BACKGROUND LEGAL RESEARCH AND ANALYSIS IN SUPPORT OF CIHR'S RECOMMENDATIONS WITH RESPECT TO THE *PERSONAL INFORMATION PROTECTION AND ELECTRONIC DOCUMENTS ACT (PIPEDA)*

(S.C. 2000, c. 5)

AS AT NOVEMBER 30th, 2001

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PART I: STATUTORY CONTEXT AND LIMITATIONS

By marked contrast with the specific powers mentioned in paragraph 26 (1) (a) of the Act, extensive discretion has been delegated to Governor in Council under paragraph 26 (1) (b). This provision empowers the Governor in Council to make regulations "for carrying out the purposes and provisions" of Part 1 (hereinafter the "*enabling clause*"). The scope of these powers is circumscribed only by section 3 of the Act (hereinafter, the "*purpose clause*"), where Parliament's intent is expressed as follows:

> "3. The purpose of this Part is to establish, in an era in which technology increasingly facilitates the circulation and exchange of information, rules to govern the collection, use and disclosure of personal information in a manner that recognizes the right of privacy of individuals with respect to their personal information and the need of organizations to collect, use or disclose personal information for purposes that a reasonable person would consider appropriate in the circumstances." (emphasis added)

Hence, a necessary balance must be struck between, on the one hand, individual privacy rights with respect to personal information and, on the other hand, organizational needs for that same personal information, these needs being assessed through the prism of a reasonable person's expectations[1].

The purpose clause, read in conjunction with the enabling clause, provides solid basis for the regulatory provisions proposed below, which also find ample support in well-recognized principles of administrative law. In the following pages, those general principles relevant to several or to all recommendations are addressed in Part II, below, whereas the legal considerations pertaining to a single recommendation are discussed, in Part III, under the applicable heading.

PART II: GENERAL PRINCIPLES OF DELEGATED LEGISLATION

Pursuant to section 26 of the Act, Parliament has delegated part of its legislative powers to the uppermost level of the executive branch, the Governor in Council. It has been observed that courts should construe regulatory powers in a very broad manner when

[1] It is noteworthy that subsection 5(3) also restricts the collection, use and disclosure of personal information to purposes "that a reasonable person would consider appropriate in the circumstances".

they are "given to so high a level of authority" [2]. Furthermore, as discussed below, the specific wording of the enabling clause, which is framed in general residual terms, justifies a broad interpretation of Governor in Council's rule-making authority.

1. Conformity with the enabling clause (subject-matter)

The scope of a regulation is obviously limited by the powers granted under its parent statute[3]. Although seemingly trite, this statement has broad repercussions.

Paragraph 26 (1) (b) is an enabling clause of a general residual nature, granting broad discretion to make regulations "for carrying out the purposes and provisions" of Part I. It is noteworthy that two opposite views have emerged on the scope of discretion delegated to a rule-making body under a general residual enabling clause.

One stream of authorities has taken a narrow approach in construing general residual enabling provisions. According to this restrictive trend, such an enabling clause merely allows the rule-maker to deal with matters of procedure, as opposed to those of substance[4]. The essence of this restrictive trend of cases has been captured as follows by professor Garant:

> *"Suivant ce second courant, l'habilitation générale doit être comprise à la lumière des fins et de l'esprit de la loi; même à l'intérieur de ce cadre, elle ne permet pas de mettre en oeuvre, pour atteindre les fins de la loi, des moyens que celle-ci n'a pas prévus. Le règlement doit rester fidèle aux principes qui sous-tendent la loi: il ne peut ni y déroger, ni y ajouter. Bref, l'habilitation générale ne permet pas d'introduire des dispositions de fond, de modifier les droits et obligations des administrés; le champ de réglementation ne recouvre alors que les questions de procédure ou de technique administrative."* (emphasis added) [5]

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[2] *Re Collins et al.* and *Pension Commission of Ontario et al., Re Batchelor et al*. and *Pension Commission of Ontario et al.*, (1986) 56 O.R.(2d) 274 at 292 (Lieutenant-Governor in Council granted power to make regulations "respecting any matter necessary or advisable to carry out effectively the intent and purpose of this Act").

[3] A federal regulation will be examined from this perspective, pursuant to the *Statutory Instruments Act*, R.S.C. 1985, c. S-22, paragraph 3 (2) a).

[4] See the first edition of: Ruth Sullivan, ed., *Driedger on the Construction of Statutes* (Toronto: Butterworths, 1974) at 200, for a discussion on the effect of a statutory provision granting powers to make regulations 'for carrying out the provisions and purposes' of an Act:

> "Regulations of an administrative or procedural character could no doubt be made under such a general authority, but it is doubtful whether in the absence of a clear indication of intent in the statute regulations affecting individual rights or creating rights and obligations could be made."

It should be emphasized that this affirmation is absent in both the second and third editions of the same treatise.

[5] Patrice Garant, *Droit administratif, Volume 1, Structures, actes et contrôles*, 4th ed. (Cowansville: Yvon Blais, 1996) at 424.

A sounder, more liberal, approach allows the general residual enabling provision to take full effect, provided the regulation actually promotes the legislator's intent. An understanding of this intent is paramount in assessing the regulation's validity. To this end, the presence of an objects, or purpose, clause will "provide the court with a concrete base for establishing the legislature's intent." [6]

Furthermore, this stream of authorities[7] views general residual enabling provisions as empowering the delegate with sufficient authority to enact substantive, as well as procedural or administrative, provisions. Indeed, such an enabling clause "must have some substantive basis in order to enable the [regulating authority] to carry out the purposes and provisions of the Act" [8]. The subject-matter of such a regulation is nevertheless limited by the matters dealt with in the parent statute itself. In *Steve Dart Co*. and *D.J.Duer & Co*., the Court ruled that a regulation, made pursuant to an enabling provision resembling paragraph 26(1)(b) of the Act, should be confined to matters expressly mentioned in the parent statute, in accordance with the following requirements:

> "[…] That section grants the additional right to make Regulations to carry out the purposes and provisions of the Act*,* but such purposes and provisions must be clearly expressed in or contained within or flow by necessary implication from other sections of the Act. It would permit the making of *ejusdem generis* regulations as those authorized in the other sections of the Act providing for the issuing of Regulations. It would also permit a Regulation required to carry out effectively a clearly-expressed provision of the Act not falling within one of the other sections authorizing the making of Regulations; it certainly does not provide the right to make Regulations covering a matter which is not even remotely referred to in the Act. (emphasis added) [9]

This ruling on the scope of subordinate legislation has been summarized as follows:

> "According to this analysis, it is not sufficient to find a general similarity in subject matter between the statute and the regulations. There must be a specific substantive section in the legislation upon which the regulator can

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[6] Denys C. Holland and John P. McGowan*, Delegated Legislation in Canada* (Toronto: Carswell, 1989) at 203.

[7] See Garant, *supra* note 5 at 420-422.

[8] See, for example: *Re Clark et al.* and *Attorney-General of Canada*, (1977) 81 D.L.R.(3d) 33 at 45 (Ont. H.C.J.) (The regulatory provision under attack prohibited releasing certain information without complying with specific conditions).

[9] *Steve Dart Co*. and *D.J.Duer & Co.,* (1974) 46 D.L.R.(3d) 745 at 749 (F.C.T.D.) (An arbitration board and appeals tribunal were established under the impugned regulatory provisions. The Court noted, *inter alia*, that no authority for creating these decisional bodies could be inferred from the parent statute).

> rely for validity to ensue. At the very least, the purpose behind the regulation must flow by necessary implication from the substance of the statute." (emphasis added) [10]

In light of the above authorities, the regulatory provisions proposed below find support in well-established principles of administrative law. First, they deal will matters expressly mentioned in the Act, while effectively promoting the purposes set out in section 3 of the Act. Furthermore, the liberal trend discussed above justifies adopting regulations having some impact on substantive rights.

2. Consistency with applicable legal norms

Subordinate legislation adopted by way of regulation must first and foremost be consistent with higher legal norms. Above all, a regulation must be consistent with fundamental rights and, in the federal jurisdiction specifically, with those set out in the *Canadian Charter of Rights and Freedoms* and the *Canadian Bill of Rights*.[11]

A regulatory provision must also be consistent with statutory norms, whether or not the latter are couched within the applicable statute[12]. This requirement prevents the rule-maker from modifying the conditions set out in the enabling statute[13]. For instance, when a term is defined in the enabling statute, a regulation should avoid expanding or reducing the scope of the statutory definition. The two following cases illustrate regulatory provisions that were found to alter the meaning of terms contained in the enabling act.

In the *Gach* [14] case, Cabinet was found to have illegally exercised its delegated legislative powers. In this leading case on inconsistency of regulations, the Manitoba Court of Appeal decided that the regulatory provision under attack actually expanded the notion of "financial resources", a term that was defined in the *Social Allowances Act*. Under the regulation, financial resources of the parent of an applicant for social allowances were deemed to be the applicant's own financial resources, until the latter became 25 years of age. The Court decided that the regulatory provision was inconsistent with the enabling statute, since the latter's definition of "financial resources", read in conjunction with another provision of the statute," actually closed the door to inclusion by regulation of the resources of a parent as part of the resources of an

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[10] Holland and McGowan, *supra* note 6 at 192.

[11] See the *Statutory Instruments Act*, R.S.C. 1985, c. S-22, paragraph 3 (2) c).

[12] On inconsistency with other than the parent statute, see: Holland and McGowan, *supra* note 6 at 189-191; René Dussault and Louis Borgeat, *Administrative Law, A Treatise*, Volume 1, 2d ed. (Toronto: Carswell, 1985) at 411-412.

[13] On this topic, see: Holland and McGowan, *supra* note *6* at 181-189; Dussault and Borgeat, *ibid.* at 406-410; Garant, *supra* note 5 at 428-429.

[14] *Re Gach* and *Director of Welfare(Brandon),(*1973) 35 D.L.R.(3d)152 (Man. C.A.).

applicant"[15]. Mr. Justice Dickson (J.C.A.) set out the following reasons for the court's finding of inconsistency:

> "In seeking, by regulation, to make the resources of a parent part of the resources of an applicant, the Lieutenant-Governor in Council was not 'carrying out the provisions of the Act', it was enlarging those provisions in a material way. The Regulation sought to effect a substantial and inconsistent addition to the Act [...]"(emphasis added) [16]

A similar finding was made by the Federal Court (appeal division) in the *Paulsen* [17] case, where the contested regulatory provision actually postponed the moment when an "interruption of earnings" was deemed to occur for a category of persons insured under the *Unemployment Insurance Act*. This provision was found to conflict with the statutory definition of "interruption of earnings", which specifically sets the moment of this interruption at the time of a lay-off or separation from employment. In his reasons, Mr. Justice Jackett observed that the regulatory power expressed in the enabling clause [18] "should not be read as authorizing a change in the rules laid down by the statute itself for determining what benefits are payable […]" [19]. He therefore decided that the impugned provision was *ultra vires*, since it "had the effect of taking away a potential right, otherwise existing, to benefits during a period of four months", a process that "substantially change[d] a right to benefits under the Act" (emphasis added) [20].

These judicial precedents still leave room for a regulation that merely clarifies terms contained in the statute, provided no substantial change is made to the Act, by either enlarging or reducing the scope of its provisions. In such circumstances, a regulation that merely provides clarity is consistent with the Act.

3. Other applicable principles

In addition to the principles mentioned above, many other limitations, which have been analyzed in depth by various experts and scholars[21], also apply when assessing the exercise of delegated legislative powers. For instance:

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[15] *Ibid*. at 154.

[16] *Ibid*.

[17] *Re Attorney-General of Canada* and *Paulsen et al.,* (1973) 38 D.L.R.(3d) 225 (F.C.A.).

[18] *Ibid*. at 230. The power conferred under paragraph 58(1)(r) of the relevant statute consisted in "defining and determining when an interruption of earnings occurs".

[19] *Ibid*. at 232.

[20] *Ibid*. at 229-230.

[21] Although the following list is far from exhaustive, see: Garant, *supra* note 5 at 387-454; Holland and McGowan, *supra* note *6* at 169-235; John M. Keyes, *Executive Legislation, Delegated Law Making by the Executive Branch* (Toronto: Butterworths, 1992) at 157-286;

- A regulation must not grant purely discretionary powers; it should establish sufficient guidelines for decisional bodies;

- A regulation must be sufficiently clear, avoiding vagueness and uncertainty: citizens should be fully aware of their legal obligations and rights if they are expected to adjust their conduct accordingly;

- A regulation must be reasonable, non-discriminatory and adopted in good faith. It should never constitute "an unusual or unexpected use of the authority pursuant to which it is to be made"[22];

- A regulation must be adopted by the appropriate body, *i.e.* the one to which the necessary legislative powers have been duly delegated [23];

- The power to regulate excludes the power to prohibit.

PART III: THE PROPOSED REGULATORY PROVISIONS

In this part, the adoption of specific regulatory provisions will be proposed. Each proposed provision will be introduced and its justification will follow, turning first to its policy reasons and then to legal considerations.

RECOMMENDATION # 1: CLARIFICATION OF THE DEFINITION OF PERSONAL INFORMATION

1. a) For greater certainty, "information about an identifiable individual", within the meaning of personal information as defined by the Act, shall include only that information that can:

i) identify, either directly or indirectly, a specific individual; or,
ii) be manipulated by a reasonably foreseeable method to identify a specific individual; or
iii) be linked with other accessible information by a reasonably foreseeable method to identify a specific individual.

Dussault and Borgeat, *supra* note 12 at 360 *et seq*.; Gilles Pépin and Yves Ouellette, *Principes de contentieux administratif,* 2d ed. (Cowansville: Yvon Blais, 1982) at 124-137.

[22] In the federal jurisdiction, see the *Statutory Instruments Act*, R.S.C. 1985, c. S-22, paragraph 3 (2) b).

[23] These principles are discussed in the context of Recommendation 3, below, more specifically with respect to paragraph 3 (1) b) of the proposed regulation.

b) Notwithstanding subsection 1(a), "information about an identifiable individual" shall not include:

- ***i) anonymized information which has been permanently stripped of all identifiers or aggregate information which has been grouped and averaged, such that the information has no reasonable potential for any organization to identify a specific individual; or***
- ***ii) unlinked information which, to the actual knowledge of the disclosing organization, the receiving organization cannot link with other accessible information by any reasonably foreseeable method, to identify a specific individual.***

c) Whether or not a method is reasonably foreseeable under subsections 1(a) and 1(b) shall be assessed with regard to the circumstances prevailing at the time of the proposed collection, use or disclosure.

A. Policy reasons

It is recognized that information may fall along a whole spectrum in terms of its potential to identify individuals, depending on its nature, its relation to other information and the context in which it was generated. However, in order to properly carry out the purposes and provisions of Part I, it is recommended that a test of reasonableness be adopted as the determining criterion. The standard of reasonableness is well developed in law and would be the most suitable and appropriate way of delimiting the term "identifiable" to a certain range of possibilities. A reasonable standard would also be most harmonious with the approach adopted in other jurisdictions, both nationally and internationally. Through the lens of reasonableness, "identifiable" would encompass only those technical possibilities that are realistically, practically and rationally foreseeable in the circumstances, while excluding those which are highly unlikely, immoderate or unfeasible to expect.

A national and international review of applicable legal norms respecting the protection of personal information in health research provides ample policy support for the specific formulation of this proposed provision.

The test of reasonableness

"Reasonable" is defined as "fair, proper, just, moderate, suitable under the circumstances. Fit and appropriate to the end in view... Not immoderate or excessive, being synonymous with rational, honest, equitable, fair, suitable, moderate, tolerable."[24]

"Reasonableness" is a living and evolving test that would allow the law to respond to technological advances. The test for reasonable forseeability should capture the prevailing context at the time of the purported contravention.

[24] *Black's Law Dictionary*, 5th ed. (St. Paul, Minn.: West Publishing Co., 1979) at 1138.

The notion of "reasonableness", "reasonable means" or "reasonably foreseeable means" is used to qualify the term "identifiable" in many international instruments, national laws and provincial laws respecting the protection of personal information. See, for instance, the definitions adopted in the following jurisdictions:

- **Council of Europe**

  "An individual shall not be regarded as identifiable if identification requires an unreasonable amount of time and manpower." [25]

- **United States (***Standards for Privacy of Individually Identifiable Health Information: Final Rule*) [26]

  "[section 164.501]

  Individually identifiable health information is information that is a subset of health information, including demographic information collected from an individual, and:

  (1) Is created or received by a health care provider, health plan, employer, or health care clearinghouse; and

  (2) Relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or
  the past, present, or future payment for the provision of health care to an individual; and

  (i) That identifies the individual; or

  (ii) With respect to which there is a reasonable basis to believe the information can be used to identify the individual."

  [section 164.514]

  (a) Health information that does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual is not individually identifiable health information.

[25] Council of Europe, *Recommendation No. R97(5) of the Committee of Ministers to Member States on the Protection of Medical Data* (Strasbourg, 1997).

[26] United States Department of Health & Human Services, *Standards for Privacy of Individually Identifiable Health Information: Final Rule,* 65 Fed. Reg. 2000 (28 December 2000); 65:82461-82510, (amending 45 CFR 160-164).

(b) A covered entity may determine that health information is not individually identifiable health information only if:

(1) A person with appropriate knowledge of and experience with generally accepted statistical and scientific principles and methods for rendering information not individually identifiable:

(i) Applying such principles and methods, determines that the risk is very small that the information could be used, alone or in combination with other reasonably available information, by an anticipated recipient to identify an individual who is a subject of the information; and

(ii) Documents the methods and results of the analysis that justify such determination; or

(2) (i) The following identifiers of the individual or of relatives, employers, or household members of the individual, are removed:

(A) Names;
(B) All geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code if, according to the current publicly available data from the Bureau of the Census:
(1) The geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people; and
(2) The initial three digits of a zip code for all such geographic units containing 20,000 or fewer people is changed to 000.
(C) All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older;
(D) Telephone numbers;
(E) Fax numbers;
(F) Electronic mail addresses;
(G) Social security numbers;
(H) Medical record numbers;
(I) Health plan beneficiary numbers;
(J) Account numbers;
(K) Certificate/license numbers;
(L) Vehicle identifiers and serial numbers, including license plate numbers;
(M) Device identifiers and serial numbers;

(N) Web Universal Resource Locators (URLs);
(O) Internet Protocol (IP) address numbers;
(P) Biometric identifiers, including finger and voice prints;
(Q) Full face photographic images and any comparable images; and
(R) Any other unique identifying number, characteristic, or code; and

(ii) The covered entity does not have actual knowledge that the information could be used alone or in combination with other information to identify an individual who is a subject of the information."

- **Commonweatlh of Australia** (*Privacy Amendment (Private Sector) Act 2000*)

"[section 6] personal information means information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion."[27]

- **New Zealand** (*Privacy and Personal Information Act)*

"[section 4] personal information means information or an opinion (including information or an opinion forming part of a database and whether or not recorded in a material form) about an individual whose identity is apparent or can reasonably be ascertained from the information or opinion." [28]

- **Saskatchewan***(Health Information Protection Act)*:

"[subsection 2(d)] De-identified personal health information means personal health information from which any information that may reasonably be expected to identify an individual has been removed." [29]

[27] Commonweatlh of Australia, *Privacy Amendment (Private Sector) Act 2000*, No.155, amending the *Privacy Act 1988*, section 6.

[28] New Zealand, *Privacy and Personal Information Act*, 1998, section 4.

[29] *Health Information Protection Act,* S.S. 1999, c. H - 0.021, subsection 2(d).

- **Ontario** (Bill 159, *Personal Health Information Privacy Act*, 2000)

  "[subsection 2(1)] personal health information means information that:
  i) identifies the individual,
  ii) can be used or manipulated by a reasonably foreseeable method to identify the individual or,
  iii) can be linked or matched by a reasonably foreseeable method to other information that identifies the individual or that can be used or manipulated by a reasonably foreseeable method to identify the individual..."[30]

"Direct" and "indirect" identification

In several jurisdictions, reference is made to "indirect" as well as to "direct" identification of individuals. As examples:

- **European Union** (Directive 95/46/EC)

  "[article 2(a)] personal data shall mean any information relating to an identified or identifiable natural person (data subject); an individual person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity." (emphasis added) [31]

- **European Group on Ethics in Science and New Technologies**
  (Ethical Issues of Healthcare in the Information Society)

  "[See the definition of "Person identifiable data"]
  Person identifiable data includes, as in the terms of the Directive 95/46/EEC, any data which either directly or indirectly identifies an individual by reference to her/his name, identification number or to one or more factors specific to her/his physical, physiological, mental, economic, cultural or social identity." (emphasis added) [32]

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[30] Ontario Bill 159, *Personal Health Information Privacy Act*, 2000 (1st. Sess., 37th Leg., Ontario 2000 - since died on the order paper), subsection 2(1).

[31] European Union Directive 95/46/EC of 24 October 1995 on the *Protection of Individuals with Regard to the Processing of Personal Data and the Free Movement of Such Data*, article 2 paragraph (a).

[32] European Group on Ethics in Science and New Technologies*, Ethical Issues of Healthcare in the Information Society*, Opinion No. 13 (July 30, 1999), at 3.

- **France** (*Loi No. 78-17 du 6 janvier 1978)*

  "[article 4] Sont reputées nominatives au sens de la présente loi les informations qui permettent, sous quelque forme que ce soit, directement ou non, l'identification des personnes physiques auxquelles elles s'appliquent, que le traitement soit effectué par une personne physique ou par une personne morale." (emphasis added)[33]

- **United Kingdom** (British Medical Association)
  "Anonymised information
  Information which does not, directly or indirectly, identify the person to whom it relates" (emphasis added) [34]

"Specific individual"

Some jurisdictions have, either through statute or jurisprudence, further qualified "identifiable" information with the condition that the information have the potential of revealing the identity of a specific individual, and not just any individual.

- **European Union** (Directive 95/46/EC)

  "[Article 2(a)] personal data shall mean any information relating to an identified or identifiable natural person (data subject); an individual person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity;" (emphasis added) [35]

- **Quebec**

  Case law has interpreted the meaning of "nominative information" and "personal information", found respectively in the public sector and private sector statutes, as follows:

  - Interpreting subsection 54 of *An Act Respecting Access to Documents held by Public Bodies and the Protection of Personal Information*, (R.S.Q., c. A-2.1), which reads: "In any document, information

[33] France, *Loi No. 78-17 du 6 janvier 1978 relative à l'informatique, aux fichiers et aux libertés*, article 4.

[34] British Medical Association, *Confidentiality and disclosure of health information* (U.K., October 14, 1999). See the definition of "Anonymised information".

[35] European Union Directive 95/46/EC of 24 October 1995 on the *Protection of Individuals with Regard to the Processing of Personal Data and the Free Movement of Such Data*, article 2 paragraph (a).

concerning a natural person which allows the person to be identified is nominative information.", the Commission has ruled:

> *« À l'aide de ces définitions des dictionnaires, on peut affirmer qu'un renseignement nominatif dans le contexte de l'article 54 doit non seulement faire connaître quelque chose à quelqu'un et avoir rapport avec une personne physique, mais il doit aussi être susceptible (permettre) de distinguer cette personne par rapport à quelqu'un d'autre ou de reconnaître sa nature*. » [36]

- Interpreting section 2 of *An Act respecting the Protection of Personal Information in the Private Sector*, (R.S.Q., c. P-39.1), which reads: "Personal information is any information which relates to a natural person and allows that person to be identified.", the Commission has ruled:

> « *En somme, est personnel, aux yeux de la loi, un renseignement qui cerne les caractéristiques d'un individu : il se définit par rapport à cette personne et à celle-là seulement. »*[37] .

- **United Kingdom** (British Medical Associationl)

> "Anonymised Information
> […]
> The BMA believes that from an ethical perspective, disclosure or breach of confidentiality occurs only when the information revealed can be linked to a specific individual." [38]

Anonymized and aggregate information

Several sources have recognized that information which has been anonymized or aggregated no longer has the potential to be used by anyone to identify an individual.

- **United Kingdom** (Medical Research Council)

> "Although anonymised data is not, strictly speaking, personal information, its use is also covered in this guide […] Unlinked Anonymised data contains no information that could reasonably be used, by anyone, to identify people."
> "[…It] contains nothing that has reasonable potential to be used by

[36] *Segal* v. *Centre de services sociaux du Québec*, [1988] C.A.I. 315, 320.

[37] *Stébenne v. Assurance-vie Desjardins-Laurentienne Inc., [1995] C.A.I. 14, 17.*

[38] British Medical Association, *Confidentiality and disclosure of health information* (U.K., October 14, 1999). See the definition of "Anonymised information".

anyone to identify individuals: the link to individuals has been irreversibly broken." [39]

- **United Kingdom** (British Medical Association)

  "Anonymised Information
  […] Anonymised data should be used wherever feasible. Care must be taken to ensure that any information which is thought to be anonymous is genuinely non-identifiable. […] Aggregating data will often serve to anonymise it." (emphasis added) [40]

- **Alberta** (*Health Information Act*)

  "[subsection 57(1)] In this section, 'aggregate health information' means non-identifying health information about groups of individuals."[41]

Linkage and access to complementary information

Finally, there is support for the idea that, in order for data to be considered as having any potential to identify a person, by means of linkage or combination with other information, the data holder must have, or be able to obtain, access to that other information - otherwise, for all intents and purposes, it is not identifiable.

- **United Kingdom** (*Data Protection Act)*

  "[section 1(1)] personal data means data which relate to a living individual who can be identified
  a) from those data, or
  b) from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller" [42]

- **United Kingdom** (Medical Research Council)

  "Personal data [...] comprise information about living people who can be identified from the data, or from combinations of the data and other

[39] Medical Research Council, *Personal Information in Medical Research* (U.K., October 2000), Glossary at pages 4 and 27.

[40] British Medical Association, *Confidentiality and disclosure of health information* (U.K., October 14, 1999). See the definition of "Anonymised information".

[41] *Health Information Act,* S.A. 1999, c. H-4.8. subsection 57(1).

[42] United Kingdom, *Data Protection Act* 1998, c. 29, subsection 1(1).

information which the person in control of the data has, or is likely to have in the future.
[…]
Linked Anonymised data is anonymous to the people who receive and hold it (e.g. a research team), but contains information or codes that would allow others (e.g. those responsible for the individual's care) to identify people from it."[43]

- **United Kingdom** (British Medical Association)

"Anonymised Information
[…]
Other identifiers can mean that information which appears anonymous actually is not since it can be linked to the individual to whom it relates in combination with other information available to the recipient. For example, information identified by only NHS number is identifiable to those people who have access to a database of NHS numbers[…]" (emphasis added)[44]

The possibility of linkage must be assessed from the perspective of the organization seeking to collect or use the data. Therefore, in determining whether unlinked data constitutes personal information, the disclosing organization would consider whether the receiving organization has access to other data that might allow it to identify specific individuals. However, the disclosing organization would not be expected to investigate the situation beyond its actual knowledge.

B. Legal considerations

Proper discharge of a rule-maker's authority to carry out purposes and provisions under a general residual enabling clause may require clarification of the terms contained in the statute. Accordingly, this first regulatory provision would seek to bring more certainty to the terms "information about an identifiable individual". This being a matter expressly referred to in the Act, it comes within the scope of Governor in Council's rule-making authority.

This first recommendation is in harmony with Parliament's intent since it facilitates achievement of the objectives stated in section 3 of the Act. The parameters selected to describe "information about an identifiable individual" ensure protection of individual privacy rights, while also recognizing legitimate organizational needs to collect, use or disclose personal information, in certain limited circumstances (*i.e.* where there is no

[43] Medical Research Council, *Personal Information in Medical Research* (U.K., October 2000), Glossary at page 4.

[44] British Medical Association, *Confidentiality and disclosure of health information* (U.K., October 14, 1999). See the definition of "Anonymised information".

reasonable possibility of identifying a specific individual, either directly, indirectly, through manipulation or linkage of information).

By no means does this regulatory provision either expand or reduce the scope of the statutory definition of "personal information", according to the tests established in the *Gach* and *Paulsen* cases discussed above[45]. Instead, it provides useful guidance by specifying which type of information actually relates to an "identifiable individual". The criteria set forth in the proposed regulation are consistent with both the general proposition ("information about an identifiable individual") and the exceptions (*i.*e., name, title, business address or telephone number) contained in the statutory definition of "personal information".

Finally, this proposed regulatory provision should enable researchers and research subjects to better understand their respective rights and obligations, through a clear definition of "personal information". The selected criteria refer to notions that not only are familiar to the scientific and legal communities, but also understandable from a layperson's perspective.

RECOMMENDATION # 2: "IN THE COURSE OF COMMERCIAL ACTIVITIES"

2. For greater certainty, personal information is collected, used or disclosed "in the course of commercial activities" within the meaning of paragraph 4(1)(a) of the Act, when the organization's activities are aimed primarily at making a pecuniary gain for the personal benefit of its members, as opposed to recovering its costs or promoting its philanthropic, charitable, scientific, health or other like objects.

A. Policy reasons

In this modern era of health research, as in other areas, the nature of an organization's activities may involve a mixture of commercial and non-commercial attributes.[46] This reality is likely to cause some uncertainty with respect to the applicability of Part I to health research. Accordingly, the present recommendation is intended to introduce a "primary aim" test to facilitate the interpretation and application of paragraph 4(1)(a) of the Act (hereinafter the *"application clause*"), whereby Part I "applies to every organization in respect of personal information that [it] collects, uses or discloses in the course of commercial activities".

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[45] See discussion above, notes 14 to 20 and accompanying text.

[46] See specific examples cited at Question 7 in: Canadian Institutes of Health Research and Canadian Institute for Health Information, *Personal Information Protection and Electronic Documents Act: Questions and Answers for Health Researchers* (Ottawa: Public Works and Government Services Canada, 2001) at 8-10.

B. Legal considerations

Pursuant to the application clause, the scope of Part I is limited to those organizations in respect of personal information they collect, use or disclose "in the course of commercial activities". The following observations flow from the wording of this provision.

a) The focus on "commercial activities" collectively

The application clause is focused on the organization's activities in their entirety, rather than on any single activity, viewed distinctly or in isolation. To come within the scope of Part I, an organization's activities, considered as a whole, must be of a true commercial nature. Indeed, paragraph 4(1)(a) states that Part I applies to an organization that collects, uses or discloses personal information in the course of "commercial activities" in the plural, not in the course of "a commercial activity" or of "any commercial activity".

The proposed regulatory provision purports to clarify the application clause, which itself if focused on the organization's activities globally. This approach is not a departure from the definition of "commercial activity" contained in subsection 2(1) of the Act. There, in determining if a particular transaction, act or conduct or any regular course of conduct consists in "commercial activity", attention is drawn to its "commercial character"[47]. However, a finding that any given activity is commercial is insufficient to determine if Part I applies to a given situation; attention must ultimately be drawn to the application clause. To this end, the primary purpose of the organization's entire set of activities will need to be considered in order to assess their true, commercial or non-commercial, character.

In light of the preceding remarks, it should be emphasized that this recommendation contrasts sharply with the regulatory provisions that were contested in the *Gach* and *Paulsen* cases [48]. Indeed, here, no alteration is made to any statutory provision or definition. Instead, a necessary clarification of the application clause is being set forth, bearing in mind the legislator's intent.

[47] Nowhere in the Act is the term "commercial" defined. The explicit enumeration contained in the definition of "commercial activity" ("selling, bartering or leasing of donor, membership or other fundraising lists") is only of limited assistance in interpreting the narrower term "commercial". Other rules must be resorted to, as discussed below.

[48] See discussion above, notes 14 to 20 and accompanying text.

b) The meaning of "in the course of commercial activities"

A better understanding of this expression is reached by applying two fundamental rules of construction: i) one which relies on the ordinary meaning of words, ii) the other, based on a contextual, historic approach.

i) The ordinary meaning of "commercial"

Since the term "commercial" is nowhere defined in the Act, not even in the statutory definition of "commercial activity", general rules of interpretation should be relied upon when drafting a regulation aimed at clarifying the application clause.

From this perspective, the rule of construction based on the ordinary meaning of words is quite insightful. This rule of statutory construction may be expressed as follows:

> "As it is presumed that the legislature wishes to be understood by the citizen, the law is deemed to have been drafted in accordance with the rules of language in common use." [49]

In Canadian common law jurisdictions, it has been stated that "the ordinary meaning of the term 'commercial purpose' is the carrying on of a business, or a private enterprise for gain." [50] Also, a commercial transaction has been described as "one having profit as the primary aim." [51] From this perspective, reliance is sometimes made by courts on dictionary definitions of commercial, such as:

> " Commercial: from the point of view of profit; having profit as the primary aim " (emphasis added). [52]

On some occasions, courts have specifically drawn their attention to social enterprises, which may or may not generate profits in the course of their activities. For instance, in

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[49] Pierre-André Côté, *The Interpretation of Legislation in Canada*", 3rd ed. (Scarborough: Carswell, 2000) at 261.

[50] *Poiron* v. *Advocate General Insurance Company of Canada*, (1984) 32 Man.R. (2d) 230 at 234 (Man.Q.B.).

[51] *R*. v. *Horseman*, [1986] 1 C.N.L.R. 79 at 84 (Alta. Prov. Ct.).

[52] *Ibid*. at 84, where the court cites *Webster's Third New International Dictionary,* 1976. To the same effect see the following definitions of commercial:

- *Merriam-Webster's Collegiate Dictionary*, 10th ed. (Springfield Mass.: Merriam-Webster,1996) at 231: "(…) 2a: viewed with regard to profit. (emphasis added)"
- De Wolf, Gregg, Harris, Scargill, *Gage Canadian Dictionary*, (Toronto: Gage Educational Publishing Company, 1998) at 311: "(…) 2. made, done, or operating mainly for profit, especially at the expense of quality, artistic merit, etc." (emphasis added).

Re Metropolitan Toronto Domed Stadium[53], the Court refused to view the contribution of the Municipality of Metropolitan Toronto to the Stadium Corporation of Ontario, as a contribution to a "commercial enterprise". The Court observed that the stadium project was a unique proposal "intended to benefit the Metropolitan corporation in a general way in terms of civic pride and prestige" and not aimed primarily at making a profit:

> "[a]ny profit it might make [wa]s secondary to its main objective of furnishing Metropolitan Toronto with a facility considered by its elected representatives to be appropriate for a large metropolitan North American centre. The proposal represents in the minds of the legislators and the members of council the most feasible and appropriate means of accomplishing this result." (emphasis added) [54]

In the tax context more specifically, courts pay particular attention to all relevant factors in order to decipher whether an enterprise's preponderant purpose is of a "true commercial nature":

> "The commercial activity test, as expressed by Evans J.A., requires a consideration and an evaluation of all factors in order to determine whether in reality the corporation is of a true commercial nature. He has also expressed the view that one activity of a commercial nature may colour the whole of the corporation's operations and be sufficient, as in the Windsor-Essex case, to classify it as a business. It would seem to me that on this last point he is really applying the preponderant purpose test, finding that one purpose may be sufficiently important to colour the whole. As I have indicated earlier, I do not reject such a suggestion, but, if it is applied to determine whether an enterprise is of a commercial nature, difficulties will arise. Many community and charitable organizations, relying from time to time on what would be termed commercial activity to raise funds for the fulfilment of their objectives, could be classed as businesses by such a test. To attach primary importance to the commercial aspect of an operation in question will offer, in my opinion, no sure or helpful guide. In my view, the commercial activity test is too indefinite to allow consistent application. I agree that, in deciding whether or not any activity may be classed as a business under the provisions of s.7(1)(b) of the Assessment Act, all relevant factors regarding an operation must be considered and weighed. However, they must be considered and weighed in order to determine not whether in some general sense the operation is of a commercial nature or has certain commercial attributes, but whether it has as its preponderant purpose the making of a profit." [55]

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[53] *Re Metropolitan Toronto Domed Stadium*, (1985) 17 O.M.B.R. 347 (Ont. H.C.J.), at 350.

[54] *Ibid*.

[55] *The Regional Assessment Commissioner* and *The Municipal Clerk of the Corporation of the Town of Hearst,* [1983] 1 S.C.R. 57 at 69-70.

This line of common law jurisprudence, as it has evolved in both the tax context and in other contexts, would seem to support an interpretation of commercial activities as activities which have, as their primary aim or preponderant purpose, the making of a profit.

Furthermore, in Québec civil law, at least as it existed prior to the 1994 reform, the notion of "commerce" traditionally meant "[a]ctivities which are carried out with the intention of making a profit, and which contribute to the production and circulation of property or the provision of services." (emphasis added). [56]

ii) The contextual interpretation of related statutes (*in pari materia*)

Parliament was the second Canadian jurisdiction, after Québec, to adopt a statute governing the collection, use and disclosure of personal information in the private sector. At that time, the Québec legislature had already adopted *An Act Respecting the Protection of Personal Information in the Private Sector* (R.S.Q. c.P-39.1, hereinafter the "Québec Act"). This statute applies to the collection, retention, use or communication of personal information "in the course of carrying on an enterprise within the meaning of article 1525 of the *Civil Code of Québec*" (section 1 of the Québec Act). Since both statutes deal with the same subject matter, it is appropriate to interpret certain terms contained in the Act in light of those mentioned in its Quebec counterpart.

This approach finds support in the rule of construction based on the "contextual interpretation of related statutes (*in pari materia*)", summarized as follows:

> "Where there are different statues in pari materia though made at different times, or even expired, and not referring to each other, they shall be taken and construed together, as one system, and as explanatory of each other."[57]

Even though Québec is a different legal jurisdiction, it is still appropriate, and in accordance with basic principles of statutory interpretation, to make such a comparison:

> " In interpreting legislation the courts often find it helpful to look at the enactments of other jurisdictions. It is standard practice to consult the legislation of other provinces when interpreting provincial legislation. Also, reference is made to provincial Acts when interpreting federal legislation and vice versa." (emphasis added)[58]

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[56] J.E.C. Brierley, ed., *Private Law Dictionary and Bilingual Lexicons,* 2d ed. (Cowansville: Yvon Blais, 1991) at 69.

[57] Per Lord Mansfield in *R.* v. *Loxdale*, (1758), 1 Burr. 445, 447, 97 E.R. 394 at 395, cited by Côté, *supra* note 49 at 343.

[58] Ruth Sullivan, *Driedger on the Construction of Statutes*, 3rd ed. (Toronto: Butterworths, 1994) at 290.

It is noteworthy that cross-jurisdictional comparisons are useful not only when the terms found within the statutes are similar, but also when they are clearly distinguishable. In either situation, one may infer the legislator's intent, whether that be to follow the approach of the first jurisdiction or to take a different route, as the case may be:

> " Where two statutes dealing with the same subject or enacted to achieve the same purpose use similar or identical words, the courts may readily conclude that the words have the same meaning and effect. Conversely, where statutes that otherwise are similar use different words or adopt a different approach, this suggests that a different meaning or purpose was intended." (emphasis added)[59].

Turning to our present concern, it is important to review the Québec experience, in order to understand the historical context surrounding the Act's adoption. Indeed, the Quebec experience described below, though different - and precisely, because of that difference – can be particularly insightful in interpreting and applying paragraph 4(1)(a) of the Act.

The Quebec experience

In 1994, the Québec legislature introduced, as part of the overall reform of Québec's Civil Code, the broad notion of enterprise appearing in Article 1525 C.C.Q., which subsumes both commercial and non-commercial activity. The "carrying on of an enterprise" thereby replaced what, until then, had been limited in scope to the notion of commercial, or profit-oriented, activity. This was in response to the growing need for increased efficiency by reducing formalistic impediments to economic operations, while ensuring proper discharge of obligations by all entities pursuing organized economic activities, whether commercial or non-commercial. This rationale was explained by the (then) Minister of Justice in his commentary published at the time of the 1994 reform:

> *"Le deuxième alinéa, lui […] étend désormais son domaine d'application aux obligations contractées pour le service ou l'exploitation d'une entreprise, commerciale ou autre.*
>
> *Cette extension reflète l'approche du nouveau code, qui remplace globalement la notion de commerce et les notions dérivées d'actes de commerce et de commerçant, par exemple, par celle d'entreprise […]*
>
> *La notion d'entreprise recouvre l'ensemble de ces activités, lesquelles dépassent donc le cadre des activités commerciales puisqu'elles visent également, entre autres, les activités artisanales, agricoles, professionnelles ou fondées sur la coopération.* » (emphasis added)[60]

[59] *Ibid*. at 291. See also: Côté, *supra* note 49 at 347.

[60] Québec (prov.), Ministère de la Justice, *Commentaires du ministre de la Justice*: *le Code civil du Québec*, Volume 1 (Québec : Publications du Québec, 1993) at 936.

In substituting the broader notion of "enterprise" for the more restrictive notion of "commerce" and its derivatives (*i.e*. "actes de commerce", "commerçant"), the Québec legislature intentionally discarded the "commercial activity" test based on the making of profits. [61]

Doctrinal writers have helped explain this evolution from the traditional notion of "commerce" as a profit-making activity, to the far broader notion of "enterprise" now codified in article 1525 C.C.Q., which includes professionals and also non-profit organizations having a social vocation:

> *"L'auteur des actes juridiques n'a pas à être un commerçant comme l'indique l'article 1525 C.c.Q. […] Il est permis désormais de parler d'entreprises commerciales, d'entreprises agricoles, d'entreprises professionnelles, […] comme c'est le cas en France.*
>
> *Qui plus est, celui qui exploite une entreprise peut ne pas en chercher un bénéfice personnel; ce serait le cas, par exemple, de l'entreprise exploitée par un fiduciaire. De plus, l'exploitation de l'entreprise peut être faite sans avoir pour objet un profit, par exemple une compagnie sans but lucratif opérant une boîte à chanson ou un théâtre, ou une association récréative exploitant un terrain de golf".* (emphasis added)[62]

As explained below, a contrasting approach was chosen by Parliament when it set the scope of Part I of the Act.

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[61] Indeed, as previously mentioned, under Québec civil law in existence prior to the 1994 reform, the traditional notion of "commerce" was defined as "activities which are carried out with the intention of making a profit […]". See Brierley, *supra* note 56 at 69.

For a concrete illustration of how, under the Québec Act, the notion of enterprise has been distinguished from the more restrictive one of "commercial activity", based on profit-making objectives, see: *Mailly* c. *Congrégation des Témoins de Jéhovah d'Issoudun-Sud,* [1996] 292 at 299 (C.A.I.), rev'd on different grounds: *Congrégation des Témoins de Jéhovah d'Issoudun-Sud* v. *Mailly*, [2000] C.A.I. 427 (C.Q.).

[62] Pierre J. Dalphond, "Entreprise et vente d'entreprise en droit civil québécois" in (1994) 54 *R.du B*. 35 at 44-45. To the same effect, see Patrice Vachon, "La notion d'entreprise de l'article 1525 C.c.Q. et son impact sur les transactions immobilières", in Barreau du Québec, Service de la formation permanente, *Développements récents en droit commercial* (1995) (Cowansville : Yvon Blais, 1995) at 117-149.

Interpreting the Act in context (in pari materia)

When Parliament drafted and adopted the *Act*, it is presumed to have been aware of the terms contained in the Québec Act, particularly since this was the only existing provincial statute at the time dealing with protection of personal information in the private sector. Parliament must have known that the Québec statute applied not only to commercial, but also to non-commercial enterprises, *i.e.* those, even professional, that were not profit-oriented. Therefore, it is reasonable to infer that, by confining the application of Part I to organizations collecting, using or disclosing personal information "in the course of commercial activities", rather than "in the course of carrying on of an enterprise", Parliament deliberately chose to limit its application to only a subset of the broader spectrum of activities covered by the Québec statute. Accordingly, it deliberately chose to include only those activities which, collectively, were profit-oriented. Professionals and non-profit organizations, whose activities are not primarily aimed at making a profit, were therefore meant to be excluded from the ambit of Part I.

RECOMMENDATION # 3: "SCHOLARLY RESEARCH" AND "SCHOLARLY RESEARCH PURPOSES"

Use and disclosure of personal information without consent are permitted under the strict conditions found in paragraphs 7 (2) (c) and 7 (3) (f) respectively. One of these requirements consists of using, or disclosing, the information "for statistical, or scholarly study or research purposes". The following provisions purport to clarify two distinct concepts: proposed subsection 3(1) sheds light on "scholarly research" whereas proposed subsection 3(2) brings more certainty to the notion of "scholarly research purposes".

3.1 "SCHOLARLY RESEARCH"

3(1) For greater certainty, the term "scholarly research" referred to in paragraphs 7(2)(c) and 7(3)(f) of the Act shall mean research which:

> ***a) aims primarily at establishing facts, principles or generalizable knowledge, which are of social value and intended to be publicly disseminated; and,***
>
> ***b) has been approved by a research ethics board that is specially designated by law or that is duly established by a university, affiliated institution, professional body, funding agency, or other similar body, where required by, and in accordance with, current applicable national and international ethical standards.***

Scholarly research may include research jointly funded by the private and public sectors.

A. Policy reasons

The term "scholarly research" has rarely, if ever, been specifically defined. However, the contexts in which the term "research" has been defined (*e.g.* in academic dictionaries, in guidelines issued by federal funding agencies or in the enabling statutes of federal funding agencies) may be particularly insightful. For example, see the following definitions, drawn from:

- *J.M. Last, ed.,* ***A Dictionary of Epidemiology***:

  "[Research is defined as] a class of activities designed to develop or contribute to generalizable knowledge (which) consists of theories, principles, or relationships, or the accumulation of information on which these are based, that can be corroborated by acceptable scientific methods of observation, inference and/or experiment." [63]

- ***Tri-Council Policy Statement (on) Ethical Conduct for Research Involving Humans***:

  "Research involving human subjects is premised on a fundamental moral commitment to advancing human welfare, knowledge and understanding, and to examining cultural dynamics. Researchers, universities, governments and private institutions undertake or fund research involving human subjects for many reasons, for example: to alleviate human suffering, to validate social or scientific theories, to dispel ignorance, to analyze policy, and to understand human behaviour and the evolving human condition. Research involving human subjects imparts at least three general categories of benefits:

  - The basic desire for new knowledge and understanding is the driving force for research.
  - The quest to advance knowledge sometimes benefits research subjects. Subjects may benefit from improved treatments for illnesses; the discovery of information concerning one's welfare; the identification of historical, written, oral or cultural traditions; or the satisfaction of contributing to society through research.
  - As well, research benefits particular groups and society as a whole. Thus, insights into political behaviour may produce better policy; information about the incidence of disease may improve public health; sociological data about lifestyles may yield social reform; and disciplines based on, for example, texts, dance, theatre or oral history, continue to illuminate past and present realities." [64]

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[63] J.M. Last, ed., *A Dictionary of Epidemiology*, 4th edition, (New York: Oxford University Press, 2001) at 157-8.

[64] Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy*

- The ***Canadian Institutes of Health Research Act:***

> "[section 4] The objective of CIHR is to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system…" [65]

Given modern funding arrangements that promote partnership between various sectors (public sector, private sector and voluntary organizations), the definition of scholarly research must reflect the reality of joint funding. Private investment does not in and of itself transform scholarly research into commercial activity. The second paragraph of proposed subsection 3(1) aims to provide greater clarity and certainty in this regard.

This proposed provision also expressly recognizes the important role of research ethics boards (hereinafter referred to as "REBs"). Review and approval by a research ethics board is a central condition for allowing "scholarly research" to proceed in any Canadian university or affiliated academic institution receiving federal funding. It is also a requirement under federal regulations with respect to clinical trials. For greater certainty and clarity, this reality should be reflected in the very meaning ascribed to the term. This may give Privacy Commissioners and courts a higher level of comfort in finding that, in the context of scholarly research, even where the exception to consent applies, there are additional protective mechanisms in place to ensure that the general purpose of the Act is being fulfilled, within a much broader and more coherent ethical framework.

Independent, multi-disciplinary REBs have been established at a local level in universities and affiliated academic institutions across the country for several years now, in some cases, well over two decades. They embody a broad range of perspectives and an enormous wealth of hands-on experience in reviewing the ethical acceptability of research protocols. REBs have acquired specialized knowledge of the inherent complexity of research proposals involving various disciplines. REBs are specially placed to play both a review and educational role; they review research protocols with the aim of determining their ethical acceptability from the point of view of the research subject; they also provide an ongoing consultative and educational function for the research community. [66]

Statement (on) Ethical Conduct for Research Involving Humans, (Ottawa: Public Works and Government Services Canada, 1998) at i.4.(hereinafter the "**TCPS**").

[65] The *Canadian Institutes of Health Research Act*, S.C. 2000, c.6, section 4.

[66] See the TCPS, in particular, Section 1 entitled "*Ethics Review*" at 1.1 to 1.12 inclusive.

REBs are well immersed in issues relating to both the protection of individual human subjects and the societal need for research. REBs review research protocols in accordance with the fundamental principles enunciated in the *TCPS* [67]. These are:

- respect for human dignity,
- respect for free and informed consent,
- respect for privacy and confidentiality,
- respect for justice and inclusiveness,
- balancing of harms and benefits,
- minimizing harm, and
- maximizing benefit.

REBs have unique experience not only with each of these principles, but also in applying them with a proportionate and flexible approach, in a manner which seeks to achieve balance overall. REBs evaluate the entire context, considering the degree of potential harm that may result to the individual, in relation to the potential benefits of the research accruing to society as a whole[68]. The functioning of REBs has come under much scrutiny in recent years given their abundant workload and limited resources. Parallel efforts must pursue to strengthen and support these bodies so that they may continue to serve their vital responsibility.

The important role of REBs in the oversight of research ethics generally, and the protection of personal information more specifically, has already been expressly recognized several times in Canadian legislation, namely in the following jurisdictions:

- ***Québec (Civil Code of Quebec)***

  "[article 21 paragraph (1)] "Any experiment on a minor or a person of full age who is incapable of giving consent, or on a group of minors or of such persons, may only be carried out within the framework of a research project approved by an ethics committee designated or formed by the Minister of Health and Social Services and under conditions determined by the Minister. Moreover, the experiment must have the potential to produce a benefit to the health of the person concerned or, if it is conducted on a group, to the health of persons of the same age group or having the same illness or handicap as the persons submitted to the experiment."

[67] *Ibid*.

[68] *Ibid.* See section entitled, "*Context of an Ethics Framework*" at pages i.4 to i.10. As for more specific guidelines on privacy, see Section 3 entitled "*Privacy and Confidentiality*" at pages 3.1 to 3.6, Section 8 entitled "*Human Genetic Research*" at pages 8.1 to 8.8, and Section 10 entitled "*Human Tissue*" at pages 10.1 to 10.4.

- **Alberta** (*Health Information Act*)

  "[section 49] A person who intends to conduct research may submit a proposal to an ethics committee for review by that committee." [69]

- **Saskatchewan** (*Health Information Protection Act)*

  "[subsection 29(1)] A trustee or a designated archive may use or disclose personal health information for research purposes with the express consent of the subject individual if: (a)…
  …(b) the research project has been approved by a research ethics committee approved by the minister…" [70]

- ***Manitoba*** *(The Personal Health Information Act)*

  "[subsection 24(1] A trustee may disclose personal health information to a person conducting a health research project only if the project has been approved under this section.

  [subsection 24(2] An approval may be given by
  (a) the health information privacy committee established under section 59, if the personal health information is maintained by the government or a government agency; and
  (b) an institutional review committee, if the personal health information is maintained by a trustee other than the government or a government agency." [71]

- **Ontario** (Bill 159, *Personal Health Information Privacy Act*)

  "[subsection 32(1)] A health information custodian may disclose personal health information to a researcher, being a person conducting a research project or program, only if a research ethics review body designated by regulation has approved the project or program in accordance with this section." [72]

[69] *Health Information Act*, S.A. 1999, c. H-4.8, section 49.

[70] *Health Information Protection Act*, S.S. 1999, c. H-0.021, subsection 29(1)

[71] *The Personal Health Information Act,*S.M.1997,c.P-33.5, subsections 24(1) and 24(2).

[72] Bill 159, *Personal Health Information Privacy Act*, 2000 (1st. Sess., 37th Leg., Ontario 2000 - since died on the order paper), subsection 32(1).

B. Legal considerations

"Scholarly research", expressly referred to but nowhere defined in the Act, is a matter that commands clarification by way of regulation, pursuant to the general residual enabling clause found at paragraph 26 (1)(b). Accordingly, proposed paragraph 3(1)(b) effectively enables researchers and research subjects alike to better understand their respective rights and obligations.

The definition set forth in proposed subsection 3 (1) is not only consistent with the purposes and provisions of the Act, it actually promotes their achievement. Indeed, under the proposed provision, a specific research will only fit into the statutory exceptions (paragraphs 7(2)(c) and 7(3)(f)), if the following conditions are fulfilled:

- The research is primarily aimed at establishing facts, principles or generalizable knowledge, which are of social value and intended to be publicly disseminated (proposed paragraph 3(1)(a)). A given research that qualifies as such is more likely to satisfy the "reasonable person test" that applies when assessing organizational needs under the purpose clause (*in fine*).

- The research has obtained prior approval by an REB, under the conditions prescribed in proposed paragraph 3 (1)(b). This condition also helps achieve the purposes set forth in section 3 of the Act, since the applicable national and international ethical standards seek to protect research subjects and their privacy rights [73].

It should be emphasized that this recommendation adds no new conditions to those set forth in paragraphs 7(2)(c) and 7(3)(f). Rather, it brings more certainty to one of the existing statutory conditions for using or disclosing personal information without consent.

In order to be valid, this regulatory provision must not be construed as an illegal sub-delegation of legislative powers. For a court to draw such a conclusion, it would first have to find that, in the circumstances, legislative powers have actually been sub-delegated.

A broad spectrum of powers, including those of a judicial, quasi-judicial, ministerial, administrative or legislative nature, may be conferred or delegated by statute to specific persons or bodies [74]. When these same powers are transferred to another entity, there is said to be a sub-delegation of statutory authority.

In certain circumstances, a proper and valid exercise of statutory powers may inappropriately be mistaken for sub-delegation. Indeed, the scope of this concept is better understood by distinguishing it from what it is not. For instance, sub-delegation should be discerned from incorporation by reference of external norms, which is

[73] For instance, see Appendix 2 of the TCPS, which contains many safeguards protecting research subjects from improper infringement of their privacy rights (in particular, see articles 2.1, 2.2, 2.4, 2.5, 2.6, 2.7, 2.8, 3.2, 3.3, 3.4 and 3.5).

[74] Dussault and Borgeat, *supra* note 12 at 415.

permitted, provided the instruments or texts incorporated by reference are well known and clearly identified by the rule-maker [75]. Sub-delegation must also be distinguished from mere reference to prior action on the part of a third body, as a condition precedent.

No sub-delegation occurs when a regulation merely takes into account the opinion or prior decision of an external body, as a condition precedent to which legal consequences are attached. This principle was set forth by the Supreme Court of Canada in *Lamoureux* v. *City of Beaconsfield* [76]. In that case, the City had adopted a by-law, wherein restrictions were made to the use of land for, *inter alia*, service station purposes. This by-law provided that no permit would be granted for such use, if two-thirds of a designated group of land-owners had previously objected to the project, according to a prescribed procedure. Appellant Lamoureux submitted that the relevant provision was *ultra vires* the powers of the City, on the grounds that it had improperly delegated its legislative powers to the land-owners. Mr. Justice Martland, writing for the majority, discarded this argument, for the following reasons:

> "This by-law spells out the conditions which are required to be met by an applicant for a permit in respect of a service station and states that, as a condition precedent to the issuance of such permit, adjacent landowners shall have an opportunity to object, and that, if a substantial majority of them register their objections, the permit will not issue […]
>
> […] The by-law does not delegate to [the land-owners] a general power of decision, as in the Vic Restaurant case and the City of Verdun case, as to whether of not service station permits shall issue. Instead the by-law takes into account, in each particular case, the wishes of adjacent landowners, who are the very people affected by the proposed use, as one of the conditions precedent to the obtaining of a specific permit. In my opinion this is in accord with the principle of zoning legislation and the provision was not ultra vires of the respondent municipality." (emphasis added) [77]

In another case [78], a Manitoban court was asked to decide whether legislative powers had been illegally sub-delegated to third bodies. Here, two commercial air carriers were accused of having violated the *Air Regulations* adopted under the *Aeronautics Act*, by failing to maintain their aircraft in accordance with manufacturer instructions. Under the regulatory scheme, the Minister of Transport had delegated an official of the Department to publish a manual containing standards of airworthiness for aircraft. This manual imposed on all carriers, as a condition of airworthiness, the obligation to follow manufacturers' recommendations (which, in turn, were published in the form of an owner's manual). The carriers contended that this requirement had the effect of illegally

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[75] *Ibid*. at 419.

[76] [1978] 1 S.C.R.134 (hereinafter, "*Lamoureux*").

[77] *Ibid*. at 141-142.

[78] *R*. v. *Perimeter Airlines (Inland) Ltd.* and *Perimeter Aviation Ltd.*, (1986) 6 W.W.R.110 (Man. Prov.Ct.) (hereinafter "*Perimeter*").

sub-delegating the minister's legislative powers to aircraft manufacturers. The Court rejected this argument and, preferring Crown's position, observed:

> "Moreover, the minister did not subdelegate his powers to the manufacturers of aircraft as alleged by the defence.[…]
>
> By the Air Regulations, the minister, as indicated above, has set general conditions respecting the terms and conditions under which aircraft may operate in Canada.[…]
>
> I agree with the submission of Crown counsel […]:
>
> > 'It is submitted that no delegation of the legislative authority over standards of airworthiness to the aircraft manufacturers has taken place by virtue of the Minister defining the maintenance program required for Canadian registered aircraft by reference to the recommendations of the manufacturers. There is no delegation because the Minister has made the decision as to what the conditions for the continuing validity of the Certificate of Airworthiness shall be. The aircraft manufacturers have no role in the determination of the condition on which the Certificate of Airworthiness is issued or will remain in force. The conditions have been set and will be enforced by the Minister. Most important, only the Minister can change the conditions' ". (emphasis added) [79]

In addition, it should be emphasized that a regulation cannot be viewed as sub-delegating authority to a third body when it merely refers to pre-existing powers already held by this entity. Indeed, the Ontario Court of Appeal once observed that the issue of sub-delegation should not even be raised, if a body has not been granted powers it did not already possess[80].

In light of these precedents, mere reference to an external body's prior actions or decisions, as a regulatory condition precedent, cannot be equated with sub-delegation. Rather, by setting such a condition, the rule-maker is actually setting the rules, not designating the third body to exercise any new powers.

The situation described above contrasts sharply with that of granting an external body discretion to apply statutory norms on a case-by-case basis. Of course, the latter approach would be illegal, since it would amount to transforming legislative powers into

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[79] *Ibid*. at 127-128.

[80] *Farm Credit Corp*. v. *Pipe*, (1993) 17 *Adm. L.R.*(2d) 308 (Ont. C.A.). Although the case dealt not with legislative powers, the Court's *obiter* , drafted by Mr. Justice Tarnopolsky, is very relevant to our concern. He observed that, in the case at hand, sub-delegation was simply not an issue, invoking the fact that "[t]he order-in-council of concern here does not confer on the respondent any new powers that it does not already have[...]" (emphasis added) (at 316).

administrative ones[81]. This would occur when a rule-maker, rather than setting general norms, grants an entity broad administrative discretion to decide individual cases, without providing it with sufficient guidelines. An illustration of such an illegal process is found in the *Dene Nation* case[82]. There, instead of setting out clear standards for the use of certain waters without a permit in its regulation, Governor in Council adopted a provision conferring the Controller discretion to decide when such use was permitted. Although, in this case, the contested provision set out general guidelines for the Controller, it provided that water could be used without a licence "if the Controller ha [d] stated in writing that he [was] satisfied that the proposed use would meet the applicable requirement of subsection 10(1) of the Act […]"(emphasis added). Mr. Justice Reed, for the Federal Court (trial division), in deciding that the regulatory provision was *ultra vires*, stated:

> "The prominent characteristic of the impugned regulation which immediately strikes one is the fact that a Controller, whose existence is nowhere contemplated in the Act, is authorized to grant authorization for the use of water without a licence when the proposed use meets "the applicable requirement of subsection 10(1) of the Act." That is, the Controller is required by the regulations to exercise a decision-making function similar to that of the territorial board.
> […]
> I agree that the Controller was not authorized to act legislatively, e.g., by making regulations or rules. What occurred instead was the transformation by regulation of a legislative power into an administrative or a quasi-judicial power, and the conferral of that power on the Controller.
> […] when authority is conferred on an entity to regulate by regulation, the power must be so exercised and not exercised by setting up some sub-delegate with discretionary powers to make the decision.[…]
> In this case there has not been a wholesale delegation as in the Brant and Brent cases, supra; some legislative guidance is given.[…however] not enough legislative guidance has been given to escape the conclusion

[81] On the illegality of this type of regulation, see: Dussault and Borgeat, *supra* note 12 at 417, where the authors observe:

> "For some questions of detail not foreseen in the statute, the regulation-making authority is expected to establish objective and uniform norms of behaviour for all citizens. However, at times, by deciding to draft regulations in discretionary terms, the authority is granted the power to make a particular decision in each case. Thus, for example, a board empowered to make regulations concerning the conditions for obtaining a licence may decide to make a regulation granting it full discretion as to the issuance of each licence sought. There is no doubt as to the illegality of this process, if it is not expressly authorized by Parliament; the exercise of a regulation-making power must involve general norms and not a system of administrative discretion".

See also the leading case on transforming legislative powers into administrative discretion: *Brant Dairy Co.* v. *Milk Commission of Ontario*, [1973] S.C.R.131, especially at 147.

[82] *Dene Nation et al*. v. *R.*, (1984) 6 *Admin.L.R.* 268 at 274 (hereinafter "*Dene Nation*").

> that an unauthorized sub-delegation has occurred. Section 10(1) does not provide a sufficiently complete code of requirement."(emphasis added)[83]

The factual background in *Dene Nation* was however quite different from the ones giving rise to the *Lamoureux* or *Perimeter* cases discussed above. In *Dene Nation*, a Controller had been given discretion to apply provisions of the Act, whereas, in neither *Lamoureux* nor *Perimeter*, had any discretion been granted to the land owners, or to the manufacturers, to decide a matter contained in the applicable statute.

In light of the principles discussed above, the reference made in proposed paragraph 3 (1) (b) to REB approval does not amount to a sub-delegation of legislative powers. Rather, by defining "scholarly research" in relation to prior REB approval, Governor in Council would actually be exercising its rule-making authority, not granting REBs any new decisional powers under the Act. Indeed REBs already have the authority to approve research projects for funding purposes, applying high ethical standards, and this authority exists independently and irrespective from the statutory scheme under the Act. In no way does paragraph proposed 3(1)(b) grant any authority to REBs to determine whether a given research project qualifies under the Act as "scholarly" research. In the event of a complaint, such a determination would be left to the Privacy Commissioner who would decide if a given case fits into one of the exceptions at paragraphs 7(2)(c) or 7(3)(f), by applying all the relevant criteria, including prior REB approval.

3.2 "SCHOLARLY RESEARCH PURPOSES"

> ***3(2) For greater certainty, the term "scholarly research purposes" referred to in paragraphs 7(2)(c) and 7(3)(f) of the Act shall include consistent purposes, such as, validating and auditing research results, conducting related research which is reasonably and directly connected to the original research purpose and, notifying individuals of any unanticipated, long-term risk of potentially adverse effects.***

A. Policy reasons

This provision identifies the scope of scholarly research purposes by referring to directly related purposes which would not constitute new purposes requiring new consent and which would justify the ongoing retention of data until such time as those directly related purposes were fulfilled. This is especially important in order to attribute a practical, workable and feasible meaning to the principles governing the retention and destruction of data set out in the CSA Code, incorporated as Schedule 1 of the Act, in particular:

> "[Section 4.2.4] *When personal information that has been collected is to be used for a purpose not previously identified, the new purpose shall be*

[83] *Ibid.* at 274-275.

identified prior to use. Unless the new purpose is required by law, the consent of the individual is required before information can be used for that purpose."

"[Section 4.5] *Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfilment of those purposes*."

A similar approach was clearly identified and articulated by the U.K. Medical Research Council in their recent guidelines on *Personal Information in Medical Research* [84]:

"[**7.1 Storage -** Article 7.1.1] *Research records need to be preserved for the longer-term for a number of reasons – other than for historical posterity. Firstly, records may be needed later on for scientific validation of research, or for future research and audit. Secondly, occasionally there is a need for access to records over the whole lifetime of patients, both by the patients themselves (who may have continuing long-term concerns about their own health) and their clinicians – for instance, where trials of novel treatments were involved*."

"[**7.2 Re-use of data by third parties -** Article 7.2.1]. *Researchers obtaining information with consent should, wherever possible, anticipate likely needs to archive the data, and to share data sets with other researchers, and make this clear to the people involved. Consent to this should be distinct from consent to the primary use of the information. Existing data sets can be shared with other researchers provided this is not inconsistent with what participants were told about how the data would be used. For example, the use of clinical trial data for meta-analyses should not, in our opinion, require new consent*." *(emphasis added)*

Canadian data protection laws [85] generally allow the use and disclosure of personal information for a purpose consistent with the original purpose for which the personal information was collected. In some cases, "consistent" purpose is expressly defined, in part, as a purpose that is reasonably and directly connected to the original purpose, or is reasonably compatible therewith.

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[84] Medical Research Council, *Personal Information in Medical Research* (U.K., October 2000) at 33.

[85] *Privacy Act*, R.S.C. 1985, c. P-21, s. 8(2)(a); *Freedom of Information and Protection of Privacy Act*, R.S.B.C. 1996, c. 165, ss. 32(a), 33(c) and 34(1)(a); *Freedom of Information and Protection of Privacy Act*, S.A. 1994, c. F-18.5, ss. 37(1)(a), 38(1)(b) and 39(a); *Freedom of Information and Protection of Privacy Act*, S.S. 1990-91, c. F-22.01, s. 28(a) and 29(2)(a); *Freedom of Information and Protection of Privacy Act*, R.S.M. c. F175, ss. 43(a), 44(1)(a) and 45(a); *Freedom of Information and Protection of Privacy Act*, S.N.S. 1993, c. 5, ss. 26(a), 27(c) and 28(a); *The Health Information Protection Act,* S.S. 1999, c. H-0.021, ss. 26(3)(a) and 27(3)(a); *The Personal Health Information Act*, S.M. 1997, c. P-33.5, s. 21(a); Ontario Bill 159, *Personal Health*

B. Legal considerations

Proposed subsection 3(2) of the regulation purports to clarify the meaning of "scholarly research purposes", given that proposed subsection 3(1) already defines the term "scholarly research".

The clarification achieved by 3(2) properly carries out a fundamental purpose of Part I, which consists in restricting the collection, use and disclosure of personal information to "purposes that a reasonable person would consider appropriate in the circumstances" (see the purpose clause, section 3, *in fine,* and subsection 5(3) of the Act).

Proposed subsection 3(2) delimits the scope of the exceptions at 7(2)(c) and 7(3)(f), while ensuring that any subsequent use or disclosure without consent will be strictly limited to purposes that are "appropriate" in the circumstances, from the perspective of reasonable person. This approach is in harmony with clause 4.3 of Schedule 1, which must be read in conjunction with these exceptions:

> **"4.3 Principle 3 – Consent**
> The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate. […]" (emphasis added)

More light is shed on the meaning of appropriateness from a reading of clause 4.3.2 and clause 4.3.5 of Schedule 1. These provisions focus specifically on the reasonable expectations of the individual at the time consent is given:

> "4.3.2
> The principle requires 'knowledge and consent'. Organizations shall make a reasonable effort to ensure that the individual is advised of the purposes for which the information will be used. To make the consent meaningful, the purposes must be stated in such a manner that the individual can reasonably understand how the information will be used or disclosed." (emphasis added)

> "4.3.5
> In obtaining consent, the reasonable expectations of the individual are also relevant. For example, an individual buying a subscription to a magazine should reasonably expect that the organization, in addition to using the individual's name and address for mailing and billing purposes, would also contact the person to solicit the renewal of the subscription. In this case, the organization can assume that the individual's request constitutes consent for specific purposes. On the other hand, an individual would not reasonably expect that personal information given to a health care professional would be given to a company selling health-

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Information Privacy Act, 2000 (1st. Sess., 37th Leg., Ontario 2000 - since died on the order paper), s. 24(3)(b).

> care products, unless consent were obtained. Consent shall not be obtained through deception." (emphasis added)

Proposed subsection 3(2) purports to apply these general principles in the particular context of scholarly research. The reasonable expectations of any research participant would very likely encompass purposes that are consistent with the primary purpose. The type of consistent purposes referred to proposed subsection 3(2) are strikingly different from the purposes considered to be "inappropriate" under clause 4.3.5 (*i.e*. a health care professional giving personal information to a company selling health-care products).

RECOMMENDATION # 4: RECEIPT OF PERSONAL INFORMATION UNDER CONDITIONS CONTEMPLATED IN PARAGRAPH 7(3)(f)

4. ***In order to give effect to the exception provided for in paragraph 7(3)(f) of the Act, an organization may receive personal information without the knowledge or consent of the individual under the conditions provided for in that subsection.***

A. Policy reasons

On a literal interpretation of the Act, the exception that allows disclosure of personal information for scholarly research purposes without consent under certain conditions at paragraph 7(3)(f) could never actually have any effect, since the organization receiving the personal information for scholarly research purposes under those same conditions would not be permitted to do so without consent. This might be the case, for instance, where the transaction involves consideration or where the receiving organization has some commercial attributes. This would have the absurd result of rendering paragraph 7(3)(f) absolutely useless.

Hence, this recommendation is intended to give effect to the disclosure exception provided at paragraph 7(3)(f), by ensuring that the receipt of the personal information is permitted under the same conditions. This provision is necessary for carrying out the ultimate purpose of Part 1, which is,

> "to establish, in an era in which technology increasingly facilitates the circulation and exchange of information, rules to govern the collection, use and disclosure of personal information in a manner that recognizes the right of privacy of individuals with respect to their personal information and the need of organizations to collect, use or disclose personal information for purposes that a reasonable person would consider appropriate in the circumstances."

In several Canadian jurisdictions, express statutory provisions have been enacted in order ensure reciprocity between the act of legally disclosing personal information and legally receiving it. As examples:

- **Federal** *(Privacy Act)*

"[subsection 5(1)] A government institution shall, wherever possible, collect personal information that is intended to be used for an administrative purpose directly from the individual to whom it relates except where […] personal information may be disclosed to the institution under subsection 8(2) [this latter provision sets out conditions under which personal information may be disclosed without the individual's consent]" [86]

- **Alberta** *(Freedom of Information and Protection of Privacy Act)*

"[subsection 33 (1)] A public body must collect personal information directly from the individual the information is about unless
[…]
(b) the information may be disclosed to the public body under Division 2 of this Part," [87]

- **Manitoba (Freedom of Information and Protection of Privacy Act)**

"[subsection 37(1)] Personal information must be collected by or for a public body directly from the individual the information is about unless:
[…]
(e) the information may be disclosed to the public body under Division 3 of this Part;" [88]

- **British Columbia** (*Freedom of Information and Protection of Privacy Act*)

"[subsection 27 (1)] A public body must collect personal information directly from the individual the information is about unless
[…]

[86] *Privacy Act*, R.S.C. 1985, c. P-21, subsection 5(1).

[87] *Freedom of Information and Protection of Privacy Act***,** S.A.1994, c. F-18.5, paragraph 33 (1) (b).

[88] Manitoba, *Freedom of Information and Protection of Privacy Act*, S.M.1997, c. 50, subsection 37(1).

(b) the information may be disclosed to the public body under sections 33 to 36 or " [89]

B. Legal considerations

By adopting this provision, Governor in Council would be exercising its rule-making authority in a responsible way. The resulting legal framework would be complete, unambiguous and actually pursue Parliament's intent, rather than produce absurd and undesired consequences. This is clearly a function that devolves primarily on the legislative, not on the judicial, branch of government.

If the inconsistencies flowing from the present wording of the Act are not resolved by regulation, they will eventually be brought before the Privacy Commissioner or the courts, when called to interpret the Act in the course of litigation.

Courts often resort to a pragmatic rule of construction[90], when interpreting and applying statutory norms that produce absurd, irrational, unjust or unreasonable[91] effects. This approach allows the Judiciary to avoid such consequences, by applying the so-called "golden rule", which has been summarized as follows:

> "[T]he grammatical and ordinary sense of the words is to be adhered to, unless that would lead to some absurdity, or some repugnance or inconsistency with the rest of the instrument, in which case the grammatical and ordinary sense of the words may be modified, so as to avoid that absurdity and inconsistency, but no farther." [92]

This rule of construction is premised on the assumption that the legislator could not have intended to adopt norms producing such absurd, irrational or unjust results. The exact scope of this rule has given rise to diverging views and still may not be definitely settled[93]. However, the following attempt to succinctly capture the current view is quite enlightening:

> "It is now well established that the consequences of applying legislation may be taken into account in every case, and to avoid absurd or unacceptable consequences, the ordinary meaning may be rejected even if it is 'plain'. There is only one limitation on the court's jurisdiction to

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[89] British Columbia, *Freedom of Information and Protection of Privacy Act*, R.S.B.C. 1996, c.165, paragraph 27 (1) (b).

[90] Côté, *supra* note 49 at 443-466.

[91] Qualifiers, other than "absurd", are indeed used to describe such results, for example: unjust, inequitable, anomalous, intolerable, inconceivable, strange, bizarre, startling, curious. On this topic, see: Côté, *ibid*. at 451-452.,

[92] Lord Wensleydale, in *Grey* v. *Pearson*, cited by Sullivan, *supra* note 58 at 80.

[93] *Ibid*. at 81-84; Côté, *supra* note 49 at 448-459.

avoid absurdity: the interpretation adopted must be one that the words are reasonably capable of bearing." (emphasis added) [94]

The hazardous results one could expect from an application of this test amply justify the clarification proposed by way of regulation. It should be incumbent on the legislative branch, not on the Judiciary, to avoid absurd consequences flowing from any statutory framework.[95] Moreover, in order to properly carry out the provisions and purposes of Part I, pursuant to the enabling clause at hand *(i.e.* paragraph 26 (1) (b)), it would seem necessary to avoid such anomalous results.

Accordingly, the present recommendation merely aims at devising a clear, complete and consistent legal framework, rather than relegating this task to a Privacy Commissioner or to a Court.

RECOMMENDATION # 5: "IMPRACTICABLE TO OBTAIN CONSENT"

5. For greater certainty, in assessing whether "it is impracticable to obtain consent" for scholarly research purposes within the meaning of paragraphs 7(2)(c) and 7(3)(f) of the Act, consideration shall be given to all of the relevant factors which may apply in the circumstances, including:

a) the size of the population being researched;

b) the proportion of individuals likely to have relocated or died since the time the personal information was originally collected;

c) the risk of introducing potential bias into the research thereby affecting the generalizability and validity of results;

d) the risk of creating additional threats to privacy by having to link otherwise de-identified data with nominal identifiers in order to contact individuals to seek their consent;

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[94] Sullivan, *supra* note 58 at 85.

[95] As Professor Côté (*supra* note 49 at 444-445) has observed :

> "[…] the legislature is deemed to respect the values and the principles of the society for which it is legislating. We suppose, for example, that a 'good legislature' or a 'reasonable legislature, could not, unless this was the clearly manifested intention, seek unreasonable of manifestly unjust results from a statute.
> […] Presumptions [of intent] are then policies applied by the courts when application of the law requires that they intervene to complete the legislative message. The courts are saying to Parliament: 'If you don't say what you want clearly enough, we will apply the law in a given fashion " (emphasis added)

e) the risk of inflicting psychological, social or other harm by contacting individuals or families with particular conditions or in certain circumstances;

f) the difficulty of contacting individuals directly when there is no existing or continuing relationship between the organization and the individuals;

g) the difficulty of contacting individuals indirectly through public means, such as advertisements and notices; and,

h) whether, in any of the above circumstances, the requirement for additional financial, material, human, organizational and other resources needed to obtain such consent will impose an undue hardship on the organization.

A. Policy reasons

In order to assist in the interpretation and application of the term "impracticable to obtain consent", this recommendation attempts to capture actual situations where, in practice, consent either cannot be feasibly or realistically obtained or, if obtained, would defeat the very purpose of the scholarly research. The list of factors is not intended to be exhaustive, but rather, only illustrative. In addition, not all of the factors must necessarily be met in a given situation. Rather, they must be considered, to the extent that they are applicable, on a case by case basis. Furthermore, the factor referred to paragraph h) would not by itself be determinative, since it would only be considered in combination with one or more of the relevant factors listed in paragraphs a) to g).

These factors have been directly inspired from CIHR's draft case studies[96] involving secondary use of personal information, specifically in the context of health services and population health research. The case studies exemplify, in concrete terms, how each of these factors (either alone or in combination with others) indeed makes it impracticable, if not impossible, to obtain consent.

B. Legal considerations

Impracticability to obtain consent is one of the five conditions that apply to the use of personal information without such consent (paragraph 7(2)(c)) and one of the four conditions imposed in the case of disclosure (paragraph 7(3)(f)). Since impracticability is a matter to which the Act expressly refers, Governor in Council is duly authorized to regulate it, pursuant to the general residual enabling clause.

Whether, in a given situation, it is "impracticable to obtain consent", particularly in the context of scholarly research, may be difficult for a Privacy Commissioner to assess,

[96] Canadian Institutes of Health Research, Draft *Case Studies Involving the Secondary Use of Data for Health Research Purposes* (forthcoming).

without useful guidance being supplied by regulation. Consequently, in order to properly carry out the aforementioned exceptions, the regulation provides a list of factors, all of which are relevant when assessing "impracticability". These factors effectively facilitate fulfillment of the general purposes of Part I, when applied from the perspective of a "reasonable person" *(i.e*. in determining whether the use or disclosure is made for appropriate purposes in the circumstances (section 3, *in fine*).

There is no inconsistency between the proposed regulatory provision and the Act, since the latter neither defines "impracticable" nor specifies when it is "impracticable to obtain consent". Although the note accompanying clause 4.3 of Schedule I does provide examples of situations where it could be "impractical", "impossible" or "inappropriate" to obtain consent, it is not incorporated into the Act[97] and has no direct application to the exceptions at 7(2)(c) and7(3)(f). Nevertheless, this note could be relied on to interpret the Act. Indeed, as observed by Driedger, "legal documents or instruments set out in a schedule may be relied on in interpreting the Act, even though they are not incorporated into the text of the Act."[98] It is noteworthy then that none of the factors appearing in the regulatory provision is inconsistent with any of the examples contained in the accompanying note to clause 4.3 [99]. To the contrary, some of these factors are quite related to the concerns expressed in the note[100].

Finally, as a concluding remark, this recommendation finds ample support in the general legal principles discussed above, in Part II.

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[97] See subsections 5(1) and 2(2) of the Act, which provide:

> "5(1) Subject to sections 6 to 9, every organization shall comply with the obligations set out in Schedule 1."
> "2(2) In this Part, a reference to clause 4.3 or 4.9 of Schedule 1 does not include a reference to the note that accompanies that clause."

[98] Sullivan, *supra* note 58 at 281, where it is stated that "materials set out in a schedule […] referred to in the body of the Act without being incorporated into the Act or given the force of law […] may be used to interpret provisions in the body of the Act." (emphasis added)

[99] The note refers to legal, medical or security reasons; defeating the purposes sought by detection and prevention of fraud or law enforcement; lack of legal capacity to give one's consent; the absence of any direct relationship with an individual.

[100] For instance, factor (c), where obtaining consent would defeat the purpose of the research, and factors b), f) and g), where there is no direct relationship.