

## RESPONSE TO NEW BRUNSWICK LEGISLATION

Item	General Comment	Comparison to COACH Guidelines
Scope of legislation	Legislation should apply to all health information regardless of who collected it or where it is held. To do anything else can create gaps, and gaps where a control in place in one piece of legislation is not in another, as in Public Sector vs. private sector legislation, creates conflicts for those attempting to implement it, and creates a great confusion for those who have to learn the rules. Application of health information regulations based on payor (as in Alberta) has proven to be problematic and results in uneven application of rules to different services provided to the same individual, as well as different individuals receiving the same services.	The COACH Guidelines do not distinguish between where the information is collected and held. In other words there is no distinction between private and public data, since it has the same value regardless of who holds it, and has the same potential for prejudicial use wherever it is collected and held. The more important distinction is made - what is it to be used for?
	Health information on employees has the same sensitivity as does information held elsewhere, and may be subject to more risk since it is held by an employer who may be tempted to misuse it to their own advantage.	Coach Guidelines do not distinguish where information is held, only what it is used for.
Recorded and unrecorded	Legislation should apply to both, for similar reasons to above. Distinguishing between written and verbal can have the unintended and negative effect that organizations may choose not to record information in order to keep it from being subject to information release. The challenge associated with controlling verbal information is greater.	Coach Guidelines do not distinguish between verbal and recorded, only what it is used for.

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Consent: General	Consent includes a requirement for knowledge and providing knowledge is a responsibility that is often not done as well as it should be. Release of personal health information to government administration should be very closely watched, and the purposes very clearly identified (such as "fraud prevention" but not as broad as "system efficiency" for example). Additionally, there should be some specific restriction in the health information legislation, above and beyond the usual FOIPPA applicable to government bodies, on the republication or repurposing of health information once in the hands of government administration.	COACH Guidelines focus on openness, and awareness of how information flows and is used.
Consent: Implied Knowledgeable	The model of implied knowledgeable consent is workable only where organizations see it in their interests to provide the knowledge. This is often not done. Provinces with different consent models for public versus private sector are finding it a challenge as health information begins to be shared across those boundaries. Participants are unaware of the differences, or ignore them - a condition which will soon begin to create issues.	The COACH Guidelines focus quite strongly on implied knowledgeable consent as a way to bring both private and public legislation to the same practical standard.
Consent: express	Express consent can be used where there is a higher risk of prejudice to the individual. Although this is a judgment which is difficult to make on behalf of another there are some categories that may benefit: genetic information, STD/AIDS, mental health, insurance, WCB.	The COACH Guidelines recommend knowledgeable implied consent so that these situations are able to be addressed by the individual based on their own perspective.

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Consent: none required.	Legislation in some province provides quite wide latitude for the use of identifiable information where it would be more privacy protective to use only de-identified or anonymous information. Specific examples where identifiers are not required are: health service provider education, planning monitoring and evaluating the health system, many uses of data for averting general risk to the public. A paradigm shift is needed wherein organizations and governments use non-nominal data as the DEFAULT with all uses of identifiable information actively justified.	The COACH Guidelines recommend that identifiable information be used for the benefit of the individual only. That includes health services, where that also includes health service education (as in when it is embedded in patient care, but not the other way around), or averting a risk to the public, where the individual also requires care or where public risk is grave. Where identifiers are needed in order to link data - that can be done with security and by arms length bodies to protect privacy, rather than simply legislating that governments may do so because of their need.
Collection, Use, Disclosure	Creating a clear responsibility in legislation, that organizations should define the purposes for which the data is to be used would be of great help in clearly setting expectations on its further use and disclosure. Without defined purposes it is difficult to then assess whether or not a new purpose is 'consistent' or the 'same' as is required in some provincial legislation.	The COACH Guidelines focus on defining the purposes for the information collection as a first step, from which all other decisions on use and disclosure are based. It also focussed on the added advantage to the organization, that is, if one knows the purpose of the data, one can judge its inherent value to the organization and the risk to which it may be subject and that knowledge can help drive decisions on how to protect it.
Collection, Use Disclosure: for a legal purpose related to what the person collecting the information (e.g.. The physician) does	This should be qualified where what the physician does is to the benefit of the individual. Rather than anything the physician does.	COACH Guidelines focus on the use of information to the benefit of the individual and where that connection lessens, to stronger control, and more use of de-identified or anonymous information. The philosophical default should be set to NO use of identifiable information unless required. While this is the intention of most privacy legislation the message does not come across strongly enough to have organizations make the shift from broadening the legislated use of identifiable information rather than creating systems which use, link and analyze de-identified information.

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Collection, Use Disclosure: to police or other investigators for accident prevention etc.	This should be qualified as to How the information is made available. What kinds of investigations? How formal? Are the investigators allowed into the data to look around and go on fishing expeditions?	Accident prevention and other system planning activities should be done on statistical or anonymized data. If the system were to accept non-identifiable information as the default, with clear justification required for use of identifiable information that would have the effect of reinforcing the importance of privacy. As it is there are more and more legislative exceptions being written which in effect undermine the default protections.
Collection, Use and Disclosure: Pastoral care	Religion is a strongly held individual belief and as it is seen differently by different individuals, the wishes of the individual should be sought before health information is used by or disclosed to pastoral care staff.	COACH Guidelines recommend consent.
Collection, Use, and Disclosure: to health researchers	Different provinces have quite different approaches to this issue. The respective benefits and drawbacks are complex and need to be carefully considered.	The COACH Guidelines recommend consent for use of identifiable data for research, however this is a complex business, which is structured differently across the country and hence that response also needs to be carefully qualified by the situation.
Access to information: by the individual	No issue with what is written.	What is written aligns with the COACH Guidelines.
Information Security and Independent Oversight	Current problems arise either because of lack of adequately resourced independent oversight, or none at all. Without adequate resources any independent oversight is ineffective. Without effective oversight controls are ignored. Requirements for independent audits should be set in legislation.	COACH Guidelines recommend strong independent oversight.