



Province of
British Columbia

Ministry of Health and
Ministry Responsible for Seniors

Information and Privacy Program
5th Floor, 1515 Blanshard Street
Victoria, British Columbia
V8W 3C8
Telephone: (604) 953-3125
Fax: (604) 387-6994

ATTACHMENT 6

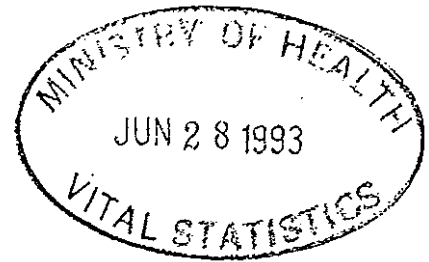
Letter from
Vel to Andrew

To: Andrew McBride
Director, Support Services
Vital Statistics Division

From: Vel Clark
Director of Information and Privacy

Date: June 24, 1993

Subject: Screening Mammography Program Proposal



=====

Thank you for the opportunity to comment on the screening mammography proposal. I am pleased to provide the following policy advice.

Question Presented

Will a release of personal information from the Client Registry to the Screening Mammography Program violate the provisions of the *Freedom of Information and Protection of Privacy Act*?

Short Answer

No.

Discussion

It is quite likely that section 22(3)(i) would prohibit the release of information for a mailing list of this kind. Section 22(2)(b) would not be sufficient to override 22(3)(i). Remember that the provisions in section 22(2) must be considered in total and not just individually.

We then move to section 35 which deals with disclosure of personal information for research purposes. It is arguable that this initiative cannot be accomplished without personal identifiers attached and the screening mammography program proposal could therefore proceed.

We do not have to rely solely on section 35. Section 32 and 34 give us clear direction that a disclosure of this kind is permissible.

Section 32 states:

A public body may use personal information only

(a) for the purpose for which that information was obtained or compiled, or for a use consistent with that purpose.

Section 34 suggests that a purpose is consistent if the use:

- (a) has a reasonable and direct connection to that purpose, and
- (b) is necessary for performing the statutory duties of, or for operating a legally authorized program of the public body that uses the information

The screening mammography proposal meets these requirements. Research of this kind is authorized by section 4 of the *Health Act* - it achieves an objective which is reducing morbidity through breast cancer among British Columbian women.

It is my understanding that an individual contacted by the program may receive follow-up letters. A practical suggestion would be to include a box on the initial contact form which would allow the individual to tick that she is not interested in participating in the program. Her name could then be removed from the mailing list and no further contact initiated.

I trust this has been of assistance to you.

A handwritten signature in cursive script, appearing to read "McLachlan".



MEMORANDUM

Andrew K. McBride
Senior Manager
Support Services and Health Registry
British Columbia Vital Statistics Agency

August 6, 1997

✓ Anita Malovec
Manager, Health Registry
British Columbia Vital Statistics Agency

Phyllis Chuly
Director, Information and Privacy
Ministry of Health and Ministry Responsible for Seniors

Re: Meeting - August 25, 1997, with Sharon Plater
Office of the Information and Privacy Commissioner

The attached issue paper has been prepared in an effort to support your discussions with Sharon Plater. The recommendations should address most of the Commissioners concerns.

I have enclosed all the previous profs notes, correspondence, and data approvals to ensure everyone is current on discussions to date.

No data has been released to date and will be held pending satisfactory resolution with the Commissioners office.

R. J. Danderfer
Director
British Columbia Vital Statistics Agency

Enclosure

pc: Janet McGregor
Assistant Deputy Minister
Corporate Programs

John Mullin
Chief Information Officer
Information Management Group

BC Cancer Agency Use of Health Registry Data

Background

Vital Statistics agreed to provide personal information from the Health Registry to the BC Cancer Agency for the purpose of contacting women aged 50-74 who had not had a recent mammogram in order to encourage them to do so.

The Freedom of Information and Protection of Privacy Commissioner has expressed several concerns regarding the clause of the Act that would permit this, the use of Canada Post to print the letters, and the appropriateness of the use of the data to produce specific, addressed letters.

No data has been released pending a meeting with staff from the Commissioners office.

Issues

(a) Authority under the FOIPOP Act

The Commissioner in his note to the Deputy Minister of Health correctly notes that this is not a research activity under section 35 of the FOIPOP Act. In addition, he notes that other sections of the Act may authorize such administrative use of the data.

Vital Statistics did not release the data under section 35 of the Act, although this impression may have arisen out of the use of the incorrect form which makes reference to research. Provision for the release of the data is provided for under sections 33 and 34 of the Act and for its use under section 32.

(b) Applicability of sections 33, 34, and 32 of the Act

Section 33(c) of the Act permits the disclosure of personal information "for the purpose for which it was obtained or compiled or for a use consistent with that purpose (see section 34)"

Section 34(1) defines use of personal information "with the purposes for which the information was obtained or compiled if the use:

- a) has a reasonable and direct connection to that purpose, and
- b) is necessary for performing the statutory duties of, or for operating a legally authorized program of, the public body that uses or discloses the information."

Section 32(a) permits the use of personal information "for the purpose for which that information was obtained or compiled, or for a use consistent with that purpose (see section 34)"

The release by the Health Registry and use by the Screening Mammography Program (SMP) of the name, age (date of birth), gender, and address of clients contained in the Health Registry has a reasonable and direct connection to the purpose of increasing the participation in the SMP and for operating a legally authorized program of public body that uses or discloses the information in that:

- the client information exists in the Health Registry as a consequence of the individual enrolling in the Medical Services Plan (MSP) to ensure eligibility for coverage of preventive health services and/or treatment of health problems or receiving such a service other than under MSP; and
- the Ministry of Health supports the Screening Mammography Program in order to identify and treat more women with breast cancer, resulting in more lives saved and/or reducing the impact through earlier treatment. The Provincial Health Officer's 1996 Annual Report shows that less than 40% of women aged 50-69 were screened for breast cancer either through the SMP or in hospitals or private x-ray facilities, billed through MSP. The Provincial Health Officer has set a proposed target of 70% screening for all women in this age group.

The issue of whether specific, addressed letters are required to achieve the objectives of the SMP has been raised. The SMP request for access to the data states that:

- "Experience from international and other provincial breast cancer screening programs have demonstrated that invitation letters are an effective tool for recruitment."
- experience from an earlier pilot project employing invitational letters in selected areas of the province "increased the recruitment rate by about 6% over the existing promotional activities for new service areas....". This pilot employed data from the Health Registry under the provisions of the clauses noted above, as well as section 35 as a research project.

Other alternatives would include:

- using the data, but addressing the letter to "occupant". This would only partially address the issue of the use of personal information and would also likely increase the chance that the letter would not be read, but be discarded as "junk" mail. It may also prove to be less effective than the personalized approach; or
- unaddressed mail-out to all households. This would be far more costly and would also have the "junk" mail risks, etc.

It appears that the use of direct personal communication is an effective means of achieving one of the ministry's goals, with no known cost-effective alternatives.

c) The Use of a Follow-up Letter

From the information on file, it appears that a follow-up letter is to be used by the MSP. There is nothing on file to indicate the effectiveness of this approach.

d) Use of Canada Post to Print and Mail Letters

The Commissioner has expressed concern that "the letter writing may be done by Canada Post under contract", which we were not aware of. Canada Post does printing (letter prepared by client), mail list merging, and stuffing on a confidential basis. If asked they will provide a letter to that effect. Alternatives exists, as recommended below.

Recommendations

The following recommendations are made:

- The ministry believes it has the necessary authority under sections 33 and 34 of the Act to release the data to the SMP for use in the above described manner.
- The ministry believes that specific, addressed letters are necessary to achieve the objectives of the SMP and the Provincial Health Officer's health objective in the area of breast cancer.
- The matter of follow-up letters should be reviewed, both in terms of their costs, effectiveness, and considerations of intrusion into the lives of recipients (once having been invited to participate is it necessary to pursue the matter further?).

- Letter printing and mail outs should be handled directly by Vital Statistics.
- The agreement should be resigned on the correct form, making reference to administrative use of the data

From: RDANDERF--BCSC02
To: CJMCLEAN--BCSC02 Claudia McLean

Date and time 09/11/97 10:25:21

From: Ron Danderfer
SUBJECT: SMPBC

for filing with the briefing note we prepared or memo I sent to Andrew with
a cc to Janet and John. thks

Regards,

Ron Danderfer
Vital Statistics,
Ministry of Health

*** Forwarding note from AKMCBRID--BCSC02 09/09/97 16:13 ***
To: RDANDERF--BCSC02 Ron Danderfer

From: Andrew K. McBride
Subject: SMPBC
fyi

Regards,

Andrew K. McBride
Snr Manager, Support Services/Client Registry
B.C. Vital Statistics Agency

*** Forwarding note from PRCHULY --BCSC02 09/09/97 12:24 ***
To: VFOERSTE--BCSC02 Vicki Foerster JMTUCK --BCSC02 John Tuck
EASOONG --BCSC02 Evon Soong AKMCBRID--BCSC02 Andrew McBride
ALMALOVE--BCSC02 Anita Malovec IOLIVO1 --INTERNET iolivott@bccancer.
CHENDERS--INTERNET chenders@bccancer.

From: Phyllis Chuly
Subject: SMPBC

Great news! I just received a call from the Commissioner's Office. He has agreed to the mailout with some minor revisions. He does not feel Section 33(c) is applicable and would like that reference removed from the MoU between the Ministry and the BCCA. He is also not happy with the MoU between Canada Post and the BCCA, but I said we were working on getting that resolved.

Once the Canada Post MoU is completed, we will get the entire package (letter from David Kelly, SMPBC invitational letter and the two MoU's) over to the Commissioner.

Phyllis Chuly, Director
Information and Privacy Branch
Phone: 604-952-0867 Fax: 604-952-0874
Internet: prchuly@bcsc02.gov.bc.ca

6. Notification Letters

The Agency agrees that the Notification Letters sent by the Program must be approved by the Ministry prior to being mailed and will make reference to the fact that the Personal Information has been supplied by the Ministry.

In addition, the Agency agrees that if the services of a contractor are employed, such as Canada Post, to print and mail the letters, the Agency will obtain in writing, with a copy to the Ministry, appropriate assurances that the protection of the privacy of the Personal Information will be in compliance with the Act.

7. Further Disclosure

The Agency shall not use or disclose the Personal Information collected for any purpose that is not specified in this Agreement.

8. Security

The parties agree that each shall take appropriate security arrangements necessary to ensure that the Personal Information provided under this Agreement shall be protected in accordance with section 30 of the Act.

9. Custody and/or Control of Information

The Ministry has custody and control of the Personal Information collected for the purposes of disclosure under the Act.

10. Cancellation or Changes to this Memorandum

Either party may cancel this Agreement by providing ten (10) days written notice to the other. Amendments to this Agreement may only be made in writing signed by both parties.



File

September 22, 1997

*XC - Ron Danderfer
Bony Gray*

David Flaherty
Commissioner
Information and Privacy
1675 Douglas St
Victoria BC V8V 1X4



FYI
File
copy to
analyzer
oct 7/
TA

Dear David Flaherty:

I am writing with respect to a decision I have made regarding release of client registry information to be used for preventive health care purposes. The Screening Mammography Program of British Columbia (SMPBC) requested on August 5, 1997, that the Ministry of Health provide them with this information. The SMPBC is committed to the early detection of breast cancer in the population of women aged 50 to 74 in the province. In order to achieve maximal health benefits, the SMPBC envisions inviting all appropriate women to participate in its program for breast screening and requires client registry data to accomplish this end. The SMPBC operates under the direction of the British Columbia Cancer Agency which is a public body accountable directly to the Minister of Health.

As you know, breast cancer is the most common significant malignancy occurring in women and 590 deaths in the province in 1996 were attributed to this disease. The number of new cases of breast cancer diagnosed in 1996 was 2,455. Breast cancer follows lung cancer as a cause of cancer death in women. The reason for breast cancer's appearance as the most common cancer, but the second most common cancer killer, is the fact that a number of breast cancer deaths can be averted through early detection and treatment whereas this is not true for lung cancer at this time. For example, Canadian data from 1994 reports 16,300 new cases of breast cancer diagnosed in that year and 5,400 deaths.

There are significant advantages to early detection and treatment of breast cancer in women. Mammography is the main tool utilized for early detection. International evidence suggests mammographic screening of the group of women aged 50 to 69 and appropriate treatment, can lead to a reduction of mortality in this group of up to 30 percent. Local experience through SMPBC data collection supports this finding and also extends the age group able to benefit to age 74.

Currently the SMPBC performs approximately 170,000 mammograms per year, but despite numerous recruitment strategies is only reaching 34 percent of the women in the target age group of 50 to 69. Recruitment of new SMPBC participants has remained stable at 41,000 over the past five years. The SMPBC has set a goal to screen 70 percent of eligible women in the target age group. Ideally close to 100 percent will eventually be screened to maximize the benefit of early detection and treatment of breast cancer.

The SMPBC has recently revised eligibility protocols to actively target women in the 50 to 74 age group, and to drop yearly screening to screening every two years. These changes were made as a result of examination of scientific evidence supporting the benefits to this age group and the effectiveness of this screening interval. The manoeuvre will free up SMPBC resources to enable the program to include a new group of women who will benefit from screening but who are currently not participating in the program.

Recruitment strategies adopted by the SMPBC to date have included: targeted educational mailings to family physicians, presentations to public and medical groups, posters and brochures for physicians' offices and public sites and television advertising,

Despite recruitment strategies to date, the SMPBC has been unable to attract large enough numbers of British Columbia women who would benefit from screening mammography. In order to target this group, the SMPBC asked the Ministry of Health to release information from the client registry to allow invitational mailings to women in the target age group. The information obtained from client registry includes patient name, date of birth, address and personal health number (PHN). It does not contain any health related information. A Memorandum of Understanding outlining the protection of personal information between the SMPBC and the Ministry of Health is attached to this letter for your information.

This database will be collated with the SMPBC database to allow elimination of the group known to attend SMPBC already, or known to have breast cancer and thus be ineligible for screening. The outcome of this data collection exercise will be to send invitational letters to 229,000 British Columbia women eligible for mammographic screening who currently do not avail themselves of this health care service. The projected impact of this one mailing alone would be to avoid breast cancer death in 20 - 30 women, if 8 - 15 percent of women respond to the letter as anticipated. Evidence suggests the response rate of women would rise to 22 - 30 percent if a second reminder letter is sent at a later date.

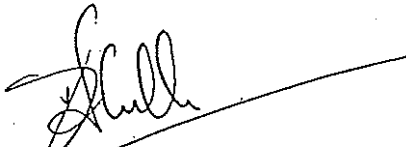
The proposal from SMPBC involves a one time mail-out to the target group of women as outlined above, followed by a reminder letter shortly thereafter. Once the mailing is accomplished the database used by SMPBC will be destroyed. In order to assure ongoing contact with women eligible for screening mammography, SMPBC would also envision receipt of a list from the client registry twice a year of all British Columbia women who have turned age 50 in the past six months and these women would be invited to attend an SMPBC centre for screening.

SMPBC has proposed using Canada Post to distribute the letters. Canada Post is experienced with, and committed to, privacy and confidentiality issues and would be able to undertake the distribution of the SMPBC letter at a cost of \$32,000 less than the cost of SMPBC distributing the letter themselves. The Memorandum of Understanding between the SMPBC and Canada Post will be forwarded to your office once the draft is completed. Concerns regarding personal information are addressed in the Memorandum.

This initiative will result in the prevention of premature deaths in women due to breast cancer. Section 33(p) of the *Freedom of Protection of Privacy Act (the Act)* allows the disclosure of personal information for "compelling circumstances ... that affect anyone's health or safety." I believe Section 33(p) of *the Act* is applicable to this situation. The invitational letters mailed to women from SMPBC will contain an explanation of the source of the personal information used for this distribution (see attached).

I appreciate the reservations you have expressed with respect to release of client registry data. However, consideration of the advantages of this SMPBC initiative leads me to believe the population of the province will benefit from this increased targeting of women for mammographic screening thus leading to a significant decrease in breast cancer morbidity and mortality.

Yours sincerely,



David S. Kelly
Deputy Minister

... 4

**MEMORANDUM OF UNDERSTANDING REGARDING
ACCESS TO HEALTH REGISTRY DATA AND CONFIDENTIALITY**

BETWEEN;

THE MINISTRY OF HEALTH AND MINISTRY RESPONSIBLE FOR
SENIORS (the "Ministry")

AND;

THE BRITISH COLUMBIA CANCER AGENCY (the "Agency")

*This actually is a Verbal Start
Agreement executed by Andrew
McBride*

1. PURPOSE

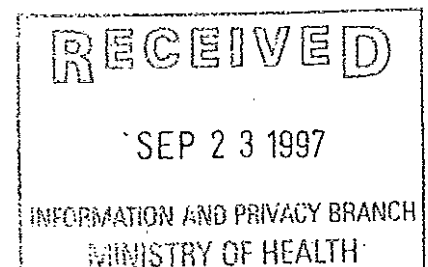
The Screening Mammography Program of British Columbia (the "Program") has been set up by the Agency and the Ministry to provide mammograms in order to facilitate the early detection of breast cancer. Early detection can improve an individual's chance of survival. Having regular screening mammograms is especially important for women aged 50 to 74. Both the Ministry and Agency support the notification of women in this age group to advise them of the importance of having mammograms every two years. The Ministry has agreed to supply the Program with information that will enable notification letters to be sent to British Columbia women in that age group to remind them of the importance of screening.

2. PERSONAL INFORMATION TO BE PROVIDED

The Ministry agrees to provide to the Agency with the;

- a) name,
- b) date of birth,
- c) residential address, and
- d) Personal Health Number

of all women residents of the Province in the Ministry's Health Registry, aged 50 to 74 (the "Personal Information").



3. USE OF THE PERSONAL INFORMATION

The Agency will use the Personal Information solely for the purposes of generating a mailing list for invitational letters to be sent to women to avail themselves of mammography screening offered by the Screening Mammography Program of British Columbia (SMPBC).

Further, the Agency will use the Personal Information provided by the Ministry to match against their own files to generate a mailing list, for the purpose of sending notification letters, that excludes:

- women who are known to have died;
- women who are known to have breast cancer; and
- women who have received a mammogram from the SMPBC in the past.

The Agency further agrees to destroy the Personal Information provided by the Ministry, as well as the generated mailing list, immediately after the mail-out (including the reminder letter to non-responders of the initial invitation).

The Ministry agrees to provide, approximately every six months, to the Agency the Personal Information of all women residents who have turned age 50 since the last Health Registry extract file was created. The Agency agrees to use the Personal Information only for the above purposes and will comply with the same provisions as above for destroying this information.

4. Authority for Disclosure of the Personal Information

The Personal Information is being provided by the Ministry to the Agency under Section 33(p) of the *Freedom of Information and Protection of Privacy Act* (the Act), as compelling circumstances affecting the health of individuals. Notice of this disclosure is being mailed to the individuals the information is about.

5. Authority for Collection of the Personal Information

The Personal Information is being collected by the Agency under section 27(1)(b) of the Act as the information may be disclosed to the Agency under section 33 of the Act.

6. Notification Letters

The Agency agrees that the Notification Letters sent by the Program must be approved by the Ministry prior to being mailed and will make reference to the fact that the Personal Information has been supplied by the Ministry.

In addition, the Agency agrees that if the services of a contractor are employed, such as Canada Post, to print and mail the letters, the Agency will obtain in writing, with a copy to the Ministry, appropriate assurances that the protection of the privacy of the Personal Information will be in compliance with the Act.

7. Further Disclosure

The Agency shall not use or disclose the Personal Information collected for any purpose that is not specified in this Agreement.

8. Security

The parties agree that each shall take appropriate security arrangements necessary to ensure that the Personal Information provided under this Agreement shall be protected in accordance with section 30 of the Act.

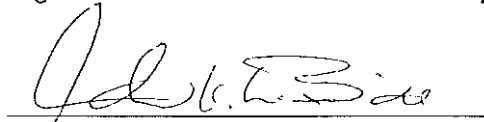
9. Custody and/or Control of Information

The Ministry has custody and control of the Personal Information collected for the purposes of disclosure under the Act.

10. Cancellation or Changes to this Memorandum

Either party may cancel this Agreement by providing ten (10) days written notice to the other. Amendments to this Agreement may only be made in writing signed by both parties.

Agreed on behalf of the Ministry,



Date: Sept 12, 1997.

Andrew K. McBride

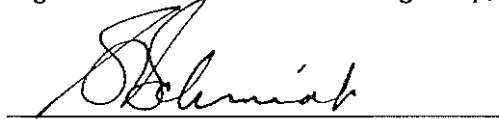
Senior Manager

Support Services and Health Registry

British Columbia Vital Statistics Agency

Ministry of Health and Ministry Responsible for Seniors

Agreed on behalf of the Agency,



Date: Sept. 18 / 97

Brian Schmidt

Provincial Operations/Administrative Leader

Freedom of Information and Protection of Privacy Act Head

British Columbia Cancer Agency