Research in the biotech age: Can informational privacy compete?

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This article examines the privacy of personal medical information in the health research context. Arguing that biomedical research in Canada has been caught up in the government's broader neoliberal policy agenda that has positioned biotechnology as a strategic driver of economic growth, the author discusses the tension between informational privacy and the need for medical information for research purposes. Consideration is given to the debate about whether privacy for medical information serves or hinders the "public good" in respect of medical research and to discussions of informed consent as an element of "fair information practices" designed to safeguard the privacy of personal information, including attempts to vacate requirements for informed consent in the medical research context.

Keywords: privacy; informational privacy; informed consent; fair information practices; biotechnology; medical research

The advent of the new economic order is calling for a new and challenging public policy paradigm where social policies that link education and skills development become the drivers of information-era growth and competitiveness, especially in terms of research and innovation.

Leaders' Forum Steering Committee, 2004, p. 6

This statement from the Leader's Forum on Health Research in Canada, which acknowledges the "new economic order" commonly referred to as neoliberalism, is indicative of the environment in which health research is conducted, an environment in which pressure is exerted on medical researchers to secure corporate funding sources and to develop research agendas that yield discoveries that can be exploited for economic value through intellectual property rights. Moreover, policy-makers in Ottawa increasingly emphasize the value of research as a mechanism by which Canada can ensure its future economic sustainability. This article argues that the prominence of the neoliberal policy agenda has attached to scientific innovation, particularly biotechnology and medical research, as drivers of Canadian growth and prosperity comes at the expense of privacy protections for personal medical information. I build my argument by first outlining how biotechnology has come to be promoted by the Canadian government as one of the new pillars for progress and economic advancement. The considerable emphasis placed on the economic implications of this science and its technological applications tends to derogate other social issues that attach to biotechnology research, including privacy interests. Within this discussion, I outline how neoliberal policy agendas are congruent with conceptual models and strategies designed to "balance" privacy protection with other public policy goals. The next section briefly illustrates the major legislative mechanisms that have promulgated in this country to protect personal medical information; legislation that responds more to data flow requirements, albeit with limitations, rather than to strict privacy protection. Despite the flaws inherent in the "balance model," it remains the dominant approach in contemporary policy debates, in large part because it satisfies a broader neoliberal agenda that attributes substantial economic promise to biotechnology research. Given the prominence of balancing, the next section of the article goes on to offer a possible counterweight to the traditional individual versus society dichotomy inherent in much of the debate about the privacy of personal medical information. The goal here is to offer an alternative conception of the "public good" that, by according substantial import to individual privacy, is capable of marshalling enough heft to tip the balance in policy discussions toward stricter privacy protection.

The final section of the article considers informed consent, as one element of "fair information practices" that aligns with both the balancing approach inherent in policy debates as well as the notion that individual privacy can contribute to the public good of medical research.

Biotechnology, Neoliberalism, and Balancing

Biotechnology presents an exceptional economic opportunity for Canada in the 21st century. This enabling technology can strengthen Canada's competitiveness and open up export markets by creating valuable-added industries in the health, pharmaceuticals, agriculture and natural resources sectors. It holds the key to a productive, prosperous economy that creates opportunities for today's young knowledge workers and the youth of tomorrow. To fully capture the social and economic benefits of federal investments in basic research and information technology, there must be opportunities to translate research discoveries into biotechnology products and services through commercialization. (Government of Canada, 2004, p. 6)

The above passage articulates clearly the increasing government-promoted commodification of biotechnology in this country, in which impetus for growth in biotechnology derives from the predicted economic benefits to be reaped as this branch of industry expands. As a matter of fact, the current situation is somewhat paradoxical, as Canada is becoming increasingly compelled to actively promote new science and technological sectors to underwrite national competitiveness in a globally traded environment characterized by capital mobility and free trade (Jessop, 1994; Griffen, 2005). In addition to the promise of parochial advantage, a number of potential social benefits are attributed to biotechnology, including the development of new diagnostic tools and therapeutic procedures to combat disease, create new crops, clean up world hunger, and new technologies that might help reverse environmental degradation (Gissell, Buer, & Durante, 1998). Genomics, a branch of biotechnology that examines the complete set of genes and their interactions for an organism, forecasts an array of positive contributions, including the identification of disease genes and the development of corresponding treatments or preventive measures. The assumption is that as researchers discover more links between particular diseases and genetic mutations, genetic tests can be developed to examine individuals who indicate symptoms or have a family medical history of a certain disease. The expanded molecular understanding of diseases facilitated by genomics research might also aid in developing preventative measures, such as improved vaccines. These brief examples are offered to illustrate the range of products and applications that researchers believe can be developed through genetic engineering. But, as an introductory statement to this section, such development increasingly is driven by corporate profit imperatives fuelled by neoliberal government agendas that focus predominantly on economic growth and prosperity. There are certainly institutions that are engaging in discussion about the broader ethical, social, and political issues that surround biotechnology, including privacy concerns. However, such work does not tend to yield tangible results beyond position statements or declarations capable of challenging, at least in any substantial way, the progress and economic growth imperatives that dominate debate about the developmental trajectory of biotechnology in Canada.

Situating within the widespread assumption that social progress is realized through unmitigated technological development and its attendant economic accumulation, the development of biotechnology appears both natural and predesigned. In the context of the now-etched information society, biotechnology, which itself was greatly facilitated by modern advances in computer technology, has become one of the celebrated means of realizing society's information destiny. Yet, because the information society and biotechnology are both by nature the natural consequence of advanced capitalist development, any debate about alternatives is silenced (Lyon, 1988). Moreover, technological change often is presumed to be progressive unless proven regressive. The burden of proof therefore often falls on those who would seek to regulate new technologies rather than those who profess its benefits. Although the environmental movement of the 1970s resulted in the introduction of some protective technological assessments, the neoliberal agenda introduced in many Western countries, particularly in North America, has resulted in a general mood hostile to regulatory initiatives (Kritsillis, 1991). Both industry and government are quick to emphasize the potential negative economic implications of stringent regulation on the commodification of science and technology, including genetic research and development (R&D). Against a backdrop of neoliberalism that
"extends the class power of large capital and erodes the collective capacity of labour and the popular sector" (Burke, Moeers, & Shields, 2000, p. 12), governments respond to this contemporary constellation of forces with agendas of deregulation and the abandonment of once public goods and services to the logic of the marketplace in an effort to stimulate national competition and economic growth (Lyon, 1988).

This situation is particularly pronounced in respect of biotechnology, which continues to be pursued in publicly funded institutions, such as universities, that themselves are progressively subjected to the imperatives and corresponding constraints imposed by capital. Reduced funding to institutions of higher learning as a direct result of the neoliberal restructuring of government agendas over the previous two and a half decades has caused universities to seek out alternative financial sources. Coupled with this is the now well-established gospel among many governments that economic growth and development depend on the ability of private enterprise to commercially apply and exploit the knowledge and innovation developed in educational institutions (Etkovitz & Webster, 1998). Indeed, the university landscape today is characterized by more and more pressure on faculty to commercialize research and develop partnerships with commercial companies—a development Ettlinga terms an epistemic drift through which the utility of science is measured according to market criteria (Etkovitz & Webster, & Healey, 1998). Of course, it might be objected that scientific ideas have long been translated into industrial applications as evidenced by the historical importance of the chemical and electrical industries to the Industrial Revolution. The differentiation in the present case is that such processes have intensified in terms of the reduced temporal span between discovery and application, and the strategic importance to industry of the knowledge developed in academic institutions. This Two-Step process pushed by governments to encourage (coerce) universities into becoming incubators for economic growth and development through partnerships with business (Etkovitz et al., 1998).

In short, the labor market for life scientists has been greatly expanded, and the cross-traffic between universities and industry is now so extensive that it is fair to consider biotech firms and universities as part of a common bargaining community. (Powell & Owen-Smith, 1998, p. 263).

In Canada, aside from admonitions from the Canadian Biotechnology Advisory Committee (CBAC) to commercialize university research, the Association of Universities and Colleges of Canada in 2002 signed a framework of agreed principles with the Government of Canada that commits universities to double the amount of research they conduct and to triple the amount of commercialization they undertake of such research (Association of Universities and Colleges of Canada [AUCC], 2002). The contemporary university might thus be viewed as providing part of an enabling infrastructure that contributes to capitalization growth and development, which increasingly relies on knowledge creation (Florida & Cohen, 1999). According to Industry Canada (2000), as of 2000, most of the Canadian biotechnology companies (defined as companies for which biotechnology is the principal activity) and that conduct biotechnology R&D were startups based on discoveries made in Canadian universities, research hospitals, and government laboratories. Between 1997 and 2000, the National Research Council Canada (NRC), a tax-funded federal research agency, alone had spun off more than 20 biotechnology companies from its 5 biotechnology laboratories.1 Between 1998 and 2003, the NRC applied for 340 patents, of which 123 had been issued by 2004. During this same period, the NRC signed 43 license agreements with various companies to transfer its research and CONsequent technologies to the marketplace (Government of Canada, 2004). The Canadian Institute of Health Research (CIHR) is also active in moving research from universities and research hospitals to the marketplace through such programs as the Trans-Canada Principle. Similarly, the Intellectual Property Management Program, which is jointly administered by the CIHR, the Natural Sciences and Engineering Research Council, and the Social Sciences and Humanities Research Council, aids universities and hospitals in developing strategies to exploit intellectual property portfolios (Government of Canada, 2004).

Such strategies are bearing fruit for governments and universities; according to a report by the Association of University Technology Managers, commercialization at Canadian universities and hospitals was at an all-time high level ever seen in fiscal year 2005 (latest available data) (Bosron, Bruce, & Flanigan, 2007). In sum, the context within which biomedical research in Canada is being conducted is influenced heavily by both government and industry pressures, and by the assumption that biotechnology is a strategic enabling technology that will help drive this country’s economic growth and development.

This broader environment has direct implications for privacy policy in this country, in that debates of the privacy of personal information must often yield to, or at least be balanced with, the imperatives of economic growth and development. Policy discussions about privacy protection have thus evolved into instrumental or functional discussions about how privacy must be balanced against competing interests, an approach that is reflected in the majority of data protection laws and policies promulgated in the past 30 years (Bennett & Raab, 2006). Regina (1995) notes that the problems related to the task of defining privacy are quite problematic in the policy process. Though there is a range of ideas that attempt to outline the boundaries of the privacy concept, many are too abstract to be empirically valid to policy discourse. The result is that most policy actors default to legal concepts, such as “expectation of privacy,” which are able to garner wide consensus, although with different meanings. Aside from being ambiguous, such notions of privacy presume it to be a right—a right that runs up against and must be balanced with other social and individual rights and interests (Regan, 1995).

The problem is that in such debates, the amenable weighting attributed to privacy erodes its prominence vis-à-vis opposing policy interests to such an extent that the former is dispensed of its legitimacy as a crucial policy issue.

A major conceptual weakness of the balancing model, as it applies to privacy, is that it is quite difficult to quantitatively determine the costs and benefits associated with privacy protection. As Raab (1999) says, "privacy often seems inexpressible in the currency of serious policy debate, in which some numbers are thought to be better than no numbers." (p. 78). Balancing requires some degree of parity between the two interests in question, which is almost impossible to determine in the context of tradeoffs involving privacy. This problem is compounded by the fact that, presumably, in many instances, only one of the privacy debates, death or life, are being debated. Moreover, the balancing model functions at an aggregated level that neglects much of the granularity that would better indicate the complete range of actors and interests involved in attempts to effect a balance in the privacy debates.

In matters of “public interest,” privacy tends to be what ever is left after more pressing elements have been resolved. Whether death or life is the issue, information users employ a common set of terms that are hostile to privacy. In the parlance of banks, police, and government agencies, privacy is a value rather than a right. It is a right that impairs efficiency and shields criminals. It is the natural enemy of freedom of information. It is a concept without definition or form.

Its enforcement is cumbersome and expensive. Thus, privacy is cast as the leche noir of law enforcement, openness, progress, efficiency, and good government. (Davies, 1997, pp. 152-153).

The neoliberal policies that dominate the political and economic agendas in Canada are reflected in the balancing model that informs policy debates and legislation in most of the country. Having established this broader context, the following section will offer a schematic outline of the extant legislative framework that regulates the flow of personal medical information in Canada, including an assessment of the degree to which such legislation reflects the promises of the “balancing model.”

**Canadian Data Protection Legislation**

The Personal Information and Protection of Electronic Documents Act (PIPEDA) came into full force on January 1, 2004. The Act covers all informa-

This approach is consistent with the assumptions made in the four Acts, which outlines similar purposes, including the following: to protect the privacy of individuals with regard to their health information; to enable access to and the sharing of health
information to provide health services and manage the health system; to prescribe rules for the collection, use, and disclosure of personal health information; to provide individuals with rights of access to and correction of their medical records; to establish remedies for contravention of the Acts; and to provide for independent reviews of decisions made under the Act. 3 All four provincial Acts apply to identifiable personal health information, which includes genetic health information. 17 All of these acts, whether at the federal or provincial level, set out exemptions for the use of personal health information for research purposes. In the case of the federal statute, an exemption from the consent requirement is permitted if the industry is for research or statistical purposes or for a scholarly study and it is impracticable to obtain consent. All four of the provincial Acts contain provisions that require ethics approval for research using personally identifiable health information. Section 50 of Alberta’s HEA empowers the ethics review board to determine whether consent is required from the individual to whom the information pertains. Similarly, Saskatchewan’s HIPA allows for use of personal health information without consent if it “in the opinion of the research ethics committee, the potential benefits of the project clearly outweigh the potential risk to the privacy of the subject individual.” 41 Manitoba’s PIIHA and Ontario’s PIIA contain very similar provisions. 42 Also of interest is the fact that the Ontario and Alberta Acts, which do define research, draw no distinction between public sector and commercial research. 43 Legislation in Saskatchewan and Manitoba does not specifically define research.

Even this summary sketch of the data protection legislation in Canada shows both the federal and provincial levels should impress on the reader that such laws have been enacted to facilitate rather than completely restrict the flow of personal information. That is, all of these statutory instruments are based on “fair information practices” that seek to balance informational privacy with other interests rather than guarantee strict informational privacy protection. A major problem with “fair information practices” is that they are less protective of privacy than personal information. They form the backs of information laws that regulate the way personal data may be collected, used, and disclosed rather than addressing the complete range of privacy and associated surveillance issues. Moreover, the protection regimes developed from “fair information practices” tend to provide a number of exemptions for governmental and research purposes. But most problematic is the fact that data protection laws fail to prevent or circumscribe the collection of personal information. In fact, by establishing regulatory regimes in respect of the collection, use, and disclosure of personal information, data protection laws actually legitimize an unchecked expansion in the number of information systems that may now be developed to serve individuals (Dovres, 1997). Current statutes designed to protect informational privacy reflect broader neoliberal policies that seek to ensure economic imperatives figure in policy development and legislation. In the Canadian context, it is clear that there are incentives to use the genetic analysis by permitting the assessment of transgenerational effects. Although the Canadian Longitudinal Study on Aging will not be fully launched until 2008, funding for the developmental and piloting work has been provided in the amount of $974,000 in 2004/2005 and $770,000 in 2005/2006 (CHIR, 2003). Both studies would collect biological samples for genetic and biochemical analysis, health records, and socioeconomic data such as household income, occupation, and place of residence (Caulfield & Ries, 2004).

The importance attributed to such long-term health research studies has been outlined by the Leaders’ Forum for Health Research (2004, p. 10), which, in a report prepared for the federal government, stated that health R&D funding priorities should be to “bolster” its research enterprise "as being vital not only to health and health care but also to Canadian economic growth and international competitiveness."

In a knowledge-based economy where businesses and jobs cluster around talent, human capital will increasingly be at the cutting edge of economic competitiveness. The need to investing in the research that will enhance the health, education and skills of Canadians will be a principle avenue to foster growth and innovation. (Leaders’ Forum Steering Committee, 2004, p. 11)
is a false equation (Willison, 2003). Perhaps a better approach is the one espoused by Priscilla Regan (1995), which frames privacy as a common value that promotes the trust needed to participate.

In a similar vein, Tunick (2001) considers the oft-touted charge alleged by privacy opponents that privacy encourages an isolated life and sense of individualism that works against the community need for public-mindedness and frequent interaction with and as others. Tunick references the sociological and anthropological literature that posits a necessary link between a certain degree of privacy and the maintenance of community. Privacy engenders respect for people, which in turn promotes the mutual respect and recognition necessary for community. Respecting the privacy of someone else demonstrates recognition of that person as a bearer of rights and worthy of some degree of self-determination. It signals the trust that person has in another to act responsibly (Tunick, 2001). Thus, a compelling justification for respecting privacy is the potential for harm to broader society that would result if an individual's privacy is violated. That is, if we accept that privacy contributes to the good social, then society collectively is harmed by privacy violations even if, as individuals, people are not directly affected by the intrusion (Mackin, 1992).

A further implication of framing privacy as a public good is that questions of medical research, which proponents of reduced privacy protection assert is a public good, come up against a similar public good rather than the private interest of a few individuals. As Valerie Streeves (2004) notes, to argue that privacy must give way to these secondary interests misses the fact that health care is delivered in the context of social relationships between moral actors. Surveillance that violates the sociological experience of privacy as it is lived in the [sic] our daily lives will break down the trust that is an essential part of health care delivery. (p. 7)

She thereby turns a typical argument advanced by medical researchers against them and points out that privacy is, in fact, necessary to ensure unbiased data as people might alter their behavior in response to privacy invasion. Opponents of strict privacy protection are thus compelled to demonstrate the societal value of any proposed research that would impinge on individual privacy (Streeves, 2004). If one accepts that a privacy invasion of one individual negatively impacts others, then the research community must act to ensure the need for individual privacy rights, then a compelling case can be developed in support of strict privacy protection for medical and genetic information. This position, of course, is the other side of the "public interest" debate that is so often invoked by medical researchers to justify unenforced use of personal medical information. But informed consent, as a "fair information principles" and information privacy, might be more appropriately conceptualized as a safeguard not only for individual information privacy but also as a means of ensuring participation in medical research studies. A way of avoiding these potential costs for health care is to guarantee the right of informed consent before personal information may be used in health research projects.

**Informed Consent in the Research Context**

The debate over the privacy of medical information focuses in large part on the purported negative effects that the requirement of obtaining informed and explicit consent for the use of patient information would exercise on medical research. Opponents of informed and explicit consent perceive it as an unnecessary hurdle that could result in partial enrollment in health studies, which, in turn, would vitiate the value of any data such studies yield (AI-Shahi & Warlow, 2005; Ingelfinger & Drazen, 2004; Tu et al., 2004). The concern articulated is that low enrollment rates might result in participation bias and thus jeopardize the generalizability of research, as those who decline to authorize access to their medical information may be different in a clinically significant way from those individuals who do participate (Gostin & Hodge, 2002; McCarthy, Shatin, Drinkard, Kleiman, & Gardner, 1999; Upshur et al., 2001). A number of medical researches in both Canada and the United States, citing appraised costs for research projects that a requirement for informed consent would generate, advise informed consent exceptions for minimal-risk observational research.

Yet as opposed to what Tu et al. (2004) assert to be the case in Canada, studies in the United States have found that the Health Insurance Portability and Accountability Act (HIPAA) regulations are not adversely affecting the work of medical researchers. Dr. Maurice Markman, chief medical research at the University of Texas M.D. Anderson Cancer Center in Houston, contends that the regulations had only a minimal impact on recruitment of patients into clinical trials:

That doesn't mean there haven't been any problems, concerns, or frustrations involving individual patients or protocols or patients. However, we have the impression that, other than the additional work required to make sure we're HIPAA compliant and the initial conversion effort, that the regulations have not had a major impact on our ability to conduct trials. (Bankhead, 2004, p. 1758)

In another case, the Christians Care Health System in Newark, Delaware, found that patient acquisition for clinical trials has actually increased from 17% to 23% since the HIPAA regulations entered into force (Bankhead, 2004). In terms of added cost incurred as a result of HIPAA compliant, researchers at Northwestern University Medical Center in Chicago found that despite an initial spike, costs returned to near pre-HIPAA levels once investigators adapted to the changes mandated by the regulations (Bankhead, 2004). Similarly, Spivak Smittit (1995) recounts experiences in Germany where such protection for the data subject increased both participation rates and data reliability.

Critics of the doctrine of informed consent also claim that such rules impose an unreasonable burden on both patient and researcher in the context of studies that involve genetic materials. The reason advanced is that it is virtually impossible to describe all potential future research protocols that might be performed on a person's tissue or information and therefore that informed consent is ill suited for research that does not email their specific practices. Such concerns assume added significance in the case of large cohort studies that follow thousands of individuals over a long span of time, as is the case with the two major Canadian health research studies outlined earlier (Caulfield & Ries, 2004). Nonetheless, a question arises as to whether consent can be truly informed if a patient does not have all the necessary information about a specific project. The intuitive response is that patients cannot be expected to understand the negative returns. Worries surrounding the privacy of medical information assume added force when one considers the growing technological capabilities that allow otherwise anonymous samples to be identified. In an attempt to reconcile privacy protection with the need to advance medical research, some researchers advocate the removal of personal identifiers from medical data before research begins (Lownace, 2003). However, at least one Canadian study has confirmed a concern raised by privacy proponents: "We removed all direct identifiers before transferring information from the electronic medical records. It was, however, still possible to indirectly identify an individual through the variables that remained" (Yaffe, Goldsmith, & Holbrook, 2003, p. 376). That is, simply removing personal identifiers from information fails to completely respond to privacy concerns, as residual information in such "deidentified" databases, including date of birth, postal code, gender, and so forth, when matched with other publicly available data sets, offers a mechanism to link medical records to individual persons (Appelbaum, 2000; Kobyn & Korn, 2002).

Alternatively, blanket consent for any and all future research uses is sometimes proposed. However, as opponents of informed consent themselves point out and as discussed earlier, it is nearly impossible to predict all the secondary uses of personal health information that might be made after initial collection, thus rendering consent meaningless and allowing the privacy protection while providing false assurances that informed consent originally had been secured (CIHR, 2002). Perhaps more important, certainly with regard to respect for the autonomy of human subjects, is the contention that individuals whose data is informed in this way do not have the authority for which their samples will be used. Such a truly informed consent would afford people the opportunity to decline to participate in research of which they disagree (Clayton, 1995). Moreover, stringent privacy policies might actually have the effect of alienating privacy by opponents. If human subjects can be convincingly assured that their health information will not be disclosed to third parties for purposes other than the research, public health researchers might be increased such that more clinical trials could be initiated to participate in research studies (Powers, 1997).

Although a number of authors assert that the use of health data without informed consent poses only a minimal privacy risk, there is very little empirical evidence to support this claim or at least to explore what "minimal risk" concretely entails for individuals and their health information. Moreover, personal information for research purposes very often involves a use that does not correspond to the original use of the data that were collected. There are strong commercial incentives for accessing health information, which in turn raises further possibilities for function creep. As more and more individuals and organizations gain lawful access to health data, there also arise substantial opportunities to lawfully collect, use, and sell personal information for purposes that patients never considered, let alone consented to, when the data were originally collected. The intimate nature of health information and these data stigmatize, particularly in the case of genetic information, leads to compound the negative effects of potential privacy violations. It is quite difficult to predict with any degree of reliability what harms might occur as a result of the disclosure of personal information (Mackin, 1992). A failure to protect personal medical information might therefore simultaneously exacerbate and reinforce
broader social inequalities. For these same reasons, Simitis (1995) argues that legislation must ensure that data provided by research participants are used to preserve their rights, meaning that personal information collected for one purpose and subsequently used for research purposes would require informed consent. As a proponent of informational self-determination and critical of approaches to data protection that imply that individuals should have the right to determine whether their information may be used for research (Simitis, 1995).

The discussion in this section is offered to illustrate that there are vital reasons in support of demands for informed consent as a privacy protection mechanism in the context of medical research. Situating this idea within the broader context of this article, we notice that admissions against the necessity of obtaining informed consent violate an important element in the fair information processing that help constitute the balancing model.

Although we may fault the balancing model for insuffi-
ciently protecting privacy, the fact remains that it pro-
vides a conceptual mechanism employed predominantly by Canadian governments when developing privacy policy. Researchers and institutions need to be reminded that engaging in research projects without obtaining informed consent violates a tenet of the fair information practices that underpin current privacy frameworks, thus threatening to throw off any balance.

Conclusion

In this article, I have tried to advance the argument that the privacy of personal medical information in the context of biomedical research is a human right. In creating an autonomous and non-coercive research environment, this article supports the principle that personal information should be collected and used for research purposes in a manner that is consistent with the needs of the individual whose information is collected.

Notes

1. The Leader's Forum on Health Research in Canada was formed in 2003 by the Council for Health Research in Canada as a multistakeholder partnership, comprising federal and provincial research agencies, scientific organizations and research advocacy organizations.

2. Fasbinder is used in that there is a wide debate in the literature about the difficulties that attend any attempt to develop a definition of pri-

3. The privacy law enacted in Canada takes as its fundamental principle to safeguard the personal information of individuals against government and corporate intrusions. Second, the protection of personal medical information is often what is meant when people consider and debate privacy in the

4. The CITC issues advisory comments to the federal and provincial governments of Canada to approve policy makers of issues related to biotechnology that will require immediate or med-term attention as well as the effects of government policy on biotechnological developments in Canada (CRTC 2004).

5. The list of the NRC Plant Biotechnology Institute in Canada includes the NRC New Athena Bioinformatics Group in Haliburton, the NRC Institute for Biological Sciences in Ottawa (pharmacological research), the NRC Biotechnology Research Institute in Edmonton, and the NRC Institute for Biosignatics in Winnipeg.

6. Though beyond the immediate scope of this article, the work of the Chief Privacy Offi-cier and his/her role with respect to the increased institutional emphasis on notions of efficiency and the resulting implications for surveillance and privacy, does relate to one of the major themes of this article. Fasbinder, C., and Uglow (1980) assert that the promise accorded to the "efficiency" criterion in contemporary organizational behavior provides justification and resale for the extended use of surveillance in increasing areas of social life. They maintain that the efficiency criterion informed debates about privacy, such that data protection principles came to focus on the management of personal data rather than the more causative issue of whether surveillance is a legiti-
mate form of bureaucratic action. The result has been an emphasis on "fair information practice" and the increased use of surveillance to enhance their surveillance activities all the while upholding to protect the priv-

7. Concerned about the effect that disparate national treat-

8. Concerned about the effect that disparate national treat-

9. OECD Guidelines for the Protection of Personal Information (the OECD Guidelines) in an attempt to spur harmonization of national legislation.

10. The OECD Guidelines set out eight basic principles that establish what are often referred to as "fair information practices": collection limitation principle, data quality principle, purpose specification principle, access and correction principle, accountability principle. These guidelines, which were adapted in part to adopt the OECD Guidelines. The importance of this context is apparent in the wide range of international data flow. The Privacy Act and the personal information protection act of 1981, which forms the legal framework for the protection of personal information in Canada, are based on the OECD Guidelines. That is, the Privacy Act is formulated using what was originally a voluntary guide to conduct.

11. Personal Information Protection and Electronic Documents Act, S.C. 2000, c. 4 ("PIPEDA")."