ASSISTED REPRODUCTION WITHOUT ASSISTING OVER-COLLECTION: FAIR INFORMATION PRACTICES AND THE ASSISTED HUMAN REPRODUCTION AGENCY OF CANADA

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Introduction
The collection, use and disclosure of information in the context of assisted human reproduction warrant careful consideration. Consider the stories of Charles and Meera.¹ Charles is interested in donating sperm anonymously. Charles’ sister and her partner used anonymous sperm to create their family, and he wants to help someone else do the same. But when he learns of the information requirements imposed by the Assisted Human Reproduction Act [AHRA], he hesitates.² Charles is worried about the extensive amount of information that his physician must collect from him and disclose to a government agency, the Assisted Human Reproduction Agency of Canada [Agency]. In particular, he is afraid that his infrequent recreational drug use will become known to the Agency. Charles is willing to disclose this information to the physician, to the recipient of his sperm and to the resulting child. However, he does not want to disclose this information to the Agency, for fear that it may negatively impact his job – or worse, lead to criminal prosecution – if it is inadvertently disclosed. Charles’ physician has advised him that should he refuse to consent to the disclosure of his information to the Agency, he will not be allowed to donate sperm.

Meera, a known egg donor, is also concerned by these requirements. Meera has decided to donate her ova (or eggs) to her sister, Anita, and her

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¹ These are fictional accounts.

partner, Sean. Anita’s eggs are not viable. They do not plan to disclose their use of assisted human reproductive technologies [ARTs] to anyone, including the child. When Meera meets with the fertility specialist to begin treatments to hyperstimulate her ovaries before collecting her ova, she is advised that pursuant to the AHRA she must disclose certain health reporting information to Anita and Sean, as recipients of her donated ova, and to the Agency. Meera suffers from a variant of lupus, a chronic condition. Lupus is not a hereditary disease, and there is no history of it in Meera and Anita’s family. Meera has not told her family or her employer. She is worried that if her employer learns of her condition she may not be promoted or may be fired. Because lupus is not hereditary, Meera does not feel that it is relevant to the resulting child’s health and well-being. Meera wants to keep her lupus secret, and decides not to disclose it to her physician. However, she does not know that the hormones used to hyperstimulate one’s ovaries have been known to exacerbate lupus and are, thus, potentially fatal.3 Meera’s failure to disclose ultimately worsens her lupus, forces her to discontinue the fertility treatment and take extended sick leave from work.

This paper considers whether the AHRA’s privacy provisions, which govern the collection, use and disclosure of information in the context of ARTs, do in fact protect the privacy of people like Charles and Meera, while ensuring appropriate disclosure of information to interested parties, such as donor-conceived offspring. Although the privacy provisions are not yet in force and the regulations not yet drafted, the AHRA’s privacy framework appears to be inconsistent with fair information practices, those practices that are considered to be fundamental to the protection of privacy. As a result, these provisions may threaten the privacy of individuals using these technologies. In doing so, they not only undermine a value fundamental to Canadian society; they create a real possibility that individuals may fail to disclose relevant health reporting information that is essential to their proper care or may avoid the use of these technologies altogether.

In Part I, I describe the privacy provisions of the AHRA, as well as provide an overview of the type of information generally collected in the use of ARTs. In Part II, I provide a brief overview of the fair information practices that are fundamental to the protection of privacy in Canada, but do not

appear to be adequately adhered to by the AHRA. In Part III, I then examine whether two of these principles, “consent” and “reasonable collection,” are respected by the AHRA. I conclude that they are not. First, the collection of health reporting information under the AHRA is not sufficiently transparent to ensure that participants can provide meaningful consent. 4 Second, section 14 of the AHRA is problematic because it requires that those using AHR technologies consent to the collection, use and disclosure of health reporting information as a condition of receiving services from the licensee. 5 Third, some of the purposes for which health reporting information is collected, used and disclosed under the AHRA are inconsistent with the reasonable collection principle. 6 Finally, in Part IV, I offer a series of recommendations needed to better protect the privacy of the individuals using these technologies, while maintaining appropriate collection, use and disclosure of information to interested persons. This is an opportune moment for lawmakers to address the concerns raised in this paper, as the regulations are not yet drafted, 7 and the AHRA is subject to a parliamentary review in the near future. 8 The focus of this paper is on donors and persons undergoing AHR procedures, not on the donor-conceived offspring’s interest in information privacy or his/her interest in knowing the donor’s identity, which would have a significant impact on the framework established by the AHRA. 9

4 Canadian Standards Association, Model Code for the Protection of Personal Information (Mississauga: Canadian Standards Association, 2003) at Principle 4.3.2. This principle requires organizations to make a reasonable effort to ensure that individuals are advised of the purposes for which the information will be used.
5 Ibid. at Principle 4.3.3. This principle prohibits an organization from conditioning consent on the receipt of services or supply of a product.
6 The reasonable collection principle is intended to restrict the over-collection of information. This principle is founded on the CSA Code and s. 5(3) of the Personal Information and Protection of Electronic Documents Act, S.C. 2000, c. 5 [PIPEDA].
7 AHRA, supra note 2, s. 65(1).
8 Ibid., s. 70.
I. Assisted Human Reproduction: The Statutory Protection of Privacy

The AHRA seeks to protect the privacy of donors of reproductive material and those undergoing AHR procedures through a series of specific provisions regulating the collection, use and disclosure of their health reporting information. The AHRA establishes a general framework for the collection, use and disclosure of information by licensees – in other words, those who carry out assisted human reproduction procedures – as well as the Agency. The details have been left to the regulations, which are not yet drafted. Indeed, the statutory provisions likely will not come into force until the regulations are promulgated. It appears that, generally speaking, the AHRA’s requirements are intended to complement those established by other federal and provincial privacy statutes. A brief overview of these legislative instruments is provided. A thorough discussion of the privacy provisions of the AHRA follows.

A. Overview of relevant federal and provincial privacy legislation applicable to AHR procedures

Before delving into the privacy framework established by the AHRA, it is useful to begin by discussing the various privacy statutes that relate to assisted human reproduction. Several federal and provincial privacy statutes protect the informational privacy of those using AHR procedures. At

10 Supra note 2, ss. 14-19.
11 With the exception of section 8 of the Privacy Act, R.S.C. 1985, c. P-21; ibid, s. 18(2).
12 In addition to statutory protection, privacy is also constitutionally protected. Although there is no constitutional right to privacy per se, sections 7 and 8 of the Canadian Charter of Rights and Freedoms indirectly protect privacy: Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (U.K.), 1982, c. 11. See also Elaine Gibson, “Health Information: Confidentiality and Access” in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds., Canadian Health Law and Policy, 3d ed. (Markham: LexisNexis, 2007) at 223. For a discussion of the constitutional protection of privacy under section 8 of the Charter, see Ian Kerr, Max Binnie & Cynthia Aoki, “Tessling on My Brain: The Future of Lie Detection and Brain Privacy in the Criminal Justice System” (2008) 50 Canadian Journal of Criminology and Criminal Justice 367.
the federal level, the Privacy Act\textsuperscript{13} and the Personal Information Protection and Electronic Documents Act [PIPEDA]\textsuperscript{14} apply in the context of AHR procedures. The Privacy Act applies to personal information collected, used and disclosed by federal government institutions, including the Agency.\textsuperscript{15} PIPEDA applies to entities in the private sector. Specifically, it applies to personal information collected, use and disclosed “in the course of commercial activity.”\textsuperscript{16} Many have complained about its “awkward fit” in the health care sector; nevertheless, it appears to apply, at least in part, to certain health information.\textsuperscript{17} Industry Canada has indicated that the activities of entities such as pharmacies, laboratories and health care providers in private practice qualify as “commercial activities,” and are subject to PIPEDA.\textsuperscript{18} It is likely that AHR procedures, which are for the most part privately funded and often occur in private clinics, would qualify as “commercial activities.”\textsuperscript{19} PIPEDA incorporates and builds upon the Canada Standards Association Model Code (CSA Code), which entrenches fair information practices in Canada.\textsuperscript{20}

\textsuperscript{13} Privacy Act, supra note 11.
\textsuperscript{14} PIPEDA, supra note 6.
\textsuperscript{15} Privacy Act, supra note 11, s. 3, Sch. 1.
\textsuperscript{16} PIPEDA, supra note 6, s. 4.
\textsuperscript{17} The Federal Court of Appeal addressed this question in Rousseau v. Canada (Privacy Commissioner), 2008 FCA 39, [2008] F.C.J. No. 151 at para. 39, where it concluded that notes taken by a doctor in the course of an independent medical examination made at the request of an insurance company are considered to be a commercial activity. See also Bonnie Freedman, “The Personal Health Information Protection Act, 2004” (2004) 24 Health L. Can. 84 at 85; Rick Shields, “Health Privacy in Canada – Shedding Light on Murky Waters” (2004) 24 Health L. Can. 73 at 79.
\textsuperscript{18} Industry Canada, PIPEDA Awareness Raising Tools (PARTs) Initiative for the Health Sector: Questions and Answers, online: Industry Canada <http://www.ic.gc.ca/eic/site/ceic-ceac.nsf/vwapj/PARTS_QandA-e.pdf/$FILE/PARTS_QandA-e.pdf> [PARTs]. See also Gibson, supra note 12 at 234-5.
\textsuperscript{19} Generally speaking, ARTs are not paid for by the province. See Arthur Leader, “New reproductive technologies: Why are we limiting choices for infertile couples?” (1999) 161 Canadian Medical Association Journal 1411 at 1411.
\textsuperscript{20} Section 5(1) of PIPEDA, supra note 6 provides: “Subject to sections 6 to 9, every organization shall comply with the obligations set out in Schedule 1.” The CSA Code is reproduced in Schedule 1 of PIPEDA.
Privacy legislation also exists at the provincial level. Four provinces have specific legislation governing the privacy of health information: Alberta,\(^\text{21}\) Manitoba,\(^\text{22}\) Ontario\(^\text{23}\) and Saskatchewan.\(^\text{24}\) Variation exists among these statutes.\(^\text{25}\) Nevertheless, they apply to information generated in the course of assisted human reproductive technologies which, as is discussed below, is wide ranging.\(^\text{26}\) Notably, \textit{PIPEDA} does not apply in those provinces which have substantially similar legislation.\(^\text{27}\) However, it does apply to information that crosses provincial borders, as will occur when information flows from the licensees in various provinces to the Agency located in British Columbia.

The provincial health legislation regulates the collection, use and disclosure of health information in the therapeutic context, as well as some secondary uses of this information. For example, provincial health legislation may require disclosure of identifiable health reporting information to the government for several purposes.\(^\text{28}\) These purposes generally include “determining eligibility for funding, funding services, auditing, planning and management, and keeping a registry of disease or body parts or fluids.”\(^\text{29}\)

\begin{enumerate}
\item Health Information Act, R.S.A. 2000, c. H-5 \([\text{HIA}]\).
\item Personal Health Information Act, C.C.S.M. c. P33.5.
\item Personal Health Information Protection Act, 2004, S.O. 2004, c. 3 \([\text{PHIPA}]\).
\item Health Information Protection Act, S.S. 1999, c. H-0.021.
\item See Gibson, \textit{supra} note 12 at 237 for an overview of some of these differences.
\item For example, in Ontario, \textit{PHIPA} applies to “regulated health care professionals” (s. 3(1)(1)), as well as: health care facilities, including hospitals (s. 3(1)(4)(i)); independent health facilities (s. 3(1)(4)(i)); and medical labs and/or specimen collection centres (s. 3(1)(4)(iv)). See, \textit{supra} note 23.
\item This is the case for Ontario’s \textit{PHIPA}, \textit{ibid.} \textit{PHIPA} has been declared to be substantially similar. \textit{Health Information Custodians in the Province of Ontario Exemption Order Personal Information Protection and Electronic Documents Act, S.O.R./2005-399}.
\item See for example Ontario’s \textit{PHIPA}, \textit{ibid.}, s. 46(1), 47(2), which mandates disclosure to a health data institute, and \textit{supra} note 21, ss. 46-47.
\item Gibson, \textit{supra} note 12 at 251. For example, there are several registries for cancer surveillance. See Barbara von Tigerstrom, \textit{et al.}, “Legal Regulation of Cancer Surveillance: Canadian and International Perspectives” (2000) \textit{8 Health L. J.} 1 at 19-20.
\end{enumerate}
B. The Privacy Provisions of the AHRA

The *AHRA* sets out a series of privacy requirements, either in addition to or in lieu of these general privacy statutes. The *AHRA* establishes a framework for the collection, use and disclosure of participants’ health reporting information for a number of purposes. Although the details have been left to the regulations, it is evident from the discussion below that these provisions are potentially quite broad and merit careful consideration.

1. Health Reporting Information

The privacy provisions of the *AHRA* apply to a wide range of information broadly defined as “health reporting information.” Section 3(1) of the *AHRA* sets out an expansive definition:

health reporting information means information provided under this Act respecting

(a) the identity, personal characteristics, genetic information and medical history of donors of human reproductive material and *in vitro* embryos, persons who have undergone assisted reproduction procedures and persons who were conceived by means of those procedures; and

(b) the custody of donated human reproductive materials and *in vitro* embryos and the uses that are made of them.\(^{30}\)

This article focuses on the collection, use and disclosure of health reporting information from two categories of individuals: persons donating reproductive materials and *in vitro* embryos and those undergoing assisted human reproduction procedures (collectively referred to as participants throughout).

What information is typically gathered in the course of AHR procedures and falls within this statutory definition? In short, it varies. The information collected depends on: the nature of the procedure (e.g. donor insemination vs. *in vitro* fertilization); the individual from whom it is collected; and the practice of the health care professional.\(^{31}\) The precise requirements will be

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\(^{30}\) *Supra* note 2, s. 3(1).

\(^{31}\) There are no guidelines that govern the collection of information in the context of ARTs over and above the basic non-identifying information collected for the Canadian Assisted Reproductive Technology Register for statistical purposes.
set out in the regulations. Nevertheless, it is possible to speak in broad terms about the type of information that may fall within the definition of “health reporting information.” As we will see, this definition potentially catches a wide range of highly sensitive information.

First, and perhaps most obvious, is an individual’s identity. The identity of both the donor(s) and the individual(s) undergoing AHR procedures will be collected by the licensee. In addition, the identity of persons conceived using these technologies will be collected. As a result, the biological, gestational and social relationships between donors, individuals undergoing AHR procedures and children will be recorded. In this way, the collection of one’s identity includes the collection of one’s family status. Further, it is possible that the identity of others will be collected incidentally through the use of these technologies, and may qualify as health reporting information. Whether one has a partner or not and the identity of that individual may be collected in the course of the medical history or mandatory psychological counselling. Where an individual has a partner, he or she may also be identified on the consent forms that are required before undergoing the procedure, which are included in the medical record. Thus, an individual’s identity and family status qualify as “health reporting information.”

Second, information about an individual’s personal characteristics is explicitly included in the definition of “health reporting information.” This may refer to a broad array of information, from relatively benign facts about height or eye colour, to more sensitive lifestyle information, such as sexual history or illicit drug use. This information may be gathered in the course of one’s medical history or during a counselling session. Information about

Practitioners in Canada are seeking to universalize certain aspects of this process. See Interview of Valerie Wilkie, Research Coordinator, Ottawa Fertility Centre, by author (21 August 2009).

32 Supra note 2, s. 14(2)(b). The precise requirements have been left to the regulations: supra note 2, s. 56(p).

33 For example, the Ottawa Fertility Centre requires an egg donor’s partner to consent to the donation of her eggs – that is, where the donor has a partner. See Ottawa Fertility Centre, “In Vitro Fertilization (IVF) Egg Donor’s Consent,” online: Ottawa Fertility Centre <http://www.conceive.ca/inffiles/library/docs/Egg-Donor-en.pdf>.

34 Health Canada, Workshop on the Licensing and Regulation of Controlled Activities under the AHR Act and the Obligations of Licensees Regarding Health Reporting Information (Ottawa: Health Canada, 2007), online: Health Canada
one’s personal characteristics may be gathered for a number of reasons. For example, a person who is donating sperm or eggs for the reproductive use of a third party may provide information to facilitate donor selection.\(^{35}\)

Third, genetic information will be obtained, either through the collection of biological samples or the taking of one’s family history. Biological samples are almost always collected in the context of AHR procedures.\(^{36}\) They may include: ovarian follicular fluids (including eggs) and surrounding ovarian cells; semen; testicular/epididymal tissues; and blood and cervical mucus.\(^{37}\) Each of these samples includes one’s DNA and is therefore a rich source of genetic information. The biological samples collected from the donor(s) and individual(s) undergoing the procedure will vary. For example, it is unlikely that ovarian specimens will be collected where the procedure is donor insemination. However, these specimens would certainly be collected in the course of *in vitro* fertilization. Results from tests conducted on these biological samples will be included in the medical record. Notably, some biological samples, including semen/sperm and embryos, may be frozen.\(^{38}\) The custody of these materials also qualifies as health reporting informa-


36 *Supra* note 31.

37 *Ibid*.

tion under the AHRA.\textsuperscript{39} In addition, genetic information in the form of a family medical history will be gathered. Whether there is a family history of a hereditary condition (such as cystic fibrosis) or a disease that is more commonly sporadic rather than hereditary (such as colorectal cancer) would be disclosed in this context.\textsuperscript{40}

Fourth, and perhaps most consistent with our common understanding of “health information,” is an individual’s medical history. A wealth of information may be gathered in the context of a medical procedure, and thereafter will form part of the participant’s medical history. The health information that is collected in the course of AHR procedures will vary from individual to individual depending on the nature of the procedure. However, this information typically includes: “age; allergies; height and weight; previous infertility treatments; miscarriages; abnormal pap tests; abdominal surgeries; use of medication....”\textsuperscript{41} In some cases, the individual’s medical or family history will prompt genetic testing for certain conditions. These results will be included in the individual’s medical record.

In addition, information in the form of a medical history is collected from donors of reproductive material and \textit{in vitro} embryos.\textsuperscript{42} The health reporting information provided by these donors is a “critical component of AHR services.”\textsuperscript{43} As with personal characteristics, information pertaining to the donor’s medical history is collected so that non-identifying information can be provided to the individuals undergoing AHR procedures, as well as the resulting offspring, if they know they are conceived through AHR technologies. As with one’s personal characteristics, this information may facilitate donor selection. Indeed, this likely explains the statutory obligation of the licensee to disclose non-identifying information of donors to users of the material.\textsuperscript{44} In addition, the medical history is also relevant to the donor-conceived offspring. It is disclosed on the assumption that one’s family history, like one’s genetic information, “will become increasingly significant

\textsuperscript{39} \textit{Supra} note 2, s. 3(1).
\textsuperscript{40} Shilpa Grover, \textit{et al.}, “Physician Assessment of Family Cancer History & Referral for Genetic Evaluation in Colorectal Cancer Patients” (2004) 2 Clinical Gastroenterology and Hepatology 813.
\textsuperscript{41} \textit{Supra} note 34.
\textsuperscript{42} The information collected may vary because of the different nature of sperm, ova and \textit{in vitro} embryo donation.
\textsuperscript{43} \textit{Supra} note 35.
\textsuperscript{44} \textit{Supra} note 2, s. 15(4).
as tests and cures for many single-gene diseases are developed and made available to individuals with a family history of certain genetic diseases. In addition, this information will be used to identify those “persons at risk of developing late-onset diseases, such as diabetes, to alter their lifestyle to minimize the effects of the disease or to possibly avoid it altogether.”

The AHRA makes no mention of ongoing disclosure of health information relevant to illness or disease. However, it is possible that such a requirement may arise in the future, especially with respect to late-onset diseases. Some have called for such a requirement, including the authority to test existing genetic samples for new diseases on an ongoing basis. It is possible that such a requirement could be imposed under the auspices of protecting the health and welfare of children (and their descendants) conceived using these technologies, which is a primary objective of the AHRA.

The medical history includes both physical and mental health. As noted above, every individual who participates in these technologies will undergo mandatory counselling. The extent of this counselling and the information to be gathered in this context is not yet clear, as it has been left to the regulations. Whatever information ends up being collected concerning an individual’s mental health will almost certainly form part of their medical history as well.

2. Collection, Use and Disclosure by the Licensee and the Agency
The AHRA requires the licensee, most often a physician, to collect certain health reporting information from the donor(s) of reproductive material and individual(s) undergoing an AHR procedure. The extent of the health reporting information to be collected by the licensee will be set out in the regulations. However, the use and disclosure of this information will be governed by the regulations.

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45 Supra note 35 at 56.
46 Ibid.
48 The health and well-being of children conceived through AHR is the first principle that governs the AHRA. See supra note 2, s. 2(a).
49 Ibid., s. 14(2)(b).
50 Although the term “licensee” is not statutorily defined (ibid., s. 40), a licensee is an individual who undertakes a controlled activity, including an assisted reproduction procedure such as donor insemination or in vitro fertilization, and therefore could include a number of different health care professionals,
regulations and, as is discussed below, may be greater than what is currently collected by physicians. The AHRA requires the licensee to advise the participant of the collection, use and disclosure requirements of the AHRA and to obtain the participant’s written consent to these requirements prior to accepting a donation of reproductive material or performing an AHR procedure.\(^{51}\)

The AHRA establishes a system whereby the licensee acts as an information intermediary between the participant and the Agency.\(^{52}\) The Agency does not collect health reporting information directly from individuals participating in ARTs. Rather, it is the licensee who collects health reporting information directly from the participant and, in turn, discloses that information to the Agency. Although the extent of the information to be disclosed to the Agency will be set out in the regulations, it is likely to be far-reaching, given the breadth of the Agency’s mandate.\(^{53}\) The licensee is statutorily obliged to collect and disclose this information to the Agency.\(^{54}\)

In addition to disclosure to the Agency, information that is collected from the patient in the therapeutic context may be used and disclosed for several other non-therapeutic purposes. This is the case for both the licensee and the Agency. Not surprisingly, the AHRA requires the licensee to disclose health reporting information: for administration of a health insurance plan; in compliance with a subpoena; pursuant to health and safety laws; and to another licensee where there has been a transfer of reproductive material or an embryo.\(^{55}\) As mentioned, the licensee must also disclose to a person undergoing an AHR procedure using donated reproductive material the non-identifying health reporting information of the donor.\(^{56}\) Finally, the licensee may disclose non-identifying health reporting information for research or statistical purposes.\(^{57}\)

The Agency, after receiving health reporting information from the physician, may use and disclose the participant’s health reporting informa-

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including physicians, pharmacists and nurses. However, the licensee is most often a physician. See supra note 34.

51 Supra note 2, s. 14.
52 Ibid., ss. 14-15.
53 Ibid., ss. 15(2)(a), 65(1)(o), 65(1)(r).
54 Ibid., s. 15(2)(a).
55 Ibid., ss. 15(2)-(3).
56 Ibid., s. 15(4).
57 Ibid., s. 15(5).
tion for a wide range of purposes. The AHRA bestows several far-reaching powers upon the Agency.\(^{58}\) The Agency: administers and enforces the AHRA; advises the Minister of Health on a wide range of topics relating to assisted human reproduction and the AHRA; monitors and evaluates developments in assisted human reproduction technologies; consults with persons and organizations within Canada and internationally; and provides information to the Canadian public and the professions about assisted human reproduction.\(^{59}\) In addition, the Agency is empowered to “collect, analyse and manage health reporting information relating to controlled activities.”\(^{60}\) In part to ease the fulfillment of these functions, as well as to carry out others, the Agency has a mandate to create and supervise a personal health information registry.\(^{61}\) It is important to note that because the definition of health reporting information is broadly worded, this registry will include both identifying and non-identifying information.

The Agency has wide latitude with respect to the use of information found in the personal health information registry. The Agency may use this information, as well as additional information otherwise relating to the controlled activities undertaken by an applicant or licensee, for: the administration and enforcement of the AHRA; the identification of health and safety risks; monitoring potential and actual abuses of human rights; considering ethical issues associated with assisted human reproduction technologies; and for any other matter to which the AHRA applies.\(^{62}\)

The Agency also has broad discretion with respect to the disclosure of personal health information, albeit some of this information is non-identifying information, over which an individual is not generally considered to have a privacy interest.\(^{63}\) The Agency may disclose non-identifying information to recipients of reproductive material, to persons conceived by means

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58 Ibid., s. 24. For a description of the Agency, see supra note 35 at Chapter 15.
59 Ibid., s. 24.
60 Ibid., s. 24(e).
61 Ibid., s. 17(1). The creation of the Agency and its role in information disclosure were among the 293 recommendations made by the Baird Commission. See Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies (Ottawa: Canadian Government Publishing for the Commission on New Reproductive Technologies, 1993) at 1023-33 (Chair: Patricia Baird).
62 AHRA, ibid., s. 18(1).
of such a procedure, and to descendants of a person so conceived.\textsuperscript{64} Some of these functions relate to traceability of the participants. For example, the Agency may also disclose whether two individuals who have reason to believe that one or both were conceived by means of an AHR procedure are genetically related.\textsuperscript{65}

Further, the Agency may disclose health reporting information, including identifying information, for the purpose of enforcement and administration of the Act.\textsuperscript{66} The Agency may disclose the identity of a donor to a physician if, in the Agency’s opinion, there is a risk to the health or safety of a person.\textsuperscript{67} The Agency may also disclose certain non-identifying information to the public, including aggregated outcomes of these procedures.\textsuperscript{68} Like the licensee, the Agency is required to disclose health reporting information pursuant to a subpoena or other lawful authority.\textsuperscript{69} Like the licensee, the Agency may disclose non-identifying information to an individual or organization for research or statistical purposes.\textsuperscript{70}

It is evident that many of the purposes to which an individual’s health reporting information may be put are not directly related to the treatment of the participant. They relate to the administration or enforcement of the AHRA, the welfare of children conceived using these technologies and their descendants, and other matters. In other words, they are outside the “circle of care,” which is defined as:

\[\text{T}h\text{e individuals and activities related to the care and treatment of a patient. Thus, it covers the health care providers who deliver care and services for the primary therapeutic benefit of the patient and it covers related activities such as laboratory work and professional or case consultation with other health care providers.}\textsuperscript{71}\]

\textsuperscript{64} \textit{Supra} note 2, s. 18(3).

\textsuperscript{65} \textit{Ibid.}, s., 18(4).

\textsuperscript{66} \textit{Ibid.}, s. 18(6)(a).

\textsuperscript{67} \textit{Ibid.}, s. 18(7). The physician may not disclose that identity.

\textsuperscript{68} \textit{Ibid.}, s. 19(i).

\textsuperscript{69} \textit{Ibid.}, ss. 18(5)-(6). Note the licensee is also authorized to carry out these functions. See \textit{ibid.}, ss. 15(2)(b)-(d).

\textsuperscript{70} For the Agency, \textit{ibid.} s. 18(8); for the licensee, \textit{ibid.}, s. 15(5).

\textsuperscript{71} \textit{PARTs}, \textit{supra} note 18.
Many of the uses of this health reporting information are made possible by the physician who indirectly collects it for the Agency. This indirect collection of information by the licensee for the Agency for several non-therapeutic purposes potentially threatens the privacy of those using AHR technologies.

III. The Protection of Privacy in Canada: Fair Information Practices

Although recognized as an important value in Canadian society, privacy is an elusive concept. In the present context, privacy is a claim allowing an individual to determine when and how information about him or herself is shared with others. Usually, this is achieved through fair information practices, which are widely considered to be fundamental to the protection of privacy in Canada and several other countries. These practices are articulated in both the OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data [OECD Guidelines], to which Canada is a signatory, as well the Canada Standards Association Model Code [CSA Code], a voluntary industry code. While the CSA Code retains the principles found in the OECD Guidelines, it “expands considerably” on them. These principles seek to balance an individual’s right to privacy and the interests of organizations in collecting, using and disclosing information. That these principles are foundational is evidenced by their direct or indirect incorporation in several statutory and non-statutory privacy instruments in Canada. Most notable is PIPEDA, where the CSA Code is incorporated directly as

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75 Supra note 4. This was recognized as a national standard in 1996.
78 For example, the Canadian Medical Association’s Privacy Code is premised on the CSA Code: Canadian Medical Association, CMA Health Information Privacy Code, online: cma.ca <http://www.cma.ca/index.cfm/ci_id/3216/la_id/1.htm>.
Schedule 1. In my view, the AHRA is inconsistent with two fair information practices: consent and reasonable collection.

A. Consent

Consent is the cornerstone of fair information practices. Two aspects of the Consent Principle are engaged by the AHRA. The first principle, 4.3.2, governs the transparency of the collection, use and disclosure of personal information:

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.

The Privacy Commissioner of Canada [Commissioner] has held that organizations must be specific about the purposes for which information is collected, used and disclosed. Overly broad or vague explanations will violate this principle.

79 PIPEDA, supra note 6, s. 5(1); PARTs, supra note 18 at para. 15.
81 Supra note 4.
The second principle, 4.3.3, known as the refusal-to-deal clause, prohibits an organization from tying consent to the collection, use and disclosure of information to the receipt of services:

An organization may not, as a condition of the supply of a product or service, require an individual to consent to the collection, use, or disclosure of information beyond that required to fulfil the explicitly specified, and legitimate purposes.  

Although this principle is concerned with consent, it also requires an examination of the purposes for which an organization wishes to collect, use and disclose an individual’s personal information.

A review of the decisions made pursuant to Principle 4.3.3 demonstrates that the purpose for the collection, use and disclosure may be relevant in two respects. First, the organization must justify its purpose for the collection, use and disclosure of information as legitimate, which requires a consideration of its merits. Second, the organization must delineate the scope of the purpose in order to show that the collection, use and disclosure of health reporting information falls within its scope. Where consent is tied to the receipt of services, the Commissioner’s decisions reveal two approaches. Often the Commissioner engages in a two-step inquiry: first, whether the purpose is legitimate, and second, where the purpose is legitimate, whether the collection, use and disclosure of information falls within its scope. In contrast, the Commissioner at times only examines the scope of the purpose without inquiring into its legitimacy.

In a few cases, the Commissioner has assessed whether the organization’s purpose is legitimate and has found it wanting. For example, the Commis-

84 Supra note 4.
sioner required a courier company to articulate and justify its purpose for requiring an individual to sign electronically for the receipt of a parcel. The electronic signature would subsequently be posted on the tracking section of the website, together with the customer’s name, address and the delivery status of the package. The company refused to deliver the package without an electronic signature. The company explained that the electronic signature was required for tracking purposes. The Commissioner concluded that the purpose of placing electronic signatures on the company website for use in tracking shipments was not legitimate, and therefore violated Principle 4.3.3. Accordingly, the Commissioner did not go on to consider whether the collection, use and disclosure fell within the scope of the stated purpose.

In several other cases, after concluding that the organization’s purpose is legitimate, the Commissioner has gone on to inquire whether the collection, use and disclosure of information falls within the scope of that purpose.

and company name are likewise unacceptable as a means of verifying a claim; supra note 80. Collection of information from an individual who registers at a hotel for secondary marketing purposes is not a legitimate purpose.

87 “Electronic Signatures,” ibid.
88 Office of the Privacy Commissioner of Canada, “PIPEDA Case Summary #2003-169 (update): Individual objects to bank’s requirement to provide Notice of Assessment for income verification purposes,” online: Office of the Privacy Commissioner of Canada <http://www.priv.gc.ca/ef-dc/2003/cf-dc_030424_2_e.cfm> [“Notice of Assessment”]. The Commissioner first concluded that determining a sole proprietor’s creditworthiness is a valid purpose where a bank is extending credit to him/her, but then determined that the Notice of Assessment contained information not required to meet the purpose of determining creditworthiness; Office of the Privacy Commissioner of Canada, “PIPEDA Case Summary # 2006-347: Investment dealer needs personal information to comply with securities regulations,” online: Office of the Privacy Commissioner of Canada <http://www.privcom.gc.ca/cf-dc/2006/347_20060815_e.asp> [“Investment”]. The Commissioner first concluded that the purpose of Regulation 1300.1 appeared to be legitimate in light of the legislated know-your-client and due diligence obligations of investment dealers, and second concluded that the personal information collected by the firm was not beyond that required to fulfill these legitimate purposes; Office of the Privacy Commissioner of Canada, “PIPEDA Case Summary # 2006-338: Reason for collecting telephone number not clearly explained,” online: Office of the Privacy Commissioner of Canada <http://www.privcom.gc.ca/cf-dc/2006/338_20060612_e.asp> [“Telephone”]. The Commissioner first concluded that the identification verification
example, the Commissioner concluded that ascertaining a sole proprietor’s creditworthiness is a legitimate purpose where a bank is extending credit to the sole proprietor; however, requiring the collection of the individual’s Notices of Assessment is not required to fulfill this purpose, and thus violates Principle 4.3.3.89

Although the Commissioner has considered whether an organization’s purpose is legitimate in several cases, no test or standard of “legitimacy” has been articulated.90 This has been further complicated by the fact that there has been some conflation of the legitimate purpose standard and the reasonable purpose standard established by section 5(3) of PIPEDA.91 As is discussed in greater depth below, what is legitimate is likely to be determined by balancing the privacy interests of the individual with the objectives of the organization.

In contrast, the Privacy Commissioner has in certain cases simply considered whether the collection, use and disclosure of information by the organization are beyond that required for achieving the principal purpose. Here the inquiry has only focused on the scope of the organization’s purpose for the collection, use and disclosure of information.92 For example, the Commis-
The Privacy Commissioner has on several occasions found that the collection, use and disclosure of information by an organization for secondary marketing purposes violates Principle 4.3.3 on the basis that marketing is beyond the purpose for which the individual initially provided personal information.93 Professor Austin argues that this aspect of the refusal-to-deal clause, examining the scope of the purpose, is useful to protect privacy because it allows one to determine what information practices are permissible in certain situations. She explains:

…under the CSA Code and PIPEDA, an [organization] cannot refuse the provision of services to an individual who refuses to consent to the collection, use and disclosure of personal information beyond what is necessary to fulfill the purposes of the collection, use and disclosure. One could therefore argue that this provision is best suited to drawing the line between information collection that is properly tied to one transaction and information collection that is best construed as a separate transaction.94

In other words, defining the scope of the purpose assists in determining what information may be properly collected, used and disclosed by the organization. The organization may collect, use and disclose information necessary to achieve its principal purpose. The collection, use and disclosure of information outside the scope of this purpose are not permissible. Rather, certain purposes should be treated as separate transactions, requiring separate consents.

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93 The cases dealing with secondary marketing include: Office of the Privacy Commissioner of Canada, “PIPEDA Case Summary # 2002-83: Alleged disclosure of personal information without consent for secondary marketing purposes by a bank,” online: Office of the Privacy Commissioner of Canada <http://www.privcom.gc.ca/cf-dc/2002/cf-dc_021016_1_e.asp> (bank was requiring the complainant to consent to a use of his personal information beyond that required to fulfill the purpose of servicing his credit card account). Supra note 80 (hotel was requiring personal information for marketing purposes).

B. Reasonable Collection

The reasonable collection principle is intended to restrict the over-collection of personal information by organizations, and has developed from the OECD Guidelines,\textsuperscript{95} the CSA Code\textsuperscript{96} and PIPEDA.\textsuperscript{97} Its effect is to limit the collection, use and disclosure of information separate and apart from the limit of individual consent. The OECD Guidelines include a Collection Limitation Principle which provides that “[t]here should be limits to the collection of personal data and any such data should be obtained by lawful and fair means and, where appropriate, with the knowledge or consent of the data subject.”\textsuperscript{98} Although the Guidelines do not limit collection to those purposes that are reasonable, they certainly indicate that “norms independent of consent may operate to limit the collection of information.”\textsuperscript{99}

The Federal Court of Appeal has also interpreted the principles of the CSA Code as limiting the collection, use and disclosure of information.\textsuperscript{100} According to the Court of Appeal, this limitation on the collection of information is manifest in several principles of the CSA Code, specifically clauses 4.2 through 4.5.\textsuperscript{101} The Court of Appeal has concluded that these principles

\textsuperscript{95} Supra note 74.
\textsuperscript{96} Supra note 4.
\textsuperscript{97} Supra note 6.
\textsuperscript{98} Supra note 74.
\textsuperscript{99} Supra note 94 at 196.
\textsuperscript{100} Supra note 76.
\textsuperscript{101} First, the Identifying Purpose Principle, 4.2, requires organizations to identify the purposes for which they are collecting, using and disclosing information. Second, the Consent Principle, 4.3, as discussed above, requires knowledge and consent to the collection, use and disclosure of information. Indeed, it is likely that the interpretation of Principle 4.3.3 discussed above has influenced the development of the reasonable collection principle. Third, the Limiting Collection Principle, 4.4, prohibits organizations from collecting personal information indiscriminately. Both the amount and the type of information collected shall be limited to that which is necessary to fulfil the purposes identified. The Limiting Collection Principle also requires organizations to specify the type of information collected as part of their information-handling policies and practices, in accordance with the Openness principle (Clause 4.8). In other words, this principle requires organizations to demonstrate that the information is necessary for the purposes originally identified.
require that the “purposes for which the information is collected, used or disclosed…must be appropriate and legitimate.”

PIPEDA also limits the collection of personal information. Subsection 5(3) requires that “[a]n organization may collect, use or disclose personal information only for purposes that a reasonable person would consider are appropriate in the circumstances.” A robust reasonable purpose test has not yet been developed. Nevertheless, courts have acknowledged that this provision requires the Court to strike a balance between “on the one hand, the right of privacy of individuals with respect to their personal information and, on the other hand, the need of organizations to collect, use or disclose personal information for purposes that a reasonable person would consider appropriate in the circumstances.” The Federal Court of Appeal has identified several factors that may be relevant in striking this balance, including: the degree of sensitivity of the information; security measures implemented by the organization; bona fide business interests; effectiveness to meet these business interests; reasonableness of the collection of the personal information as measured against other alternative methods at comparable costs and with comparable benefits; and proportionality of the loss of privacy against the costs and operational benefits. Accordingly, the purpose must be “analysed in a contextual manner looking at the particular circumstances of why, how, when and where collection takes place.”

102 Supra note 76 at para. 42.
103 Supra note 77 at 32.
104 PIPEDA, supra note 6, s. 5(3).
105 Supra note 94 at 212. Austin speculates that this is because there is an overemphasis on consent and insufficient discussion of the reasonableness requirement.
106 Eastmond v. Canada Pacific Railway, 2004 FC 852, [2004] F.C.J. No. 1043 at para. 129 [Eastmond]. In that case, the Court identified several factors that had arisen in labour cases where arbitrators were required to adjudicate privacy issues under collective agreements involving camera surveillance. However, the Court noted that these factors would not necessarily be relevant in other contexts.
108 Eastmond, ibid. at para. 131.
The reasonableness limit on the collection, use and disclosure of personal information has developed in a haphazard way, and is manifest in the jurisprudence in different contexts: in some cases under Principle 4.3.3, where services are conditioned on consent (as discussed above), and in others under subsection 5(3). There is no indication of how the legitimate purpose standard, which has been applied in the context of Principle 4.3.3, fits with the reasonable collection principle. Indeed, in many cases, the Commissioner has conflated the two.\(^\text{109}\) This may be because the approach to the interpretation and application of these principles is guided by “flexibility, common sense and pragmatism.”\(^\text{110}\) Because Schedule 1 is drafted in non-legal terms, neither the principles nor the Act itself is subject to the otherwise “rigorous” construction of legislation.\(^\text{111}\) For the purpose of this article, I will assume both involve balancing the privacy interests and expectations of a reasonable person against the information needs of the organization.\(^\text{112}\)

A reasonableness requirement, although often overlooked, is an accepted and important norm to protect an individual’s privacy.\(^\text{113}\) Perhaps most obvious, it requires organizations to articulate and justify their purposes underlying the collection, use and disclosure of information. In addition, the reasonableness norm plays an important role in protecting privacy where consent does not. As Austin notes, consent is neither necessary nor sufficient to protect privacy in many instances.\(^\text{114}\) Indeed, as is evident from the discussion above, the courts and the Privacy Commissioner have relied on the reasonableness limit in several instances to protect privacy. The significance of this norm in protecting privacy is also confirmed by the fact that it is one of the explicit requirements for privacy legislation to be deemed substantially similar to PIPEDA. To be substantially similar, the legislation must “restrict the collection, use and disclosure of personal information to purposes that are appropriate or legitimate.”\(^\text{115}\)

\(^{109}\) Supra note 91.

\(^{110}\) Supra note 76 at para. 46.

\(^{111}\) Wansink, supra note 107 at para. 19.

\(^{112}\) Supra note 94 at 211, 214.

\(^{113}\) Ibid. at 183. See also supra note 76 at paras. 42, 45-46.

\(^{114}\) Supra note 94 at 188.

In my view, the privacy provisions of the AHRA foreshadow some significant problems in terms of respecting fair information practices. First, the indirect collection of information by the physician for the Agency for broadly stated purposes may not be sufficiently transparent for a participant to understand why and how the information collected from them is being used, thereby undermining the participant’s consent. Second, the fact that the AHRA requires consent to the collection, use and disclosure of health reporting information as a condition of receiving services further undermines the participant’s consent. Third, the secondary purposes for which the licensee and Agency may use and disclose health reporting information are overbroad and may violate the reasonable collection principle.

IV. The AHRA: Inconsistent with Fair Information Practices?

A. Lack of Transparency

The collection of health reporting information appears to lack the transparency required by fair information practices. Both the manner of the collection and the stated purposes may make it difficult for a participant to reasonably understand what health reporting information is being collected and how it will be used and disclosed. As a result, the participant may be unable to provide meaningful consent to the collection, use and disclosure of their health reporting information.

The AHRA muddies the transparency of the collection of information by requiring the licensee to act as an information intermediary between the participant and the Agency. Although participants must be advised in writing of the AHRA’s requirements regarding their health reporting information, it is possible that participants may not reasonably understand how and why their health reporting information will be used and disclosed because of the indirect collection of information for the Agency. The indirect collection relationship between the licensee and the Agency may obscure the purpose for which the licensee is collecting information. It may be unclear whether the licensee is collecting health reporting information for its own purposes, such as the treatment of the participant, or whether it is collecting health reporting information for the Agency. This concern is aggravated by the possibility that the licensee may have to collect more health reporting information than is necessary in the therapeutic context so that the Agency may fulfill its broad mandate. Indeed, given the difference in collection practices from physician to physician, there is a distinct possibility that this framework
will require them to collect more information than they are currently for therapeutic purposes.\(^{116}\)

Transparency is further obfuscated because the purposes for which health reporting information is collected, used and disclosed under the AHRA are broadly stated and are arguably vague. This is especially true of the Agency. As mentioned above, the Agency may use health reporting information to fulfill a range of purposes, some of which are susceptible to multiple interpretations. Two examples nicely illustrate how the broad language used in the AHRA could prevent an individual from reasonably understanding how his or her health reporting information will be used or disclosed by the licensee and the Agency.

First, the use of health reporting information for any “other matters to which [the AHRA] applies.”\(^ {117}\) Such vague language makes it virtually impossible for an individual to know how his/her health reporting information will be used or disclosed. It could be used for any reason imaginable that is related, even remotely, to ARTs. Not surprisingly, the use of this catch-all wording has been criticized by the Privacy Commissioner in the commercial context, and has been found to violate the consent principle.\(^ {118}\)

Second, the language of the AHRA makes it difficult for participants to determine whether they are or may be subject to an ongoing disclosure requirement. The AHRA is silent on this possibility, although the regulations might address it. The AHRA does not explicitly require donors to continue disclosing health reporting information to the licensee or the Agency. Nor does it explicitly limit or prohibit the collection, use and disclosure of health reporting information after the time of the procedure. However, by stating the purposes in broad language, there is room in the statute for “function creep” – that is, for additional uses of the information.\(^ {119}\) In practical terms,

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116 Supra note 31. Basic non-identifying information is collected by all participating physicians for the purpose of entering it into a database, the Canadian Assisted Reproductive Technologies Registry (CARTR). Beyond that, each physician exercises his/her own discretion in determining what information is relevant and should be collected. For example, some physicians collect psychosocial information, whereas others do not.

117 Supra note 2, s. 18(1).

118 Supra note 83.

ongoing disclosure is certainly possible. The digitization of health information will facilitate ongoing disclosure because digitized information is easier to access and transfer.\(^{120}\) Indeed, with the advent of the electronic health record, it may be possible to link the participant’s electronic health record with the record held by the Agency. This would provide up-to-date information to children conceived using these technologies. This linkage could be justified on the basis that it promotes the health and well-being of the child, one of the overarching principles of the AHRA.

It is useful to return to our two case studies to illustrate the lack of transparency inherent in the AHRA. It is unlikely that our gamete donors, Charles and Meera, will sufficiently understand the purpose or purposes for which their health reporting information is being collected, used and disclosed by their respective physicians. Recall Charles wishes to act as an anonymous sperm donor. Charles is willing to provide his health information to the recipients of his sperm and any children conceived therefrom, but he is concerned about disclosure to the Agency. Before Charles consents to donating sperm, he wants to know what the Agency can do with the information he discloses to his physician. As mentioned, he is especially concerned about the possibility of criminal charges arising from his recreational drug use. He is also concerned about the possibility of linking his electronic health record kept by his family physician with the Agency’s database. As currently drafted, Charles will be unable to determine the purposes for which his health information may be used by the Agency.

Meera, who plans to donate ova to her sister but does not want to reveal that she suffers from lupus to her family or employer, wants to know who will have access to her health reporting information, specifically that she suffers from lupus. Like Charles, Meera will not have a sufficient understanding of why and how her information is being collected and used by her physician and the Agency. Meera may not understand whether her physician requires information about pre-existing conditions such as lupus for the purpose of providing her with appropriate treatment, whether it is for disclosure to the recipients and offspring, or whether the physician is asking for it in order to fulfill the Agency’s broader mandate – whether that be advising the government, monitoring and administering the AHRA, creating and maintaining a personal health information registry, or one of its other functions.

\(^{120}\) Ibid.
B. Tied Consent

The *AHRA* is also problematic in that it requires participants to consent to the collection, use and disclosure of health reporting information as a condition of receiving services from the licensee. Section 14 of the *AHRA* prohibits the licensee from accepting a donation of human reproductive material or an *in vitro* embryo from any person and from performing an AHR procedure on any person that has not consented to the collection, use and disclosure of health reporting information as required by the *AHRA* and the regulations.\(^{121}\) Thus, section 14 conditions service on consent.

Informational privacy in Canada operates on a consent-based system, the cornerstone of fair information practices.\(^{122}\) Many privacy statutes are premised on consent to the collection, use and disclosure of personal information.\(^{123}\) This is also true of the *AHRA*: “the principle of free and informed consent must be promoted and applied as a fundamental condition of the use of human reproductive technologies.”\(^{124}\) This principle applies not only to the decision of whether or not to participate in AHR technologies, but also to the collection, use and disclosure of health reporting information in that context.

Yet section 14 of the *AHRA* does not appear to protect, let alone promote, consent. By tying consent to services, participants are not given the choice of opting out of the extensive and vague disclosure scheme under the *AHRA* and yet still receive services. If the participant wants services, he or she must consent to the collection, use and disclosure of highly sensitive information pertaining to their health, genetic make-up and family status, not only for the purpose of his or her own health care, but also to fulfill the Agency’s much broader purposes. The participant has no choice but to allow the licensee to pass along his or her information to the Agency. The participant can withhold the information only so long as he or she is willing to forego these services. Once the participant opts for services, however, he or she no

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\(^{121}\) *Supra* note 2, s. 14.

\(^{122}\) Gibson, *supra* note 12 at 241.

\(^{123}\) See for example *Privacy Act, supra* note 11, ss. 7-8; *PIPEDA, supra* note 6, s. 5(1), Sch. 1 Principle 3: Consent (“the knowledge and consent of the individual is required for the collection, use or disclosure of personal information, except where inappropriate”). *Supra* note 23, s. 18. There are many exceptions to consent set out in each of these statutes.

\(^{124}\) *Supra* note 2, s. 2(d).
longer has control over the use or disclosure of his or her health reporting information. So, for example, an anonymous sperm donor such as Charles, who refuses to disclose certain information or declines to consent to the disclosure of some aspects of his health reporting information to the Agency, would be precluded from donating.

Are these purposes legitimate? At first blush, it appears that some are and others are likely not. A detailed analysis of these purposes follows. However, it seems obvious that the collection, use and disclosure of certain health reporting information is necessary for the licensee to carry out the AHR procedure and provide proper care to the patient. Thus, the collection, use and disclosure for a therapeutic purpose will likely be considered legitimate or appropriate. In contrast, it may be more difficult to establish that disclosure of extensive information to the Agency for a broad range of non-therapeutic purposes, such as monitoring the use of these technologies, is legitimate. The participants’ expectations that their health reporting information will be rigorously protected, the breadth of the non-therapeutic purposes, and the fact that most are for the benefit of third parties or society at large raise difficult questions about the appropriate balance to be struck between the privacy interests of the participants and the state’s interest in other social goals.

C. Reasonable collection of information

The AHRA also appears to be inconsistent with the reasonable collection principle. There is a palpable tension in the AHRA between the protection of highly sensitive information and the use and disclosure of this information for numerous purposes enumerated above. This is a difficult balance to strike. However, in my view, a reasonable person would likely consider a few of the purposes for which extensive health information is collected, used and disclosed to be illegitimate, inappropriate or unreasonable. In certain situations the balance is skewed, and the state (through the Agency) appears to be adopting an excessive and overbroad approach to information collect-

125 Indeed, implied consent is often considered acceptable in the therapeutic context or within the “circle of care,” in recognition of the necessity of this information: supra note 23, s. 18(3). Personal health information may be collected, used and disclosed on the basis of implied consent within the circle of care. Industry Canada has so concluded under PIPEDA as well: PARTs, supra note 18.
126 See Part I.B., above.
tion. The AHRA seems to require the licensee to over-collect information from participants, thereby undermining their privacy.

It is likely that a reasonable participant would conclude that the collection, use and disclosure of their health reporting information by the physician to the Agency for a wide range of purposes are neither legitimate nor appropriate. As discussed above, the Federal Court has provided some guidance on how to strike this balance. To determine whether a purpose is legitimate or appropriate, we must weigh the privacy interests of the participants against the information needs of the organization.\textsuperscript{127} On the one hand, the participant’s privacy interest in this information is likely acute because of its highly sensitive nature. Individuals using these technologies will expect that the privacy of their health reporting information will be rigorously protected. On the other hand, collection, use and disclosure by the licensee and the Agency for those purposes that can be clearly discerned appear to be beneficial for participants as well as to a number of others, including children conceived using these technologies and society at large, as is discussed below. However, the effectiveness of the collection, use and disclosure of this information for some of these purposes is questionable; in fact, there may be alternative, less privacy-invasive means to achieve these ends.

The health reporting information that is contemplated by the AHRA is highly sensitive for a number of reasons. Health information is considered to be among the most sensitive information about an individual because it “goes to the personal integrity and autonomy of the patient.”\textsuperscript{128} The consequences of disclosing health information are serious. As the former Federal Privacy Commissioner observed, a “violation of health care privacy can be catastrophic for the individual...could change your entire life, and deny you a whole range of opportunities.”\textsuperscript{129} Further, participants may be acutely aware of the consequences arising from inadvertent disclosure of their genetic information. Professor Lemmens describes some of the factors that make genetic information especially sensitive:

\textsuperscript{127} See Part III.B., above.
\textsuperscript{129} George Radwanski, “An address to the Legislative Assembly of Ontario, Standing Committee on General Government on the Government of Ontario’s Proposed personal health information legislation (Bill 159)” (Address delivered to the Legislative Assembly of Ontario, Standing Committee on General Government, 8 February 2001), online: Office of the Privacy Commissioner of Canada <http://www.privcom.gc.ca/speech/02_05_a_010208_e.asp>.
...the volume of data likely to become available; the fact that so much information can be gathered from one sample, which itself can be kept for an indeterminate length of time, the relatively high predictive value of many of the tests combined with remaining uncertainty and difficulty of interpretation, the often fatal or incurable nature of the predicted disease, and the way others (such as family members and ethnic groups) could be affected by genetic data gathered from individuals.\textsuperscript{130}

Further, genetic information provides information that can be used for purposes unrelated to the therapeutic context. For example, this information is relevant to determinations of parental status and also raises the possibility of genetic discrimination.\textsuperscript{131} Thus, individuals will likely be concerned about leakage or unauthorized disclosure of their health reporting information by the Agency.\textsuperscript{132}

Also concerning is the inadvertent disclosure of one’s family status, whether as the donor or the person undergoing the assisted human reproduction procedure, when one has donated reproductive materials anonymously.\textsuperscript{133} The legal rights and responsibilities of donors of reproductive


\textsuperscript{132} There have been instances of inadvertent disclosure of sensitive health information by the government in Canada. See for example Lisa Vaas, “Canada Fumbles Health Data in Security Breach,” online: eweek.com <http://www.eweek.com/c/a/Security/Canada-Fumbles-Health-Data-in-Security-Breach/>.

materials or *in vitro* embryos are generally undefined in Canadian law. The seriousness of the disclosure of one’s family status, albeit in the context of adoption, was recognized by the Ontario Superior Court of Justice in *Cheskes*.

Individuals may also be apprehensive about the inadvertent disclosure of the fact that they used these technologies. The information gathered in the context of assisted reproductive technologies is considered by some to be highly sensitive because of the secrecy that often surrounds their use.

In Canada, assisted human reproduction operates on the principle of donor anonymity. Neither the identity of the donor nor identifying information about the donor can be disclosed without the donor’s express consent. Further, there is no requirement for heterosexual parents to inform donor-conceived children of the manner of their conception. This reluctance is due, in part, to the stigma that still persists for some around the use of these technologies.

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135 Under some provincial law it is possible that a donor could qualify as a parent: *ibid*. See also *supra* note 35 at 57. See generally, Angela Cameron, Vanessa Gruben & Fiona Kelly, “De-Anonymising Sperm Donors in Canada: Some Doubts and Directions” (2010) Canadian Journal of Family Law (forthcoming).


138 This was the subject of heated debate. Indeed, the Standing Committee recommended that “only donors who consent to have identifying information released to offspring should be accepted.” See Standing Committee on Health, *Assisted Human Reproduction: Building Families* (Ottawa: House of Commons, 2001) at s. 8(ii) (Chair: Bonnie Brown).

139 For example, section 15(1)(a) of the *AHRA, supra* note 2, states that:

No licensee shall disclose health reporting information for any purpose except

(a) with the written consent of the person to whom the information relates allowing its disclosure for that purpose.

140 As the Nova Scotia Court of Appeal in *Cameron v. Nova Scotià (Attorney General)* observed: “in various cultures and at various times, infertility – particularly in the female – has been regarded as a disadvantage – an unworthy state, the
In addition to the sensitive nature of this information, the expectation of privacy in respect of health reporting information may be high because individuals expect that they should be able to use these technologies free from the prying eye of the state. Individuals may believe that they should be free to restrain the state from gathering such extensive and sensitive information about them, especially where the stated purposes for the collection, use and disclosure of the information are so broad.\textsuperscript{141} This apprehension may be heightened by the possibility of the state matching their health reporting information with other personal information collected about them in other contexts.\textsuperscript{142} For example, the information collected by the Agency may be matched with other disease registries, DNA databanks or social assistance databases.

Let us return to my previous examples involving Charles and Meera. Both Charles’ and Meera’s information is highly sensitive in different ways. For Charles, the information about his recreational drug use is quite sensitive as its inadvertent disclosure may have an impact on his job. Further, Charles may be concerned about the possibility that if his recreational drug use is disclosed to a government agency, it may be linked with other government databases or may lead to criminal charges.\textsuperscript{143} Finally, the inadvertent disclosure of his identity and family status might also have significant financial and emotional consequences for Charles. After all, Charles may be of the view object of derision, banishment and disgrace.” See \textit{Cameron v. Nova Scotia (Attorney General)} (1999) 204 N.S.R. (2d) 1, [1999] N.S.J. No. 297 at para. 183.

\textsuperscript{141} Florencio & Ramanathan, \textit{supra} note 131 at 82. See also Avner Levin & Mary Jo Nicholson, “Privacy Law in the United States, the EU and Canada: The Allure of the Middle Ground” (2005) 2 University of Ottawa Law & Technology Journal 357.

\textsuperscript{142} Gibson, \textit{supra} note 12 at 254.

\textsuperscript{143} The principal concern in this context is whether the patient’s worries about disclosure to the Agency, and ultimately the state, will result in non-disclosure to the physician or avoidance of health care services. Whether information disclosed to the Agency could, in fact, give rise to criminal charges is an interesting question. However, a full examination of this issue is beyond the scope of this paper. In \textit{R. v. Jarvis}, the Supreme Court of Canada considered the privacy interest of the taxpayer in information disclosed to tax officials for the purpose of an audit which ultimately gave rise to charges of tax evasion. The Court concluded that collection by tax officials for one purpose and then subsequent use for a secondary criminal purpose was consistent with ss. 7 and 8 of the \textit{Charter}: \textit{R. v. Jarvis}, 2002 SCC 73, [2002] 3 S.C.R. 757.
that inadvertent disclosure of his identity by the Agency is more likely than by his physician, who owes a clearer and more direct duty of confidentiality.

Meera’s health reporting information is also sensitive. Meera may consider disclosure of certain health information to be acceptable for therapeutic purposes as well as some non-therapeutic purposes. For example, Meera, like several other members of her family, suffers from a thyroid condition. Meera will likely be willing to disclose this information to her physician so that she receives proper care, as well as to Anita and Sean because it appears to be a hereditary condition. However, the fact that she suffers from lupus is more sensitive. Meera is willing to discuss this with a physician for therapeutic purposes. But Meera does not want to disclose information about her lupus for non-therapeutic purposes to Anita and Sean or to the Agency, as will likely be required by the AHRA. Finally, neither Meera, Anita nor Sean intends to tell the child, their family or friends about their use of ARTs or the use of Meera’s ova. Thus, the mere use of the ARTs will be highly sensitive information as well.

Having considered the perspective of the reasonable person and the subjective considerations of Charles and Meera, we now turn to consider the Agency’s position. Many of the Agency’s purposes appear to be important and beneficial. From the Agency’s perspective, health reporting information gathered, albeit indirectly, from the participants is useful for a number of reasons. Those who may benefit from these purposes include the participants themselves, but also children conceived using these technologies and others who may use these technologies in the future. But the fact that the information is useful to the Agency, or to society writ large, does not justify it as a “reasonable collection” – whether it comports with the purpose or not. I will examine two purposes, which although important may not necessitate the collection, use and disclosure of health reporting information to the extent contemplated by the AHRA.

First, the Agency may use and disclose health reporting information collected from participants to protect the health and safety of children conceived using these technologies. The Agency may: provide these children with non-identifying information about their donor parents; may advise them if they are genetically related to a potential partner; and may provide physicians with the donor’s health reporting information if there is a health or safety risk to the child.144 There is no doubt that the protection of chil-

144 Supra note 2, s. 18.
dren conceived using these technologies is important, and that the disclosure of certain psychosocial and health information is necessary for their well-being. Medical information and genetic information, such as whether a donor is the carrier of the BRCA gene marker, may prompt the child to undergo genetic testing or early screening for breast cancer.\textsuperscript{145}

However, we must ask whether it is reasonable and necessary for the Agency to use and disclose participants’ health reporting information to the extent provided in the \textit{AHRA} to achieve this purpose. Take children conceived using the reproductive materials of their biological parents – in other words, where no reproductive material from a third party is being used. By disclosing medical and genetic information to children conceived using reproductive technologies by their biological parents, the \textit{AHRA} privileges these children over children not conceived through reproductive technologies.\textsuperscript{146} Generally speaking, children do not have a right to access the medical and genetic information of their biological parents. They will only receive this information if their parents choose to disclose it to them. Children who grow up in single parent families may not have access to one parent’s family history. Similarly, physicians do not have a duty to disclose genetic information to the biological relatives of their patients.\textsuperscript{147} However, the privacy provisions are broadly drafted such that children conceived using these technologies may have access to the health reporting information of their known biological parents who have conceived through AHR procedures.\textsuperscript{148}

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\textsuperscript{146} Supra note 35 at 58.

\textsuperscript{147} Jennifer Miller, “Physician-Patient Confidentiality and Familial Access to Genetic Information” (1994) 2 Health L.J. 141.

\textsuperscript{148} Section 18(3) of the \textit{AHRA} states that the Agency shall, on request, disclose health reporting information relating to a donor of the human reproductive material to a person conceived by means of an AHR procedure. It is possible that where a couple undergoes IVF using their own reproductive material, they may qualify as a “donor,” and thus be subject to this disclosure requirement. For example, the regulations pursuant to section 8 characterize a person who uses their own reproductive material for an AHR procedure as a “donor.” Similarly, it is possible that the regulations pursuant to section 18 may include the same broad definition of “donor.”
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More broadly, some question the use of the family history as a necessary way to prevent and treat disease.\textsuperscript{149} One’s family history reveals the risks and probabilities of certain conditions, which is certainly useful in prompting someone to test for a certain disease. However, it is possible that the health information disclosed by the donor is incomplete or inaccurate. The use of one’s own genetic information, rather than the genetic history of one’s biological relatives, may be more clinically relevant, and will continue to be more useful as genetic technologies develop.\textsuperscript{150} In addition, it is questionable whether it is necessary for the Agency to undertake this role. The physician is well positioned to take steps to protect the health and safety of the individuals using these technologies and the children conceived of these technologies (where the disclosure of clinically relevant information is necessary, for example). Indeed, this appears to be explicitly required by the AHRA.\textsuperscript{151}

Second, the Agency may use and disclose health reporting information to monitor the use of these technologies to ensure that they are undertaken in an ethical way consistent with human rights norms. It is of utmost importance that there are mechanisms in place to ensure that these technologies are used in a safe and ethical manner. Although close monitoring and supervision of these technologies may prevent and address human rights abuses stemming from the use of these technologies, there are other means to achieve this end. Perhaps most obvious: the use of an adjudicative body whereby individuals can bring a complaint against a licensee. This is a common method for protecting human rights. Indeed, the discriminatory use of AHR technologies has been addressed by human rights bodies in the past.\textsuperscript{152} A complaints mechanism that ensures the anonymity of the individuals will likely better protect the privacy of participants than the monitoring of health reporting information. Alternatively, individuals have access to complaints mechanisms that already exist. For example, a participant could bring a disciplinary complaint against a health care professional in the context of AHR procedures.\textsuperscript{153}

\textsuperscript{150} Pasquale Patrizio, Anna C. Mastroianni & Luigi Mastroianni, “Disclosure to children conceived with donor gametes should be optional” (2001) 16 Human Reproduction 2036.
\textsuperscript{151} Supra note 2, s. 15(1)(d).
In my view, the balance appears to be skewed against the privacy interests of the donors of reproductive material and in vitro embryos and those using AHR procedures. The potential uses and disclosure of health reporting information can be carried out in more effective and less privacy invasive ways. Therefore, it appears that at least some of the purposes for which health reporting information is used and disclosed by the Agency are inconsistent with the reasonable collection principle.

It is difficult to say what the consequences, if any, of this over-collection of information by the physician for the Agency’s broad mandate will be. Licensees suspect that a “majority” of patients will be reluctant to disclose information to the Agency, given the range of possible uses.\(^{154}\) Indeed, it is possible that patients may avoid the use of these technologies altogether rather than provide sensitive health and personal information. These statements may reflect a wider concern about the effect of these provisions on the role of the physician vis-à-vis her patient, and the impact of these provisions on the trust integral to the physician-patient relationship.\(^ {155}\)

**IV. Recommendations**

The above analysis warns of potential problems with the collection, use and disclosure of information under the *AHRA*. These provisions appear to be inconsistent with fair information practices and, as such, do not adequately protect the privacy of donors of reproductive material and in vitro embryos and individuals undergoing AHR procedures. As mentioned, these provisions are not yet in force, and likely will not be until the regulations are promulgated. Although the concerns expressed above may seem premature, this is an opportune moment to carefully scrutinize the legislation, highlight its potential shortcomings and offer suggestions about how best to address them. This will be useful not only in drafting the regulations, but also in the context of the upcoming parliamentary review of the *AHRA* due in the near future.\(^{156}\) Accordingly, a few recommendations are in order.

First, in drafting the regulations, the Agency’s role with respect to health reporting information and the purpose for which the Agency may use health

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154 *Supra* note 34 at 27.
156 *Supra* note 2, s. 70.
reporting information must be clarified. The Agency’s purposes must be clearly articulated, using precise language, so that it is clear what uses and disclosures are permitted under the AHRA. Further, it must be clear whether the information collected by the physician is for therapeutic purposes or for the Agency’s wider purposes. This is necessary for participants to reasonably understand how and why their health reporting information is being used and disclosed. In addition, any unanticipated future uses will require a second consent. Anything less will preclude participants from giving meaningful consent.

Second, great care must be taken to circumscribe the Agency’s role with respect to health reporting information. The non-therapeutic purposes should be limited to those which are reasonably necessary and cannot be achieved through less privacy invasive means. The licensee should not collect any additional information from individuals other than that which is reasonably necessary in order for the Agency to fulfill these narrow purposes. This reasonableness limit on the Agency assumes an essential role in protecting the privacy of those using ARTs because the AHRA ties consent to services. As a result, consent may not be voluntary, and the cornerstone of privacy protection would therefore be absent. Thus, it is essential that the reasonable collection principle be rigorously applied in the AHRA.157

Third, wide consultations should be held with participants, physicians, licensees, members of the Agency and the public in order to strike the proper balance between the privacy interests of the participants and the needs of the Agency.158 These consultations are required for lawmakers to gain a better sense of what health reporting information participants’ reasonably expect should be collected by the licensee, and what uses and disclosures are legitimate or reasonable. All stakeholders should be consulted. Participants, both donors and persons undergoing AHR procedures, should be asked for their input on several issues: what type of information do they reasonably expect the physician to collect? What type of information do they reasonably expect the Agency to collect? What information do they reasonably expect the physician to disclose and to whom? What information do they reasonably expect the Agency to disclose and to whom? What informa-

157 See Part III.B., above.
158 According to the Health Canada website, preliminary consultations have been held with stakeholders but more consultations with patients have been recommended by stakeholders: supra note 34 at 27.
tion would they not be willing to disclose to the Agency? What restrictions, if any, should be placed on the use of their health reporting information by the Agency? Should database matching be a restricted use? Is ongoing disclosure of their health reporting information permissible? If so, to whom? Would the effect of excessive disclosure requirements cause them to avoid donating reproductive materials or avoid the use of these technologies altogether? Donor-conceived offspring, who are directly affected by these provisions, should also be consulted on the nature and extent of information they expect to receive from donors and on the role they expect the Agency to play vis-à-vis their health information. Health care professionals should be asked: to distinguish between the information that is reasonably necessary for them to carry out AHR procedures, as opposed to that required for donor selection; what donor information is necessary to promote the health and well-being of the donor-conceived offspring; and what are the proper roles of the physician and the Agency with respect to the collection, use and disclosure of health reporting information. The Agency should be consulted on the information that it reasonably needs to fulfill its mandate and on whether the Agency’s functions can be achieved in ways that minimize the extensive collection of health reporting information of participants and donor-conceived children.

These consultations may reveal that certain purposes, such as administration and enforcement, are legitimate, while others, such as monitoring for possible ethical and human rights violations, are not because the latter can be achieved in other ways. Consultations with stakeholders will also be useful to gauge what level of disclosure may inhibit some individuals from disclosing relevant health reporting information to the licensee, thereby jeopardizing their primary care or potentially discouraging them from participating in these technologies altogether.

Fourth, based on these consultations, the AHRA should require two separate consents for the collection, use and disclosure of health reporting information by the licensee and the Agency, respectively. The first consent would be required for the collection, use and disclosure of health reporting information in the therapeutic context and for certain non-therapeutic purposes which are considered reasonable or legitimate in the context of the participant and licensee relationship. A second consent would be required for the collection, use and disclosure of health reporting information for those non-therapeutic purposes considered to be illegitimate or unreasonable. This would constitute a second, separate transaction. Of course, the ability to refuse consent must be explicitly provided to the participant in respect of this second transaction. In other words, participants could refuse
consent to the collection, use and disclosure of their health reporting information for certain secondary purposes and still receive services. In this way, individuals using these technologies will be reassured that their privacy is protected, which in turn will encourage the safe use of these technologies. This recommendation is consistent with Professor Austin’s vision for the role of the refusal-to-deal clause and the reasonableness requirement, as described above. This may be one way to address the overbroad purposes of the AHRA.

**Conclusion**

The AHRA appears to sacrifice individual privacy for a number of non-therapeutic purposes unrelated to the patient. By muddying the purposes associated with information collection and the parties to whom these purposes pertain, the AHRA makes it difficult, if not impossible, for participants to determine why their information is being collected and how it will be used. By tying consent to the receipt of services, individuals are forced to disclose health information to the physician and the Agency in order to use these technologies. By authorizing the collection of information for overbroad purposes unrelated to the participant, there is an over-collection of patient information. As a result, there is a real risk that participants will fail to disclose important health information or that they will avoid the use of these technologies altogether.

There is no question that the Agency has an important role to play in the use of these technologies, and that some of the non-therapeutic purposes for collecting health information are important. But this does not mean that the privacy of those using these technologies should be sacrificed unnecessarily. Although the regulations have yet to be published, the framework found in the AHRA foreshadows some significant problems from a privacy perspective, requiring a proper balance to be struck. The rather modest recommendations offered above seek to better protect and promote the privacy of those subject to the AHRA, with the hope that access to these technologies will not be chilled or undermined because of the perception of excessive disclosure requirements mandated by the Agency.