" (1992) 18 Melbourne U L Rev 601 at 603. Magnusson refers to the recognition of proprietary rights and argues that *nullius in bonis* "… rests upon remarkably frail foundations." Canadian courts, however, have affirmed the 'no property' rule: see for example, *Davidson v Garrett*, 1899 OJ 193, 30 OR 653, and *R v Polimac*, 2006 CanLII 40108 (ON SC), 149 CRR (2d) 161.

[165] Pawlowski, *supra* note 164 at 36.

[166] *Ibid* at 38. See also *Miner, infra* note 169. The Manitoba Court of Appeal in *R. v Mills* (1992) 81 Man. R. (2d) 281, 30 W.A.C. 281, [1993] 4 SCR 277 reviews the history of burial practices in England, and notes that "… [a] body could not be cast out so as to expose it to violation, or to offend the feelings or endanger the health of the living" at 3. In *Mills*, the Court of Appeal was asked to determine if the accused's method of burying bodies which resulted in the collapse of some buried coffins amounted to the intention of committing an indignity to a body under s. 182 of the *Criminal Code*. In a 2:1 decision, the Court interpreted the section to refer to the body itself, and not any offense to the living (at 15), and that indignity to a body could not occur when the body was buried (at 14). The Court took an opposing view in *R v Moyer*, [1994] 2 S. C. R., where it was held that an indignity to a grave marker is synonymous with an indignity to a body.

[167] *Davidson v Garrett* [1899] O.J. No. 193, 30 O.R. 653. A claim in trespass against doctors who performed a coroner's autopsy under the belief they had authority to do so (the warrant had been withdrawn without their knowledge) failed. The Court found that the doctors had "… acted in good faith and in the honest belief that they were discharging an important public duty." At ¶ 29.

[168] *Ibid* at ¶11.

Subsequently, in *Miner v Canadian Pacific Railway Co.*,[169] the Court of Appeal reviewed American, Australian and United Kingdom law, and deemed the deceased's mother had a property right in the body expressed as her duty to the body's proper disposition.[170] Interestingly, the Court also held the plaintiff, the mother of the deceased, "… had a property interest in [the body], independently of and anterior to her right as executrix,"[171] suggesting a potential claim of control by genetic next of kin having no legal authority as executors to control the body.

The limited right to the body by next of kin was further expanded to extend after burial In *Mason v. Westside Cemeteries Ltd*.[172] In setting damages, this case differentiated the ashes of the deceased from the deceased himself, holding that "… the ashes themselves were of very little [value]…,[173] the Court awarding the plaintiff general damages for mental distress. Molloy J noted that the monetary value on which to determine damages was not in the ashes themselves, but what the remains represented to the plaintiff, specifically the now deceased individual.[174] Based on this decision, next of kin's interest in a body may not be contingent on either the condition of the body nor its location,[175] but what the remains represent to the next of kin, that is, the deceased individual. Relying on *Mason*, in the context of genetic research, a similar interest could be extended to human remains, including tissue and organs if the genetic information within the tissue was to be deemed analogous to the individual decedent, for example.

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[169] *Miner v Canadian Pacific Railway Co.*, 1910, 15 W.L.R, 1911 Carswell 23, 18 W.L.R. 476. The plaintiff, the mother of the deceased and executrix of his estate was awarded damages for mental distress as a result of the company temporarily misplacing the remains of her son, such that he had undergone decomposition when recovered. The company appealed.

[170] *Ibid* at ¶¶ 21-22.

[171] *Ibid* at ¶ 30. This finding was considered by the Court in awarding compensatory damages for the plaintiff's mental suffering (at ¶ 33). Today, the Supreme Court of Canada has held that a defined mental illness is necessary for an award of damages: see Stephen Aylward, "The Idea of Privacy Law: *Jones v Tsige* and the Limits of the Common Law" (2013) 71 UT Fac L Rev 61 at ¶ 34, citing *Mustapha v Culligan of Canada Ltd*.

[172] *Mason v Westside Cemeteries Ltd*., [1996] O.J. 1387 at ¶ 23. The plaintiff sued the defendant cemetery for mental suffering over the permanent loss of the cremated remains of his parents. The Court held that there was "… no limitation period defence with respect to either breach of bailment or negligence" at ¶ 59.

[173] *Ibid* at ¶ 40.

[174] *Ibid.*

[175] *Report of the National Cremation Investigation* by The Right Honourable Dame Elish Angiolini DBE QC (17 June 2016) online: www.gov.scot/Resource/0050/00502116.pdf at 29.

The significance of cremated remains as a representation of the deceased has also been addressed in a wider context. A recent report was released concerning the systemic intermingling of the cremated ashes of adults and children in Scotland. The author noted in the report that this intermingling of remains is "… deeply shocking, will offend the sensibilities of the wider community and cause great distress to those whose babies were created there. It will also cause profound concern to the next of kin of any unrelated adults who were cremated in Aberdeen."

However, in a disparate decision, the location of deceased individuals did influence legal control by the next of kin. The Court in *O'Connor v Victoria (City)* accepted the claim in trespass by the owners of land in which bodies were buried (and which were illegally moved by the municipality), the Court finding that "… when the body is deposited in the ground it becomes in law a part of the freehold, as it does in the course of time in fact."[176] Based on this ruling, next of kin would have no claim to the body if they did not also own the land in which it was buried, and control of a body by the next of kin after disposition would be terminated.[177] The Court's reasoning in *O'Connor* likely assumes that the body eventually decomposes and becomes physically indistinguishable from the ground, that is, the 'disappearance' of the body proceeds by means of decomposition. The ruling, however, does not consider the circumstance ion which a body may be exhumed prior to complete decomposition when under the authority of a death investigator[178] or when consented to by the next of kin. Today, archaeological samples of buried remains may be recovered after extended periods of time and may yield significant personal information about the living through the genetic information recovered.[179] Further, complete decomposition in reference to genetic material may be a moot point, as techniques currently exist to extract DNA from soil.[180]

In *Edmonds v Armstrong Funeral Home Ltd.*,[181] the Court, citing *Miner*,[182] found that the right to the body for disposition was "… subordinate to the demands of justice or public good…,"[183] including the control of the body by a coroner.[184] Noting (at the time) the legal authority of next

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[176] *O'Connor v Victoria (City)* 1913, CarswellAlta 279 at ¶ 1.

[177] This follows the finding in *Mills* (*supra* note 166) concerning the indignity to a body where a body once buried, cannot suffer an indignity.

[178] See, for example *R v Polimac*, 2006 CanLII 40108 (ON SC), 149 CRR (2d) 161,.

[179] See, for example, the genetic linking of living heirs with King Richard III of England: University of Leicester, "RIII DNA Results," online: http://www.le.ac.uk/richardiii/science/resultsofdna.html; and Turi E King *et al*, "Identification of the Remains of King Richard III" (2 December 2014) *Nature Communications* 1.

[180] Alexandra L Emmons, "The Persistence of Human DNA in Soil Following Surface Decomposition" (2017) 57 Science and Justice 341.

[181] *Edmonds v Armstrong Funeral Home Ltd.* [1930] A.J. No. 66, [1931] 1 D.L.R. 676. The plaintiff, after refusing permission to perform an autopsy, sued the defendant funeral home for mental suffering in allowing the autopsy to be performed by the defendant doctor. The case was dismissed at trial on the grounds of no cause of action found by the trial judge in the statement of claim, and the ruling was appealed. The Court allowed the appeal, relying on the American case of *Larson v Chase*, 14 L.R.A. 85, at ¶ 24, and *Dame Phillips v The Montreal General Hospital* at ¶ 23.

[182] *Supra* note 169.

[183] *Supra* note 181 at ¶ 16.

[184] There is no indication in the ruling that the doctor performed the autopsy under the authority of a coroner.

of kin to override a deceased's ante mortem consent for body donation,[185] the Court ruled in favour of the plaintiff husband, the wording of the judgment of interest: " If then, as seems clearly established, the plaintiff had the right to the custody and control of the remains of his deceased wife any unauthorized interference with that right, such as is alleged, was an invasion of his right and would give a cause of action."[186] Here, the Court clearly indicates that the right lies in the living next of kin, and not in the body, although this may simply reflect the legal authority of family over ride in organ donation at the time.[187] The Court also found that the plaintiff would be subject to s. 237 of the *Criminal Code*, the equivalent of the current s. 182 of the C*riminal Code of Canada*,[188] had he not performed his duty of disposition of the body, regardless of whether he had chosen to take on the duty, or if it had been imposed on him.[189] Today, the *Criminal Code of Canada*, section 182(a) states that "[e]very one who neglects, without lawful excuse, to perform any duty that is imposed on him by law or that he undertakes with reference to the burial of a dead human body or human remains, is guilty of an indictable offence and liable to imprisonment for a term not exceeding five years."[190] Thus, there is a duty (also referred to as a right of sepulcher"[191] in American jurisprudence), to dispose of a body in Canada, the failure to do so being a criminal offence. This duty may be legally imposed, as in the government's duty to appropriate disposal of unclaimed and unidentified bodies,[192] for example, or by an undertaking.[193]

The Court in *Edmonds* cited *Phillips v The Montreal General Hospital*,[194] a case with similar facts, in which the Québec Civil Law Court stated that "… [t]he control of a husband or wife

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[185] *Supra* note 181 at ¶ 17, citing the *Anatomy Act*, 1832, c. 75.

[186] *Ibid* at ¶ 18. Emphasis added.

[187] Supra note 181 at ¶ 17. At the time this case was heard, the legal next of kin had a legal right to override organ donation.

[188] *Criminal Code*, RSC 1985, c C-46, s 182.

[189] *Supra* note 181 at ¶ 14.

[190] Supra note 188, s 182(a).

[191] The right of sepulcher includes …"(1)the next of kin's right to possession of a decedent's corpse for the purpose of burial; (2) the right to receive the decedent's body in the condition it was when life left it; (3) the right to determine the time, place and manner of burial; and (4) the right to be notified of the decedent's death before its burial or cremation; and (5) rights relating to the disturbance of the grave or right of repose): see Remigius N Nwabueze, "The Concept of Sepulchral Rights in Canada and the U.S. in the Age of Genomics: Hints from Iceland" (2005) 31 Rutgers Computer and Technology Law J 217 at 241.

[192] See discussion of unclaimed and unidentified bodies below at 57.

[193] See for example, *Edmonds*, supra note 181.

[194] *Phillips v The Montreal General Hospital,* 1908 CarswellQue 8, 33 Que. S.C. 483. The plaintiff widow of the deceased alleged that the performance of a clinical autopsy on her husband's body against her wishes resulted in her

over the remains of the other and their burial is paramount … Relatives come next in order of kinship,"[195] clearly establishing here the subordinate position of other (including genetic) next of kin for the purpose of disposition. At the time of the ruling, French civil law, unlike English common law, recognized the right to consent to donate one's body after death, including body parts, unless the donation was contrary to "… public order or police regulations."[196] Davidson J, in reviewing English common law, noted that "… a dead body does not represent property in the ordinary sense of the word."[197] Upon consideration of French law, however, the Court found that "… [i]n the absence of personal directions, the remains are the property of the family, just as is the body of an animal."[198] In effect, the Court deemed the cadaver to be personal property, and more importantly, akin to something non-human.[199] However, Davidson J relied on American case law in finding that "… an unauthorized autopsy constitutes such an unlawful trespass on personal rights, and is possible of arousing such a sense of outrage and of mental suffering as to constitute proper elements of compensatory damages,"[200] specifically, the rights and mental suffering of the living next of kin. Importantly in this case, the autopsy was not performed under the authority of a coroner's warrant (that is, it was performed under no legal authority), which may have influenced the Court's conclusions as to the rights to the body, suggesting that this ruling could be extended to forensic research that is not statutorily mandated.

More recently in Canada, the nature of the duty to appropriate disposition was judicially considered in *Saleh v Reichert*.[201] Bell J, who held that "… religious law had no bearing on the case…," found only a legal obligation to bury.[202] The Court found that the right of next of kin to

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mental and physical suffering. The defendants argued that the plaintiff's right to her husband's body, if any, had not been included in her claim.

[195] *Ibid* at ¶ 26.

[196] *Ibid* at ¶ 19.

[197] *Ibid* at ¶ 14.

[198] *Ibid* at ¶ 19. John-Paul Boyd "Dealing with Pets after Separation, Part 1: Understanding the Law on Personal Property" *LawNow Magazine* 40:4 (March 1, 2016) 1 at 1 notes that Canadian jurisprudence "… continues to regard animals as personal property."

[199] In the context of genetic research, one's genome remains unchanged after death, that is, it is a human genome, making the analogy of a cadaver to an animal not relevant in this context.

[200] *Supra* note 194 at ¶ 18.

[201] *Saleh v Reichert,* [1993] O.J. No. 1394, 104 D.L.R. (4th) 384. The deceased, a Muslim, had expressed her wish to be cremated prior to her death, and her husband, the Administrator of her estate, planned to cremate her remains. Her Muslim father was unsuccessful in his attempt to legally prevent the cremation, despite arguing that her burial was necessary on religious grounds.

[202] *Ibid* at ¶ 25.

a body for the purpose of disposition must respect the deceased individual's choice as to how disposition will proceed, even if that choice is in opposition to the next of kin's (here, the decedent's genetic next of kin) religious beliefs. Thus, *Saleh* is in keeping with the right of an individual to control their body after death, here the method of their disposition.[203]

The right to control a body was considered in a criminal proceeding in Ontario, in the context of the accused's right to privacy. In *R v Polimac,*[204] the Court was asked to determine the nature of the rights that the accused, the common law partner of the victim, had in relation to the body of the deceased. The accused sought to prevent the admission of evidence arising from a second autopsy performed on the exhumed victim, arguing a privacy interest in the buried body, and a breach of his right to privacy under section 8 of the *Charter.*[205] The Court held that the accused's control of the burial plot in which his spouse had been interred " … was not absolute, and his expectation of privacy accordingly limited."[206] The court reviewed the history of quasi-proprietary interests in a body, and concluded that "… a person does not, with some possible exceptions, have an ownership right or a property right in another's body. Case law from the 1600s to present day has held that a human body is not property, at least not in the normal sense."[207]

The Court cited Ontario's *Coroner's Act* section 51(2)(b), legislatively granting a coroner the authority to disinter a body without the consent of the legal next of kin.[208] The Court did not accept the accused's assertion that his privacy had been breached because of the disinterment:

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[203] If one can control the disposition of one's intact body, individuals may also have a right to control disposition of components of their body, such as organs and tissues.

[204] *R. v Polimac*, [2006] O.J. No. 4758.

[205] *Ibid.*

[206] *Ibid* at ¶ 18. The expectation of privacy in cadaveric derived personal information is discussed below at 103.

[207] *Ibid* at ¶ 19.

[208] *Ibid* at ¶ 17-18. There is similar authority in other provinces and territories authorizing a disinterment for the purpose of a death investigation. See for example, *Coroners Act*, SBC 2007, c 15, s 11(d); *Fatality Inquiries Act*, RSA 2000, c F-9, s 28;*The Coroners Act*, SS 1999, c C-38.01, s 15; *The Fatality Inquiries Act*, CCSM 1990, c F52, s 38(1); *An Act Respecting the Determination of the Causes and Circumstances of Death*, CQLR c R-0.2, s 36; *Coroners Act*, RSNB 1973, c C-23, ss 27.1, 28; *Fatality Investigations Act*, SNS 2001, c 31, s 22; *Coroners Act*, RSPEI 1988, c C-25, s 11; *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 23; *Coroners Act*, RSY 2002, c 44, ss 7(2)(b), 3; *Coroners Act*, RSNWT 1988, c C-20 s. 15, the latter the only legislation that explicitly requires notification of the next of kin.

"Given the limited right in this situation, and the fact that no personal information about the accused himself was targeted, there is no objective basis for saying that the accused had a reasonable expectation of privacy in the information that the autopsy might reveal."[209]

The second autopsy was requested to correlate anatomic pathological findings with a witness statement concerning the behavior of the victim immediately prior to death, and not to recover "… core biographical data…,"[210] suggesting that the Court's decision may have differed, had the exhumation been requested for the purpose of collecting evidence potentially containing genetic information, including the DNA of the accused.[211]

In summary, these cases illustrate that generally, Canadian Courts have found that the legal next of kin's right to or control of a body is contingent on purpose, that is, appropriate disposition. Further, where the deceased had chosen the manner of his post mortem disposition, a Court has respected that choice, that is, the personal autonomy of the now deceased individual, even in the presence of opposition by next of kin, relevant to cadaveric and organ donation in Canada. However, other countries including America have followed a different path in determining the control of next of kin to a body.

Case Law - America

American law has recognized a "'quasi-property right"[212] in a cadaver. What this property right actually entails has not been clearly defined, the cases turning on respective state statute and the presented facts.[213] The nature of this property right is equally nebulous amongst scholars. Nwabueze suggests that "quasi-property" is "… a legal fiction …", where any property right is instead merely the responsibility of the next to kin to appropriately dispose of the body.[214] Pawlowski argues that it does not reflect an absolute proprietary interest, but one in which the

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[209] *Supra* note 204 at ¶ 46.

[210] *Ibid*.

[211] In this scenario, the Court's reasoning may have followed that of the Supreme Court of Canada's decision concerning the expectation of privacy in genetic material, as in *R v Dyment*, for example.

[212] Pawlowski, *supra* note 164 at 36.

[213] Conran, *supra* note 152.

[214] Remigius N Nwabueze, "Biotechnology and the New Property Regime in Human Bodies and Body Parts" (2002) 24 Loyola of Los Angeles International and Comparative Law Review 19 at 31.

"possessor of the body … holds it in "trust" for family and friends who have an interest in its disposition."[215]

What does appear to be a common thread in the American cases, however, is the Court's consideration of the purpose of controlling the body by the parties. For example, in *Brotherton v Cleveland*,[216] the Court found that common law granted not only a possessory right to the body, but also a claim for disturbance of the body. Further, the Ohio *Uniform Anatomical Gift Act* granted the plaintiff the right to disposal of the body.[217]

In *Whaley v County of Tuscola,*[218] , the Court gave the "… next of kin … a constitutionally protected "property right" which, if infringed, may give rise to a civil claim in damages."[219] In elucidating this right, the court held that "… the next of kin had a right to possession of a body for burial and to prevent its mutilation."[220] Brown J explained the court's definition of the nature of the right to a dead body:

> Regardless of the legal label the State places on the rights in a dead body it chooses to create, these rights nevertheless exist. Moreover, they closely correspond with the "bundle of rights" by which property has been traditionally defined. For this reason alone, we conclude that Michigan, like Ohio, provides the next of kin with a legitimate claim of entitlement and thus a property interest in a dead relative's body, including the eyes.[221]

More recently in California, the United States Court of Appeals 9th District affirmed the right of next of kin of having a property interest in a body,[222] "… the deprivation of which must be

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[215] Pawlowski, *supra* note 164 at 37.

[216] *Brotherton v Cleveland*, 923 F 2d. 477 (6th Cir. 1991). The Court found that the plaintiff, the deceased's wife, and the administrator of the deceased's estate, had a "legitimate claim of entitlement" to his body, including the corneas removed by the coroner, and that the entitlement was "protected by the due process clause of the 14th Amendment." The coroner had removed the corneas as permitted by statute. The plaintiff however, had declined organ donation, a fact included in the deceased's hospital chart. The Coroner's office was not informed of this fact, having not read the medical record, and did not ask the deceased's widow.

[217] *Ibid.*

[218] *Whaley v County of Tuscola*, United States Court of Appeals, 6th circuit, no. 94-1451, 1995. The facts, like *Brotherton*, concerned the removal of the eyes of the plaintiff while under the control of the medical examiner.

[219] Pawlowski, *supra* note 164 at 37.

[220] *Supra* note 218.

[221] *Ibid* at II. The Court here included the next of kin's rights to disposition to include the eyes, relevant in the context of organ retention: see discussion of organ retention below at 74.

[222] *Newman v Sathyavaglswaran*, No. 00-55504 (9th Cir. 2002). The issue before the Court, as in *Brotherton* and *Whaley* was the retention without notification or authorization by next of kin of corneas.

accorded due process of law under the Fourteenth Amendment of the United States Constitution."[223]

Further, in *Hainey v Parrott*,[224] Beckwith J analogized the release of the body by the coroner to "a return of property in the coroner's custody to its rightful owner" in finding a "cognizable property interest in a body."[225]

Thus, in America jurisprudence, next of kin have been conferred a property interest in a body[226] as compared to Canadian Courts, the latter more in keeping with a temporary responsibility to ensure appropriate disposition of the body, akin to a trust.[227] In practice, the effect of this "quasi-property" right in the context of forensic autopsies is that some jurisdictions in the United States do have to notify the next of kin that an autopsy will be performed,[228] although this notification is, however, not a request for authorization , i.e. consent from next of kin. This responsibility to notify, but not obtain consent from next of kin also arises in the context of organ retention in Canada.[229]

Case Law - Europe

A recent case heard in the European Court of Human Rights raises several relevant issues concerning the control of a body by next of kin in relation to subsequent use of recovered tissue in the course of a death investigation. In *Elberte v. Latvia*,[230] the European Court of Human

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[223] *Ibid* at 1.

[224] *Hainey v Parrott,* US District court southern district of Ohio, Western div, No. 1: 02-CV-733, 2005 U.S. Dist. LEXIS 44837. This class action claim concerned the retention of organs for diagnostic purposes by the coroner, without the knowledge of the plaintiffs. The coroner's office did not inform the plaintiffs that the organs could be recovered by them for disposal after the forensic examination was complete. The organs were subsequently disposed of by the coroner, without the knowledge or authorization of the plaintiffs.

[225] *Ibid.*

[226] In Canada, the Court in *Piljak Estate v Abraham*, 2014 ONSC 2893 found a property interest in tissue.

[227] See discussion of the appropriate disposal of a body at 33.

[228] *Supra* note 152 at "Authorization for Forensic Autopsy."

[229] See below at 74.

[230] *Elberte v Latvia*, European Court of Human Rights, January 13, 2015, Application no. 61243/08, Final 13/04/2015. The plaintiff claimed mental suffering and interference with her right to a private life under Article 8, s. 2 of the *Convention for the Protection of Human Rights and Fundamental Freedoms***.** The claim arose from the plaintiff's discovery, two years after a forensic autopsy performed on her husband, that tissue had been collected without her consent, and had been retained for the purpose of transfer (for which the forensic department was paid) to a German pharmaceutical biotechnology company for scientific research, where the tissue was subsequently used in bio-implants (it is unclear if the tissue's use included genetic research). The forensic department had a contract with the company for this purpose, resulting in a systematic transfer of tissue from many individual cadavers, under

Rights found that a widow's right to respect for her private life guaranteed in Article 8, section 2 of the *European Convention on Human Rights*[231] (analogous to the Canadian *Charter* section 7[232]) had been violated.[233] The Court, relying on the *Convention on Human Rights and Biomedicine* and *the Additional Protocol*, concluded that the documents were applicable to both the living and the dead:

> The object of these treaties is to protect the dignity, identity and integrity of "everyone who has been born, whether now living or dead… respect for human dignity forms the very essence of the Convention; treatment is considered 'degrading' within the meaning of Article 3 of the Convention when, *inter alia*, it humiliates an individual, showing a lack of respect for human dignity. The applicant's suffering was caused not only by the breach of her rights as the closest relative and the ensuing uncertainty about what had been done in the Forensic Centre, but was also due to the intrusive nature of the acts carried out on her deceased husband's body and the anguish she suffered in that regard as his closest relative.[234]

Elberte illustrates post mortem interest may lie with a decedent's closest legal relative.[235] However, in Canada, next of kin may not have a legal interest in a body. For example, an executor, or a provincial government (in cases of unclaimed and unidentified bodies), may have

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the State-approved legal authority of a presumed consent model. The Court concluded that Articles 3 and 8 of the *European Convention on Human Rights* had been violated. (at ¶ 155).

[231] Article 8 of the *European Convention for the Protection of Human Rights and Fundamental Freedoms*, as amended by Protocols Nos. 11 an 14, supplemented by Protocols Nos. 1,4,6,7,12, and 13, Entry into force 3 September 1953, Council of Europe, states in section 1 that "Everyone has the right to respect for his private and family life, his home, and his correspondence", and in section 2, "There shall be no interference by a public authority with the exercise of this right except such as in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others." Article 3 states that "No one shall be subjected to torture or to inhuman or degrading treatment or punishment."

[232] *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, s 7.

[233] *Supra* note 230 at ¶ 117. At ¶ 107, the Court held that "… there had been an interference with the applicant's right to respect for her private life under Article 8 of the Convention." Here, the circumstances on which the Court relied were that the applicant (the decedent's widow, described by the Court as "… one of his closest relatives..." (at ¶ 105)), was not aware that the decedent's tissues collected at a forensic autopsy were sent out of country for use in bio-implants (at ¶ 105). Therefore, the applicant did not have the opportunity to consent to or refuse to the use of the decedent's tissue for this purpose (at ¶ 105). The Court held "… that the interference with the applicant's right to respect for her private life was not in accordance with the law…" (at ¶ 117).

[234] *Supra* note 230 at ¶ 142.

[235] In Canada, see also *Edmonds*, *supra* note 181, for example.

legislated control of a body, limited by purpose of control. Further, this authority may extend to consent to cadaveric genetic research, to be discussed below.

Controlling One's Own Body after Death

Executors and Control of a Body

A long-standing legal means of fulfilling the obligations to the dead is the execution of wills.[236] The executor (who may be neither the deceased's legal or genetic next of kin) is "…the postmortem manifestation of the antemortem person, … obliged to carry out the will of the person."[237] The executor is acting as an administrator of the estate,[238] following the directions documented by the individual when alive. Unlike a trust,[239] the directions in the will are simply to be followed, without any necessary interpretation to ensure that the best interests of the testator are being met. The testator no longer has any claim to the property owned in life. He may, however, determine the disposition of his body after death in a will. In effect, the will is a means by which the personal autonomy of the decedent is respected by society,[240] analogous to the personal autonomy of a cadaveric donor.[241]

In England, the right and duty to dispose of human remains belongs to the executor of the deceased's estate, rather than the next of kin. However, this is not the case in the United States, where, because the body is not considered property included as part of the probate estate, is not subject to administration by the executor. Instead, the right to a body in the United States rests with the decedent's next of kin - the person or persons most closely related to a decedent by

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[236] *Probate Act*, RSPEI 1988, c P-21; *Succession Law Reform Act*, RSO 1990, c S.26; *The Wills Act*, CCSM c W150; *The Wills Act*, 1996, SS 1996, c W-14.1; *Wills Act*, RSNB 1973, c W-9; *Wills Act*, RSNL 1990, c W-10; *Wills Act*, RSNS 1989, c 505; *Wills Act*, RSNWT 1988, c W-5; *Wills Act*, RSY 2002, c 230; *Wills and Succession Act*, SA 2010, c W-12.2; *Wills, Estates and Succession Act*, SBC 2009, c 13.

[237] Cordner, *supra* note 151 at 307.

[238] Daphne A. Dukelow, ed, *The Dictionary of Canadian Law,* 3d ed (Scarborough, ON: Thomson Carswell, 2004) *sub verbo* "executor"

[239] *Ibid sub verbo* "trust": "A trust arises… whenever a person is compelled in equity to hold property over which he has control for the benefit of others (the beneficiaries) in such a way that the benefit of the property accrues not to the trustee, but to the beneficiaries."

[240] Ernest Partridge, "Posthumous Interests and Posthumous Respect" (1981) 91 Ethics 243.

[241] See below at 68.

blood or affinity,[242] the likely basis of the American common law quasi-property right to a body granted to the decedent's next of kin.

In Canada, the English model is generally followed.[243] In effect, if the deceased's next of kin is not the executor of his estate, he will not have control of the body for the purpose of disposition. The executor will also retain the right after burial, to avoid the opportunity for disinterment in the case of a conflict between the executor and the next of kin.[244] In Canada, a court has limited an executor's control of a body only for the purpose of disposition. [245] Further, in British Columbia and Québec, the executor is statutorily bound by the wishes of the deceased, including disposition preferences.[246] However, the Québec legislation subordinates an executor to legal next of kin regarding the disposition process, where, "[i]n the absence of wishes expressed by the deceased, the wishes of the heirs or successors prevail."[247] This may not be the case elsewhere in Canada. For example, in *Waldeman v. Melville (City)*,[248] the Court affirmed *Miner*, finding the right of an executor overrides any right of the next of kin, and "… continues after the burial of the body."[249] The Court also held that the executor is not legally bound to follow the wishes expressed by the deceased.[250]

Although legal next of kin or an executor may have a right to a body for disposition, one may control the use of one's body after death by choosing (or not) to donate one's body for the purpose of research prior to disposition by means of a post mortem directive.

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[242] Bremenstul, *supra* note 164 at 223.

[243] See, for example, *Sopinka (Litigation guardian of) v. Sopinka*, 2001 CanLII 27996 (ON SC) at ¶ 31 (LexisNexis).

[244] Kimberly A Whaley & Dina Stigas, "The Body, Ashes & Exhumation – Who has the Last Word?" (6 April 2009), Whaley Estate Litigation, online: http://whaleyestatelitigation.com/resources/WEL_BodyAshesExhumation.pdf at 6, citing *Waldman v Melville*.

[245] *Hunter, supra* note 7 at ¶ 47.

[246] *Supra* note 244, citing the British Columbia *Cremation, Internment and Funeral Services Act*, s 6, and Article 42 of the *Civil Code of Québec*. The British Columbia *Act* absolves the executor from complying with the instructions of the deceased if the wishes are deemed "… unreasonable or impracticable or cause hardship". The deceased's request must also comply with the British Columbia *Human Tissue Gift Act* (s. 6).

[247] *Civil Code of Québec*, CQLR c C-1991, Art 42.

[248] *Waldeman v Melville (City)*, [1990] S.J. no. 13, 81 Sask. R. 141.

[249] Here, the deceased's sister wished to disinter the body. The executor, the deceased's common law partner, opposed the disinterment.

[250] The deceased had expressed to the executor his wish to be cremated. He was, however, buried after his next of kin spoke with the executor, who followed their wishes. This is not the case in British Columbia, as noted above, where there is a duty to follow the wishes of the deceased if in writing: see *Cremation, Interment and Funeral Services Act*, SBC 2004, c 35, s 6. See also *Saleh*, supra note 7.

Cadaver Donation for Research and Teaching

The International Federation of Associations of Anatomists good practice guidelines[251] state that "[t]he study of human cadavers is essential for teaching, advanced training, and research in medical and anatomical sciences."[252] In most provinces and territories,[253] legislation is in place to delineate the criteria for gifting one's body for research after death.[254]

In some provinces, directives in a will, for example, may include not only opting in, but ensuring one's body is not used in research. In British Columbia, for example, section 7 of the *Anatomy Act*[255] specifies that a will directive indicating that one's body is not to be used for research will override any other claim for the body under the *Act*.[256] Here, research refers to "anatomical research … solely for the advancement of anatomical science or instruction,"[257] although, the *Act* does not define the parameters of "anatomical research" and "anatomical science."[258] The *Human Tissue Gift Act*[259] requires witnessed written consent of an adult for the use of his body after death for " … therapeutic purposes, medical education or scientific research."[260] The wording of these statutes indicates specificity of use in the consent, that is either teaching or

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[251] International Federation of Associations of Anatomists, "Recommendations of Good Practice for the Donation and Study of Human Bodies and Tissues for Anatomical Examination", online: http://www.ifaa.net/wp-content/uploads/2017/09/IFAA-guidelines-220811.pdf.

[252] *Ibid* at 1. The policy document also indicates the necessity of obtaining informed consent from donors and maintaining the anonymity and privacy of the donor (at 1-2). Cadaveric teaching has also been shown to have greater benefits than multimedia teaching alone (see Andrew J Saltarelli, Cary J Roseth & William A Saltarelli, "Human Cadavers Vs. Multimedia Simulation: A Study of Student Learning in Anatomy" (2014) 7 Anatomical Sciences Education 331).

[253] *An Act to Facilitate Organ and Tissue Donation,* SQ 2010, c 38; *Human Organ and Tissue Donation Act*, SNS 2010, c 36; *Human Tissue Act*, RSNL 1990, c H-15; *Human Tissue Act*, RSNWT 2014, c 30; *Human Tissue Donation Act*, RSPEI 1988, c H-12.1; *Human Tissue Gift Act*, RSY 2002, c 117; *Human Tissue Gift Act,* RSBC 1996, c 211; *Human Tissue Gift Act,* SNB 2014, c 113; *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5; *The Human Tissue Gift Act*, CCSM c H-180; *The Human Tissue Gift Act,* RSS 2015, c H-15.1; *Trillium Gift of Life Network Act*, RSO 1990, c H.

[254] *Ibid.* The provincial organ and tissue donation statutes allow for donation of an intact body, organs and tissues.

[255] *Anatomy Act*, RSBC 1996, c 13, s 7.

[256] This assumes that a body in a death investigation system is identified: see discussion of unidentified bodies below at 61.

[257] *Supra* note 255, s 4(1).

[258] For example, genomics technology is being used in medical school training (Glenn S Gerhard, Barbara Payton, & Steven N Popoff, "Integrating Cadaver Exome Sequencing into a First-Year Medical Student Curriculum" (2016) 315:6 JAMA 555), creating a potential for secondary use of derived cadaveric genetic personal health information.

[259] *Human Tissue Gift Act*, RSBC 1996, c 211.

[260] *Ibid* s 4.

research or both, if authorized by the donor. This Act also specifies that a coroner acting under the *Coroner's Act*[261] is not considered to be "lawfully in possession of the body," that is, does not have authority to give consent to have the body used for scientific research,[262] affirming the limited investigatory role of the coroner in this jurisdiction,[263] and indicating statutory authority to decide the use, if any, of one's body after death.

Donation by next of kin if no in vivos directive

In Canada, if no directive is made while alive for the use of one's body for post mortem research, the responsibility for consent then falls to the deceased's legal next of kin.[264] Absent direction to opt out of research in a will or advance directive, a body may be donated by the person who has control of the body for the purpose of its disposition.[265] Depending on the province, the specified use of the body after donation may vary. For example, in British Columbia, a body may be moved "… for the purpose of research or teaching… at a department of a university or college."[266] The same province's *Human Tissue Gift Act* grants the legal next of kin the authority to give consent to the donation of the body " … for therapeutic purposes, medical education or scientific research."[267] An exception is included to the consent of the next of kin which is important in the context of this paper: "…[a] person must not give a consent under this section if the person has reason to believe that the person who died … would have objected to

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[261] *Coroners Act*, SBC 2007, c 15.

[262] *Supra* note 259, s 5(5)(a).

[263] Other death investigation and provincial human tissue legislation do not explicitly refer to a medical examiner or coroner`s authority to authorize research on a body.

[264] *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 12(1)(b); *Human Tissue Act*, RSNL 1990, c H-15, s 7(1); *Human Tissue Act*, RSNWT 2014, c 30, s 4(2); *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 5(2); *Human Tissue Gift Act*, RSY 2002, c 117, s 5(1); *Human Tissue Gift Act,* RSBC 1996, c 211, s 5(1); *Human Tissue Gift Act,* SNB 2014, c 113, s 5(1); *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, s 4(2); *The Human Tissue Gift Act*, CCSM c H-180, s 1; *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 10(1); *Trillium Gift of Life Network Act*, RSO 1990, c H, s 5. In Québec, *An Act to Facilitate Organ and Tissue Donation,* SQ 2010, c 38 requires an individual to indicate their wishes in writing concerning organ donation, when registering for or renewing their health card. This statutory directive may have application elsewhere in Canada, in the context of genetic research on forensically obtained genetic information (see below at 113).

[265] *Ibid.*

[266] *Cremation, Interment and Funeral Services Act*, SBC 2004, c 35, s 19(1)(b)(ii).

[267] *Human Tissue Gift Act,* RSBC 1996, c 211, s 5(1).

it."[268] Similar legislated limitations in other jurisdictions are placed on the person or persons in control of the cadaver.[269]

The Northwest Territories human tissue donation legislation further grants objection on the grounds of objection by the "same class as the person" as the donor.[270] In effect, this section of the *Act* could be interpreted to allow for religious and cultural objection by a group. Unlike the objection clauses of next of kin, however, where there is an assumption in the statute that the next of kin consenter had specific knowledge of the donor's choice to donate or not donate after death, reflecting respect for the deceased's personal autonomy, the expansion to include objection by "the same class as the person" undermines the personal autonomy of the individual donor, and the individualistic nature of dignity owed the cadaver by the legal next of kin.[271] Except for the Northwest Territories statute, the general limitation in control of the body is, however, a two-edged sword. On one hand, the acknowledgment by the next of kin of the deceased's objection to the use of his body for research after death reflects the words of Phillips J in *R. v. Pearce,*[272] that is, the spirit of the legislation relating to the donation of a body for research is to respect the right to choose while alive what happens to one's body when dead. However, absent documented direction, how does one prove that the objection to the use of a body for research after death reflects the choice of the deceased, and not the decision of the legal next of kin? The practical effect is that, even if a written ante mortem directive by the deceased is created, the legal next of kin may object to post mortem research and may invoke their knowledge of subsequent objection by the deceased as justification for their own intention that the body not be donated for research. Thus, absent proof beyond hearsay, the living legal next of

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[268] *Ibid*, s 5(2).

[269] Alberta's *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5,s 4(3)(c); *The Human Tissue Gift Act*, CCSM c H-180, s 3(5)(a), which includes not only objection, but if donation would be "contrary to religious beliefs of the deceased person"; see also *Trillium Gift of Life Network Act*, RSO 1990, c H, s 5(3); *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 5(5)(c); *Human Tissue Gift Act,* SNB 2014, c 113, HTGA s 5(2); *Human Tissue Act*, RSNL 1990, c H-15, s 7(2), *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 10(3); *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 12(6); *Human Tissue Gift Act*, RSY 2002, c 117, s 5(2); *Human Tissue Act*, RSNWT 2014, c 30, s 5(4)(c).

[270] *Human Tissue Act*, RSNWT 2014, c 30, s 5(4)(d) which states: "A person may not consent under this section … if he or she has reason to believe that a person in the same class as the person giving the consent would object to the consent."

[271] However, this section may be in reference to First Nations in Canada, specifically to aboriginal title, for example, a discussion of which is beyond the scope of this paper. However, the unique legal status of First Nations may be relevant to genetic research in Canada): see, for example, *Havasupai*, *supra* note 100.

[272] *R v Pearce*, 2014, O. J. No. 1686.

kin may in practice trump the deceased's choice for use of his body after death, undermining the autonomy of the individual when alive, an issue that also occurs in the context of organ donation.[273] In short, donor autonomy may potentially be undermined by the living next of kin, inconsistent with statutory protection of a decedent's personal autonomy while alive.[274] This raises the question of whether a cadaver may have inherent rights after death.

The above discussion illustrates that that there are limits at law in the control of a cadaver, both for the death investigator, whose control is for the purpose of determining cause and manner of death, and the body's legal next of kin, whose control is predicated on final disposition of the body. However, some academic authors have adopted the term 'rights *of* a body'. If a cadaver itself has rights, but by nature of being dead cannot consent to the use of its organs and tissues in genetic research, this suggests that cadaveric tissue cannot be used in research absent antemortem donation. However, as will be discussed below, the term "rights of a body" is misleading.

Control as a Right *of* a Body

Canadian Courts seem to have found that any inherent rights *of* a body in fact reflect the relationship that the deceased individual had and continues to have post-mortem with the living. In this context, rights are, in practice, obligations by the living to the deceased.
The Court's statement regarding the treatment of the body as a reflection of the value society places on life in *R v Pearce*,[275] for example, raises the question of whether the body itself has any "rights" comparable to those of living humans. Baglow has argued that the dead body does have rights arising from "…[o]ur obligation to the corpse … to see it safely on its way, while, as is the case with other considerations of rights, weighing its rights in bodily integrity, dignity, and respect against conflicting rights of society, and effecting the best possible balance."[276] The author further notes "… the family, in claiming the corpse of a family member, is actually

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[273] See Maeghan Toews & Timothy Caulfield, "Evaluating the 'Family Veto' of Consent for Organ Donation" (2016) 188 CMAJ 17.

[274] *Supra* note 25.

[275] *Supra* note 272.

[276] John Sutton Baglow, "The Rights of the Corpse" (2007) 12:3 Mortality 223 at 235.

carrying out an obligation to that corpse, rather than asserting rights or "ownership" over it."[277] Thus the rights of a cadaver according to Baglow are "… rights to proper disposal, to dignity, …[and]… to bodily integrity."[278]

In response to Baglow, Taylor and Spital[279] argued that the dead do not have rights, only the living:[280] "… If rights are generated by obligations concerning the treatment of corpses, it is the surviving relatives and friends, not the corpses, who hold those rights,"[281] a view that reflects the court's interpretation in *R. v Pearce.*[282]

Smolensky however, suggests that the dead do have certain inherent rights.[283] Invoking the Interest Theory, [284] the author illustrates the limits of post-mortem rights, based on the principles of "…impossibility, the right's importance, time limits,[285] and conflicts of interest between the living and the dead."[286] Smolensky argues that "…[w]hat drives many posthumous rights is not only the recognition that some interests survive death, but also a desire to respect decedents' wishes."[287] However, this theory effectively supports respect for the autonomy of the individual while alive, rather than a right of the body when dead.[288] Further, Harris considers that neither the interest theory[289] nor the choice theory[290] of rights can be applied after death.[291]

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[277] *Ibid* at 236.
[278] *Ibid.*
[279] James Stacey Taylor & Aaron Spital, "Corpses Do Not Have Rights: A Response to Baglow" (2008) 13:3 Mortality 282.
[280] *Ibid* at 282.
[281] *Ibid* at 285.
[282] *Supra* note 272.
[283] Kirsten Rabe Smolensky, "Rights of the Dead" (2009) 37:7 Hofstra L Rev 763 at 764.
[284] *Ibid.* Smolensky argues that laws protecting interests such as reputation or medical information confidentiality after death give the dead "…de facto legal rights that can be enforced against the living."
[285] *Supra* note 283 at 789. The author argues that the deceased's ties to the living decrease with time. This is reflected in Canadian legislated privacy protection of the dead: see below at 93.
[286] *Supra* note 283 at 765.
[287] *Ibid* at 771.
[288] Hilary Young, "The Right to Posthumous Bodily Integrity and Implications of Whose Right It Is" (2013) 14:2 Marquette Elder's Advisor 197. Young's considers post-mortem critical interests (at 212), where the author argues in favour of respect for an autonomous decision made in life concerning one's post mortem body. Young concludes (at 214) that "… the claim that living individuals have an interest in what happens to their corpses rests not on interests that survive death, but rather on the benefit to them of knowing, while they are alive, that their wishes will be respected."
[289] John Harris, "Law and Regulation of Retained Organs: The Ethical Issues" (2002) 22:4 Legal Studies 527 at 534. Harris defines choice theory as "… rights as securing 'the protection and promotion of autonomy or liberty'.
[290] *Ibid.* Harris defines interest theory of rights as "… serving to further individual wellbeing or welfare."
[291] *Ibid.*

A view that a body has no posthumous rights is also shared by Partridge,[292] who, in using wills as an example, suggests a basis for his argument in social contract theory, where "… the violation of such contracts, when widespread, can make a profound difference to the living, and to those who follow."[293]

Levenbook views posthumous interests in reference to harm,[294] arguing that "… once the moment of death occurs, there is no subject who can be harmed. Indeed, …[]… the subject who is harmed is the living-person-who-was."[295] In effect, the posthumous harm reflects disrespect for the personal autonomy of the individual while alive. In practical terms, this "postmortem interest" is the legislated protection of post-mortem privacy, of importance in relation to risk associated with genetic research.[296]

Tomasini considers death as a relational change which "gives rise to harms done to the surviving relatives and their *beliefs and experiences* about how their loved ones should be treated."[297] Fisher's view of inherent rights of a body is also based on both posthumous harm and benefit in the context of relationships between the dead and the living.[298] The author concludes that "[w]hen the interests of the dead are promoted, not only is the ongoing connection between the living and the dead respected, but also the dead are benefited."[299] In applying this concept pragmatically to cadaveric genetic research, genetic personal health information statutory privacy protection safeguards not only the genetic privacy of the cadaver, but also that of his genetic next of kin.

Case Law

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[292] Ernest Partridge, "Posthumous Interests and Posthumous Respect" (1981) 91 Ethics 243.
[293] *Ibid* at 260.
[294] Barbara Baum Levenbook, "Harming Someone After His Death" (1984) 94:3 Ethics 407.
[295] Barbara Baum Levenbook, "Harming the Dead, Once Again" (1985) 96:1 Ethics 162 at 162.
[296] See below at 93.
[297] F Tomasini, "Research on the Recently Dead: An Historical and Ethical Examination" (2008) 85 British Medical Bulletin 7 at 13.
[298] Josie Fisher, "Harming and Benefiting the Dead" (2001) 25 Death Studies 557 at 567.
[299] *Ibid* at 568.

In Canada, it has been held that the dead do not have rights protected by the *Charter.*[300] Although Cameron J in *Nowakowski* held that despite the lack of consent from the decedent's executor or next of kin in obtaining the post mortem samples,[301] the deceased had no "…privacy interest beyond that of dignity and respect which our society accords any human body…" in the requested autopsy and toxicology results,[302] it is possible that a request for blood or tissue samples, or genetic data may have led to a different ruling.[303] The Court noted that "…[a]bsent the consent of the deceased or his next of kin, it would require a coroner's warrant or a warrant of a Justice of the Peace to obtain and analyze body fluids of a deceased."[304]

Control of a Body in Canada - Summary

Canadian case law concerning the disposition of a body is grounded in the control of a body, relating to ensuring the dignity of the body[305] until disposition, and in some circumstances, extending the control to continue after disposition. The above review suggests that, in general, a cadaver is owed dignity until its final disposition, and arguably thereafter until it no longer exists.[306] Both legislation and case law in Canada frequently refer to the 'dignity of a body', that is, respect for the dignity of a cadaver. The question then is raised as to what does "dignity" in the context of a cadaver mean? The following discussion will consider the relationship between dignity, autonomy and privacy in order to explain the basis of dignity's role in the requirement for consent for cadaveric genetic research in death investigation systems.

Dignity and the Body

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[300] *Nowakowski v Mroczkowski Estate*, 2003 CanLII 47378 (ON SC), mid trial ruling, January 2003 at ¶ 24. In a mid-trial ruling, the Court held that the coroner's case file including toxicology results from an autopsy performed on the defendant, the driver of a vehicle alleged to have injured the plaintiff, were admissible as evidence at the civil trial.

[301] *Ibid* at ¶ 22. The samples had been collected under the authority of Ontario Coroner's Act (at ¶ 6).

[302] *Ibid* at ¶ 23. The results in question did not include genetic material or data.

[303] See for example *Dyment, supra* note 13.

[304] *Supra* note 300 at ¶ 23.

[305] Walter F Kuzenski, "Property in Dead Bodies" (1924) 9 Marq L Rev 17 at 22.

[306] *Supra* note 176.

In considering the dignity owed a cadaver, it first must be stated that "dignity" as a general concept in the academic literature and in jurisprudence is nebulous and complex.[307] For the purpose of this paper, the intrinsic worth[308] of the human cadaver, including the individual's genetic data, is a practical interpretation of the concept of dignity. Foster argues, however, that it may be that the "… ubiquity [of dignity] means that the law will have to work with it,"[309] as Courts have done in Canada. In practice, however, the meaning of 'dignity' will likely vary with its judicial application.[310] In the context of this paper, dignity, specifically of one's body, does not end with death.[311]

The *Criminal Code of Canada* offers a baseline parameter of what is deemed an "indignity to a dead human body."[312] A recent case in Ontario that arose from a charge under s. 182(b) of the *Criminal Code*[313] offers an interpretation of this concept. In *R. v. Pearce*,[314] the defendants struck and killed a skateboarder while driving a pick-up truck, and subsequently disposed of the victim by the side of the road after discovering the body in the bed of the truck. Phillips J, noting "… the

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[307] Russell Brown, "Rethinking Privacy: Exclusivity, Private Relation and Tort Law" (2006) 43 Alta L Rev 589 at ¶ 51. Foster considers dignity and autonomy as distinct but related concepts: see Charles Foster, "Dignity and the Ownership and Use of Body Parts" (2014) 23 Cambridge Quarterly of Healthcare Ethics 417 at 67-68. Arguments against the use of "dignity" in bioethics have also been made, suggesting that dignity is effectively autonomy: see, for example, Alasdair Cochrane, "Undignified Bioethics" (2010) 24:5 Bioethics 234; , Timothy Caulfield & Roger Brownsword, "Human Dignity: A Guide to Policy Making in the Biotechnology Era?" (2005) 7 Nature Reviews Genetics 72; Ruth Macklin, "Dignity is a Useless Concept" (2003) 237 BMJ 1419.

[308] Lawrence Burns, "Gunther von Hagens' BODY WORLDS: Selling Beautiful Education" (2007) 7:4 The American J of Bioethics 12 at 17, citing Kant. The author at 18 notes that "… it makes good sense to attribute dignity to the dead, recognizing that doing so protects our own dignity while living and sets valuable boundaries on the uses to which we put 'human resources'."

[309] Foster, *supra* note 307 at 417.

[310] Charles Camosy, "No View from Nowhere: The Challenge of Grounding Dignity without Theology" (2015) 41:12 BMJ 938 at 938, citing Foster.

[311] *R v Ladue*, 1965 CarswellYukon 2, [1965] 4 C.C.C. 264, 45 C.R. 287. The defendant was found guilty at trial of having sexual intercourse with a body, and on appeal, he argued that he did not know the woman was dead. The Court inferred that an indignity to a body may occur both in life and death.

[312] *Supra* note 10.

313 *Criminal Code*, RSC 1985, c C-46, s 182 states: "Every one who (*a*) neglects, without lawful excuse, to perform any duty that is imposed on him by law or that he undertakes with reference to the burial of a dead human body or human remains, or(*b*) improperly or indecently interferes with or offers any indignity to a dead human body or human remains, whether buried or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding five years." Unlike in Canada, legal relief in America for 'indignity to a body' lies in tort law: Remigius N Nwabueze, "Biotechnology and the New Property Regime in Human Bodies and Body Parts" (2002) 24 Loyola of Los Angeles International and Comparative Law Review 19, citing section 868 of the American Restatement of Law, 2d, Torts. Here, the tortfeasor is "… subject to liability to a member of the family of the deceased who is entitled to the disposition of the body." Of note, section 868 is not a statute and is not binding on courts. (Nwabueze at 35).

[314] *Supra* note 272.

lack of sensitivity to the victim's body…" by the defendants, held that the "offensive" nature of their actions reflected society's relationship with the dead: "… to a large degree the way we treat the dead demonstrates the value we place upon life… It is also true that mistreatment of someone's remains is an affront to their surviving loved ones."[315] Thus, dignity in life is expected to continue in death, specifically by ensuring the dignity of the cadaver. Maintaining this dignity from life to death results in respect for the living, including both the next of kin and society.

Further, in *R. v N.A.*,[316] the court acknowledged the significance of the indignity inflicted on the body by the accused to society. The significance of an indignity to a body to "… the community in general…"[317] was also stated by Rideout J in *R. v. Murray* in finding the accused guilty of the charge: "Society has required that human remains be treated with dignity. Parliament has mandated that if a person fails in this requirement, that person should be criminally penalized for the indignity which has been occasioned to the remains."[318]

Although these cases have resulted in the finding that an indignity to a body has occurred, Courts have not established a legal test in reaching this conclusion, resulting in no legal definition of the term. Rideout J specifically addressed the issue, and, reflecting on the contextual nature of section 182(b) of the *Criminal Code,*[319] stated:

> It is not my intention to establish a test to determine what is an indignity. As well, what may constitute an indignity today, may not tomorrow, as practices change. However, I believe we can take a page out of the determination of obscenity by saying, while I have great difficulty in describing what constitutes an indignity to dead human body or human remains, I know it when I see it.[320]

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[315] *Ibid* at ¶ 23. In *R v Houle*, [2013] A.J. No. 889, 2013 ABQB 70, the Court made a similar interpretation of s. 182(b), where the accused had dismembered a body in order to expedite disposal of the remains. Manderscheid J, at ¶ 29, in reference to the dismemberment, stated: "That show of disrespect for his now dead companion is matched by a total disrespect and disregard for the emotions of the family and friends who must mourn the loss of …[the deceased]", indicating that the indignity to the body impacted not only next of kin, but friends of the deceased.

[316] *R v N.A.*, [2013] O.J. No. 1655, 2013 ONCJ 184. On finding her one-month old child not breathing, the accused put the body in a dumpster, and at trial was found guilty, including the charge under s 182(b) of the *Criminal Code.* Bourque J at ¶ 9, in sentencing, and on reviewing case law concerning section 182(b) in connection with a homicide, stated: "All of these cases speak to the moral repugnance that society feels towards these indignities to human remains…".

[317] *R v Murray*, [2007] N.B.J. No. 222, 322 N.B.R. (2d) 177 at ¶ 30.

[318] *Ibid* at ¶ 32. The accused, who owned a funeral home business, was not licensed as a funeral director or embalmer, and stored bodies on his premises for extended periods when the families believed the bodies had been either buried or cremated.

[319] *Supra* note 10.

[320] *Supra* note 317 at ¶ 29.

It may be assumed, however, that if an indignity to a body is a criminal offence in Canada, then society expects a cadaver will be treated with dignity through to its final disposition, including use in research.

Dignity – Based Appropriate Disposition of a Body in Canada

Canadian jurisprudence referencing dignity to a body in relation to what is deemed appropriate body disposition generally considers the concept in reference to specific procedures.[321] For example, in Ontario, burial and cremation are legally deemed to be dignified methods of disposition.[322] In *Abeziz*, Farley J stated that "[t]he fundamental obligation is that the body be appropriately dealt with – that is disposed of in a dignified fashion. Burial and cremation come to mind as being specifically sanctioned in Ontario."[323]

Although burial and cremation are common and easily available methods of body disposition in Canada, other cultural and religious tenets relating to a dignified disposition of a body exist which hold that burial and cremation may not be deemed dignified in some cultures within Canada's diverse society. Christians who bury their dead may see the sky burials of the Zoroastrians and Tibetans,[324] or the death rituals of the Indonesian Torajans[325] as inappropriate and disrespectful to the body, and vice versa.

Equally, the condition of the body at the time of disposal is important to the concept of post mortem dignity, relevant to forensic autopsy procedures performed prior to final disposition. For example, violation of the body is discouraged in the Jewish[326] and Muslim[327] faiths, and in Native American cultures.[328] However, clear legal obligations may trump religious beliefs of

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[321] An exception being *Pearce, supra* note 272. See also for example, *Saleh, supra* note 7.
[322] Whaley, supra note 244 at 7, citing *Abeziz v Harris Estate* [1992] OJ LEXIS 1271.
[323] *Abeziz v Harris Estate* [1992] OJ LEXIS 1271 at 7.
[324] William W McCorkle, Jr., *Ritualizing the Disposal of the Deceased: From Corpse to Concept* (New York: Peter Lang Publishing Inc., 2010) at 14.
[325] Amanda Bennett, "Where Death Doesn't Mean Goodbye" (April 2016) *National Geographic* 53.
[326] *Supra* note 161 at 253; Burton*, supra* note 152.
[327] *Supra* note 152.
[328] Megan L Townsley, "Is There Any Body Out There? A Call for a New Body of Law to Protect Individual Ownership Interests in Tissue Samples Used in Medical Research" (2015) 54 Washburn L J 683 at 715.

family members with no legal control of the body.[329] The contextual and relational[330] nature of dignity reflects these variables, including individual beliefs and philosophy, as is illustrated in the fact based approach of Canadian Courts to body disposition, discussed above. This suggests that an application of legal principle in relation to a dignified means of disposal of a body would likely reflect not only the legal next of kin, but variation in Canadian societal norms.

Concepts of Dignity and the Cadaver

Canadian case law and legislation address the dignity of the body in reference to disposition in binary terms, that is, either there is dignity or there is not. The concept of dignity in the literature has been interpreted in a broader context, allowing for an examination of the underlying basis of the concept of post-mortem dignity.

Bates, in reference to the BodyWorlds[331] exhibit, which entails public viewing of dissected human cadavers, notes:

> The critics [of the exhibit] focus on dignity rather than rights – an approach that leaves room for recognizing obligations to things that cannot hold rights, like cadavers, Yorkies, van Goghs, and sequoias. Our rights die with us; our dignity lives on. Still, what society owes the dead is often analyzed by comparison to what it owes the living.[332]

In short, dignity unlike *Charter* protected rights, transcends death.[333] Badcott considers why this may be so:

> Failure to treat human remains with respect and dignity reflects badly on society. Not because the dead are harmed, but because such behavior betrays the trust that most

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[329] *Saleh,* supra note 7.

[330] The use of the word 'relational' refers to the relationship of the deceased with the living: see *infra* note 338.

[331] "BODY WORLDS exhibitions were conceived to educate the public about the inner workings of the human body and to show the effects of healthy and unhealthy lifestyles." Importantly, the website notes: "Body donation is and remains the ethical cornerstone of Plastination for BODY WORLDS." The website does not indicate if consent for donation was informed, that is, donation for the purpose of plastination and public display of the cadaver: Bodyworlds online: https://bodyworlds.com/.

[332] Stephen Bates, "Prenates, Postmorts, and Bell-Curve Dignity "(2008) 38:4 Hastings Center Report 21 at 22. See also David Badcott, "The Basis and Relevance of Emotional Dignity" (2003) 6 Medicine, Health Care and Philosophy 123 at 127.

[333] Burns, *supra* note 308; Thomas D Holland, "'Since I Must Please Those Below': Human Skeletal Remains Research and the Law" (2015) 41 Am J L & Med 617 at 648. The author notes that the underlying principle of legal instruments such as the *Nuremburg Code* and the *Declaration of Helsinki* are based on the principle of inherent dignity and respect.

> human beings have that their bodily remains will be treated decently, with dignity and in accordance with any declared wishes.[334]

Respect, as an acknowledgement of dignity,[335] "… is in part context dependent, and can vary, based on the intent and the objective."[336] Wicclair notes that what is deemed by society as "…respectful treatment of corpses can vary considerably from culture to culture, group to group, time period to time period, and even person to person."[337] This 'relational dignity'[338] that is, a relationship between society and the deceased, in reference to dignity owed a body, relates to the individual who the body was in life, rather than simply the physical cadaver.

Killmister's interpretation of "dignity"[339] has a neater application to cadaveric genetic research if her use of the term "self-worth" is considered in a relational context. For example, a cadaver can clearly not have its own "self-worth." However, the cadaveric "self-worth" may be considered as the value of the cadaver to the next of kin. In this way, the dignity or value of the body to the legal next of kin is reflected in their responsibility to appropriate disposal. Further, "relational dignity" refers to society's expectation that the disposition of a decedent will be done with dignity, where dignity is a duty of the living to the deceased.

These attempts at defining the concept of "dignity to a body" all reflect the contextual nature of dignity,[340] and indicate that the concept of dignity is both individualistic and relational to society.[341] In effect, dignity owed a cadaver is dependent on relationships, and for the deceased, the relationships are those that the individual had while alive. This relationship may most

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[334] Badcott, *supra* note 332 at 127.

[335] Mark R Wicclair, "Ethics and Research with Deceased Patients" (2008) 17 Cambridge Quarterly of Healthcare Ethics 87 at 89.

[336] *Ibid* at 90.

[337] *Ibid*. The role of time in relation to dignity of the deceased reflects relationships with the living: see Badcott, *supra* note 332 at 127.

[338] Zachary R Calo, "Human Dignity and Health Law: Personhood in Recent Bioethical Debates" (2012) 26 Notre Dame J Law, Ethics and Public Policy 473 at 495 refers to Habermas' understanding of human dignity in a relational sense. Specifically, "[h]uman dignity … is not a property like intelligence or blue eyes, that one might 'possess' by nature; it rather indicates the kind of 'inviolability' which comes to have a significance only in interpersonal relations of mutual respect, in the egalitarian dealings among persons."

[339] Suzy Killmister, "Dignity: Not Such a Useless Concept" (2010) 36 J Med Ethics 160.

[340] Brown, *supra* note 307 at ¶ 53.

[341] Daryl Pullman, "Death, Dignity, and Moral Nonsense" (2004) 20:3 Journal of Palliative Care 171 at 176.

broadly reflect one's place in society, that is as a human being.[342] It may also be considered on a smaller scale, that is, the individual's family. For example, ensuring the dignity of a body in genetic research has been suggested to be accomplished by obtaining the consent for research of the next of kin, which would demonstrate and acknowledge the "… feelings of surviving family members."[343]

Burns frames dignity, as have Canadian Courts,[344] in the context of relationships:

> The respect we pay to the memories of the deceased and the elaborate rituals for the disposition of the corpse signify that relationships endure long after one's death, both on a personal and collective level. Anthropological evidence helps us to see that our relationship to our ancestors plays a significant role in the formation of social bonds. As long as we are positively influenced by relationships of this kind, it makes good sense to attribute dignity to the dead, recognizing that doing so protects our own dignity while living and sets valuable boundaries on the uses to which we put "human resources."[345]

This relational view of dignity is useful in differentiating dignity from individual autonomy, as consent is grounded not only in dignity,[346] but in autonomy or self-governance.[347] Whether there is a difference between dignity and autonomy is a matter of debate in the academic literature.[348] Here, the argument is made that dignity and autonomy are related, but separate concepts, both important to the requirement for consent in cadaveric genetic research. In short, dignity in death may be argued to reflect relationships with the living, whereas autonomy of the individual lacks a relational component.[349]

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[342] Caulfield, *supra* note 307 at 75 refer to "the conventional rights-based concept of human dignity." This concept is relevant to cases of unidentified and unclaimed bodies, discussed below at 57.

[343] Wicclair, *supra* note 144 at 147. The authors state that "… concern about the feelings of surviving family members is recognized in statutes that prohibit "abuse" or "desecration" of corpses," that is, indignity to a body.

[344] In the context of appropriate disposition of a body.

[345] Burns, *supra* note 308 at 18, where "human resources" refers to cadavers.

[346] *Supra* note 17.

[347] Killmister, *supra* note 339 at 164; Picard, *supra* note 99.

[348] Caulfield, *supra* note 307.

[349] Some authors argue that autonomy may be considered in a relational context: see for example, Jean Keller, "Autonomy, Relationality, and Feminist Ethics" (1997) 12(2) Hypatia 152; Jennifer K Walter, and Lainie Friedman Ross, "Relational Autonomy: Moving Beyond the Limits of Isolated Individualism" (2014) 133 Pediatrics S16; Carolyn Ells, Matthew R Hunt & Jane Chambers-Evans, "Relational Autonomy As An Essential Component of Patient-Centred Care" (2011) 4(2) The International Journal of Feminist Approaches to Bioethics 79.

Autonomy versus Dignity

Vines describes how dignity differs from personal autonomy in legal terms, whereby "…when one is alive in law the concept of personal autonomy rather than property has the major role of protecting human dignity, so one sues in trespass to the person (a dignitary tort) for damage to the living body rather than in conversion (a proprietary tort).[350]

Burns, in discussing the complex nature of defining and assigning dignity to a cadaver,[351] suggests that dignity and personal autonomy are not synonymous, whereby dignity outlasts personal autonomy in death.[352]

In differentiating autonomy and dignity, Harris argues that "… the dead cannot be autonomous, and so cannot have their autonomy violated. Equally, the dead cannot have their bodily integrity violated, for violation consists not simply in a breach of bodily integrity, but in a breach of bodily integrity that is not consented to."[353] However, if the autonomy in question in the context of this paper is the autonomy of the person while alive,[354] grounding their right to determine the use of their body after death, Harris's argument is consistent. That is, it is not the autonomy of a cadaver grounding the need for consent in genetic research, but the autonomy of the individual when alive to decide the use of his body after death.

Tanassi differentiates personal autonomy and dignity using the principle of voluntary informed consent.[355] The author argues that the public exhibition of cadavers, for example, may be deemed dignified if the donors of the bodies had consented to this use,[356] where, "… one may allow this

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[350] *Supra* note 161 at 237.
[351] *Supra* note 308.
[352] *Ibid* at 18. The author argues that "relational dignity", that is, society's respectful relationship with the deceased, "… protects our own dignity while living and sets valuable boundaries on the uses to which we put "human resources"".
[353] John Harris, "Law and Regulation of Retained Organs: The Ethical Issues" (2002) 22:4 Legal Studies 527 at 531-532.
[354] *Supra* note 288 at 231-232. Young considers that not respecting the autonomy of the individual while alive is "harm to a critical interest." The author refers to post mortem rights as interest based (at 208).
[355] Lucia M Tanassi, "Responsibility and Provenance of Human Remains" (2007) 7:4 The American J of Bioethics 36.
[356] *Ibid* at 37.

‘cultural happening’ to fit within moral brackets”[357] in this context. That is, the choice of the individual to have his body viewed after death may trump the living’s view that the act is not dignified. The absence of post mortem autonomy is thus not an issue in the context of cadaveric genetic research if consent has been obtained in life from the donor, where the autonomy of the donor should be respected after death.[358]

The relationship between dignity and autonomy, for the purpose of this paper, is where dignity is a “… rights-based concept … manifested in a respect for individual autonomy.”[359] If dignity grounds autonomy, then dignity’s role in the right to privacy must be considered.

Dignity and Postmortem Privacy

It is likely not possible to crystallize the relationship between dignity and privacy in the form of a legal ‘dignity test’ for privacy.[360] However, Canadian Courts have repeatedly affirmed dignity as an underlying principle of privacy, and the right to privacy is entrenched in sections 7 and 8 of the *Charter*.[361] Although *Charter* rights are not protected after death,[362] the relationship of dignity and privacy has been argued on the basis of dignity’s key role in the protection and respect for privacy,[363] which does have post mortem statutory protection in Canada.[364] Like post mortem dignity, post mortem privacy protection reflects the deceased’s relationship with the living.[365]

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[357] *Ibid.*

[358] *Supra* note 353 at 535. Simona Giordano, “Is the Body a Republic?” (2005) 31 J Med Ethics 470 at 471 notes that “…[t]he rationale for respecting a person’s post-mortem decisions is that it is considered a way of respecting patient autonomy.”

[359] Caulfield, *supra* note 307 at 75.

[360] Aylward, *supra* note 171 at ¶ 29.

[361] *Ibid* at ¶ 17.

[362] *Supra* note at 300.

[363] *Supra* note 145 at ¶ 7. Aylward, supra note 171 at ¶ 17, notes how the Supreme Court of Canada “… linked the concept of privacy with the Charter’s underlying concept of dignity, and held that privacy was one of the *Charter* values that the common law should strive to protect” citing *Hill v Church of Scientology*, [1995] 2 SCR 1130,126 DLR (4th) 129.

[364] See below at 93.

[365] See for example, the temporal limits to post mortem privacy protection in provincial and federal privacy legislation, below at 93. Informational privacy of the individual is protected post-mortem both federally and provincially: Regulating government institutions, the *Privacy Act,* RSC 1985, c P-21, s 1(m) requires consent for use of personal information, when the use is not that for which consent was obtained; but this requirement is waived for individuals dead greater than 20 years. The *Personal Information Protection and Electronic Documents Act, SC* 2000, c 5 (federal private sector legislation), allows for disclosure of personal information without consent if an

Although ‘dignity’ is not neatly definable, a Canadian Court has recently interpreted the breach of privacy under tort law in terms of “intrusion of seclusion” as “interference with personal information,”[366] or in the words of Bloustein, “…a blow to human dignity…,”[367] supporting the argument for a relationship between individual informational privacy and dignity.[368]

The importance of individual privacy is not a new concept, [369] but privacy issues have taken on greater significance in relation to informational privacy and genetic research.[370] The relational basis of privacy,[371] like dignity, justifies the need to maintain privacy after death, as illustrated in Hunt’s definition of privacy, which in part, is stated as “… a claim to be free from unwanted sensorial access (including that which is technologically aided) in relation to information which are [either] … intimate …or…personal in the sense that most people in our society would not want them widely known...,”[372] in the context of this paper, privacy in genetic information.

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individual has either been dead for more than 20 years, or 100 years after the creation of a personal information record (at ss (h)(1) and (2)). The *PIPEDA* does allow for disclosure of personal information without consent at any time for the purpose of identifying a body (at s d.4). Provincial privacy statutes also have a post mortem limit of privacy protection: See below at 93.

[366] Aylward at ¶ 25, citing *Jones v Tsige*, 108 O.R. 93d) 241, 2012 ONCA 32. Sharpe JA, writing for the Court, noted that “… no provincial legislation provides a precise definition of what constitutes an invasion of privacy” at ¶ 54, although British Columbia, Manitoba, Saskatchewan and Newfoundland have created a tort of privacy through legislation (*Jones v Tsige* at ¶ 52).

[367] Edward J. Bloustein, “Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser” (1964) 39 NYUL Rev 962 at 974.

[368] C L Hunt, **“**Conceptualizing Privacy and Elucidating its Importance: Foundational Consideration’s for the Development of Canada’s Fledgling Privacy Tort” (2011) 37:1 Queen’s LJ 167 at 181-182 considers Article 8 of the *European Convention on Human Rights* to include the right to control personal information. This view expands the Court’s ruling in *Elberte* (*supra* note 230-231), where the Court found the decedent’s wife had a privacy interest in requiring consent for the removal of deceased husband’s organs and tissues. Canadian jurisprudence does not support a privacy interest of legal next of kin in a body, but a duty, grounded in dignity for appropriate disposal of the body.

[369] Donald Willison, “Privacy and the Secondary Use of Data for Health Research: Experience in Canada and Suggested Directions Forward” (2003) 8(1) J Health Services Research and Policy S1:17 at 20-21 notes that “[a] high regard for privacy has been associated with ancient Greece, English Protestantism and common law traditions, and with American constitutionalism … Aristotle, for example, asserted that maintenance of the private is essential to the individual *and* the body politic … []… Indeed, privacy is fundamental to a free and democratic society – of interest to both the individual and the community.”

[370] Gina Kolata, “Poking Holes in Genetic Privacy” *The New York Times*, June 16, 2013; Dove, Edward S *et al*, “Genomic Cloud Computing: Legal and Ethical Points to Consider” (2014) 23 European Journal of Human Genetics 1271.

[371] Hunt, *supra* note 368 at 191 describes the relational aspect of privacy: “Privacy is … a relational rather than solipsistic concept. To be private, a matter must be private against another party.”

[372] *Ibid* at 201.

Scarre argues that a right to privacy is commensurate with a right to dignity after death, reflecting the individual's autonomy while alive.[373] The author neatly sums up the relational aspect of post mortem dignity and privacy in reference to scientific research:

> People care about their privacy because they care about their dignity, and invasions of privacy threaten dignity by removing a person's ability to control how he is represented in public perception. Since those perceptions outlast the individuals they concern, living people are naturally concerned about how they are represented after they are gone…Posthumous events such as …the use of his physical remains for medical research …may constitute serious defeats for such lifetime desires.[374]

If dignity of the body is sustained post mortem, then it is reasonable to justify that a right to information privacy[375] transcends death, and Canadian privacy legislation does support a right to privacy in death.[376] The limits placed on this right are temporal, illustrating not that the deceased's dignity wanes over time, but that the legislated privacy protections are in place to reflect the relational aspect of privacy, that is, the cadaver's privacy protection in reference to its effect on the living.

The right of privacy after death has been described by Hermann as a fluid relational process:

> …[F]undamental rights such as the right to respect to private life and the flowing right to secrecy concerning health information do extend to the deceased person. The protection does, however, decrease as time passes by, as the opposing interests gain ground in the balancing and as the passage of time in itself may minimize the legally protected integrity of the deceased.[377]

If it accepted that the right to privacy after death, ground in the dignity of the decedent, then this right should also extend to deceased individuals under the authority of a death investigation system.

Dignity in Death Investigation Systems – Genetic Research

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[373] Geoffrey F Scarre, "Privacy and the Dead" (2012) 19:1 Philosophy in the Contemporary World 1.

[374] *Ibid* at 13.

[375] *Dyment*, supra note 13 at ¶ 22. Laforest J, writing for the majority, wrote that information privacy is "…based on the notion of the dignity and integrity of the individual."

[376] *Supra* note 365.

[377] Janne Rothmar Herrmann, "Use of the Dead Body in Healthcare and Medical Training: Mapping and Balancing the Legal Rights and Values" (2011) 18 Eur J Health L 277 at 281.

In a medicolegal death investigation, it is unlikely that genetic research on a cadaver that is necessary to determine cause of death, that is, within the death investigator's legislated mandate, would be deemed an 'indignity'. However, genetic research that is deemed beyond the respective provincial mandate could potentially result in a Court's finding of an indignity to a body under s. 182(b) of the *Criminal Code*. For example, commodification of a cadaver and its parts could be found to be an indignity to the body.[378] In *R v Kelly*,[379] where body parts stolen from a teaching hospital were used to create an art exhibit, and from which the accused received financial gain, the Court found that a custodial sentence was necessary to maintain public trust in scientific research performed on human cadavers.[380]

The use of consent, either through antemortem donation or post mortem consent obtained from next of kin, would likely mitigate the finding of an indignity to a body that is a subject in genetic research. However, in the circumstance of unidentified and unclaimed bodies, this consent could not be ascertained.

Unidentified and Unclaimed Bodies – Dignity's Role

The above discussion illustrates that when the legal next of kin have been legally granted control of a body, that control is not absolute. The interest is expressed broadly as a responsibility to dispose of the remains appropriately, but extends to either prevent the use of the body for research if the legal next of kin knew that the deceased would not have wanted to donate his body for research, or to consent to its use, both of which are intended to reflect the autonomy of the deceased. However, if the body remains unclaimed,[381] and/or if the body is unidentified[382]

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[378] Kristin Solum Steinsbekk *et al,* "We're Not in it for the Money – Lay People's Moral Intuitions on Commercial Use of 'Their' Biobank" (2011) 16 Med Health Care and Philos 151found in their study that, in relation to biobank tissue, commodification of tissue reflected dignity concerns by the participants.

[379] *R v Kelly* [1998] 3 All ER 741.

[380] *Ibid* at 5.

[381] An unclaimed body refers to a body that has no known legal next of kin or authorized representative to take responsibility for appropriate disposition of the body: see Quinet, Kenna, Samuel Nunn & Alfarena Ballew, "Who Are the Unclaimed Dead?" (2014) 61 J Forensic Sciences S 131 at 131;
D Gareth Jones, "Use of Bequeathed and Unclaimed Bodies in the Dissecting Room" (1994) 7:2 Clinical Anatomy 102 at 102. An unclaimed body may be identified or unidentified.

[382] For the purpose of this paper, an unidentified body is a body with no established identity.

while under the authority of a death investigation system, the degree and magnitude of the control of the body rests with the respective provincial government.[383]

In practice, respecting the dignity of an unidentified cadaver may be reflected in assuming the deceased did not want his body used for research, as instruction declining use of one's body in research could exist in a will.[384] However, post mortem directives of unidentified and unclaimed bodies would not be available to a death investigator. In such circumstances, the parameters of dignity owed unidentified and unclaimed bodies in death investigation systems in Canada requires consideration.

Although a right to privacy may not be invoked until a body is identified,[385] the absence of next of kin to do so does not diminish the dignity owed a body, if one considers it in terms of dignity relationally to society. Society's role in relation to ensuring dignity of unclaimed bodies is illustrated in history, both in Canada and elsewhere.

Unclaimed bodies were historically used for medical education, specifically the teaching of anatomy to medical students.[386] The activities and public response to the activity of body snatchers in the 19th century, that is, the disinterment of buried bodies for the purpose of sale to medical schools,[387] resulted in Anatomy Acts in the United Kingdom[388] and in Canada. Recent data suggests that approximately 20% of cadavers used in medical schools in Canada are unclaimed bodies.[389] Federal vital statistics data (2012) indicates there are less than 10

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[383] See for example, *An Act Respecting Medical Laboratories, Organ and Tissue Conservation and the Disposal of Human Bodies*, CQLR c L-0.2; *Anatomy Act*, CCSM 2006, c A80; *Anatomy Act,* RSBC 1996, c 13; *Anatomy Act*, RSNB 2011, c 110; *Anatomy Act*, RSNS 1989, c 13; *Anatomy Act*, RSO 1990, c A.21; *Fatalities Investigations Act*, SNL 1995, c F-6.1; *Public Health Act,* 1994, SS 1994, c P-37.1.The Yukon, Nunavut, the Northwest Territories and Prince Edward Island have no statutory reference to the disposition of unclaimed bodies.

[384] *Anatomy Act,* RSBC 1996, c 13, s 7.

[385] Holland, *supra* note 101 at 654.

[386] M E Rogers, "Human Bodies, Inhuman Uses: Public Reactions and Legislative Responses to the Scandals of Bodysnatching" (2003) 12:2 Nottingham Law J 1 at 10.

[387] Deepa Francis, "Bodysnatching in Canada" (2001) 164:4 CMAJ 530.

[388] *Supra* note 386 at 13.

[389] Neela Dasgupta, Dasgupta, Neela, "Unclaimed Bodies at the Anatomy Table" (2004) 291:1 JAMA 122 at 122.

unidentified bodies per year in Canada,[390] but the number of unidentified decedents in Canada may higher.[391] Today, not only anatomy, but genomics may be taught with the use of cadavers,[392] and the use of unclaimed bodies in scientific research is not without precedent.[393] Most provincial legislation refers only to unclaimed bodies, except for Alberta and Newfoundland death investigation legislation. The Alberta statute refers to unidentified bodies,[394] and the Newfoundland *Fatalities Investigations Act* specifies unidentified and unclaimed bodies in reference to their disposition for research.[395] The permitted statutory uses for unclaimed bodies also vary between provinces.

For example, in accordance with the New Brunswick *Anatomy Act,*[396] "… the body will be used only for the promotion of anatomical or pathological science."[397] Here, it is reasonable to assume that such a use could include genetic research within the parameters of "pathological science", although a definition of "pathological science" is not included in the legislation.[398]

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[390] See Canada, Statistics Canada, Vital Statistics - Death Database (CVSD), "Data Accuracy", 2012, online: http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=257641. The most recent data vital statistics data does not include this information: see Canada, Statistics Canada, Vital Statistics - Death Database (CVSD), 2017, online: http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3233.

[391] Renata D'Aliesio & Kathryn Blaze Carlson, "Substantial Gap Discovered in RCMP Database of Anonymous Dead" *The Globe and Mail* (updated 12 May 2018) online: https://www.theglobeandmail.com/news/national/substantial-gap-discovered-in-rcmp-database-of-anonymous-dead/article23467796/.

[392] Glenn S. Gerhard, Barbara Payton, & Steven N Popoff, "Integrating Cadaver Exome Sequencing into a First-Year Medical Student Curriculum" (2016) 315:6 JAMA 555. The paper does not indicate if the cadavers were donated or unclaimed. Although not strictly research, this paper illustrates how genomics has been integrated into traditional uses of cadavers in medical school teaching, relevant to the interpretation of the provincial *Anatomy Acts*, for example.

[393] *Supra* note 73 at 274 for a review of Project Sunshine in America.

[394] *Fatality Inquiries Act*, RSA 2000, c F-9, s 18(1).

[395] *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 17.

[396] *Anatomy Act*, RSNB 2011, c 110.

[397] *Ibid* s 8.

[398] The term "pathological science" is not defined in the statute. The term has been described in general as synonymous with pseudo science: see Henry H Bauer, "'Pathological Science' Is Not Scientific Misconduct (Nor Is It Pathological)" (2002) 8:1 HYLE International Journal for Philosophy of Chemistry 5. However, in the context of this legislation, a possible interpretation of the term may relate to the science of pathology, which would include genetic research, as in molecular genetics pathology: see Mark E Sobel *et al*, "The Evolution of Molecular Genetic Pathology: Advancing 20th-Century Diagnostic Methods into Potent Tools for the New Millennium" (2008) 10:6 The Journal of Molecular Diagnostics 480.

Nova Scotia's *Anatomy Act*[399] gives authority to the medical examiner to transfer a body whose disposal will be "at the public's expense"[400] to the "Inspector of Anatomy,"[401] who may then transfer the body to "…any legally established medical school or college [within Nova Scotia] for the advancement of anatomical or pathological science."[402] The *Act* does not specifically exclude the use of an unidentified body,[403] and as noted above, may be read to include genetic research within the definition of "pathological science."[404]

The *Anatomy Act*[405] in British Columbia allows for the use of an unclaimed body only for "anatomical research or education,"[406] and does not reference a need for identification. The *Act* does not define "anatomical research,"[407] but specifically does not include "scientific research" in potential uses of the unclaimed body.[408] The British Columbia *Human Tissue Gift Act'*s requirement for consent prior to donation for "scientific research,"[409] and clear exclusion of the coroner's right to donate a body for the purpose of scientific research, regardless of whether it is unidentified or unclaimed, suggests that "anatomical research" may exclude genetic research, and apply only to the study of anatomy as in a medical school, for example. This is interesting, in that it may indicate an acknowledgement by legislators in British Columbia that consent by the donor, that is, the now deceased individual, is required for genetic research.[410]

In Alberta, the use of unidentified bodies is granted under the *Fatality Inquiries Act,*[411] where a body, and if requested by an educational institution, may be used for "…anatomical or scientific

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[399] *Anatomy Act*, RSNS 1989, c 13.
[400] *Ibid* s 5(1), 'at the public's expense' is read as synonymous with 'unclaimed'.
[401] *Ibid* 2(a).
[402] *Supra* note 400.
[403] *Ibid.*
[404] *Supra* note 398.
[405] *Anatomy Act,* RSBC 1996, c 13.
[406] *Ibid* s 4.
[407] *Supra* note 405.
[408] It is unclear where the use of cadaveric genomics in teaching would fall with this legislation.
[409] *Human Tissue Gift Act,* RSBC 1996, c 211.The term "scientific research" is not defined in the statute but would likely be deemed to include genetic research.
[410] *Supra* note 151 at 308. The authors argue that "… [i]n research, the use of an unidentified or "unclaimed" body is considered unethical, as it is not possible to meet the consent requirement…." See also *supra* note 381 in the context of anatomical dissection and teaching.
[411] *Supra* note 394.

study or research at the university."[412] Manitoba's *The Anatomy Act*[413] gives carte blanche authority to "[m]embers of the staff and medical students or dental students of the university, with the approval of the physician or pathologist performing a medico-legal autopsy, if authorized by the medical examiner in charge of the body, or the chief medical examiner"[414] to collect biomaterials from the body "for anatomical or other scientific instruction or requirements,"[415] wording that clearly would allow for the use of the body in genetic research absent consent. The *Human Tissue Gift Act*[416] of Manitoba also gives authority to the Inspector of Anatomy to use an unclaimed body for scientific research.[417]

How long legal next of kin or a representative may have to claim a body before the possibility that it may be donated to a facility for research purposes, that is, designated unclaimed, varies between provinces, the most generous being British Columbia at 3 months,[418] with Manitoba potentially rushing the unclaimed remains to a research facility after only 72 hours.[419] Alberta,[420] Nova Scotia[421] and Newfoundland[422] each have a 7 day waiting period, and 14 days in New Brunswick[423] and Ontario[424] are allotted for claiming of a body. As noted above, the onus of identifying a body lies squarely with the death investigator, whose efforts in contacting the next of kin using available resources will determine the likelihood that a body remains unidentified and /or unclaimed.[425]

Based on the above legislation, an unidentified body could legally be used in genetic research in some provinces, without the consent of the deceased, a clear infringement of their personal

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[412] *Post-Secondary Learning Act,* SA 2003, c P-19.5, s 37(1).
[413] *Anatomy Act*, CCSM 2006, c A80.
[414] *Ibid* s 7(2)
[415] *Ibid* s 7(2)
[416] *The Human Tissue Gift Act*, CCSM c H-180.
[417] *Ibid* s 3 (1.1)(c).
[418] *Anatomy Act,* RSBC 1996, c 13 s 4.
[419] *Supra* note 413 ss 4(1) and 6(1).
[420] *Supra* note 394 ss 18(1) and 18(2).
[421] *Supra* note 399 ss 2 and 5(1).
[422] *Supra* note 395 s 17(1).
[423] *Supra* note 396 ss 3(1), 4 8(b).
[424] *Anatomy Act*, RSO 1990, c A.21 ss 4 and 5.
[425] Renata D'Aliesio & Kathryn Blaze Carlson, "Ontario Revamps Efforts to Name Unidentified Dead" *The Globe and Mail* 12 May 2018, online:http://www.theglobeandmail.com/news/national/ottawas-strategy-on-identifying-anonymous-dead-falls-short/article23255991/.

autonomy while alive, and arguably their dignity in death. Despite this legal authority, a body without formal identification is still owed dignity, specifically "relational dignity" in the context of society's obligation to the decedent. The privacy of an unclaimed body's unique genome as personal health information should be afforded legal protection, whether or not the individual cadaver has been identified by a death investigator. Bloustein argues that "… community concern for the preservation of the individual's dignity … is the key issue of privacy law.[426] Further, privacy and consent are concepts grounded in respect for persons,[427] or dignity. Therefore, the privacy and dignity of all cadaverically sourced genetic information should be protected equally. As Ogbogu and Burningham note:

> Even when genetic information is de-identified… [as would be the case in an unidentified body] …, it remains unique to an individual and could potentially be linked to that person (or his genetic relatives) if used in conjunction with other personal health information or publicly available information.[428]

Re-identifying genetic information is in effect the goal of the valuable service provided to identify unidentified bodies, that is, matching their DNA sample to other available demographic data, including the DNA of potential genetic relatives.[429] Therefore, assuming a body is and will remain unidentified for the purpose of genetic research is not factually based, with the exception of those bodies that remain unidentified in Canada.[430]

If a cadaver, regardless of whether the deceased individual is officially identified in a death investigation system is owed dignity, the next question to be considered in relation to genetic research becomes whether that individual body is a potential human research subject in Canada.

Is a Cadaver a Research Subject in Canada?

Legislation

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[426] *Supra* note 367 at 1007.

[427] Lisa Eckenwiler, "Genetics Research and Third Parties: Implications for Education in the Health Professions" (2001) 21 The J of Continuing Education in the Health Professions 278 at 280.

[428] Ogbogu, *supra* note 16 at 475.

[429] Government of Canada, Public Safety Canada, The National Missing Persons DNA Program, "Backgrounder" online: https://www.canada.ca/en/public-safety-canada/news/2018/03/the-national-missing-persons-dna-program.html.

[430] *Supra* note 391.

The Newfoundland and Labrador *Health Research Ethics Authority Act*[431] is the sole Canadian statute that defines the parameters of "human beings as research subjects."[432] Importantly, the definition "... includes human remains, cadavers, tissues, biological fluids …and records pertaining to them."[433] Further, "health research involving human subjects" is defined as "… activities whose primary goal is to generate knowledge in relation to human health, health care and health care systems, and involving human beings as research subjects, health care information respecting human beings and human biological material."[434] Thus, the *Act* clearly includes cadaveric tissue and biological fluids such as blood, as well the personal health information of deceased individuals as human research subjects. Significantly, the commonality of genetic personal information is clear from the materials listed in the statute, whereby consent for the use genetic information is required for use in research. However, Canadian federal policy is much less definitive in considering whether deceased individuals are human research subjects.

Policy

Canada

The 2014 edition of *The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*[435] (TCPS2) does not specify that a 'participant' must be living.[436] Importantly, what is unclear from the TCPS2 is whether the references to tissue of deceased participants refer to tissue recovered from cadavers, or tissue recovered in life (with consent), where the participant is dead at the time of the proposed research. In the latter scenario, primary consent for removal of the tissue would have been obtained. If the assumption is that it is the former, the TCPS2 may not be applicable to cadaveric tissue recovered in a forensic autopsy, where tissue is collected in the absence of consent, albeit for diagnostic purposes. However, for

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[431] *Health Research Ethics Authority Act,* SNL 2006, c H-1.2, as amended by 2011 c22; 2012 c33 s1.

[432] *Ibid* s 2(e).

[433] *Ibid* s 2(e). The definition also includes embryos and foetuses, human biological material that will not be considered in this paper.

[434] *Ibid* s 2(d).

[435] *Supra* note 17.

[436] *Ibid* at 207. A research "participant" is defined as "[a]n individual whose data, or responses to interventions, stimuli, or questions by a researcher are relevant to answering a research question; also referred to as "human participant," and in other policies/guidance as "subject" or "research subject." Importantly, it does not specify that the individual be living. See also *supra* note 101 at 442.

the purpose of this paper, it will be assumed that the policy's reference to dead participants includes cadaveric sourced tissue.

International

There is no policy agreement internationally as to whether a cadaver is a research subject. For example, the Helsinki Declaration[437] and the *Australian National Statement on Ethical Conduct in Human Research*[438] do not differentiate living and deceased research subjects. The United States, however, specifically does not consider a cadaver to be a research subject, and thus cadaveric tissue would not be subject to a research ethics review.[439]

In the United Kingdom, there is distinct legislation for Scotland and for England, Wales and Northern Ireland concerning the status (living or dead) of the tissue source:

> The Human Tissue (Scotland) Act 2006 applies only to tissue from the dead, whereas the Human Tissue Act 2004 (which is the relevant legislation throughout the rest of the UK) embraces tissue from the living and the dead…. [the latter] … also makes no distinction between living and dead cells, only whether the cells have come from a living or dead body. The status of the tissue removed from a living body, in terms of the need for consent for storage or for various uses, does not change when the individual dies; it continues to be regarded as tissue taken from a living body.[440]

There are several arguments in favour of not differentiating living and cadaveric research participants specifically in genetic research, and thus considering post mortem biomaterials as "human." The TCPS2 does not differentiate living from deceased "human genetic research",[441] or "identifiable [personal] information",[442] likely for the simple reason that human genetic

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[437] WMA Declaration of Helsinki, *Ethical Principles for Medical Research Involving Human Subjects*, 64th WMA General Assembly, adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964 and amended by the Fortaleza, Brazil, October 2013.

[438] Australian Government, National Health and Medical Research Council, Australian Research Council, Universities Australia, *National Statement on Ethical Conduct in Human Research*, 2007 (updated 2018) at 7.

[439] Rebecca L Walker, Eric T Juengst, & Warren Whipple, "Genomic Research with the Newly Dead: A Crossroads for Ethics and Policy" (2014) 42:2 J Law Med Ethics 220 at 222. See also *supra* note 70 at ¶ 2, where Bach notes the National Institute of Health in the United States stipulates that human research designation requires that the tissue be collected from a living subject.

[440] J C E Underwood, "The Impact on Histopathology Practice of New Human Tissue Legislation in the UK" (2006) 49 Histopathology 221 at 222.

[441] *Supra* note 17 at 205.

[442] *Ibid* at 205.

information remains unique to the individual after death, the basis of which forensic DNA identification of cadavers is performed.[443]

Cadaveric Research as Human Research - Academic Opinion

Bach suggests that risk of "… possible bodily desecration and transgression of religious rules, cultural taboos, or personal beliefs"[444] supports the view that cadaveric research is human research, in keeping with the dignity based, relational respect owed the body by the living. Further, the inability to control one's private interests and dignity after death makes the cadaver "especially vulnerable"[445] as a research participant. As stated by Scarre, "… we should not invade the privacy of the dead in circumstances in which, or in a manner which, we would think it wrong to invade that of the living."[446]

In genetic research, the risk of harm lies in breach of privacy of cadaveric genetic information,[447] and supports the argument that cadaveric genetic research should fall within the umbrella of human research. Since the human genome remains unaltered for the purpose of identification after death,[448] and if genetic privacy is legally protected in life, then genetic informational privacy should also be protected in death, as it is in Canada through federal and provincial privacy legislation.[449]

Applying the relational aspect of post mortem dignity and privacy[450] to Bach's risks associated with post mortem genetic research, a cadaver should be considered a human research subject, as the risks associated with genetic research are the same for the living and the deceased, the risk being breach of informational genetic privacy.[451] To date, there is no case law in Canada on this point.

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[443] *Supra* note 429.
[444] *Supra* note 70 at ¶ 14.
[445] *Supra* note 373 at 14.
[446] *Ibid.*
[447] *Supra* note 70 at ¶ 13.
[448] *Supra* note 429.
[449] *Supra* note 100.
[450] *Supra* note 373.
[451] See below at 93 for discussion of the risks associated with breach of privacy of personal information in genetic research.

Having considered the legal control of a cadaver by the living, this paper will next review the control of cadaveric organs in the context of organ donation, where consent has been granted in life by the organ donor or in the absence of donor consent, from the legal next of kin after death for post mortem use of the organ. This contrasts with organ retention, a situation that occurs when no consent was granted by either the cadaveric organ source or his next of kin for retention of the organ. The legal implications of retained organs will be then considered in the context of their subsequent use in genetic research.

The Law and Cadaveric Organ Donation – Who Has Control?

Donating one's individual organs, rather than one's entire body [452] represents another means by which cadaveric genetic data may become available for research from a cadaver under the authority of a death investigator. In Canada, the legal next of kin's control of a deceased's organ under organ donation legislation is again limited: specifically, if an individual gave valid consent[453] to post-mortem organ donation, legal next of kin cannot legally override that consent. Toews and Caulfield note that "… existing legislation respects an individual's donation decision – whether for or against – by making the decision binding and safeguarding the ability to change one's mind."[454] However, the next of kin cannot override valid donor consent for organ donation.[455] Importantly, in the context of this paper, consent is required for use of an organ after death, including genetic research under organ donation legislation in all provinces and territories

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[452] As noted above, what is a body, an organ or tissue is confusing (above at 6), as well as from a legal, and practical medical perspective. Human tissue donor legislation in Canada is not consistent in defining an "organ" for the purpose of the legislation. For example, *Human Tissue Gift Act,* RSBC 1996, c 211, s 1,;*The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 2; *The Human Tissue Gift Act*, CCSM c H-180, s 1; *Trillium Gift of Life Network Act*, RSO 1990, c H, s 1; *Human Tissue Gift Act,* SNB 2014, c 113, s 1; The *Human Tissue Act*, RSNWT 2014, c 30, s 1; *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 1; *Human Tissue Act*, RSNL 1990, c H-15, s 1; *Human Tissue Gift Act*, RSY 2002, c 117, s 1. All define "tissue" as including an organ, but do not define an "organ." Alberta's *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, s 1 defines organs as "human organs, whether whole or in part", and specifies that tissue is distinct from an organ. Nova Scotia (*Human Organ and Tissue Donation Act*, SNS 2010, c 36, s differentiates tissue (s 2(y)) from organs, and despite not defining what an organ is, states that partial organs include an organ for the purpose of the legislation(s 2(r)).

[453] Valid consent refers to consent that "… meets the formal legislative requirements": See *supra* note 274 at 17.

[454] *Ibid* at 18.

[455] *Ibid.*

in Canada, including when a deceased individual falls within the jurisdiction of a death investigation system.

Organ donation in Canada is an important and topical issue,[456] including the need for more cadaveric organ donors.[457] The role of death investigators in cadaveric organ donation is limited, but important.[458] This section will include a focussed consideration of cadaveric organ donation, specifically, the legal control of cadaveric organs by the donor and their next of kin in the context of potential organ use in genetic research under a death investigation system. Issues relating to organ donation in Canada in general are complex and controversial, including the definition of death.[459] For the purpose of this paper, the assumption is made that death has occurred,[460] although a death investigator may in practice have authority in relation to organ donation of an individual on life support.[461]

In Canada, all provinces and territories have a legislated requirement for consent to organ donation.[462] This requirement for consent[463] that is statutorily mandated in Canada contrasts with

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[456] Timothy Caulfield *et al*, "Incentives and Organ Donation: What's (Really) Legal in Canada?" (2014) 7 Canadian J of Kidney Health and Disease 1 at 2; Canadian Institute for Health Information, Media Release, "Organ Donations Continue to Fall Short of Meeting Demand" (17 March 2016), online: https://www.cihi.ca.

[457] Canadian Institute of Health Information, Report, "Deceased Organ Donor Potential in Canada" (December 2014), online: https://www.cihi.ca/web/resource/en/organdonorpotential_2014_en.pdf; Canada, Library of Parliament, Legal and Social Affairs Division, Parliamentary Information and Research Service, *Organ Donation and Transplantation in Canada*, (background paper), by Sonya Norris, no. 2018-13-E, 14 February 2018, online: http://www.lop.parl.gc.ca/content/lop/researchpublications/2011-113-e.pdf; S Rumsey, D P Hurford, & A K Cole, "Influence of Knowledge and Religiousness on Attitudes Toward Organ Donation" (2003) 35 Transplantation Proceedings 2845.

[458] Below at 70. A death investigator does not have the legislative authority to consent to organ donation on behalf of the donor (except on Prince Edward Island) but may have a mandate to deny donation for the purpose of death investigation.

[459] The medicolegal definitions of death in relation to organ donation are controversial: see Robert M Sade, "Brain Death, Cardiac Death, and the Dead Donor Rule" (2011) 107:4 JSC Med Assoc 146; Richard B Freeman & James L Bernat, "Ethical Issues in Organ Transplantation" (2012) 55 Progress in Cardiovascular Diseases 282. The Canadian federal government has also referred to either cardiac death or brain death in relation to organ donation: see Norris, supra note 457.

[460] *Supra* note 101 at 418-419. This assumption relies on the following: "Legislation governing organ and tissue transplantation for the most part does not define death, but rather, accepts medical determination of death as authoritative."

[461] Teresa J Shafer *et al*, "Vital Role of Medical Examiners and Coroners in Organ Transplantation" (2003) 4 American Journal of Transplantation 160.

[462] *Supra* note 457 at 12.

[463] Also referred to as an opt-in system: see *supra* note 457 at 12; see also Mark Amman, "Would Presuming Consent to Organ Donation Gain Us Anything but Trouble?" (2010) 18(2) Health Law Review 15 at ¶ 7.

an opting out, or presumed consent system,[464] whereby "…consent to donate is presumed unless a person has expressly indicated otherwise during his or her lifetime."[465]

Donor Autonomy

The requirement for consent reflects respect for the right of the individual donor while alive to choose or not to choose to donate after death, that is, the individual's autonomy. Skene notes that "… [t]he basis of human transplant legislation is not strictly a gift but consent to use a body or tissue in certain ways."[466] However, as with whole body donation statutes, consent as required by the legislation may be valid, but "… does not impose a standard of 'informed consent',[467] the standard required for research on human subjects in Canada.[468]

Clearly, the use of donated organs in medical research is valuable to society.[469] The option of cadaveric organ use in research when transplantation is not possible may also be beneficial in specific societies by increasing organ donation in communities that may not accept organ donation for transplantation.[470] For example, Chandler notes that "Singapore, which has adopted a priority system, permits Muslims to refuse cadaveric organ donation but still access the priority award if they instead register to donate their bodies for medical education or research."[471] Thus, by requiring consent for the specific use of an organ, trust in the process of organ donation has been solidified, where cultural views may have deterred individuals from consenting to post mortem

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[464] Norris, *supra* note 457 at 11-12. See also Ammann, *supra* note 463 at ¶ 11, who describes a presumed consent system for cadaveric organ donation in which "… all deceased patients are presumed to have consented to be organ donors in the absence of a specific withdrawal of consent (generally recorded in a national central registry)."

[465] Norris, supra note 457 at 11. Several consent models for organ donation have been suggested for use in organ donation, and include opt-in, opt-out, mandated choice: see Henrietta K Consolo & Stephen J Wigmore, "Ethical and Legal Issues Associated with Organ Donation and Transplantation" (2014) 32:7 Surgery 333 at 335; and priority system consent models: see Jennifer A Chandler, "Priority Systems in the Allocation of Organs for Transplant: Should We Award Those Who Have Previously Agreed to Donate?" (2005) 13 Health L.J. 99; Brent Arnold, "Legal Solutions to Ontario's Organ Shortage: Redrawing the Boundaries of Consent" (2005) 13 Health L J 139 at 146.

[466] Loane Skene, "Arguments Against People Legally Owning their Own Bodies, Body Parts, and Tissue" (2002) 2 Macq L J 165 at 170-171.

[467] *Supra* note 274 at 17.

[468] See for example, *supra* note 137, 138.

[469] Andreas Winkelmann, Anne-Kathrin Heinze, & Sven Hendrix, "Acknowledging Tissue Donation: Human Cadaveric Specimens in Musculoskeletal Research" (2016) 29 Clinical Anatomy 65.

[470] Chandler, *supra* note 465.

[471] *Ibid* at ¶ 38.

organ retrieval. The inclusion of purpose of use in organ donation consent legislation has also been followed in Canada.

Organ Donor Consent and Specificity of Use in Research

Virtually all provinces' and territories'[472] organ donation statutes specify that consent may include scientific or medical research as a potential use of the organ, several provinces' legislation including the phrase "therapeutic purposes, medical education or scientific research" to indicate the potential for an organ donated after death to be used in research.[473]
All provinces' and territories' organ donation legislation also specify that valid donor consent includes the donor's specified use of the organ after death.[474] Importantly, some provinces also legislate that an organ not used for the purpose indicated in the consent must be disposed of and not used for another purpose. For example, section 8 of the British Columbia *Human Tissue Gift Act* specifically states: "If a gift under this part cannot for any reason be used for any of the purposes specified in the consent, the subject matter of the gift and the body to which it belongs must be dealt with and disposed of as if no consent had been given."[475] Similar wording is employed in Saskatchewan,[476] Manitoba,[477] Ontario,[478] New Brunswick,[479] Nova Scotia,[480]

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[472] Québec to date has no legislation governing organ and tissue donation for research purposes: see *An Act to Facilitate Organ and Tissue Donation*, SQ 2010, c 38 refers only to organ transplantation (2.0.9(1)).

[473] *Human Tissue Gift Act,* RSBC 1996, c 211, s 4(1); *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, s 4(1), *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 5(1)(b); *The Human Tissue Gift Act*, CCSM c H-180, s 3(1)(c); *Trillium Gift of Life Network Act*, RSO 1990, c H, s 4(1)(b); *Human Tissue Gift Act,* SNB 2014, c 113, s 4(1), *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 11 (1)(b) refers to "…transplantation, education or scientific research…"; *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 12; *Human Tissue Act*, RSNL 1990, c H-15, s. 6(b); *Human Tissue Gift Act*, RSY 2002, c 117, s 4(1); *Human Tissue Act*, RSNWT 2014, c 30, s 1(1) (c)-(e).

[474] *Human Tissue Gift Act,* RSBC 1996, c 211. s 4(3); *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, ss 3(3) and 8(1)(b); *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 5(3); *The Human Tissue Gift Act*, CCSM c H-180, s 2 (3); *Trillium Gift of Life Network Act*, RSO 1990, c H, s 4(3); *Human Tissue Gift Act,* SNB 2014, c 113, s 4(3); *Human Tissue Act*, RSNL 1990, c H-15, s 6(3); *Human Tissue Gift Act*, RSY 2002, c 117, s 4(3); *Human Tissue Act*, RSNWT 2014, c 30, s 10; *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 10(1.2); *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 11(1).

[475] *Human Tissue Gift Act,* RSBC 1996, c 211, s 8.

[476] *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 9.

[477] *The Human Tissue Gift Act*, CCSM c H-180, s 5(1).

[478] *Trillium Gift of Life Network Act*, RSO 1990, c H, s 8.

[479] *Human Tissue Gift Act,* SNB 2014, c 113, s 9.

[480] *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 9.

Prince Edward Island,[481] Newfoundland,[482] Yukon,[483] and the Northwest Territories. [484] Alberta's statute requires a specified purpose of use but does not require disposal of the organ if not used for that purpose,[485] potentially allowing for secondary use of the organ in research. The significance of requiring purpose of use in the respective province's statutes is that valid consent is arguably required for an organ donated after death to be used in research. In other words, research cannot be performed on a cadaveric organ that was obtained without valid consent.[486] This underlies the importance in practice for the donor to indicate his wishes as to how his organ(s) will be used after his death, that is, respect for his autonomy while alive. Valid organ donation consent recognizes the deceased's personal autonomy they had when alive, and extends that right to the time that the cadaveric donation takes place.[487] As in any context, however, personal autonomy is not an absolute right, and as such, there are exceptions to valid consent in cadaveric organ donation for use in research, including the legislative mandate of death investigators.

Exceptions to Valid Consent for Cadaveric Organ Donation

Death investigation

Death investigators are clearly in a key position to address the cadaveric organ shortage issue within their jurisdictional limits.[488] It is important to note, however, that a death investigator,

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[481] *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 10(4), where tissue not usable specifically for transplantation must be disposed of unless there is specific consent for, and including, scientific research.

[482] *Human Tissue Act*, RSNL 1990, c H-15, s 10 and *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 15.

[483] *Human Tissue Gift Act*, RSY 2002, c 117, s 8.

[484] *Human Tissue Act*, RSNWT 2014, c 30, s 13.

[485] *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, s 3(3).

[486] The human tissue donation legislation in the Northwest Territories/Nunavut, and Manitoba may be exceptions, where the term 'direction', rather than 'consent' is used in the respective statutes. It is unclear if 'direction' is synonymous with consent', or if the respective provincial legislatures were suggesting that the cadaver is part of the individual's estate, a discussion of which is otherwise beyond the scope of this paper. Here, direction will be considered synonymous to consent in that both terms refer to authorization, rather than informed consent. Further, the Manitoba legislation does not specifically state that the consent is legally binding, but that consent is "full authority" (s. 3(5)): personal communication, M Toews, Faculty of Law, University of Alberta.

[487] Jeffrey C Kirby, "Organ Donation: Who *should* decide? – A Canadian Perspective" (2009) 6 Bioethical Inquiry 123 at 124 includes other examples of post mortem respect for personal autonomy analogous to consent to cadaveric organ donation, including "… property wills … [and] affidavits used as testimony in courts of law."

[488] Christopher L Jaynes and James W Springer, "Decreasing the Organ Donor Shortage by Increasing Communication Between Coroners, Medical Examiners and Organ Procurement Organizations" (1994) 15:2 The American J of Forensic Medicine and Pathology 156; Donald Jason, Jason, Donald, "The Role of the Medical Examiner/Coroner in Organ and Tissue Procurement for Transplantation" (1994) 15:3 The American J of Forensic

does not have the statutory authority to consent to organ donation of a body under his legislative jurisdiction, with one exception.[489] When a body is under the authority of a death investigator in Canada, organ donation may be requested and either authorized or declined.[490] Balancing the need for organ donation and fulfilling their death investigation mandate to determine the cause of death is not without challenges,[491] but a death investigator's authority or control of a cadaveric organ is legislatively focussed on the limited purpose of the death investigation in Canada, with the exception of Prince Edward Island.[492]

Next of Kin

In the absence of valid consent from the donor, the legal next of kin may be asked to consent to cadaveric organ donation for use in scientific (genetic) research.[493] Unlike other provincial statutes, the Manitoba legislation gives authority not only to the legal next of kin, but, in their absence to the Inspector of Anatomy to use recovered material, including organs from a body for scientific research.[494]

Medicine and Pathology 192; Teresa Shafer *et al*, "Impact of Medical Examiner/Coroner Practices on Organ Recovery in the United States" (1994) 272:20 JAMA 1607.

[489] The Human *Tissue Donation Act*, RSPEI 1988, c H-12.1 s 5(4) is the only organ donation statute in Canada that gives a coroner the authority to consent to organ donation, absent legal next of kin.
Human Tissue Gift Act, RSBC 1996, c 211, s 5(5)(a); *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 11(1)(a); *Trillium Gift of Life Network Act*, RSO 1990, c H, s 5(5)(a); *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 12(1)(a)(i); *Human Tissue Gift Act*, RSY 2002, c 117, s 5(4)(a); *The Human Tissue Gift Act*, CCSM c H-180, s 3(2)(a); *Human Tissue Gift Act,* SNB 2014, c 113, s 1, "person lawfully in possession of the body".
The *Human Tissue Act*, RSNL 1990, c H-15, *Human Tissue and Organ Donation Act*, RSA 2006, c H-14.5, and the *Human Tissue Act*, RSNWT 2014, c 30 do not address the death investigator's authority in reference to consent to organ donation.

[490] *Supra* note 461.

[491] For example, see Dwayne A Wolf & Sharon M Derrick, "Undetermined Cause and Manner of Death After Organ/Tissue Donation" (2010) 31:2 Am J Forensic Med Pathol 113.

[492] *Supra* note 489.

[493] All provincial legislation governing organ donation give authority to legal next of kin the option to consent to organ donation for research in the absence of valid donor consent: *Human Tissue Gift Act,* RSBC 1996, c 211, s 5(3); *The Human Tissue Gift Act,* RSS 2015, c H-15.1, s 6(1), (3); *Trillium Gift of Life Network Act*, RSO 1990, c H, s 5(4); *Human Tissue Gift Act,* SNB 2014, c 113, s 5(1) and 5(3); *Human Organ and Tissue Donation Act*, SNS 2010, c 36, s 14(1); *Human Tissue Donation Act*, RSPEI 1988, c H-12.1, s 5(1)(b); *Human Tissue Act*, RSNL 1990, c H-15, amended 2006, c40 s21, 7(1) , 7(3); *Human Tissue Gift Act*, RSY 2002, c 117, s 5(1), 5(3); *Human Tissue Act*, RSNWT 2014, c 30 s 2(2) and 2(3).

[494] *The Human Tissue Gift Act*, CCSM c H-180, s 3(1.1)(c).

Although no legal authority for family override of valid donor consent exists in Canadian law,[495] the rationale in giving the next of kin control in cadaveric organ donation in practice likely hinges on several factors that relate to concepts in relation to the control of the cadaver. For example, concerns about mutilation of the body is a factor likely aggravating the potential for next of kin overriding valid consent to organ donation.[496] Political ideology, gender, race and regional cultural variables may also impact organ donation policy,[497] and impact the next of kin's values concerning what is the appropriate treatment of a body. With rare exceptions, such as the Shinto faith, organ donation is at the most encouraged, and at the least, left to the individual to choose in most religions.[498] For example, it has been argued that the low cadaveric transplantation rate in China is not due to religious dogma of Confucianism, Buddhism and Taoism, but reflects inadequate rituals in modern Chinese culture that highlight the familial and altruistic expectations associated with these belief systems.[499]

Ammann argues that "… the fear that removing [an organ] over familial objections would draw significant negative attention and undermine the trust needed between the public and medical profession" is the most important factor in seeking the consent of families.[500] The voluntary nature of organ donation is a key factor in the public's perception of the process:

> This is not to say that the ethical acceptability of an organ donation programme can be determined by popular vote. However, public debate is an important check upon the organ donation process and serves as a reminder that organ donation practice reflects upon the medical profession as a whole.[501]

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[495] *Supra* note 274.

[496] Marina Vamos, "Organ Transplantation and Magical Thinking" (2010) 44 Australian and New Zealand J of Psychiatry 883 at 886. See also Tom Blackwell, "BC hospital kept patient alive for 10 days because family's culture did not accept brain death" *National Post*, (28 June 2015), online: http://news.nationalpost.com/health/vancouver-area-hospital-paid-to-keep-brain-dead-patient-alive-for-10-days-for-cultural-reasons.

[497] Stephen J Ceccoli and Roland A Glean, Ceccoli, Stephen J & Roland A Glean, "Explaining Individual Level Support for Organ Procurement Policy" (2013) 50 Social Science Journal 426 at 434.

[498] The Gift of a Lifetime, Understanding Donation, Religion and Organ and Tissue Donation, online: http://www.organtransplants.org/understanding/religion/.

[499] Yu Cai, "On the Impacts of Traditional Chinese Culture on Organ Donation" (2013) 38 J of Medicine and Philosophy 149.

[500] Ammann, *supra* note 463 at 16, citing the United Kingdom organ retention scandals as examples. See also Lucy Modra & Andrew Hilton, "Ethical Issues in Organ Transplantation", (2015) 16:7Anaesthesia and Intensive Care Medicine 321 at 322-323.

[501] Modra, *supra* note 500 at 323.

In effect, the relationship between the cadaver and the next of kin may result in family override, and as discussed above, undermines the autonomy of the donor. It would thus appear that the removal of an organ, whether for transplant or research is the key factor for some next of kin, reflecting the issue and need for 'body wholeness'. In reference to the *Human Tissue Acts 2004 and 2006* in the United Kingdom, Colsolo and Wigmore suggest the root of the "de facto veto power"[502] of families, that is, legal next of kin:

> They may object to donation on whatever grounds they see fit and retrieval will not take place …. The difficulty here, as one prominent medical ethicist stated is that 'the law is primarily individualistic while social practice is primarily communitarian, that is, it views the deceased individual as part of a family.'[503]

Thus, the dichotomy between a legally recognised individual's donor autonomy and the next of kin's need for 'body wholeness' has lead some authors, such as Emson, to attempt to mitigate consent issues in the practice of organ retrieval for donation by favouring a utilitarian philosophy in relation to organ donation,[504] suggesting that "[t]he body should be regarded as on loan to the individual from the biomass, to which the cadaver will inevitably return."[505] However, challenges in adopting a utilitarian model to organ donation exist. Such a model would undermine the personal autonomy of the donor while alive. Equally, a consent model grounded in utilitarianism, that is a presumed consent model, could consequently erode public trust in organ donation programmes.[506] The respect for the body in the process of cadaveric organ donation as viewed by the decedent's next of kin is key:

> It is thus critical that when family members are asked to consider organ donation, attention be given to what type of special care they might want in terms of the physical treatment of the body, and any relevant ritual such as prayer. Reassurance that the body will be treated with gentleness and respect needs to be clearly given.[507]

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[502] Consolo, *supra* note at 335.

[503] *Ibid*, citing JF Childress.

[504] For example, see H E Emson, "It is Immoral to Require Consent for Cadaver Organ Donation" (2003) 29 J Medical Ethics 125 and David B Hershenov and James J Delaney, "Mandatory Autopsies and Organ Conscription" (2009) 19:4 Kennedy Institute of Ethics Journal 367.

[505] Emson, *supra* note 504 at 125.

[506] Jennifer S Bard, "Lack of Political Will and Public Trust Dooms Presumed Consent" (2012) 12:2 The American Journal of Bioethics 44.

[507] Vamos, *supra* note 496 at 886.

In summary, respect and dignity in the organ donation process may be reflected by not only what is done, but how it is done, ensuring public trust. Valid consent[508] respects the personal autonomy of the individual cadaveric organ donor when consent was granted by the donor. With rare exceptions, this is expressed by the legislative requirement for consent for cadaveric organ donation for research in Canada from either the donor, or in the absence of valid donor consent, his next of kin (reflecting the donor's choice of use of his body after death).[509]

If consent is generally required for cadavers used for research, including genetic research, and provincial and territorial legislation requires consent for research of donated organs, the question then arises as to whether organs retained for diagnostic purposes in a death investigation system require consent from next of kin (absent valid donor consent) for subsequent use in genetic research? [510]

The Law and Organ Retention – Who Has Control?

Since consent is required for use in research from the donor of an organ, or in in the absence of such consent, from his next of kin, it seems reasonable that consent would also be required for organs retained for determining cause of death in a forensic autopsy. However, the process of organ retention in death investigation systems, with the potential subsequent use of retained organs in genetic research is not legally analogous to organ donation, as will be discussed below. Organ retention is statutorily authorized in only three provinces: Alberta,[511] Saskatchewan[512] and Prince Edward Island.[513] The legislatively mandated retention refers to "any part of the body"[514] and although not defined in the respective statutes, would reasonably include organs recovered at a forensic autopsy. In the context of this paper, the purpose of use for organ retention is

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[508] That is, consent analogous to authorization.
[509] The exceptions being in Prince Edward Island (supra note 489) and Manitoba (supra note 494).
[510] M Brazier, "Organ Retention and Return: Problems of Consent" (2003) 29 J Med Ethics 30 at 33. Brazier considers organ retention to fall under the same legal principles as organ donation, that is, grounded in the personal autonomy of the individual source of the organ.
[511] *Fatality Inquiries Act*, RSA 2000, c F-9, ss 25(2)(a)(b).
[512] *The Coroners Act*, SS 1999, c C-38.01, s 14(4).
[513] *Coroners Act*, RSPEI 1988, c C-25, s 10(4).
[514] *Supra* notes 511-513.

importantly limited only to "establishing the cause and manner of death."[515] Equally significant in the context of this paper, Alberta, Nova Scotia and Newfoundland and Labrador death investigation statutes refer to the respective province's organ donor legislation in giving authority for removal for research use,[516] thus requiring consent as discussed in the previous section of this paper. Further the Alberta *Fatality Inquiries Act* gives the medical examiner the authority to retain "anything that may be directly related to the death",[517] but requires that the seized item (which arguably may include an organ) be repatriated to the body or the next of kin.[518]

In other provinces, organ retention is either not referenced in death investigation legislation, or discretion is given to the pathologist performing the autopsy under the authority of the death investigator, or to the death investigator. For example, in Manitoba, the death investigation statute gives authority to "…excise or remove a part of the body…",[519] but does not refer to retention, with subsequent disposal of the organ requiring approval by the Chief Medical Examiner.[520] The Québec death investigation legislation gives discretion to the coroner in reference to "specimen removal,"[521] again not referencing the term 'organ retention.' In Ontario, "[t]he pathologist who performs the *post mortem* examination may conduct or direct any person other than a coroner to conduct such other examinations and analyses as he or she considers appropriate in the circumstances,"[522] which could be deemed to extend beyond diagnostic purposes to research, if interpreted broadly.

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[515] *Supra* notes 512-513. The wording of the Alberta statute (*supra* note 511) differs slightly, where the purpose of retention is for "establishing the cause of death and the manner of death."

[516] *Supra* note 511, s 26, *Fatality Investigations Act*, SNS 2001, c 31, s 14(1), and *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 15(1).

[517] *Supra* note 511, s 21(1).

[518] *Supra* note 511, s 21(2). This section of the statute does not specifically refer to parts of the body retained in an autopsy. Section 25(2)(b) gives the pathologist performing the autopsy authority to "excise, remove and retina any part of the body or any object found in the body for the purpose of establishing the cause of death and the manner of death." It does not, however, direct if the removed part of the body must be returned to the body or next of kin.

[519] *The Fatality Inquiries Act*, CCSM 1990, c F52, s 13(1).

[520] *Supra* note 520, s 13(2).

[521] *An Act Respecting the Determination of the Causes and Circumstances of Death*, CQLR c R-0.2, s 74.

[522] *Coroners Act*, RSO 1990, c C.37, s 28(6). The Chief Forensic Pathologist is given similar legislative authority in s 28(7).

What may be concluded from provincial death investigation legislation is that no statute gives specific authority to retain organs recovered in the course of performing a forensic autopsy for the purpose of subsequent use in research. In provinces and territories that do not statutorily specify a purpose for organ retention, it is unclear who may have control of organs retained for diagnostic use in a death investigation, in order to determine if the retained organs could be subsequently used in research. As with the whole cadaver, the next of kin have played a key role in control of organs retained in a death investigation.

Dignity and Body Wholeness

In the previous section, it was illustrated that what is legally deemed the dignified treatment of a dead body reflects individual and societal values. Laws exist that reflects the level of dignity expected by society, that is, owed the cadaver until its final disposition. Not limited to the intact body, the dignity and respect owed a deceased individual has been at the heart of controversy relating to organ retention.[523] Next of kin's responses to organ retention illustrate that the purpose of the retention is a less significant factor than the relatives' control over the final disposition of the organ. The exception is when there is perceived indignity to the deceased individual from whom the organ was collected and retained.

The question arises as to whether the dignity owed to a cadaver for appropriate disposal extends to separate organs. A murder trial in Alberta offers an example of how the perceived "undignified" use of a decedent's organ in the forensic context may be relevant not only to the next of kin, but to society.[524] In this case, the decedent was a member of the First Nations community.[525] The suggestion arising from this incident is that there is an expectation that a separated part of a body be treated with dignity. In other words, an organ from a body is owed

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[523] S Dewar & P Boddington, "Returning to the Alder Hey Report and its Reporting: Addressing the Confusions and Improving Inquiries" (2004) 30 J Med Ethics 463.

[524] Ryan Cormier, "'This was 'demeaning': Body part as evidence in Cindy Gladue murder trial comes under fire" National Post 30 March 2015 online: http://news.nationalpost.com/news/this-was-demeaning-body-part-as-evidence-in-cindy-gladue-murder-trial-comes-under-fire.

[525] Elizabeth Renzetti, "Cindy Gladue was reduced to a body part", *The Globe and Mail* (updated 14 May 2018) online: http://www.theglobeandmail.com/globe-debate/reduced-to-a-body-part/article23790508/. The victim, a First Nations sex trade worker on whom a medicolegal autopsy had been performed, had her vagina presented as evidence at the accused's trial. The author of the article notes that, at the time of writing, the body part admitted as evidence in the trial had not been repatriated with the body, that is, "… she still isn't whole."

dignity, as dignity is owed to an intact body. Such views are not limited to First Nations in Canada. In Maori tradition, for example, the body, including its organs, is significant in relation to the tribal culture, whereby

> … customary practice entails the body being interred whole to allow life to be returned from where it originated. Reunion of the body prior to burial (in the case of donated organs and even the return of tissue samples) is thus considered important for the ancestral line and descendants' connection to the future.[526]

These examples illustrate the importance of 'body wholeness' and its cultural importance to aboriginal communities globally. However, societal views as to how a body is cared for prior to disposition, including its constituent organs, is not limited to defined cultural or religious dogma, but may reflect individual philosophy.[527] As in the concept of 'dignity to a body', the individualistic nature of beliefs concerning organ retention is illustrated in the organ retention scandal experienced in the United Kingdom. Systemic retention of organs and tissues from adults and children in the course of forensic autopsies resulted in "… considerable public concern and much distress to some families…"[528] and lead to the *Human Tissue Act 2004* and the *Human Tissue (Scotland) Act 2006.*[529] Price addressed the underpinning of the legislation:
When introducing the Bill to the House of Commons, Rosie Winterton observed that "[t]he origins of the legislation lie in the distress, grief and anger felt by families in Bristol and Liverpool when they discovered that the organs of their deceased loved ones had been retained without consent … The aim of the legislation is to ensure that it will not happen again.[530]

Formal inquiries held prior to the enactment of the legislation lead to "… opprobrium …[]… heaped upon the medical profession for their failure to elicit informed consent and perceived paternalistic practices."[531] Leith argues that the issues giving rise to the legislation are not only that of informed consent, but of "body wholeness."[532] In short, the next of kin, many of whom

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[526] R M Shaw and R Webb, "Multiple Meanings of 'Gift' and its Value for Organ Donation" (2015) 25:5 Qualitative Health Research 600 at 601.

[527] William W McCorkle, Jr., *Ritualizing the Disposal of the Deceased: From Corpse to Concept* (New York: Peter Lang Publishing Inc., 2010). McCorkle at 132 argues a transhuman psychological basis for "ritualized disposal of dead bodies."

[528] *Supra* note 440 at 221.

[529] *Ibid.*

[530] David Price, "Legislation: The Human Tissue Act 2004" (2005) 68:5 Modern Law Review 798 at 818-819.

[531] *Supra* note 9 at 1024.

[532] *Ibid* at 1026-1031.

were parents whose children had undergone forensic coronial mandated autopsies, felt that their child was not resting in peace if an organ had been retained and not repatriated with the body. Of note, this belief was generally not expressed in a religious context.[533] In effect, "… [i]n death, as in life, parents continued to have a relationship with their dead child."[534]

A similar understanding of the need for 'body wholeness' at final disposition was expressed by the Australian Health Ethics Committee report concerning the impact of organ retention on next of kin:

> Laying the dead to rest with due respect is a value universally shared, even though cultures, and also groups within a culture, may differ in their sense of which practices will manifest such respect. Not everybody shares the conviction that if possible human bodies must be buried or otherwise laid to rest with all their organs. All can recognise, however, not only that this conviction is very widely held, but also that is expresses a serious sense of respect for the dead.[535]

Drayton considered the concept of 'body wholeness',[536] concluding that families' views of the body at final disposition reflect that "… the body is depicted as neither a sacred relic to be forever left untouched nor insignificant detritus. It remains the person, even as its changes in appearance confirm the permanent absence of the person."[537] In other words, "… the notion of 'wholeness' takes on a resonance which encompasses but transcends that of bodily integrity: it cuts to the issue of identity."[538] These views suggest that next of kin who take issue with organ retention do so on the basis that a non-intact body no longer represents the previously living individual, thus negatively impacting their ability to maintain their relationship with the deceased, and thus unable to ensure the dignity of the deceased individual.

It is also worthwhile to note the argument supporting the retention of organs in forensic autopsies on the part of the medical profession that supports Leith's suggestion of paternalism: citing the transcript of a paediatric pathologist's testimony at an inquiry:

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[533] *Supra* note 9 at 1030, and in keeping with McCorkle's view (*supra* note 528).

[534] *Supra* note 9 at 1031.

[535] Michael Wooldridge, "Organs Retained at Autopsy – Ethical and Practical Issues", Advice of the Australian Health Ethics Committee to the Federal Minister of Health, August 2001 at 5.

[536] John Drayton, "Bodies in Life/Bodies in Death: Social Work, Coronial Autopsies and the Bonds of Identity" (2013) 43 British J of Social Work 264.

[537] *Ibid* at 279.

[538] *Ibid* at 276.

> Our views were based on common practice, the law and ethics, so much as we considered them in those days. I think our view was that tissue which was lawfully obtained and was no longer required for its original purpose could ethically be used for the greater good, if you like.[539]

This comment reflects not only Leith's assertion of paternalism as a core basis of the UK's scandal, but more importantly an apparent precedence of public well-being over that of the next of kin in the decision to retain the organs without knowledge or consent.[540] The result was deemed to be an undermining of the right of the next of kin in determining the final disposition of the organs.

Further support of the importance globally of 'body wholeness' in the context of organ retention exists in French law. Article 230-30 of the *French Criminal Procedure Code* authorizes, by means of a court order, body parts be returned to next of kin for disposition "… if these samples are the only elements allowing the deceased person to be identified…., … subject to public health constraints."[541] The authors note that in this circumstance, "… the organ symbolically represents the entire body of the deceased person, and only in [this] case is restitution considered."[542] Thus, the organ itself, absent the source body, represents the deceased, and the return of the individual organ fulfills the concept of 'body wholeness,'[543] allowing the dignity of the deceased individual to be maintained.

Next of Kin Control of Retained Organs

Canada

In Canada, the historical lack of input from next of kin in the retention of organs following forensic post mortem examinations has been said to be based on the desire by death investigators

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[539] *Supra* note 9 at 1032, citing the transcript of the testimony of Professor Berry at the Bristol Royal Infirmary Inquiry.

[540] Emson, *supra* note 504. This utilitarian approach has been suggested in relation to organ donation.

[541] C Rougé-Maillert, V Dupont & N Jousset, "The Problem with Medical Research on Tissue and Organ Samples Taken in Connection with Forensic Autopsies in France" (2016) 38 J Forensic and Legal Medicine 5 at 7.

[542] *Ibid.*

[543] The importance of organs and body parts in the absence of an intact body to next of kin was illustrated in the handling of some remains following the 9/11 terrorist attack in New York City: see for example, Elisabeth Bumiller, "Air Force Mortuary Disposed of 9/11 Remains in Landfill", *The New York Times* (29 February 2012) online: New York Times < www.nytimes.com>.

"… not to worsen the grief…" of the deceased's family.[544] However, in their study addressing the issue of next of kin's views on organ retention in forensic (non-consented) autopsies, Krinsky *et.al*. found that, "[r]ather than contributing to the stress of the grieving family, numerous comments … indicated that the next of kin appreciated being involved in the decision-making process and having their wishes considered."[545]

The Ontario government amended the *Coroners Act*, Regulation 180, requiring that the legal next of kin not only be advised that an organ will be retained, but giving them the authority to determine that body part's final disposition.[546] Importantly, the effect of the Regulation is not to require consent for organ retention from the family, but to inform them that the organ has been retained, giving the next of kin the opportunity to choose that organ's final disposition, rather than choose whether it will be retained, as in the Krinsky *et al* study.[547] This consultation with family concerning the retained organ allows the opportunity for 'wholeness' of the body to be ensured at final disposition, if desired by the next of kin.[548] The Regulation also respects the individualistic nature of the issue of cadaveric integrity, at the heart of organ retention controversies elsewhere.[549]

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[544] Alex Nino Gheciu, "Ontario Coroners Have Kept Over 4000 Organs from Autopsies. Now They're Asking What They Should Do With Them" *National Post* 13 (June 13 2012) online: http://news.nationalpost.com/news/canada/ontario-coroners-have-kept-over-4000-organs-from-autopsies-now-theyre-asking-what-they-should-do-with-them.

[545] *Supra* note 26 at 421. The authors, in differentiating hospital and forensic autopsies, note that "…in any medicolegal case where the pathologist deems the retention of an organ essential for a complete and thorough medicolegal death investigation the next of kin should be merely notified of the retention of the organ and not asked if the organ retention meets with their approval". This is in keeping with the purpose of the forensic autopsy in the death investigation process: see *supra* note 50.

[546] RRO 1990, Reg 180, s 11.

[547] *Supra* note 26. See also s*upra* note 537 at 266: Drayton suggests that in the context of organ retention, the term 'consent' is not employed in the legal sense: consultation with the family "… allows for formal consideration of any concerns the family may wish to raise. It is important to note here that this is not a process of consent seeking … [as the] ultimate decision-making authority resides with the coroner."

[548] *Supra* notes 537 and 9.

[549] *Supra* note 524 at 466-467, where the authors note that "… [r]espect means different things to different people."

To date, legislation similar to Ontario's Regulation 180 does not exist elsewhere in Canada,[550] and there is no case law in Canada that considers the issue of organ retention.[551] However, a complaint in Ontario[552] to the Health Professions Appeal and Review Board reflected analogous issues of next of kin's perceived medical paternalism and lack of dignity in relation to a retained organ, and lead to the recommendation that the family's wishes be addressed in regards to the final disposition of the retained organ.[553] Specifically, the Board noted that "… the Applicants were upset with the manner in which their daughter's heart was disposed of, disagreeing … that it was done "in a respectful and dignified manner."[554] Further, it was found that "…the Applicants and [the] Dr. … obviously had very different perceptions as to what constituted 'a respectful and dignified manner' of disposition,"[555] again illustrating the individualistic nature of the concept of 'dignity to a body.'

Elsewhere, the province of British Columbia collaborated with the First Nations Health Authority in 2014[556] in relation to the retention of organs during the course of infant post mortems.[557] The policy is now defined by the following: "…BCCS [British Columbia Coroner's Service] no longer routinely requires the retention of the brain, and will only retain it in cases where other evidence and/or gross autopsy findings indicate a need for further neurological

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[550] *Coroners Act*, SBC 2007, c 15, s 13(6)(b) indicates that a coroner must be notified before a body is disposed, but does not specify organs; The *Fatality Inquiries Act*, RSA 2000, c F-9, s 25 (2)(b) gives authority to remove "any part" of a body and retain it for "the purpose of establishing the cause of death and the manner of death." Similar wording is used in s 14(4) of t*he Coroners Act*, SS 1999, c C-38.01, and section 10(4) of the *Coroners Act*, RSPEI 1988, c C-25. *The Fatality Inquiries Act*, CCSM 1990, c F52, s 13(2) requires notification regarding disposal of the organ but does not address retention of the organ; other provincial death investigation statutes do not specifically authorize retention of organs for the purpose of the death investigation.

[551] A class action has been filed in Ontario: see Harrison Pensa, online: http://harrisonpensa.com/organ-retention-class-action.

[552] *M S v J N E*, 2011 CanLII 57991 (ON HPARB).

[553] *Ibid* at ¶ 35.

[554] *Ibid* at ¶ 33.

[555] *Ibid.*

[556] The basis of this collaboration is " … to ensure that the Coroners Service, in undertaking its statutory role, also undertakes to ensure cultural practices, customs, and family perspectives are considered and respected '": see First Nations Health Authority, News, First Nations Health Authority and BC Coroners Service Partnership, online: http://www.fnha.ca/about/news-and-events/news/first-nations-health-authority-and-bc-coroners-service-partnership. This statement suggests that collaboration with the Coroner's Service may also be applicable to beyond the First Nations community.

[557] *Ibid.*

examination…"[558] Specifically, the policy does not reference this retention to be for the purpose of potential 'research', nor does it indicate that legal consent is required for retention.

Although no federal legal authority for organ retention in forensic autopsies currently exists in Canada, other countries have legally addressed the issue of organ retention, which may offer guidance on the issue.

America

In *Kohn v United States*, the Court held that the organs of a Jewish soldier retained during the forensic autopsy should not have been cremated by the hospital, but should have been returned prior to the burial of the deceased.[559] Noting that "[m]ost religions in the world hold that the remains of a deceased must be treated with honor and respect,"[560] Nickerson J did not question the government's authority to perform the autopsy, but held that there was no duty to cremate the retained organs, rather than return them to the family,[561] finding "[t]o say that a practice is 'accepted' is not to justify it."[562]

In a decision following different reasoning, a recent appeal court ruling in the state of New York held that the medical examiner was not required to return organs retained in the course of a forensic autopsy, nor to notify the next of kin that the organ was retained and not accompanying the body at the time of its disposition.[563] In a 5:2 decision, Pigott J summarized for the majority:

> There is simply no legal directive that requires a medical examiner to return organs or tissue samples derived from a lawful autopsy and retained by the medical examiner after such an autopsy. The medical examiner's obligations under both the common-law right of sepulcher and Public Health [s.] 4215 (1) are fulfilled upon returning the deceased's body to the next of kin after a lawful autopsy has been conducted.[564]

In their reading of the New York Public Health legislation, the majority's interpretation of the term "remains of the body" was key to their decision:

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[558] *Ibid.*

[559] *Kohn v United States*, 591 F. Supp. 568 (E.D.N.Y. 1984).

[560] *Ibid* at IV A.

[561] *Ibid.*

[562] *Ibid*. Standard practice in cremating organs without the knowledge or authorization of next of kin was not held to be a valid defence. The Court also found the government liable for embalming the body, also forbidden by Jewish law.

[563] *Shipley v City of New York* N.E.3d - 2015 N.Y. Slip Op. 04791.

[564] *Ibid* at 20.

> The issue thus boils down to whether the statutory language "remains of the body" refers to what is left of the body after the autopsy has been conducted (as the City argues), or requires the medical examiner to turn over not only the body itself but also any organs or tissue samples that have been removed during the autopsy (as the Shipleys contend).[565]

The ambiguous nature of the undefined term "remains of the body" in section 4215(1) of the *Act*, when compared to the specific use of "tissues, organs and body parts" in reference to their treatment and disposition, resulted in the majority ruling that the medical examiner was granted legislated discretionary power to retain organs and tissues in the course of performing the autopsy.[566]

The dissenting opinion written by Rivera J relied on the Public Health legislation's right to autopsy without the consent of the next of kin infringing on the common law right of sepulcher, stating that "… [a]s the laws authorizing an autopsy are in derogation of the common law right of sepulcher, they must be strictly construed."[567] Rivera J wrote:

> The majority suggests that any change in the rights of the next of kin should come from the legislature. That is indeed so because the majority has interpreted the law as applied to cases involving an autopsy in such a way as to deny the next of kin the right to demand return of their loved one in as undisturbed a condition as possible. Perhaps the majority's ruling will result in greater awareness of the right of sepulcher. Even so, for those who indeed know enough to seek the return of the deceased's organs, the majority provides no "solace and comfort," and little assurance, that their request will be honored by the medical examiner.[568]

Despite the hope of Rivera J that the right of sepulcher in New York will receive greater weight through public knowledge and legislation, it had been suggested several months prior to the Shipley decision that the "decay" of the right of sepulcher had already begun in New York appellate court decisions.[569]

Other American cases have considered the next of kin's control of retained organs in reference to a property interest. The case of *Hainey v Parrott*, involving the retention and subsequent

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[565] *Ibid* at 13.

[566] *Ibid* at 15.

[567] *Ibid* at 9.

[568] *Ibid* at 23.

[569] Christopher A Bacotti, "Right of Sepulcher: Reconciling Changing Views and Standards", (April 2, 2015) New York Law Journal, online: www.newyorklawjournal.com.

cremation of a brain collected at autopsy for diagnostic purposes resulted in a substantial class action settlement against the Ohio state government.[570] Beckwith J, in finding a "constitutional property interest" in the retained organs,[571] noted that although the coroner had the authority to retain the organs for diagnostic purposes, there was no legal prohibition keeping the coroner from contacting the plaintiffs after the examination had been completed to allow them the choice of disposition,[572] as in the *Kohn* decision.

The Ohio state government's response to this decision was legislation deeming retained forensic autopsy specimens, including organs, to be medical waste, bypassing the requirement for consent from the legal next of kin for instruction as to find disbursement of the organ.[573] This legislation resulted in a subsequent finding of no property interest of next of kin in a brain retained for the purpose of a death investigation.[574] The Ohio state's decision to legislate retained organs as waste effectively opened the door to the subsequent use of the retained organs in genetic research.[575]

The Michigan Court of Appeal in *Waeschle v Dragovic* found that a plaintiff had not proven a constitutionally protected property interest in her mother's brain, retained and subsequently cremated in the course of a death investigation,[576] but concluded that they''…were under no obligation to determine the existence of the scope of Waeschle's right to her mother's brain in the present case."[577]

In *Newman v Sathyavaglswaran*,[578] the Court, in reaching its decision, stated that: "Under traditional common law principles, serving a duty to protect the dignity of the human body in its

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[570] *Hainey v Parrott*, 2005 U.S. District Lexis 44837, case no. 1:02-CV-733, Motion granted by *Hainey v Parrott*, 2007 U.S. Dist. LEXIS 69647 (S.D. Ohio, Sept 20, 2007).

[571] *Ibid* at III A.

[572] *Ibid* at III C. The Court noted that unlike *Brotherton*, the organs here were retained for diagnostic purposes. (at III A). In Brotherton *v Cleveland*, 923 F 2d. 477 (6th Cir. 1991), and *Whaley v County of Tuscola* 58 F.3d 1111; 1995 US Court of Appeals, (6th Cir.), no. 94-1451, the respective Courts also found the next of kin had a property interest in retained organs.

[573] *Supra* note 228 at "Organ Retention in Forensic Autopsy."

[574] *Albrecht v Treon*, 617 F. 3d 890, 2010 U.S. App. LEXIS 17659, 2010 FED App. 0260P (6th Cir).

[575] Subsequent use of organs and tissue

[576] *Waeschle v Dragovic*, 576 F. 3d 539, 2009 U.S. App. LEXIS 18127, 2009 App. 0286A (6th Cir.).

[577] *Ibid* at II A 2.

[578] *Supra* note 222.

final disposition that is deeply rooted in our legal history and social traditions, the parents had exclusive and legitimate claims of entitlement to possess, control, dispose and prevent the violation of the corneas and other parts of the bodies of their deceased children."[579]

These American cases illustrate that Courts have not barred a death investigator from retaining organs for the purpose of the death investigation, but have, in some instances, found a responsibility to notify next of kin to enable them to choose a means of disposition for the retained organ, as in Ontario's *Coroner's Act* Regulation 180. Importantly, the Courts were not asked on the facts to consider a case where the retention included research as a subsequent use. In Canada, in provinces without legislated authority to retain organs, a Court may reach a similar decision as in the American cases, finding a right to retain for death investigation purposes, but a responsibility to notify and consult next of kin as to the organ's subsequent disposition, as has been legislated in Ontario.

United Kingdom

The issue of organ retention at autopsy has also made its mark in the United Kingdom, leading to statutory control of the process, as noted above, taking an opposite approach to the Ohio legislated solution in relation to the control granted to the next of kin. In summary, organ retention, unlike organ donation, is for the purpose of determining cause of death in death investigation systems, and importantly, unlike organ donation, does not require consent from the deceased's next of kin for this purpose. When a deceased's legal next of kin, either based on religious, cultural or individualistic grounds take issue with organ retention, the importance of 'body wholeness', body identity and the desire that the deceased and his separate organs be treated with dignity become apparent. Respecting the next of kin's control of the retained organ may be acknowledged, not by requiring consent for retention, but by acknowledging the family's right of disposal when the organ is no longer relevant to the death investigation, as has been legislated in Ontario, although not in other provinces to date.

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[579] *Ibid.*

Retained organs would appear to lie in legal limbo: would such organs be deemed as donated, and thus require consent for use in genetic research as per provincial organ donation legislation, or would these retained organs be considered equivalent to tissue samples retained at a forensic autopsy for diagnostic purposes? What is an 'organ' and what is 'tissue' is neither consistent nor clear in Canada.

Not only the cadaver, but its constituent organs have significance to the deceased's family and society. The next of kin's potential role in organ disposition gives rise to the question of the necessity for consent of the decedent's legal next of kin for organ retention if it is to be used for research on the grounds of their legal right to control disposition of the deceased. The legal question is thus whether consent of the deceased's legal next of kin is required for retention of whole organs in mandatory (forensic) autopsies for diagnostic non-research purposes in Canada.[580] In provinces that do not statutorily authorize retention of organs for this purpose, the answer is unclear, although a Court has yet to consider this legal question. It is therefore necessary to consider the control of tissue collected in a forensic autopsy in Canada, specifically in reference to who may have control of tissue collected for diagnostic purposes, and how that may impact the requirement for consent in its potential use in genetic research.

The Law and Tissue – Who Has Control?

The previous sections of this paper argued that the legal next of kin have control of the body, grounded in the dignity owed the deceased. The control of the body is limited for the purpose of final disposition of the cadaver. This relationship between the living and the decedent also exists in the context of organ retention by a death investigator, where subsequent control of the retained organ granted by next of kin for disposition reflects the importance of 'body wholeness' to the family. Respect for the autonomy of the donor when alive, when expressed through the consent process, is protected in body and organ donation legislation. Organs may therefore be owed dignity in the context of organ retention in a death investigation system or may reflect the personal autonomy of a donor who consents to post mortem use in organ donation legislation.

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[580] See *supra* note 46. The authors argue against the need for consent from next of kin to retain organs in death investigations.

This section will consider the control of tissue recovered at a forensic autopsy that is subsequently used for genetic research: should similar autonomy and dignity - based respect be extended to tissue samples and data?[581] It will be argued that protection of the decedent's genetic information privacy, and thus that of his genetic relatives is required through a consent process.

In determining if consent is required for research use of post mortem tissue derived under the jurisdiction of death investigation systems, several questions will be considered concerning genetic research on cadaverically derived tissue, in general. First, is consent required for the use of the physical tissue, or for the genetic information within the tissue? Jurisprudence in Canada,[582] America,[583] Australia[584] and the United Kingdom[585] have found a property interest in excised human tissue, legally differentiating tissue excised from cadavers and organs, where control in the latter is purpose-based, and not proprietary in nature. Limited to date to a single lower court common law case in Canada, a property model has nevertheless been set as precedent in relation to human tissue.[586] This model is problematic in Canada as a basis for a consent model in cadaveric genetic research, however, as will be discussed below. Instead, it will be argued that "human tissue is, in a fundamental sense, personal health information that can be forever linked to the individual who provided it."[587]

Secondly, if consent relates to genetic data use, is genetic data personal health information? Both Canadian jurisprudence and academic literature indicate that the answer is yes.
Finally, if genetic data is personal health information, from whom is consent required, that is, the decedent or his next of kin? It will be argued that consent is required from the cadaveric donor, not his legal next of kin for genetic research from forensically derived genetic information. If this consent is not obtained in life, genetic research should not proceed. If cadaveric consent had

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[581] Anne Marie Tassé, "Biobanking and Deceased Persons" (2011) 130 Human Genetics 415 at 420.
[582] *Piljak Estate v Abraham*, 2014 ONSC 2893.
[583] See below at 92.
[584] See below at 92-93.
[585] *Supra* note 379.
[586] Jessica Wright *et al*, "Regulating Tissue Research: Do We Need Additional Rules to Protect Research Participants?" (2010) 17 European Journal of Health Law 455 at 460.
[587] Timothy Caulfield, "Who owns your tissue? You'd be surprised" *The Globe and Mail*, (20 June 2014), online: https://www.theglobeandmail.com/opinion/who-owns-your-tissue-youd-be-surprised/article19256582/.

been obtained in life, consent form genetic next of kin is also required for genetic research using shared cadaveric DNA.

Consent for Use of Tissue in Genetic Research

Death Investigation Legislation

Provincial death investigation legislation in Canada is disparate in reference to tissue and its use in research. Death investigation statutes in Québec, New Brunswick and the Yukon do not address the issue,[588] whereas Nova Scotia, Alberta, and Newfoundland and Labrador legislation allows for retrieval of tissue if consent has been obtained under the respective provinces' tissue donor legislation.[589]

Some provinces specifically limit use only for the purpose of the death investigation.[590] At the other end of the spectrum, Ontario's *Coroner Act* gives the Chief Coroner legislated authority to disclose personal information for the purpose of research, if the requesting body ensures the privacy and confidentiality of the information, to be approved by the province's Information and Privacy Commissioner.[591] Genetic information derived from a body whose death was investigated under this *Act* would likely fall under this section of the statute. If reliance is placed on anonymity of genetic data,[592] however, ensuring privacy and confidentiality of the information may not be possible in practice.

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[588] *An Act Respecting the Determination of the Causes and Circumstances of Death*, CQLR c R-0.2; *Coroners Act*, RSNB 1973, c C-23; *Coroners Act*, RSY 2002, c 44.

[589] *Fatality Inquiries Act*, RSA 2000, c F-M 9, s 26 does not refer to use of removed tissue in research, relying on the province's organ and tissue donation legislation for this purpose. The *Fatality Investigations Act*, SNS 2001, c 31, s 14(1), and the *Fatalities Investigations Act*, SNL 1995, c F-6.1, s 15 specifically refer to research as a potential use. This suggests that in these provinces, use of the forensically derived tissue in research requires consent, here through the respective province's donor statutes. The *Coroners Act*, SBC 2007, c 15, s 6(3) allows for the transfer of tissue from the province if consent has been obtained under the province's *Human Tissue Gift Act*. This section is significant in reference to the use in research of cadaveric tissue recovered in a coroner's authorized autopsy, whereby it would preclude the transfer of the tissue outside of the province absent consent, for example, although genetic data recovered from the tissue in the province, and then shared outside of the province, may not be protected by this section of the legislation. Arguably, this section could also be read to suggest that tissue recovered at autopsy, absent consent for use under the *Human Tissue Gift Act,* remains associated with the body, potentially giving next of kin authority for the tissue's disposition.

[590] *Coroners Act*, RSPEI 1988, c C-25, s 10(4), *The Coroners Act*, SS 1999, c C-38.01, s 14(4) refer to "any part of the body", which would include tissue. *The Fatality Inquiries Act*, CCSM 1990, c F52, s 13(1) uses the term "a part of the body for scientific or laboratory examination."

[591] *Coroners Act*, RSO 1990, c C.37, s 52.1.

[592] *Supra* notes 106, 107.

Finally, legislation in Nunavut,[593] Manitoba[594] and Newfoundland and Labrador[595] allow for removal without consent of a cadaveric pituitary gland for clinical use, that is, treatment of growth hormone deficiency. Although clinical use of cadaveric pituitary gland tissue ceased in 1985,[596] these statutes do currently give legislative authority for cadaveric tissue use, but only for clinical use, and not explicitly for subsequent research.

In summary, relying on death investigation statutes, tissue collected under the authority of a death investigation could potentially be used for genetic research in Québec, New Brunswick, the Yukon, Ontario, and British Columbia. The Québec legislation only refers to consent for transplantation,[597] leaving Québec without legislative guidance on this issue. However, the human tissue donor statutes of the remaining four provinces/territories would be applicable to decedents under the authority of a death investigation system, and therefore, and relying on these statutes, consent would be required for use of tissue in research, as it would be for decedents not undergoing a death investigation.[598] Relying on these statutory authorities and with the exception of Québec, consent is required for use of forensic cadaveric tissue in genetic research. However, a lower court case in Ontario added a new legal layer to the question of who has control of excised tissue in Canada. In *Piljak Estate v Abraham,*[599] a proprietary interest was held to exist in human tissue.

Case Law - *Piljak Estate v Abraham*

Until recently, Canadian jurisprudence has not been clear on the proprietary interest (if any) in human tissue.[600] In *Piljak Estate v Abraham,*[601] the Ontario Supreme Court established that

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[593] *Coroners Act*, RSNWT(Nu) 1988, c C-20, s 14(4).
[594] *The Human Tissue Gift Act*, CCSM c H-180, s 6(1).
[595] *Human Tissue Act*, RSNL 1990, c H-15, amended 2006, c40 s21, s 16.
[596] Heather Dean, "Growth Hormone Therapy in Children in Canada: What Have We Learned in the Past Decade from an Unlimited Supply of Growth Hormone?" (1999) 22:2 Clinical and Investigative Medicine 60 at 61; Vageesh S Ayyar, "History of Growth Hormone Therapy" (2011) 15:3 Indian Journal of Endocrinology and Metabolism 162.
[597] *An Act to Facilitate Organ and Tissue Donation,* SQ 2010, c 38, s 2.0.9(1).
[598] *Supra* note 473.
[599] *Supra* note 582.
[600] *Supra* note 587.
[601] *Supra* note 582.

human tissue is property.[602] In *Piljak*, the question arose as a procedural matter[603] concerning the defendant physicians' request for genetic testing on excised tissue removed in the course of their treatment of their patient, Ms. Piljak.[604] Two issues arose: "… whether a human tissue sample is personal property, and whether … the [genetic] tests are necessary to the determination of the issue of standard of care."[605]

On the first issue, the court held that tissue was property belonging to the hospital,[606] the decision relying on a single medical peer reviewed article admitted as evidence by the defendants.[607] In the evidentiary paper, Cheung and Asa argue that tissue, specifically diagnostic tissue as would be recovered at a forensic autopsy, is the property of the hospital or institution where it was collected.[608] Relying on *McInerney v McDonald*,[609] the authors argue that the individual tissue source should not have an interest to access the tissue, since "… tissue cannot be duplicated without destroying a portion of the original…"[610] This assertion may be true of the tissue itself, but fails to address the genetic data for which the tissue would be used in research, which is easily duplicated.[611]

The Court further differentiated the deceased patient from her excised tissue in finding that Rule 33[612] was not applicable to the question of whether the plaintiffs should receive a copy of the

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[602] *Ibid* at ¶ 27.
[603] Rule 32.01(1) of the Ontario *Rules of Civil Procedure*, RRO 1990, Reg 194 states: "The court may make an order for the inspection of real or personal property where it appears to be necessary for the proper determination of an issue in a proceeding." Rule 32.01(2)(c) specifies that "[f]or the purpose of the inspection, the court may …permit the taking of samples, the making of observations or the conducting of tests or experiments."
[604] Supra note 582. The defendants removed a colonic tumor from the patient (while alive), which was diagnosed microscopically as benign. The patient subsequently developed metastatic cancer and died. The estate of Ms. Piljak sued the defendants for negligence in Ms. Piljak's death. The defendants argued that genetic testing of the tumor would go to the defendants' standard of care, as the testing may indicate that the tumor expressed the DNA of a cancer known to be easily missed due to its appearance alone.
[605] Ibid at ¶ 18.
[606] Ibid at ¶ 27.
[607] Ibid at ¶ 26, citing Carol C Cheung, Bella R Martin, & Sylvia L Asa, "Defining Diagnostic Tissue in the Era of Personalized Medicine" (2013) Can Med Assoc J 135. At ¶ 27, The Court, relying on this paper, found that "… the excised tissue is subject to rights of ownership and since the tissue is clearly a moveable,…[concluded] that it is personal property to which inspection and testing under rule 32.01 may apply."
[608] *Supra* note 81 at 137.
[609] *McInerney v MacDonald,* [1992] 2 RCS 138, 93 DLR (4th) 415.
[610] *Supra* note 81 at 137.
[611] Jay Shendure & Erez Liberman Aiden, "The Expanding Scope of DNA Sequencing" (2012) 30:11 Nature Biotechnology 1084.
[612] Ontario *Rules of Civil Procedure*, RRO 1990, Rule 33 addresses "medical examination of parties."

report of the genetic testing results. [613] Here, the Court reasoned that a medical examination of excised tissue (removed while she was alive) is not synonymous with a medical examination of the now deceased patient.

The role of consent in this case is pertinent. Ms. Piljak would have been required to give informed consent to the excision of the tissue in question.[614] The genetic next of kin, who would have been affected by the results of the genetic testing of the tumor, did not consent to the genetic testing of the tissue.[615] In its review of the evidence on the motion concerning the genetic testing of the tissue,[616] the Court recognized factors specific to the nature of the testing, noting that the "normal purpose"[617] of genetic testing of excised tissue is for the treatment of the source patient, and for genetic counselling of family.[618] The court also recognized the potential significance of the genetic information results to the genetic next of kin.[619] In effect, the court differentiated the tissue from the information to be extracted from the tissue. Thus, although property in tissue in this limited legal context was determined, the genetic information within that tissue was differentiated.

The significance of *Piljak* remains uncertain,[620] as no subsequent Canadian case law to date has applied the finding of tissue as property, and the issue has not come before the Courts in Canada in the context of genetic research. If tissue is held to be property, how this squares with the dignity based jurisprudence concerning cadavers and their constituent parts remains unclear, that is, whether the tissue is property in the context of American jurisprudence,[621] or is more in

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[613] *Supra* note 582 at ¶32.

[614] See for example, *supra* note 81 at 138. The terms of the consent in *Piljak* are unknown, as the consent form was not admitted as evidence. The court did note that the tissue was "… initially excised for diagnostic purposes." (at ¶ 29). It is unlikely that the use proscribed by the defendant physicians would have been included as a potential use in Ms. Piljak's informed consent, i.e. for the purpose of their defense in a court matter.

[615] *Supra* note 582 at ¶ 16.

[616] The motion was dismissed. Piljak at ¶ 39 and 56.

[617] *Supra* note at ¶ 16.

[618] *Ibid* at ¶ 16

[619] *Ibid* at ¶ 16.

[620] *Supra* note 587. Caulfield notes that *Piljak* "… was focused on a relatively narrow procedural matter and does not have much precedential weight. Still, this is the first Canadian legal decision on point. It will be influential, if only in a symbolic sense."

[621] See above at 83.

keeping with the trust model, whereby an institution is deemed to hold tissue in trust,[622] the latter consistent with the concept of respecting dignity.

Although a thorough discussion of "tissue as property" models is beyond the scope of this paper, what is important to note is that a property interest in tissue has been judicially differentiated from the genetic information within the tissue. Further, a Canadian Court has held that the value of tissue slides lies in the potential recoverable data from the tissue, rather than the tissue itself,[623] legally differentiating genetic information from a tissue property model.[624]

Consent to Use of Information in Genetic Research

Thus, consent in genetic research refers to the use of the source cadaver's genetic information, not the tissue. LaForest J, in *R v Dyment*, differentiated information privacy from its source biomaterials, stating that "… the use of a person's body without his consent to obtain information about him, invades an area of personal privacy essential to the maintenance of human dignity"[625] and found that any property interest in the blood sample that may be claimed by the hospital as "wholly irrelevant."[626] In the context of this paper, the genetic data recoverable from forensically derived cadaveric tissue would thus be unlikely to give rise to a legal property interest in Canada.

In America, the privacy right in cadaveric tissue has been held to rest with the cadaver, and not his genetic or legal next of kin, grounded in the "… right to make decisions concerning the integrity of one's body."[627] Importantly, this decision was based on the consent for removal of

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[622] Ogbogu, *supra* note 77. See also Charo, *supra* note 30 at 1519, who suggests that" … our relationship with our bodies may be viewed as a trusteeship."

[623] For example, in *MacKenzie et al. v. Baker et. al.*, 56 O.R. (3d) 716, [2001] O.J. No. 4506 at ¶ 19, MacLeod J, in determining damages for microscopic human tissue slides damaged by flooding in a researcher's home, found that the value rested in the loss of further research opportunities, not in the tissue slides themselves.

[624] In the Australian case of *Roche v Douglas* as Administrator of the Estate of Edward John Hamilton Rowan (Dec) [2000] WASC 146, the held that tissue had by a laboratory was property but did not determine ownership pf the tissue. Importantly, the Court noted that DNA testing was not at issue, thus legally separating the proprietary interest in the tissue from the genetic information contained therein.

[625] *Supra* note 132 at 431-432.

[626] *Ibid* at 432.

[627] Arnold, *supra* note 465 at 158, citing *Tillman v Detroit Receiving Hospital,* 360 N.W. 2d 275 (Mich. Ct. App. 1984); 138 Mich. App. 683 (1984). In this case, the decedent's next of kin argued that the removal of decedent's

the tissue itself, not on the basis of genetic information with the tissue. It has been argued that consent to research includes the right to control of tissue with the right to refuse consent for future research, grounded in rights including the right of privacy.[628] The authors further conclude "identifiable information" that remains in donated[629] tissue following its use in research gives the donor a "limited right of control" of that information.[630] If the identifiable information in donated tissue retains a right to privacy, it is likely that tissue not donated, but used in research (as may occur in death investigation systems), would grant at least the same right to privacy.

Despite the "property in tissue" model's potential role in adding to those who may control a cadaver in Canada, the fundamental issues of dignity and autonomy in consent in genetic research relate to risk of a breach of privacy in relation to an individual's genetic information. Those at risk include the cadaver if the breach occurs within the time limit in which his privacy is statutorily protected (supporting the need for consent for use of the decedent's genetic information), as well as those relatives who share the cadaveric genetic information used in research.

Cadaveric Genetic Information - Risk of Privacy Breach in Research

Postmortem Personal Information Privacy Protection in Canada

To determine if there is risk to cadaveric genetic information in research, it must first be determined if the dead have privacy rights in Canada. Both provincial and federal privacy legislation protect, but temporally limit the general personal information privacy interests of the

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corneas was unlawful and done without their consent. Further state legislation granted the medical examiner the right to remove corneas in certain circumstances, including no knowledge of objection of corneal removal by the next of kin.

[628] Ogbogu, *supra* note 31, relying on *Moore v Regents of the University of California*, 51 Cal 3d 120 (Sup Ct 1990).

[629] It is assumed that "donated" implies consent for use of the tissue.

[630] Ogbogu, *supra* note 31, relying on *Washington University v Catalona,* 490 F 3d 667 (8th Cir 2007).

dead. Both the public[631] and private sector[632] federal privacy legislation protects personal information for up to twenty years after death. The *Personal Information Protection and Electronic Documents Act* (PIPEDA) specifies that this protection extends to personal health information.[633]

Provincial statutes concerning the privacy interest in personal information after death have similar time limits. Provinces' time limits for protection of postmortem personal information include 25 years in Alberta,[634] Yukon,[635] Prince Edward Island,[636] and Saskatchewan,[637] 10

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[631] *Privacy Act*, RSC 1985, c P-21, s 3(m). This time limit relates to use (s 7), disclosure (s 8), and includes the personal information about another individual (s 26), the latter supporting the argument that genetic next of kin be required to consent to genetic research. The Act defines personal information as "…information about an identifiable individual that is recorded in any form…" and includes information about "…information relating to the race, national or ethnic origin, [and] colour" ('personal information', s3(a)), information that is consistent with genetic information).

[632] Personal Information Protection and *Electronic Documents Act*, SC 2000, c 5, s 3(h), after which disclosure may be made without consent.

[633] *Ibid*, s 2(1)(c).

[634] *Freedom of Information and Protection of Privacy Act,* RSA 2000, c F-25, s 43(1)(a)(i).

[635] *Access to Information and Protection of Privacy Act,* RSY 2002, c 1, s 39, with disclosure specified for 'archival or historical purposes.' Sections 25(3)(d) states" "…A disclosure of personal information is not an unreasonable invasion of a third party's personal privacy if… the disclosure is for a research … purpose in accordance with section 38, a section which authorizes use of identifiable information if "… any link between the record and any other records is not harmful to the individuals that the information is about and the benefits to be derived from the record linkage are clearly in the public interest…" (s 38(b)).

[636] *Freedom of Information and Protection of Privacy Act,* RSPEI 1988, c F-15.01, s 40(a)(i)(C). This section refers to disclosure after this time period specifically for research purposes.

[637] *The Freedom of Information and Protection of Privacy Act,* SS 1990-91, c F-22.01, s 30(1).

years in Manitoba,[638] 20 years in British Columbia, [639]New Brunswick,[640] Nova Scotia,[641] and Newfoundland.[642]

In Ontario, a time limit of 30 years is included in the protection of personal information legislation after the individual's death.[643] However, personal health information in Ontario is generally protected for 50 years.[644] The Ontario statute's definition of "personal health information" does specify that the data be identifiable to an individual.[645] However, British Columbia's specific e-health information protection legislation[646] does not specifically refer to the health information of the dead, unlike Ontario's personal health information protection

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[638] *The Freedom of Information and Protection of Privacy Act,* CCSM c F175, s 17(4)(h). This section states that "…Despite subsection (2), disclosure of personal information is not an unreasonable invasion of a third party's privacy if…the information is about an individual who has been dead for more than 10 years." Section 2(a) states that "…personal information is personal health information." Therefore, in Manitoba, there is no indefinite legislated protection of genetic information, again supporting the need for consent for research involving genetic next of kin of decedents in a death investigation system.

[639] *Freedom of Information and Protection of Privacy Act,* RSBC 1996, c 165, s 36(1)(c). This section falls under the heading of "disclosure for archival or historical purposes", which could include an archived genetic database, such as a biobank.

[640] *Right to Information and Protection of Privacy Act,* SNB 2009, c R-10.6, s 21(3)(i). Section 21(3) states that disclosure of personal information is not an unreasonable invasion of a third party's privacy…" beyond this 20 year period.

[641] *Freedom of Information and Protection of Privacy Act,* SNS 1993, c 5, s 30(c). This section falls under the heading of 'disclosure by public archives', which could include a public biobank. As in the Alberta statute, disclosure is allowed beyond this time period if it is personal information (s 20). In this *Act,* 'personal information' (s 3(1)(i)) is defined as "… recorded information about an identifiable individual, including … an individual's race…color" (s 3(1)(i)(ii)), …sex…"(s3(1)(i)(iii)), "blood type or inheritable characteristics…" (s3(1)(i)(v) and "…information about the individual's health-care history…" (s3(1)(i)(vi). Importantly, however, disclosure for research purposes is authorized as reasonable concerning third party privacy (s 20(4)(d)), including for identifiable personal information (s 29).

[642] *Access to Information and Protection of Privacy Act,* 2015, SNL 2015, c A-1.2, s 71(c). Section 40(2)(e) states: "A disclosure of personal information is not an unreasonable invasion of a third party's personal privacy where…the disclosure is for a research or statistical purpose," and in s 70(a)(b), "…the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form… [and]… any record linkage is not harmful to the individuals that information is about and the benefits to be derived from the record linkage are clearly in the public interest."

[643] *Freedom of Information and Protection of Privacy Act,* RSO 1990, c F.31, s2(2), where "personal information" does not include information about an individual who has been deceased for more than 30 years."

[644] *Personal Health Information Protection Act,* SO 2004, c 3 schedule A, s 9(1).

[645] Supra note 644, s 2 'individual'., and 'personal health information' "…relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance" (s 4).

[646] *E-Health (Personal Health Information Access and Protection of Privacy) Act,* SBC 2008 c. 38. Genetic data stored in electronic format would fall under this legislation.

legislation,[647] in which an "individual" is defined as living or deceased,[648] and refers to previous, as well as contemporaneous collection of personal health information.[649]

In The United States, the HIPPA[650] privacy rule, like the Ontario personal health information privacy legislation, applies for 50 years after death, with an important exception relevant to this discussion: disclosure is permitted "…for research that is solely on the protected health information of decedents."[651] Again, the privacy of the personal health information of the deceased's next of kin is trumped by that of the living next of kin. In Canada, for example, Alberta's *Health Information Act,* RSA 200, c H-H, s 32(1) allows disclosure of non identifying health information by a custodian for any purpose. However, the province's Privacy Commissioner must be notified by the custodian of the data disclosure if the purpose includes data-matching *and* if the disclosure will not be made to a custodian, as defined in the *Act*.[652] Interestingly, neither the *Act* nor the *Act*'s Regulation[653] include individuals operating under the *Fatality Inquiries Act*, *i.e.* death investigators as 'custodians', suggesting that, at least in Alberta, death investigators may not be subject to the above disclosure provisions in the *Health Information Act.*

As Kels and Kels note, the 50-year protection period, roughly equivalent to two familial generations, reflects the attrition over time of family members available to give consent for release of the deceased's personal health information, supporting the view that privacy of cadaveric personal health information is, in effect, protection of the privacy of the genetic relatives' shared genetic information:

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[647] *Personal Health Information Protection Act,* SO 2004 c. 3 schedule A.

[648] *Supra* note 647, s 2 "individual"

[649] *Ibid.*

[650] *Health Insurance Portability and Accountability Act*, 45 CFR 160.103. This statute will also be referred to as (*HIPAA*).

[651] *Ibid*, definition of "protected health information." Knoppers notes that de-identified data is also not considered 'human subject' research, and thus would not require the approval of a research ethics board (see Bartha M Knoppers, "Consent to 'Personal' Genomics and Privacy" (2010) 11:6 EMBO Reporter, 416 at 418.) It is not clear if cadaveric genetic research that includes genetic information of next of kin would be protected by the 50-year non-disclosure in the *HIPPA*.

[652] "Data-matching" is defined in the *Act* as "…the creation of individually identifying health information by combining individually identifying or non-identifying health information or other information from 2 or more electronic databases, without the consent of the individuals who are the subjects of the information" in s 1(1)(g), suggesting support for Knoppers opinion (*ibid.*)

[653] Alta Reg 70/2001, s 2.

> "… the fact that personal representatives who can authorize disclosure are increasingly hard to locate with the passage of time suggests that there may be fewer individuals remaining who are intimately linked with the decedent and likely to require protection from intrusion."[654]

These statutory privacy protections further lend credence to the argument that consent should be required for cadaveric genetic research. If a government gives legal precedence of the privacy interests of the living over the privacy of the dead, then, to ensure the dignity-based autonomy governing the right to choose what is done to one's body after death, an individual should have the right to choose to participate (or not) in genetic research after death. Equally, if consent is required in research to ensure the participant is aware of their risks, and the potential harm associated with cadaveric genetic research is risk of breach of privacy, the protection of post mortem information privacy supports the need for consent from the information source, that is, the deceased individual when alive.

Although post-mortem privacy protection is in place in Canada, the degree of privacy expected after death is not legislated, particularly in reference to expected privacy of personal information in research. Both Articles 5.5A and 12.3A of the TCPS2 include a requirement by researchers to simply "… protect the privacy of individuals."[655] It is therefore necessary to review the jurisprudential parameters of what is a reasonable expectation of privacy in reference to personal information in Canada, and specifically, one's personal genetic information. In practice, a deceased individual clearly can not have a reasonable expectation in his privacy, as he cannot be autonomous, as discussed above. However, the relational aspect of privacy[656] leads to the supposition that living relatives who share genetic information with the deceased would have a reasonable expectation of privacy in the context of cadaveric genetic research.

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[654] Charles G Kels & Lori H Kels, "Medical Privacy After Death: Implications of New Modifications to the Health Insurance Portability and Accountability Act Privacy Rule" (2013) 88:10 Mayo Clin Proc 1051 at 1052.

[655] *Supra* note 17, articles 5.5A (c), 12.3A (c).

[656] Hunt, *supra* note 368, and post mortem time limits on privacy protection above at 93.

Reasonable Expectation of Privacy in Genetic Information in Canada

Legislation

Some but not all the provincial and territorial personal information protection statutes require consent for use of personal information, including personal health information.[657] Research ethics boards are left to determine if consent is required for use in the context of research in the Northwest Territories,[658] and the New Brunswick[659] legislation requires consent for collection.[660] In research, disclosure of an individual's personal information does not require consent in Saskatchewan, [661]Newfoundland and Labrador,[662] Nova Scotia[663] and Manitoba.[664] The need for consent for disclosure of personal information in research is left to research ethics boards in

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[657] *Freedom of Information and Protection of Privacy Act,* RSA 2000, c F-25, s 39(i)(b); *Freedom of Information and Protection of Privacy Act,* RSO 1990, c F.31, s 41(1)(a), although he Act does not apply in the hospital or education setting (s 8.1), but may apply to stand alone death investigation facilities that do not have academic associations with universities, for example; *The Freedom of Information and Protection of Privacy Act,* SS 1990-91, c F-22.01, s 28(a), (b), and includes purpose of use; *Personal Health Information Privacy and Access Act*, SNB 2009, c P-7.05, s 19(1)(e), which requires express consent for research; *Access to Information and Protection of Privacy Act,* 2015, SNL 2015, c A-1.2, s 66(1)(b); *Access to Information and Protection of Privacy Act,* RSY 2002, c 1, s 35(1)(b); *Access to Information and Protection of Privacy Act,* SNWT 1994, c 20, s 43(a),(b), and includes purpose of use. Consent for use of personal health information is required by *The Health Information Protection Act*, SS 1999, c H-0.021, s 29(1); *Health Information Privacy And Management Act*, SY 2013, c 16, 55(1)(b); *Personal Health Information Protection Act,* SO 2004, c 3 schedule A, s 29; *Personal Health Information Act*, SNS 2010, c 41, 11.

[658] *Health Information Act*, SNWT 2014, c 2, s69, 71(b), where the need for consent for the use of research is left to a research ethics board.

[659] *Personal Health Information Privacy and Access Act*, SNB 2009, c P-7.05, 27(1)(a).

[660] The *Freedom of Information and Protection of Privacy Act,* RSBC 1996, c 165, s 26(d)(i) requires consent for collection of information, except when disclosure is authorized, as it is in research (s 35(1)(a),(b)).

[661] *The Health Information Protection Act*, SS 1999, c H-0.021, s 29 if the information must be identifiable for the purpose of the research, steps are taken to protect the privacy of the subject and the benefits of the research outweigh the individual's risk to privacy of the information.

[662] *Personal Health Information Act*, SNL 2008, c P-7.01, s 38(e) specifically states that the personal health information of decedents may be disclosed without consent.

[663] *Personal Health Information Act*, SNS 2010, c 41, s 57 has similar wording concerning the need for identifiable information. The statute also allows for disclosure without consent if it is impractical to do so (s 57(c)(v).

[664] *Personal Health Information Act*, CCSM c P33.5, s 24, where similar wording is used to the Saskatchewan and Nova Scotia statutes, and where research ethics board approval is required.

Alberta,[665]Prince Edward Island,[666] Ontario,[667] and New Brunswick.[668] The requirements for disclosure ('release') of personal information in Québec are unique to that province.[669] However, except for British Columbia, Manitoba, and Prince Edward Island, consent is statutorily required for either use or collection of personal information, and except for the Yukon *Access to Information and Protection of Privacy Act*,[670] consent is not necessarily required for disclosure of personal information in research. Therefore, relying on this legislation, consent obtained in life for subsequent cadaveric research in a death investigation system would need to include risks associated with disclosure, collection, and use of genetic information, allowing an individual to choose (or not choose) to consent to post mortem genetic research.[671]

Third party disclosure of personal health information for the purpose of research is authorized (that is, not an unreasonable invasion of the privacy of the third party) in some provinces, if the research is in the public interest,[672]if the research requires that the information be identifiable,[673]

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[665] *Health Information Act*, RSA 2000, c H-5, s 50(1)(a), except if obtaining consent would be unreasonable, impractical or not feasible (s 50(1)(a)(iv).

[666] *Health Information Act,* RSPEI 1988, c H-1.41, s 30(a).

[667] *Personal Health Information Protection Act,* SO 2004, c 3 schedule A, s 44.

[668] *Personal Health Information Privacy and Access Act*, SNB 2009, c P-7.05, s 43(3), where again, consent may be waived if unreasonable or impractical to obtain (s43(3)(c), and if reasonable safeguards to protect the privacy of the information are in place (s 43(3)(d)(1).

[669] The public sector legislation, *Act respecting Access to documents held by public bodies and the Protection of personal information*, CQLR c A-2.1, s 59(5) allows for release of personal information for research purposes "…to a person authorized by the Commission d'accès à information…", the Commission referred to in s 125, including for research. The *Act* in s 53(1) states that personal information is confidential, unless consent for disclosure is obtained from the "…person to whom the information relates." The reference to confidentiality infers a duty to maintain the privacy of the personal information.
The private sector statute, *Act respecting the protection of personal information in the private sector*, CQLR c P-39.1, s 18(8) states that: A person carrying on an enterprise may, without the consent of the person concerned, communicate personal information contained in a file he holds on that person to a person who is authorized to use the information for … research … purposes in accordance with section 21…", the latter section again referencing the authority of The Commission d'accès à l'information.

[670] *Access to Information and Protection of Privacy Act,* RSY 2002, c 1, s 25(2)(3)(a).

[671] See below at 103 in reference to risk to breach of privacy in genetic research.

[672] *Freedom of Information and Protection of Privacy Act, SNS* 1993, c 5, s 29(b), but the *Personal Health Information Act*, SNS 2010, c 41, s 57(c)(iii) requires that the information be as de-identified as possible. *The Freedom of Information and Protection of Privacy Act,* CCSM c F175, s47(4)(b)(iv); *Access to Information and Protection of Privacy Act,* SNWT 1994, c 20, s 35(b).

[673] *Freedom of Information and Protection of Privacy Act, SNS* 1993, c 5, s 29(a); *Freedom of Information and Protection of Privacy Act,* RSPEI 1988, c F-15.01, s 39(a); *Access to Information and Protection of Privacy Act,* 2015, SNL 2015, c A-1.2, s 70(a); *Access to Information and Protection of Privacy Act,* 2015, SNL 2015, c A-1.2, s 70(b); *Access to Information and Protection of Privacy Act,* SNWT 1994, c 20, s 49(a); *Access to Information and Protection of Privacy Act,* SNWT 1994, c 20, s 49(b). The reliance on de-identification of data in the context of genetic information may now be moot: see Amy Gutmann, "Data Re-Identification: Prioritize Privacy" (2013)

and linkage of the data would not harm the privacy of the third party.[674] These exceptions allowing disclosure of third party personal information support the argument that genetic next of kin do not have the genetic information that they share with deceased relatives legislatively protected in Canada.

Case Law

Canadian *Charter* challenges, including those within the scope of the criminal law have been considered by the Supreme Court in reference to privacy of genetic information. Although *Charter* protection is not extended to the dead,[675] *Charter* principles may be applied to reflect Canadian societal values in non-*Charter* claims, as in *Hill*[676] and *Jones.*[677] Equally, the "[c]riminal law has always existed for the purpose of defining the limits of permissible human conduct."[678] Thus, although the Supreme Court of Canada has not specifically considered the issue of research use of forensically derived cadaveric tissue, the Court has defined parameters for the reasonable expectation of privacy of personal information.

The Supreme Court of Canada's criminal law decisions concerning protection of genetic information under section 8 of the *Charter* differentiate tissue discarded, from that obtained directly from the body.[679] However, McKay argues that the "… mischaracterization of genetic material as a mere object, … rather than as core biographical information forming a part of the individual …" in *Stillman* by the Supreme Court of Canada "… fail[ed] to recognize that the

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39:6123 Science 1032; Melissa Gymrek *et al*, "Identifying Personal Genomes by Surname Inference" (2013) 339:6117 Science 321; *Access to Information and Protection of Privacy Act,* RSY 2002, c 1, s 38(a).

[674] *Freedom of Information and Protection of Privacy Act, SNS* 1993, c 5, s 29(a); *Freedom of Information and Protection of Privacy Act,* RSPEI 1988, c F-15.01, s 39(b); *Access to Information and Protection of Privacy Act,* 2015, SNL 2015, c A-1.2, s 70(b); *Access to Information and Protection of Privacy Act,* SNWT 1994, c 20, s 49(b); *Access to Information and Protection of Privacy Act,* RSY 2002, c 1, s 38(b).

[675] *Supra* note 300.

[676] *Hill*, *supra* note 131.

[677] *Jones*, *supra* note 131.

[678] Morris Manning & Peter Sankoff, *Manning, Mewett & Sankoff: Criminal Law*, 5th ed (Markham, Ont: LexisNexis Canada Inc., 2015) at 13.

[679] Margaret H McKay, "Case Commentary: Genetic Material and Section 8: The Other Side of *Stillman*" (1998) 8 WRLSI 139 at ¶ 149-151.

ongoing relationship between individuals and their genetic material survives the necessary discard of [the individual's tissue]."[680]

The Court also considered what is a reasonable expectation in informational privacy in *R v Plant*, a section 8 *Charter* challenge concerning a warrantless search of an electrical utility's computer records of a home.[681] In a 6:1 decision, Sopinka J, for the majority, wrote that "[t]he purpose of s. 8 is to protect intrusion of the state on an individual's privacy." [682]

In relation to information privacy protection under section 8, the Court framed a "personal and confidential" standard:

> In fostering the underlying values of dignity, integrity and autonomy, it is fitting that s. 8 of the *Charter* should seek to protect a biographical core of personal information which individuals in a free and democratic society would wish to maintain and control from dissemination to the state. This would include information which tends to reveal intimate details of the lifestyle and personal choices of the individual.[683]

The majority, despite finding that the warrantless seizure of the computer records was not unreasonable,[684] did, however, indicate that "[i]f commercial records contain material which meets the 'personal and confidential' standard set out above, the commercial nature of the relationship between the parties will not necessarily foreclose a s. 8 claim,"[685] as might occur if cadaveric tissue resulted in financial gain for a researcher as a result of its use in genetic research, for example.[686]

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[680] *Ibid* at 150.

[681] *R. v. Plant*, [1993] 3 R.C.S. The Section 8 challenge also concerned a perimeter search of the home by police in their investigation as to whether marijuana was being grown in the house. The majority found that the perimeter search was unreasonable, but the seizure of the computer records was not.

[682] *Ibid* at 291.

[683] *Ibid* at 293.

[684] *Ibid* at 282.The Court held that the records were not confidential, reflecting only electrical consumption use, and did "… not reveal intimate details of the accused's life.".

[685] *Ibid* at 294. The "personal and confidential" standard would be likely met in a breach of personal health information, including genetic data. See for example *McInerney, supra* note 18 at 148, where LaForest J notes that personal health information goes to "… the personal integrity and autonomy of the individual."

[686] The case of Henrietta Lacks in America is a well-known example of a researcher's financial gain from the use of an individual's genetic information in research. Ms. Lacks' cancerous cells were removed from her cervix without her knowledge or consent during surgery to remove a tumour from her cervix (see Skloot at 33). At the time, consent was not required for removal of tissue at surgery but was required for performing an autopsy including removal of tissue (Skloot at 89). Ms. Lacks underwent an autopsy with the consent of her husband prior to which he was informed that the autopsy's purpose included the doctors' wish to "… run tests that might help his children someday." (Skloot at 89-90). A discussion of the subsequent legal issues raised by Ms. Lacks genetic next of kin concerning the use of her cancerous cells (HeLa cells) in world-wide research is beyond the scope of this paper,

For example, in *R v Spencer,*[687] the Supreme Court of Canada has recently affirmed that within the concept of information privacy is the right to control the dissemination of that information,[688] and that the expectation that confidential information "… shall remain confidential to the persons to whom, and restricted to the purposes for which it is divulged, must be protected."[689] Relying on *Spencer*,[690] in a death investigation system, the initial "divulging" of the genetic data, *i.e.* the collection of tissue proceeds without consent, would require subsequent "divulging" predicated on the consent of the tissue donor. The only point of control is when consent is given to the use of the genetic information.

Although only genetic next of kin may be considered to have an ongoing expectation of privacy of their shared genetic information in the context of genetic research, a Canadian Court may find that only the deceased individual may consent to use of his genetic information in research on the grounds of the individualistic nature of privacy. In *AW v CW,*[691] the Court, in interpreting the *Status of Children Act,* ruled that living individuals, whether legal next of kin or otherwise, could not consent on behalf of the deceased to the use of the body for parental genetic testing. In referring to the right to choose in relation to the cadaver, Barrett J stated

> … [t]he decision to face the possibility [of paternity genetic testing] will no doubt often be a deliberate one. Individuals may have many different reasons for giving or withholding their co-operation. The reason will generally concern aspects of their private lives on which they are entitled to make judgments in their own interests and the interests of family members and others to whom they bear affection or owe moral duties.[692]

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including whether the autopsy consent was informed (see for example, Barry K Shuster, "In the Wake of Henrietta Lacks: Current U.S. Law and Policy on Control and Ownership of One's Body Tissues Used in Medical Research" (2017) 3:2 *The Journal of Healthcare Ethics & Administration* 8. The significant difference however, between the Lacks case and an autopsy performed in a death investigation system in Canada is the absence of consent for the procedure in the latter. Thus, the collection of Ms. Lacks' malignant cells at surgery is analogous to the collection of tissue at forensic autopsies in Canada, that is, there is no requirement for consent for collection of tissue during the procedure. Subsequent use in research, however, does have legal and policy requirements, as discussed elsewhere in this paper.

[687] See *R v Spencer*, [2014] SCC 43 at ¶ 17, a section 8 *Charter* challenge concerning pornography viewed on a home computer.

[688] *Ibid* at ¶ 40, citing *R v Dyment.*

[689] *Ibid* at ¶ 40, citing *R v Duarte.*

[690] *Spencer, supra* note 683.

[691] *AW v CW*, [2002] NSWSC 301.

[692] *Ibid* at ¶ 19.

In relation to genetic research, there is clearly a risk to privacy associated with unexpected results, including those related to parentage, and thus, the cadaveric source should be a requirement for valid consent to the use of his genetic information in research, even if genetic relatives have given their consent.

In Canada, in *L.D. (Guardian ad litem of) v Provincial Health Services Authority*,[693] and *Jones v Tsige*,[694] a reasonable person standard was applied to a reasonable expectation of privacy, with differing results. The plaintiffs in *L.D.* did not prove a privacy breach, but rather their claim relating to privacy was based on risk of a breach.[695] Sewell J concluded that

> *Arndt* at para. 9 makes it clear that a reasonable person must be taken to possess the patient's reasonable beliefs, fears, desires, concerns and expectations, which will usually be revealed by the questions posed by the patient. [The plaintiff] does not allege that she ever made her concerns about long term storage or what would be done with the blood samples after testing known to the Authority or to the midwives who collected the blood samples. I see no genuine issue as to whether a plaintiff who failed to make her particular concerns known to the Authority could rely on the failure of the Authority to provide information with respect to those concerns to vitiate her consent to the taking of the blood samples.[696]

With respect, Sewell J's finding that the plaintiff was unreasonable because she did not make her concerns regarding subsequent storage and use of the blood sample known at the time of initial consent for taking the blood for diagnostic purposes relies on a significant assumption: that is, that the practice of storage and secondary use of samples, including for genetic research, was known to the plaintiff at the time of collection of the sample. A similar lack of public knowledge likely exists concerning potential use of forensically derived cadaveric tissue in genetic research. It is generally accepted that the onus of providing information concerning research rests squarely with the researcher.[697]

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[693] *Supra* note 134.

[694] *Jones, supra* note 131 at ¶ 72. In *Jones,* the claim to a privacy breach was accepted on evidence by the Court.

[695] *Supra* note 134.

[696] *Supra* note 134 at ¶ 43.

[697] *Supra* note 17, Art 3.2. Picard, *supra* note 99 at 177 note that the duty to inform of risks in research is greater than in therapeutic treatment, i.e. "… it is the most exacting duty possible" in research.

Research participants understanding of genetic data sharing, including through secondary use of tissue and derived genetic data has been said to be "… directly linked to the principle of respecting privacy."[698] As risk in genetic research includes breach of privacy of genetic information, consent or authorization for use of forensically derived tissue without explanation of this risk is likely inadequate for use of genetic data in research.[699] A recent study by Goodman *et al* considered genetic research participants views on consent, and found that re-consent for the use of their genetic data in research performed at a different research centre was preferred by genetic research participants, including use of their de-identified genetic information.[700]

Reasonable Person Standard in Research Risk

For living next of kin who share cadaveric genetic data, Canadian health care case law concerning risk recognizes a reasonable person standard[701] for informed consent in research. The reasonable person standard was applied in *Halushka v University of Saskatchewan*.[702]
In assessing risk to privacy associated with genetic research, it is useful to consider how Canadian Courts have framed what a reasonable person would expect in relation to their information privacy. In *Parent c R.,*[703] for example*,* the Court noted that research involving human subjects, including genetic research, is of a nature that participants expect confidentiality,[704] and without a guarantee of confidentiality, they would likely not consent to participate.[705]

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[698] Iris Jaitovich Groisman, Nathalie Egalite and Beatrice Godard, "Consenting for current genetic research: is Canadian practice adequate?" (2014) 15:80 BMC Medical Ethics 1 at 2.

[699] Deborah Goodman *et al*, "Consent Issues in Genetic Research: Views of Research Participants" (2016) 19 Public Health Genomics 220.

[700] *Ibid* at 220. At 225, the authors also reported that "… 69% of participants felt re-consent was important prior to including previously collected data in a federal database", further illustrating participants preference for autonomy in the use of their genetic information in research.

[701] Daryl Pullman, "Subject Comprehension, Standards of Information Disclosure and Potential Liability in Research" (2001) 9 Health L J 113 at ¶ 8. The author states "[t]he reasonable person standard is generally viewed as a compromise between the professional practice standard and the subjective person standard."

[702] *Supra* note 137.

[703] *Parent c R.*, 2014 QCCS 132. This application was held to determine whether researchers could keep research results confidential based on researcher –participant confidentiality privilege. The Court ruled in favour of the privilege in relation to an interview that the Crown requested to be used as evidence in a criminal trial.

[704] *Ibid* at ¶ 129. See also *supra* note 667.

[705] *Ibid* at ¶ 135.

The risk associated with breach of genetic privacy that could reasonably be expected should be included in the consent process of specific genetic research. As privacy of genetic data can no longer be guaranteed,[706] the guarantee of confidentiality may be a moot point in genetic research.[707] Given that an individual's genetic data is also their personal health information,[708] the growing concern of data linkage resulting in identifiable data once thought to be anonymous,[709] the non health related uses of genetic data both in the public and private sectors,[710] and a documented provincial government breach of research participants' personal information,[711] the protection of privacy of the personal health information obtained through cadaveric genetic research may not be possible to secure.

Such acknowledged risks to privacy protection of information data, including genetic information, will likely re-define the reasonableness standard in relation to genetic research risk in Canadian jurisprudence, further weighing on the need for informed consent in forensic cadaveric genetic research.

In summary if, as Ogbogu, Burningham and Caulfield[712] suggest, there is a "… continuing interest in the information derived from biological materials …",[713] consent "… is recognition of a patient's right to autonomy over his or her intact physical body and the right to privacy and confidentiality over his or her identifiable health (including genetic) information.[714] As stated by LaForest J, in *R. v. Dyment*,[715] "… the sense of privacy transcends the physical. The dignity of the human being is equally seriously violated when use is made of bodily substances taken by

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[706] Lunshof, s*upra* note 109.
[707] See for example, *Act respecting Access to documents held by public bodies and the Protection of personal information*, CQLR c A-2.1, and the reference to confidentiality, *supra* note 667.
[708] *Supra* note 31, *supra* note 587, *supra* note 106 at 406.
[709] Jeanette J McCarthy, Howard L McLeod, & Geoffrey S Ginsburg, "Genomic Medicine: A Decade of Successes, Challenges, and Opportunities" (2013) 5:189 Science Translational Medicine 1 at 10; *supra* note 31 at 277-278.
[710] *Supra* note 33.
[711] British Columbia, Office of the Privacy Commissioner, "Investigation Report F13-02, Ministry of Health," by Elizabeth Denham, 26 June 2013.
[712] *Supra* note 31.
[713] *Ibid* at 25.
[714] Cheung, *supra* note 30 at 138.
[715] *Dyment*, *supra* note 13. At issue was whether a blood sample collected for medical purposes and subsequently given to police by a physician without a warrant for the purpose of an impaired driving conviction was a section 8 *Charter* violation. The Court, in a 5:2 majority, with McIntyre J dissenting and LeDain J abstaining, held that the action was a *Charter* breach.

others for medical purposes in a manner that does not respect that limitation."[716] The use of forensically derived genetic information in research should require consent from the source individual, in practice through donor legislation that specifies purpose of use in genetic research, ensuring the subsequent dignity and privacy of the deceased human research subject. In the absence of valid consent for the use of the forensically derived body, organ or tissue, genetic research on a cadaver in a death investigation system should not proceed. If cadaveric consent has been obtained, criteria for consent of genetic relatives could be determined by how genetically "readily identifiable" the relative is, based on the proposed research.[717]

Conclusion

Scientific researchers' interest in the body after death has historically progressed from the anatomists' interests in the whole body, to genetic researchers' interest in the cadaver's genomic data. This anatomical and temporal progression framework has been followed in this paper to identify who has legal control of the cadaver and its separate organs and tissue, and for what purpose, when under the authority of a death investigation in Canada. Several key concepts were identified that support the requirement for consent[718] for use of forensically derived cadaveric genomic information in research in Canada: the significance of dignity of the person, and dignity's transcendence of death; personal autonomy reflected by the right to choose what is done to one's body after death; and the necessity of maintaining public trust, both in reference to genetic research and in the application of the death investigation systems' legislative mandate.

Parliament has indicated the importance to Canadian society of ensuring the dignity of a cadaver, and Courts' interpretation of section 182 of the *Criminal Code of Canada* illustrates the importance to both the decedent's next of kin and to society of maintaining post mortem dignity of the body.[719] The duty to ensure that the cadaver is treated with dignity exists prior to disposition, in the means by which disposition occurs, and after disposition of the body. Legal

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[716] *Ibid* at 439.

[717] Amy L McGuire, Timothy Caulfield, & Margaret K Cho, "Research Ethics and the Challenge of Whole-genome Sequencing" (2008) 9 Nature Reviews Genetics 152 at 154.

[718] Valid consent (authorization) for the use of the body, organ or tissue, and genetic relatives' informed consent for subsequent genetic research.

control of a body, including its constituent organs, reflects the next of kin's relationship with the individual when alive, and reflects the purpose for which the body or organ is being used. This relationship to the body by the living (and its organs when retained by death investigators for diagnostic purposes) is expressed in the academic literature as 'body wholeness', grounded in the duty to appropriate disposition.

Personal autonomy, the right to choose how one's body is used (or not used) after death is the basis of the requirement for consent in provincial and territorial body, organ and tissue donation legislation. In the absence of donor consent, the donor's next of kin may legally consent to or deny organ donation based on their knowledge of the wishes of the donor, assuring the personal autonomy of the decedent. An example that may facilitate this process is adoption nationally by other provincial and territories of *An Act to Facilitate Organ and Tissue Donation,* SQ 2010, c 38, requiring donation wishes (consent or no consent) to be actively indicated when renewing a health card in Québec.

Genetic privacy, like dignity, is a concept grounded in relationships, where the privacy of the decedent's genome is important not only to his genetic next of kin, but to society, reflected in public trust. Ogbogu and Burningham note that in the context of genetic research, "…public opinion surveys suggest that Canadians believe genetic information should attract added or heightened privacy protection."[720] Statutory protection of one's personal genomic information, like dignity, continues in death but is limited temporally to reflect the potential harm of a privacy breach to the living. To ensure the autonomy of the living, society's expectation of how individuals will be treated in death, and, in the absence of requirements for consent from the individual genetic source in provincial and territorial privacy protection legislation supports the need for consent of the genetic source that includes risks associated with breach of privacy. Caulfield, Rachul and Nelson recently suggested that "[t]he relationship between trust and public perceptions on issues like consent and control also highlights how fragile public opinion likely

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[720] *Supra* note 16 at 487.

is. Past experience has taught us that even one high profile controversy can have a tremendous impact on perceptions."[721]

The Supreme Court of Canada has found that a reasonable expectation of privacy includes the right to control dissemination of one's personal information, and for what purpose. Protecting the personal autonomy of the individual when alive by means of the opportunity to choose if one's genetic information is used in research after death is the surest method of mitigating breach of privacy risk associated with genetic research, and thus maintaining dignity after death.[722] If a cadaver is a human research subject in Canada, as argued above, consent should, at a minimum, be in reference to use of an individual's genetic information, not simply the body, organ or tissue in which it is contained, which could exempt the use of unclaimed and unidentified bodies, and secondary use of tissue recovered under the authority of a death investigation system for genetic research.

A balance between public trust in genetic research and protection of individuals' genetic informational privacy can be achieved through governance and policy reform.[723] In a death investigation system, where authority to examine cadavers without consent from next of kin is statutorily granted, public trust is temporally, culturally and geographically contextual in nature due to the interpretation of what is deemed to be society's interpretation of "dignity to a body." Pounder notes[724] that:

> A medicolegal dissection (autopsy) is an important tool in death investigation. However, it is also an intrusion by the state into what is otherwise the private matter of the death of a family member. The need for the state to seize the corpse and to dissect it for investigative purposes must be balanced against the rights of the family to privacy …

A death investigation system's standard of good faith could be achieved through public education in the potential research use of forensically derived cadaveric genetic information to

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[721] Timothy Caulfield, Christen Rachul & Erin Nelson, "Biobanking, Consent and Control: A Survey of Albertans on Key Research Ethics Issues" (2012) 10:5 Biopreservation and Biobanking 433 at 437.

[722] A discussion of the degree of disclosure required in this circumstance, that is, how informed the donor must be for the consent to be valid is beyond the scope of this paper: see supra note 137, 138, for examples.

[723] *Supra* note 16 at 491.

[724] Derrick Pounder, Matthew Jones & Heiko Peschel, "How Can We Reduce the Number of Coroner Autopsies? Lessons from Scotland and the Dundee Initiative" (2011) 104 J R Soc Med 19 at 19.

ensure next of kin’s and society’s confidence that bodies undergoing a death investigation are treated with dignity. Such an approach would also reassure the living that they can trust that their personal autonomy will be protected after death, in choosing whether to participate (or not participate) in post mortem genetic research when under the authority of death investigation systems in Canada.

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