

This hand-out was provided to members of the **Select Special Health Information Act Review Committee** prior to a presentation by Mr. Larry Phillips (president) and Ms. Wendy Armstrong (board member) in September 2004. The presentation was in response to a consultation document on proposed amendments to the *Alberta Health Information Act* circulated in the summer of 2004. A final report of the Committee was released in October of that year. In the summer of 2005 new proposed amendments to the *Act* based on the Committee Report were also circulated.

1. Minimal Recommendations
2. Experience of Alberta Consumers' Association
3. Consumer Reality Check - What Albertans Say?
4. Real and Potential Harm
5. From Our Files – Patient Stories
6. The “Human Factor”
7. Openness Lacking - Provincial Government
8. Registration Information (What is it?)
9. A Cautionary Note from the Past
10. Value Drug Mart's Proposal: Education or Marketing?

Also included were “Farmer's troubles with medical records a cautionary note”, guest column, Edmonton Journal, March 17<sup>th</sup>, 2003 and copies of Consumers' Association Summer 2004 Bulletin (“How Private Credit Reports Can Affect Your Life” and “Are we inadvertently cultivating an environment for identity theft to thrive?”)

## Minimal Recommendations

to the Select Special *Health Information Act* Review Committee, September 2005

### **STOP - LOOK - LISTEN** (to the people of Alberta)

1. Do not expand scope to other bodies until major issues resolved.
2. Remove "provider information" from the *Act* or provisions that prevent access to provider information for system planners, public and patients. (Note: This clause is often used to restrict patient access to reports from specialists to a family physician.)
3. Do away with patient charges and remove barriers to patient and family and trusted friends' access to information - with recommendation to redesign system so more information is automatically provided to patients.
4. Introduce new restrictions on access to information without consent for research, particularly commercial research. Look to Manitoba for some ideas on how to manage aggregate databases in the public interest.
5. Define and restrict definitions of personal health information to be used to exclude determinants of health for purposes of sharing. Keep data minimal.
6. Insist on cost/risk/benefit evaluations of computerization and automated functions within the system. Confidentiality and privacy provisions, the ability of patients to scrutinize their own records, routinely obtain copies of authorization forms they sign and access to information about providers are all part of the "cost of doing business". It needs to be factored in to payment to health care providers.
7. Do not expand any more opportunities for disclosure without notification or permission and retract as many existing provisions as possible.
8. Remove the first purpose of the *Act*. It is misleading and deceptive.
9. Insist the Province act on its duty to disclose details of collection, use and disclosure for all identified purposes as described in the Openness Principle of the OECD Guidelines on the Transborder Flow of Data.

## Experience of the Consumers' Association

The following are a sample of the issues related to increasing computerization and automation, the emergence of "stealth" marketing, increased citizen surveillance, loss of citizen privacy and increasing barriers to accessing information (on private markets and governments) in which we have been involved over the past 15 years.

### Related Issues

- Impact of new third party liability provisions re: *Hospitals Act* (1991-1996)
- National "Cards, Cards, Cards" Conference in Ottawa (1991)
- Registries information, databases, use and sales in Alberta (1990s)
- Banking and financial services during 1990s (incl. student loans fiasco)
- Presentation to 1993 FOIP Committee
- Arranged to have Ralph Nader address 1993 FOIP Committee
- National Industry Canada Task Force on Electronic Commerce
- Alberta Health's new diagnostic billing system for physicians (1992-1995)
- Proposed Alberta Integrated Health Info System (Bill30/Bill40) (1990-2004)
- Proposed Drug Information System & Drug Utilization Committee (1994-1995)
- FINESTONE House of Commons Committee Consultations (1997)
- National Forum Conference on Health Info-Structure (1998)
- National Privacy Working Group Consultations re: PIPEDA (including issues around collection, use and access to information for insurance companies)
- PIAC/CAC focus groups Secondary Uses of Health Information
- National Privacy Coalition Lobby related to introduction of PIPEDA
- Alberta Health "Core and Complementary" Consultations/Task Force (1990s)
- Expert witness in Ontario Case re: OHIP refusal to correct records
- CIHR Invitational Workshop on Health Information for Research
- Population health and health determinants linkages consultations
- National Industry Canada Task Force on Electronic Commerce
- Monitoring changing private insurance practices
- Monitoring changes in Credit reporting agencies
- Loyalty Points Programs (e.g.) Airmiles related to stealth marketing
- 1994 Proposal for multi-purpose citizen tracking card - Steve West
- Telecommunications and Internet practices and rules (hearings)
- National ID Card proposals
- Alberta's New Drivers License
- National Information Highway and Health Infoway Consultations
- Development of CSA Privacy Code
- Unauthorized breaches of rules and unauthorized or undisclosed uses and sales of data by provincial & federal governments
- Emerging genetic technologies and intellectual property issues
- Genetic testing and insurance or employment discrimination.
- New identify theft and fraud related to widespread collection and use of personal information.

## Consumer Reality Check - What Albertans Say

Albertans have repeatedly expressed their growing discomfort with the loss of privacy relating to their personal information, the lack of ready access to their own health information and the lack of access to information about health providers. Even the willingness of Albertans to support initiatives such as Electronic Health Record repositories is predicated on their ability to control access and use.



**In 2000 and 2003, the Office of the Information and Privacy Commissioner (OIPC) in Alberta engaged GPC to conduct two surveys to assess Albertans awareness and concern related to privacy issues.**

For the purpose of these surveys privacy was considered as *control over the distribution and use of one's personal information*. In 2003, respondents overwhelmingly agreed that it is important to protect individual privacy in Alberta (98%), an increase from 78% in the 2000 benchmark survey. Nearly 3/4 of respondents were concerned that the privacy of personal information is at risk in Alberta, a significant increase from the 56% recorded in the 2000 survey period. 82% of respondents were concerned about the privacy of their own personal information, an increase of 11% from 2000 survey. In response to questions about the importance of keeping information safe: the highest ratings were for financial data, personal mail, and health records.

### **The Provincial Government's Response to Albertans' Concerns (2003)**

In the spring of 2003, an amendment to the *Health Information Act* passed without any public discussion or consultations. It removed an existing requirement for even the limited one-time consent for personal information being placed in an electronic health record for access by many other parties without notification or permission. The media release on May 23<sup>rd</sup>, 2003 was entitled "*Health Information Amendment Act protects patient confidentiality while providing needed access*".

### **OIPC Survey on Electronic Health Records (2003)**

After the amendment passed, the Privacy Commissioner released a survey specifically related to Electronic Health Records. It stated: "Many Albertans expressed strong or moderate support for electronic health records - **but the exercise of individual consent of who can obtain access to an Electronic Health Record was considered extremely important to Albertans.**" 89% of respondents believed it is very important for an individual to be able to exercise consent on who can obtain access to their Electronic Health Record, 8% said it was moderately important to maintain control and only 3% said it wasn't important."

### **Is anyone listening?**

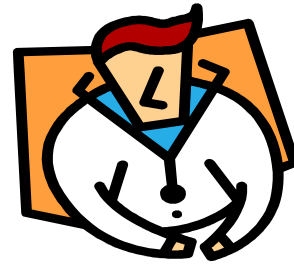
## Real and Potential Harm

**What is the real and potential harm from diagnostic labeling in an electronic medical record?**

### **BIAS IN PSYCHIATRIC DIAGNOSIS**

Paula J. Caplan and Lisa Cosgrove (Editors)

<http://www.RowmanLittlefield.com/ISBN/0765703750>



"The public has a right to know that when they go to a therapist, they are almost certain to be given a psychiatric diagnosis, no matter how mild or ordinary their problems might be. It is unlikely that they will be told that a diagnosis will be written forever in their chart and that alarming consequences can result solely from having any psychiatric diagnosis. These consequences range from loss of child custody to denial of health insurance and employment to removal of one's right to make decisions regarding legal affairs. It would be disturbing enough if diagnosis was a thoroughly scientific process, but the general public would be surprised to find out that it is not. The unscientific nature creates a vacuum into which biases of all kinds can rush. It is a timely and important topic, especially given the skyrocketing use of psychoactive drugs in toddlers, children and adolescents as well as in adults, and especially because receiving a psychiatric label vastly increases the chances of being prescribed one or more of these drugs."

**Other types of diagnosis in your medical files can be just as problematic and just as inaccurate. This can be due to incomplete information, provider fraud, sloppy data entry, unreliable tests, and hurried health professionals.**

Medical conditions are multifactorial in cause and they affect each and every person differently. **Yet a recorded history of a named pre-existing condition (real, suspected, alleged, or "at risk of") such as migraines, back pain, cancer, or multiple sclerosis, routinely prevent many Canadians obtaining life, health or disability insurance.** This leaves many unable to obtain insurance to protect their family income and assets or access to care should illness occur.

With the shrinking comprehensiveness of coverage of public health plans, access to such private insurance policies has become more urgent. **These pre-existing conditions can also affect access to bank credit, mortgages, jobs and education.**

As Canadians become more reliant on benefits tied to their place of employment these records become barriers to accessing a job due to the risk of additional costs to employer benefit plans. Employer-based health insurance premiums are rising more rapidly than public health costs both in Canada and in the U.S.

## From Our Files – Patients' Stories



Complaints, inquires and problems with access to one's own medical records are not new to the Consumers' Association. However, the increasingly fragmented health care environment, the influence of commercial interests, changing public policies, and the introduction of electronic databases have made this issue take on new significance.

People do not understand why the copy of a one-page test or specialist's report in their doctor's hand during a visit or in a hospital chart, cannot simply be photocopied and handed to them as a matter of course. This is particularly true of individuals with chronic and ongoing health needs who like to have this information in order to be able to more effectively negotiate the system. But they are often told that this is not allowed because of "privacy" laws.

As Albertans, we are repeatedly told to take more responsibility for our health and health care, but far too often no one even writes the name of a doctor or health condition on a piece of paper for us. We know that active participation in one's care can have a dramatic and very positive influence on outcomes. It's difficult to participate without information about own condition and treatments.

Problems with unreasonable delays, hassles and financial barriers to access of one's own medical records appear to have increased with the advent of the *Health Information Act* and with the emergence of electronic records in many health care organizations. **It is difficult to sort out where the problem rests. Is the problem the Act itself? computerized records? or the new healthcare environment?** We have also had reports of adulterated [electronic] records, and complaints about refusals to allow access to one's own health information or that of a dependent.

Some callers to our Association have questioned why it is their medical information can be readily disclosed without their consent to the lawyers and liability insurers for hospitals and physicians to protect themselves, but patients are blocked or denied access to such records to protect themselves?

At the same time, most people who feel their information has been disclosed or shared inappropriately within the system are reluctant to complain. They feel complaining will only lead to greater exposure of sensitive information to more people; the very situation they hoped to avoid.

Following are some examples which illustrate some of the issues.

### Story 1 - Refusal of Hospital/Region to Provide Records

"My 19 year-old son was seriously injured in a ski accident and hospitalized in Calgary. As well as other medical problems he had a life-threatening reaction to a specific dye used in a medical test. Upon discharge he was anxious to get back to his friends in BC and left while he was still recovering. I wanted to make sure that if he had complications, the medical people in BC would know what they were dealing with. I

contacted the Calgary Health Authority to find out what he had to do in order to get a summary of his injuries and treatment and his reaction to this dye. The clerk said he couldn't have such a record, and if he had any problems in BC, the doctor should simply call the hospital and they would provide the information. But problems don't always happen during office hours. Why couldn't my son get a copy of this information?"

### **Story 2 - "All or Nothing" Authorizations**

"Today I attended a physical therapy clinic for the first time in a couple years. I was presented with the "CRP Condition of Services Form" and required to sign it. Signing authorizes the government to pay for my physical therapy. So far, so good. It also authorizes the government to collect my health information for, among other reasons...to carry out purposes that Capital Health is authorized to carry out under legislation that governs its activities . . . and conduct research under conditions authorized by an ethics committee. I am assured 'whenever possible your health information will be made anonymous...' When did this happen? What are these 'purposes' and under what conditions might it not be 'possible' to protect my privacy? What can you tell me about this? And did this section of the *Health Information Act* fly by without any discussion in the legislature? Has no one else complained about this signing away right to health information privacy being crowded in under authorization for payment? I have a copy of the form if you would like to see it.

I crossed out what I objected to but not after great consternation at the clinic. The clerk said if I refused to sign the form I would have to pay for my treatment myself. So this privilege is only for those who can't afford more than basic AHC? Next thing you know we the great unwashed will be recruited for more corporeal research: exploratory gynecological surgery, perhaps? After our 'discussion' another client came up to the desk with a muffled question, to which the clerk brayed: 'I imagine the only reason they need this information is so they know who hasn't paid their health care premiums.' He signed his form."

### **Story 3 - Harm from Inaccurate Records**

"My sister started up her own business and applied for disability insurance. She was turned down. The company said it was because it found out my sister had a history of repeat physician visits for 'psychological counseling' from medical records she had authorized them to access at the time of her application. It turned out her physician, someone everyone in our family had gone to for years because she was so friendly and spent time talking when we would go in with routine problems, had been billing all these appointments as 'psychological counseling'.

My sister went and confronted the doctor about this since she has never had any 'psychological' problems requiring treatment and never sought help for any 'psychological problems'. The physician said, 'Well how else am I going to get paid for the real amount of time I spend to provide you with good care?' They had quite the battle. The irony is that this visit for my sister to confront the doctor on this issue was billed as 'psychological counseling'. No disability insurer will touch her. Nor does she feel she can

destroy our mother and father's relationship with the doctor by filing a complaint with authorities."

#### **Story 4 - Barriers to Access for Family Members**

"During a visit with my mother in a long term care facility, I became worried about her decreasing ability to transfer from her wheelchair, or walk small distances. I had fought hard to get her on a regular "walking program" when she first admitted and I also make regular visits to help her do some exercises and walk short distances. I'd found that a little bit of walking and exercise helped to keep her mood up, her pain at bay, and maintain her ability to get in and out of my car. I asked the evening nurse to check if Mom was still being walked because Mom's own memory is so unreliable. The nurse checked her chart and told me that although Mom was still in the program, a temporary shortfall in assistants had resulted in her not being walked by anyone for the last 3 weeks.

This lapse in communication led me to ask to see Mom's chart to make sure there weren't other changes I wasn't aware of. As Mom's proxy decision-maker though a legal advanced directive, I knew I had this right. The nurse obliged by providing me with two pages of nursing notes to look at - *not* the full chart as requested - and I did find other things I needed to be aware of such as frequent nosebleeds which she'd had in the past and I knew how to correct. Of course, this led me to wonder "Is there something else they aren't telling me?"

The next day I had a call from the Manager to express her concern and apologize that she had not kept closer tabs. I said her apologies were accepted, but that given just how understaffed the unit was, I felt I'd like to check Mom's chart once a week. She said that was fine, but that I'd have to sign a special log-book each time I looked at the chart indicating what parts of the chart I had reviewed. Furthermore, a licensed health professional (such as a registered nurse) would also have to be present when the chart was reviewed in case I had any questions, *and* this wasn't always possible on busy evening shifts when I regularly come in. She went on to say that under the "new FOIP Act" the facility can charge me \$45 to take a look at a chart and another \$45 for each 15 minutes to have a health professional supervise and explain things to me. While she said her institution didn't charge these as a matter of course, they could, which seemed to imply a threat to do so if I caused any problems." Is this true? This seems like highway robbery to me, as well as flying in the face of all the recent talk about making the health care system more accountable."

#### **Story 5 - Loss of Patient Autonomy and Third Party Advocacy**

Five years ago, a male resident of a nursing home requested I become his advocate. Soon after meeting this resident, I made contact with his older brother who gave me written consent to act in this capacity. The residents brother and other family members live out of country. I communicate with the brother on an ongoing basis to keep him informed of cares issues and efforts to resolve them. When the resident is hospitalized, I am the designated contact person. As a result of his illness, he is wholly dependent on others to meet his needs. He is confined to a wheelchair that he cannot move- but can comprehend



and speak. He cannot physically hold a pen long enough to put written words on a page, but he still has the ability to mark his signature with an X.

In a recent discussion with the resident, I advised him that he has the right to access his health information, including the list of his medications, under the Health Information Act. I approached the Unit Manager on his behalf to request a copy of his current medication profile. The Manager denied my request saying I did not have the legal authority to act on his behalf. She went on to advise the facility requires an individual to make his or her request in writing. I pointed out that he couldn't write - that the HIA does not require a written request and that the facility's policy was placing this resident and others with similar disabilities at a grave disadvantage. I referred to Section 104(1) of the HIA: Exercise of Rights by Other Persons which says - Any right or power conferred on an individual by this Act may be exercised (i) by any person with written authorization from the individual to act on the individual's behalf. I requested the Manager send me a written response.

Her verbal response simply suggested I contact a certain individual at the Office of the Information Privacy Commissioner. This person seemed to be knowledgeable about the situation in advance of my call. She indicated the resident would need an agent under a Personal Directive or legal guardian to act on his behalf. She suggested the facility must ensure they're handing over information to authorized persons. When I suggested the resident could use section 104 of the Act to authorize me to write a letter in his stead, she inferred the facility may have concerns about the intent behind my initiating this action for the resident. The irony is that this individual later gave consent to be part of a research study on his disease with me assisting him to record his answers. One of the survey questions is, What medications are you taking? His answer: "I can't answer that because the facility won't tell me what medications they're giving me."

### **Story 6 - Response to Health Surveillance and Impersonal Data Collection**

"I was upset when I got a letter telling me that I was due to have a Pap test and tore the letter up because I felt so intruded upon. Now, I have to go and get my regular mammogram so my doc gave me the required form etc. I can choose the location but in Calgary all this sort of stuff (mammograms, bone density, ultra-sound, x-ray etc) is done by Radiology Consultants Associated. They now have a centralized booking operation Anyway...I call the number to make an appointment and as soon as I identify myself the operator then asks if my birth date is September 14th. So she has already looked me up in the system and I am there. Then this very nice woman asks me if I have a breast lump or pain (presumably if I do, then they would give me an earlier appointment). I don't. Then she asks me if I have a history of breast cancer.

Anyway...to make a long story short, by the time I had secured an appointment I had told her all about previous surgeries, reconstruction etc. It's a very strange feeling to be talking about this to someone you can't see, don't know, all the time knowing that it is being entered into a computer. It's very different from telling the person who is actually giving you the mammogram. Also, since I have had many mammograms all that history is already in the files. Once again, I felt that in the name of efficiency the patient-health professional relationship had been trampled. This may be good for "the system" but it is

not good for people. It's very invasive and made me feel as though I were just one of thousands of "stats" who need to be recorded."

### **Story 7- Barriers to Access Affecting Patient Participation**

"Can you tell me what law guarantees my right to my health records? Test results? I am guaranteed such, right? But where, how, who? Is it federal, the Supreme Court, what? I am in yet another fight over copies of test results. I am being told they 'prefer to give them to your family doctor' and 'We don't do that' AND 'We will charge you \$50 per transaction.'"

### **Other comments. . .**

"People are shocked when unexpected illness incapacitates a friend, spouse, parent or child and they find themselves unable to advocate on their behalf, help negotiate the system or even make necessary decisions on their behalf because medical information required to make informed decisions is denied them. As they find out more about the rules, their bewilderment and anger often grows. 'How come I can't just automatically get this information? How do I make decisions? Why should I need to go through this formality? How can there be unlimited access to this information by complete strangers who aren't even involved in my care - and no access for me - or my family? I had no idea that my son or trusted friend would not be able to access my information or deal with health professionals unless I make him an agent *before* I get ill.' Many people can't afford the cost of guardianship which they are advised they need to get to access records - or the cost of records. Worse still, the information is so delayed, it has lost its value for making decisions by the time access is available."

"Somehow we have managed to take away the family and community supports that people so desperately need at the time they are ill -by refusing to provide information. Yet this deeply personal information is readily shared with complete strangers for reasons that are not always in someone's interest."

" It smacks of paternalism."

## The Human Factor”

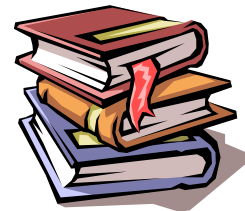
**Won't more sharing of information without having to get permission or notify people improve patient safety and reduce administration costs to the benefit of all?**

**No.** Simply introducing more technology and putting more information in the hands of more people **will not** automatically improve the safety, efficiency and effectiveness of the healthcare system. In fact, current and proposed legislation and practices around integrated health information systems are threatening patient safety, reducing autonomy and creating new public health threats by making individuals reluctant to disclose symptoms or seek treatment. These are also driving up costs and creating no end of stress for health professionals as well as patients and families. Instead, smart applications of technology (including hardware design, organizational policies, and laws) that respect and respond to the **Human Factor** and the social environment hold great potential. Such policies would include genuine provisions for confidentiality and privacy, ready access to one's own health information, no unreasonable barriers to obtain information about providers and more enlightened redress and remedies for inadvertent harm. For insights into some of these issues, we recommend:

### **The Human Factor by Kim Vincente**

**Revolutionizing the Way People Live with Technology**

Edited review from: <http://www.randomhouse.ca/>



"What links the frustrations of daily life, like VCR clocks and voicemail systems, to airplane crashes and a staggering "hidden epidemic" of medical error? Technologies as diverse as stove tops, hospital work schedules and airline cockpit controls lead to 'human error' because they neglect what people are like physically, psychologically, and in more complex ways. The results range from inconvenience to tragic loss of life. There is a divide in the world of technological design -- just as there is in the world more generally -- between humanistic and mechanistic world-views. The two groups aren't talking to each other. As the author puts it, "our traditional ways of thinking have ignored -- and virtually made invisible -- the relationship between people and technology." He offers a host of examples. For instance, the medical community traditionally holds individual doctors and nurses responsible for mistakes. When things go wrong we tend to blame people -- when in fact they may have made heroic efforts to use poorly designed technology. Errors in hospitals are more often the result of systemic flaws: none is wholly at fault, but together they interact to cause accidents. The final level of human nature which *The Human Factor* addresses is the political.

Vincente shows us that when political elements -- laws, funding, regulations -- ignore what we know about human nature, dangers arise."

## Openness Lacking - Provincial Government

**PRESS RELEASE, April 25th, 2001, Alberta Government, "Government Proclaims Health Information Act"** "The Health Information Act protects of the personal health information of all Albertans. Patients will be given access to their information upon request but will have to sign a consent before it can be released. Health *data* will only be used to improve patient care and the management of the health system."

**FACT:** This legislation allows widespread sharing of in-depth identifiable *registration* and health information of Alberta citizens (without their specific authorization or notification) among a 'controlled arena' of people and organizations for multiple purposes. These purposes include administration, management, debt collection, and research as well as diagnosis and treatment. Yet the same legislation which provides such generous access to patient information restricts patient and public access to information about the activities of healthcare providers. It has introduced significant charges and barriers to access of one's own medical records and access by one's family support network at time of illness. It also allows sharing of personal information by providers with legal counsel and liability insurers if they fear that a patient or family is upset.

**PRESS RELEASE, May 23rd, 2003, Alberta Government "Legislative Amendments to the Health Information Act"** will protect the confidentiality of patient information while giving health professionals and families the access they need" Alberta Government Press Release (May 23rd, 2003)

**FACT.** Legislative changes removed a requirement for informed consent or notification by custodians (or affiliates) to post one's medical record information on a central electronic databases and pull such information from databases based on an honor system. It is now left up to a patient to proactively advise a health professional if they want to keep certain information confidential, but there is no obligation to honor such requests. (i.e. negative option)

**FACT:** Current 2004 HIA Review proposals enable even more sharing among an ever widening circle of authorized persons and organizations for an increasing number of purposes with less notification and fewer requirements for disclosure or consent.

## Registration Information (defined in HIA)

**So just what is the Alberta Health and Wellness "registration information" everyone wants to be able to access without notification or authorization for an expanding number of purposes?**

### Registration information defined in HIA REGULATIONS

The following information, where applicable, relating to an individual is registration information for the purposes of section 1(1)(u) of the Act: (a) demographic information, including the following:

- name, in any form; signature;
- photograph or electronic image of the individual's face for identification purposes;
- personal health number or any other unique identification number that is used to identify the individual as eligible for, or a recipient of, a health service;
- gender;
- date of birth; birth information, including (A) the birth facility, and (B) birth order, in the case of a multiple birth;
- marital status;
- date of death;
- treaty status, including band number;
- whether the individual is a registrant or a dependant of a registrant under the Health Insurance Premiums Act;
- location, residency and telecommunications information, including the following: home, business and mailing addresses, electronic address and telecommunications numbers;
- health regions, as established under the Regional Health Authorities Act, in which the individual resides and previously resided;
- citizenship or immigration status, including the date on which the individual's current immigration status expires if the individual is not a Canadian citizen or landed immigrant;
- date of entry into Canada and into Alberta;
- province or country of birth or of last residence;
- date on which the individual became or expects to become a permanent resident of Canada;
- in the event the individual is registered as a registrant or dependant under the Health Insurance Premiums Act and the individual intends to be temporarily or permanently absent from Alberta, (A) date of departure; (B) destination and intended date of arrival at the destination; (C) forwarding address; (D) intended date of return, where the individual intends to be temporarily absent; (E) purpose of absence;
- health service eligibility information, including the following: whether the individual is registered as a registrant or dependant under the Health Insurance Premiums Act; (ii) **whether the individual is eligible to receive health**

**services that are directly or indirectly paid for by the Government of Alberta, in full or in part;** (iii) whether the individual has elected to opt out of the Alberta Health Care Insurance Plan and the Hospitalization Benefits Plan; (iv) whether the individual is exempt from the requirement to register under the Health Insurance Premiums Act; (v) whether the individual is exempt from the requirement to pay premiums under the Health Insurance Premiums Act; (vi) **whether the individual is eligible to receive a reduction or waiver of premiums or charges payable in respect of health services and the level or amount, or both, of that reduction or waiver;** (vii) information about any program of a custodian that is related to the information described in subclauses (i) to (vi), including the effective and termination dates of the program and, if applicable, the program name;

- billing information, including the following: information about amounts owed by the individual to the custodian; method of payment; the individual's account number; if another person is liable for or will be billed for the amount owed by the individual, that person's name and account number.

NOTE: (m) "health service" means a service that is provided to an individual (i) for any of the following purposes and is directly or indirectly and fully or partially paid for by the Department: (A) protecting, promoting or maintaining physical and mental health; (B) preventing illness; (C) diagnosing and treating illness; (D) rehabilitation; (E) caring for the health needs of the ill, disabled, injured or dying,

## **A Cautionary Note from the Past**

“Without someone to speak for individual rights, the mantra of "public interest" or perhaps the mantra of ‘greater efficiency’ will inevitably win the day. Allowing health bureaucrats and researchers to represent the patients' interests risks putting Colonel Sanders in charge of the chicken coop.”

Bruce Phillips, Canada's first federal Privacy  
Commissioner

## Value Drug Mart's Proposal: Education or Marketing?

**Should Value Drug Mart and other retail pharmacies be allowed to use personal health information without someone's knowledge or consent for monitoring therapy adherence, prescription reminders and "wellness initiatives" such as diabetes and cholesterol testing and education events?**

**NO!** The Consumers' Association of Canada, Canadian PharmaWatch, the Working Group on Women and Health Protection, Health Action International, Healthy Skepticism and Drug Safety Canada all oppose this. It would drive the unnecessary and dangerous use of drugs, reduce patient autonomy, be impossible to monitor, and lead to unnecessary fear-mongering and more unnecessary physician visits and drug use. **Let them ask permission. This is a thinly disguised marketing proposal.**

As Terence Young, President of **Drug Safety Canada** explains, "Major pharma have been chomping at the bit to get their hands on patients' info to push "compliance" for years. "Wellness initiatives", "monitoring" and "therapy adherence" are all just cover-ups for direct mail and telemarketing. This is about sales - pure and simple.

A huge number of patients stop taking their pills for various reasons. Certainly it is sometimes because they make them feel worse - the source of which is either conscious or subconscious. The drug industry would never admit this and pretends that issue doesn't exist.



Direct mail companies would love to send out personalized letters to the miscreants that dare to do this. Here is the future they would love. (Envelopes would be designed to look as official as possible - perhaps like registered mail, with "Urgent: Time sensitive material" in red letters and with a return address from a newly formed subsidiary called something like "Health Guard Canada". The text would be in fairly large print so seniors could read it easily and at a grade six level so everyone could understand it - unlike their warnings which are in tiny print, cryptic and impossible to understand. High-speed variable printing allows them to use names to "personalize" a mass mailing at a low cost. 1- 800 lines, unlike lines where patients can ask genuinely qualified people about adverse reactions, would be answered 24 hours a day.)

**Pesky customer consent and knowledge is in the way.**

Why would anyone want our health information? Well, aside from drug companies, insurance companies and employers would love to know anyone who is likely to go on sickness/disability benefits or die an early death, things that can be expensive and troublesome to people trying to run a business."