

Opt Out: What does it mean?

The Prevention Program for Cervical Cancer (PPCC) is a program of the Saskatchewan Cancer Agency, funded by the Ministry of Health. The goal of the PPCC is to decrease the incidence of, and mortality from, invasive cervical cancer. The PPCC is responsible for:

- Overdue Notification: Women are notified by letter when they are overdue for a Pap test.
- Result Notification: Women are informed by letter of their Pap test results.
- Follow-up of Abnormal Results: All abnormal and unsatisfactory Pap test results are tracked to help ensure proper follow-up care is received. When information is not received indicating that follow-up has occurred, a letter is sent to the healthcare provider encouraging follow-up with his/her patient.

Prior to the PPCC, health region cytology laboratories were responsible for tracking follow-up of abnormal results.

Your Health Information

The PPCC collects and stores demographic, cytology, histology and colposcopy information required to operate the program. The Saskatchewan Cancer Agency acts as an information manager for the provincial cytology laboratories operated by the Regina Qu'Appelle and Saskatoon Health Regions. This includes storing, updating and providing the laboratories with access to the information required for proper analysis and diagnosis of Pap tests. This service provision operates separately from the PPCC.

Personal health information collected and stored by the Agency is secure and confidential. Appropriate policies, procedures and technical safeguards are in place to protect information from unauthorized access.

How did you get my information?

All Saskatchewan women between the ages of 18 and 69 with healthcare coverage are automatically enrolled in the PPCC. Saskatchewan legislation allows the Saskatchewan Cancer Agency to receive health information in connection with the PPCC. The PPCC obtains information from the Ministry of Health and health region laboratories.

How does this benefit me?

The health information stored on the provincial database:

- allows the PPCC to provide overdue and result letters and to ensure that further testing occurs when necessary
- allows laboratories to have medical information required for proper analysis of Pap tests
- offers healthcare providers a resource for patient information and tracking for improved patient care

Who has access to my health information?

Personal health information can only be accessed by:

- health region laboratory staff analyzing Pap tests
- PPCC staff as required to operate the program
- Saskatchewan Cancer Agency staff involved in providing information management services to the health regions.

All individuals having access to health information are bound by *The Health Information Protection Act* (HIPA) and have signed confidentiality agreements. HIPA addresses the collection, storage, use, access and disclosure of personal health information.



Can I choose not to participate in the PPCC?

Yes. Women can choose not to be part of the PPCC. There are two levels of opt out available:

Level 1—Decline Mail Option:

- Women may choose to decline receiving any further letters from the PPCC.
- The PPCC will continue to track follow-up of abnormal and unsatisfactory results through health care providers.

Level 2—Data Masking Option:

- Women may choose to have their data masked so that it is not accessible for purposes of the PPCC.

IMPORTANT: Follow-up provided by the PPCC (previously provided by the health region cytology laboratories) for abnormal and unsatisfactory Pap test results will no longer occur. Follow-up will be the sole responsibility of the health care provider. Due to the implications for clinical patient management, consultation with your health care provider is strongly recommended before choosing this option. The PPCC will continue to receive and store information as per the role as information manager for the provincial database. The cytology laboratories require continued access to this information in order to perform proper ongoing Pap test analysis.

How do I opt out of the PPCC?

To activate Level 1 option:

- complete an opt-out form indicating you wish to decline letters from the PPCC.

To activate Level 2 option:

- complete an opt-out form to have your data masked, acknowledging that you are aware of the potential health risks associated with choosing this option. Opt-out forms must be mailed to, or dropped off at the PPCC office.

Can I opt back into the PPCC?

Yes. Women who would like to receive letters, or have their data unmasked for follow-up purposes, should contact the PPCC office for an opt-in form. Opt-in forms must be mailed to, or dropped off at the PPCC office.

Discuss your Options

Please discuss options with your healthcare provider prior to making your decision. Level 2 opt out has implications for quality of care and clinical patient management.

If you have questions about the PPCC, options and implications of opting out, or how to complete an opt-out or opt-in form, please call the PPCC at 1-800-667-0017 or 359-0550 (Regina).