



**Alberta Cancer
Board**

Privacy Issues in Cancer Initiatives

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Outline

- Alberta Cancer Board - Introduction
- Examples of Cancer Related Privacy Issues
- Consent
- Alberta Cervical Cancer Screening Program:
 - Overview
 - Complaints to Alberta Privacy Commissioner
- German Proposals
- References

Alberta Cancer Board

- Coordinates, in cooperation with Alberta's 9 health regions, the planning and delivery of provincial cancer initiatives.
- Operates cancer treatment facilities:
 - Cross Cancer Institute in Edmonton,
 - Tom Baker Cancer Centre in Calgary,
 - 4 associate cancer centres, and
 - 12 community cancer centres in rural Alberta

Alberta Cancer Board – Mission

Reduce the burden of cancer through:

- Prevention
- Screening
- Diagnosis
- Treatment
- Palliation
- Education
- Research

Cancer-related privacy issues include:

- Obtaining informed consent in clinical trials
- How to de-identify information

Examples of Privacy Issues (Continued)

- When Privacy Impact Assessments (PIAs) are needed under Alberta's *Health Information Act (HIA)*
- Distinguishing between research, surveillance and quality assurance for ethics review purposes

Consent

“[E]very patient has the right ... to determine what medical procedures will be accepted and the extent to which they will be accepted. ... This includes the right to be free from medical treatment to which the individual does not consent.”

Ciarlariello v. Schacter, [1993] 2 S.C.R. 119 at paragraph 39

Consent (Continued)

- At common law:
 - Oral or written
 - Express or implied

Elements of Consent

- Must be voluntary
- Patients must have capacity to consent
- Must be referable to both treatment and provider
- Must be informed

From: Erin Nelson, “The Fundamentals Of Consent” in Jocelyn Downie, Timothy Caulfield & Colleen Flood, *Canadian Health Law and Policy*, 2d ed. (Toronto: Butterworths, 2002) 111.

Expansive Notion of Consent

- Cancer Screening Program context:
 - How to respect the “expressed wishes” of the person (*Alberta Health Information Act* language)
 - » “Person” not “patient” – generally these are healthy people
 - “Expressed wishes” regarding health information and undergoing screening tests
 - » Not only about consenting to medical procedures

Alberta Cervical Cancer Screening Program Overview

- Cancer Programs Act mandates prevention, detection and diagnosis of cancer
- Cervical cancer is preventable, thus the need for an aggressive screening program

Alberta Cervical Cancer Screening Program Overview (Continued)

- Program goal – to reduce the incidence and mortality from cervical cancer

Program Background

- Program intensively researched before starting:
 - New Zealand, Australian and Canadian approaches to cervical cancer screening investigated
 - Communications firm contracted re confidentiality concerns of young women
 - Focus groups and surveys of Alberta women conducted

Security and Privacy Measures

- Privacy Impact Assessment undertaken by Alberta Cancer Board and Alberta Health and Wellness (Information Management Service Provider)
- Accepted by Alberta Privacy Commissioner

Information Flow Parties

- Alberta Health and Wellness (person directory information)
- Alberta Cancer Board
- Woman
- Physician completing Pap test
- Lab analyzing test results

Initial Approach to Non-Participation in Program

- From Program inception, women had the option of not receiving correspondence from the Alberta Cancer Board:

“Correspondence Opt-Out”

Complaints to Privacy Commissioner

- Seven complaints (out of 300,000 women tested) argued:
 - Woman should have choice about participating in screening
 - Pap test results being disclosed to Alberta Cancer Board without consent – results should be only between woman and physician

Complaints to Privacy Commissioner (Continued)

- Was not possible to remove name from the Program (except to decline to receive letters)
- Alberta Health and Wellness should not have disclosed personally identifying information (name, address, etc) to Alberta Cancer Board without consent

Findings

- Alberta Cancer Board has authority to collect, use and disclose health information to operate the Program
- Alberta Cancer Board properly secured the information
- The Program allows women to opt out of receiving correspondence such as Pap test notice reminder and follow-up letters

Findings (Continued)

BUT

- Women have no control over the disclosure of their information to the Program
- Insufficient processes re respecting a woman's "expressed wish" about disclosing her health information to the Program

Findings (Continued)

- Alberta Cancer Board took a *policy* approach versus a *case-by-case* approach in deciding there would be no full exclusion from the Program but only a no correspondence option – this was found not to be acceptable

Changes Made by Alberta Cancer Board During Investigation

- In discussions between the Alberta Cancer Board and the Privacy Commissioner, the Board decided to implement a full exclusion feature of the Program
- The Privacy Commissioner intended to recommend this to the Board, but it was no longer necessary, so no recommendations were made

Volume of Pap Tests Conducted

- 636,000 screening Pap tests conducted on 332,000 women since Program began in October 2003

Program Impacts of Full Exclusion Option Following Complaints – Minor

- 19 women have been excluded from the Program at their request since the full exclusion process was implemented in 2005

Correspondence Only Opt-Out

- 5,400 women have opted out of receiving correspondence since the Program began in 2003

Reflections

- To Alberta Cancer Board's knowledge, this was the first time a Privacy Impact Assessment had been accepted and then the organization which submitted it was found not to be in compliance with the *Health Information Act*

Reflections (Continued)

- The Privacy Commissioner and Alberta Cancer Board agreed that both parties acted in good faith throughout the Privacy Impact Assessment submission and acceptance process.
- Only on subsequent detailed scrutiny upon receipt of the complaints was the Board found in non-compliance with the *Act*.

Proposed Reforms in Germany

- People diagnosed with preventable cancers who failed to undergo regular testing would pay more toward their treatment than those who underwent screening.

Proposed German Reforms (Continued)

- Payment for treatment would be based on 2% of earnings

Compared to:

- People who underwent regular testing would pay 1% of earnings.

Emphasis of Alberta Screening Program

- Personal autonomy
- Privacy of the individual

Emphasis of German Proposals

- Individuals taking responsibility for their health as directed by the state

In both the Alberta and German Examples

- Individuals are encouraged to care for themselves to prevent cancer
- There are potential societal benefits through a healthier public
- With reduction of cancer, health care costs are reduced

How far should
consent/expressed
wishes go in cancer
prevention?

Further Reading

On consent:

Erin Nelson, “The Fundamentals of Consent” in Jocelyn Downie, Timothy Caulfield & Colleen Flood, *Canadian Health Law and Policy*, 2d ed. (Toronto: Butterworths, 2002) 111.

Further Reading (Continued)

- On the Alberta Cervical Cancer Screening Program:

[http://www.cancerboard.ab.ca/
accsp/index.html](http://www.cancerboard.ab.ca/accsp/index.html)

- For the Alberta Privacy Commissioner's Investigation Report:

[http://www.oipc.ab.ca/ims/client/
upload/H2005_IR_002.pdf](http://www.oipc.ab.ca/ims/client/upload/H2005_IR_002.pdf)

Further Reading (Continued)

- Regarding the Proposed Reforms in Germany:

Annette Tuffs, “Germany will Penalise Cancer Patients who do not undergo Regular Screening” (2006) 333 British Medical Journal 877