

It is recommended that if you wish to obtain your cervical screening history, that you ask your doctor to request it from the CCR in order for the doctor to explain it to you.

How can I withdraw from the CCR?

If you would prefer not to be included in the Register, please notify the CCR in **writing**, as set out in the *Health (Cervical Cytology Register) Regulations 1991 (WA)*, providing your full name, date of birth, address and Medicare number. This will enable the CCR to select the correct record and remove your identifiable data. The CCR will then send you a letter of acknowledgment and provide you with 'NOT FOR REGISTRY' stickers.

Each time you have a Pap smear or other cervical screening test in the future you will need to tell your doctor that you do not want your results to be forwarded to the CCR. Otherwise they will be sent automatically. Alternatively, you can supply your doctor with these stickers to clearly mark the pathology request form.

How do I make a complaint?

If you think the laboratories or the CCR have not complied with regulations or with the principles outlined in this pamphlet, a complaint can be made with the Office of Health Review on 9323 0600 (or 1800 813 583 toll-free from the country) or by visiting the website at www.healthreview.wa.gov.au

Where can I get more information?

WA Cervical Cancer Prevention Program
2nd Floor Eastpoint Plaza
233 Adelaide Terrace, Perth WA 6000
Phone **13 15 56** (cost of a local call)

If you have difficulty communicating in English phone the Translating and Interpreting Service for assistance on 13 14 50 (for the cost of a local phone call).

National Cervical Screening Program
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Helping Deliver a Healthy WA

The Cervical Cytology Registry (CCR) of WA and Use and Collection of Information

This pamphlet will explain how your personal information you provide at the time of your Pap smear and other cervical screening tests, such as biopsies and HPV DNA tests, is collected, used and stored by the Cervical Cytology Registry (CCR), and how your privacy is protected.

What happens to my screening results?

When you have a Pap smear or other cervical screening test, a sample is collected from your cervix and sent to a pathology laboratory for testing. Your doctor will then discuss your results with you once they are received from the laboratory.

Some of the information relating to your Pap smear or other cervical screening test is also sent to the CCR unless you tell your doctor that you do not want this to occur. This is detailed further on in this brochure.

What is the CCR?

The CCR is a part of the Department of Health's WA Cervical Cancer Prevention Program (WACCPP), reporting to the Commissioner of Health. The CCR maintains and operates the Register - a central computerised confidential database of all WA women's Pap smear, cervical biopsy and HPV DNA test results.

Why are my results held in the Register?

Information is collected by the CCR, as required by the *Health (Cervical Cytology Register) Regulations 1991 (WA)*.

The CCR acts as a 'safety net' to ensure, where possible, women are reminded when their Pap smear is overdue, and that all abnormal results are followed-up. If you forget to attend for your Pap smear follow-up and you become overdue, the CCR will send you a reminder letter.

How is my personal information kept confidential?

The pathology laboratories and the CCR are required to keep your cervical screening test results confidential and may only disclose information to the extent authorised by the *Health (Cervical Cytology Register) Regulations 1991 (WA)*.

How does my personal information get into the Register?

When your Pap smear or other cervical screening test is sent to the laboratory for screening, some personal information about you is also sent by your doctor. The laboratory uses this information for billing purposes (under the Medicare system) and may also forward the following information to the CCR:

- your name
- your date of birth
- your address
- your Medicare number
- the date and results of your Pap smear and other cervical screening tests.

In addition, the laboratory will also supply:

- identifying codes for the laboratory that examines your Pap smear or other cervical screening test
- identifying codes for the doctor who took your Pap smear or other cervical screening test.

The details of what is sent to the CCR and how that information is transferred to and stored by the CCR are governed by the *Health (Cervical Cytology Register) Regulations 1991 (WA)*.

How does the CCR use my information?

- To check when your next Pap smear is due and to send a reminder letter, if you are overdue for your check-up.
- To follow-up with your doctor after an abnormal or unsatisfactory test result.
- To provide your doctor or pathology laboratory with a comprehensive up-to-date record of your results, if required.

The CCR uses the information in the Register for other reasons too. These are set out in the *Health (Cervical Cytology Register) Regulations 1991 (WA)* and include publishing statistics:

- to increase public awareness
- for planning and performance monitoring by the Commissioner of Health
- for national reporting requirements
- for approved research into cervical cancer and its prevention.

Data provided for public awareness and national reporting do not contain any information that would identify you or any other woman in the Register.

How can I access my CCR record?

You can request access to your own record by contacting the WACCPP (please refer to the contact details over). If you believe the information is inaccurate or incomplete, you can request this be corrected.

Your recent cervical screening test results are available from the CCR, however the results are in a coded format (as received from the laboratory who examined your test) and do not include the interpretative text that is supplied by the laboratory to your doctor.