



# **Consumer and Community Engagement**

Proposed amendments to the  
Public Health Act 1997 - PART 7  
Division I – Registers  
**Cervical Cytology Register**

September 2009

## Background

Tasmania has been a part of the National Cervical Screening Program since 1993 when the Tasmanian Cervical Cytology Register (TCCR) was developed. The role of the Register has been to record the histories of Pap smears and other cervical cancer tests. The Register sends reminder letters to women who are overdue for their regular two-yearly Pap smear. It also provides a safety net for women who have had unsatisfactory or abnormal Pap smears and are overdue for follow-up tests.

Legislation regarding the Register is incorporated in the Tasmanian Public Health Act 1997 (Sections 137 – 142). Recent medical and scientific discoveries regarding the development and progression of cervical cancer have resulted in changes to the prevention, early detection and management of the disease. These scientific developments require changes to the Public Health Act so the Tasmanian Register can monitor and manage the screening and prevention of cervical cancer appropriately.

Following are some questions and answers regarding the proposed changes.

## QUESTIONS AND ANSWERS

### SOME QUESTIONS YOU MAY HAVE ABOUT WHY THE PUBLIC HEALTH ACT IS BEING AMENDED FOR THE CERVICAL SCREENING PROGRAM IN TASMANIA

#### Q1: Why are you telling us about this change?

**A:** Because consumer and community engagement is particularly important in times of change and it provides the opportunity to inform you, the public, of the changes and explain why these changes have been requested. It means we will be able to find out what you think about the changes and this will help us to understand your concerns and questions so we can provide you with responses.

#### Q2: What is being proposed for change?

**A:** On the 16<sup>th</sup> July 2009 Cabinet approved the drafting of amendments to Part 7- Registers, Division 1 of the *Public Health Act 1997*, at the request of Cancer Screening and Control Services. The amendments will:

- Ensure that information contained on the Tasmanian Cervical Cytology Register can be shared with corresponding interstate Registers, the National Human Papillomavirus (HPV) Vaccination Program Register and Medicare Australia;
- Ensure that the Register is able to receive and store information provided to it by the bodies above; and
- Amend the Act to ensure that the name of the Register and the purpose for which the Director of Public Health may use the information on the Register adequately reflects its role and function.

#### Q3: Why does the legislation need to be changed?

**A:** The current statutory provisions governing the Tasmanian Cervical Cytology Register no longer align with national policy regarding the management of women who participate in the National Cervical Screening Program. Developments in the scientific understanding of the prevention, diagnosis, medical management and treatment of cervical cancer require changes to some of the functions of the Register. As part of the National Cervical Screening Program, the Tasmanian Register needs to be able to share with, and store information from corresponding Registers Australia-wide. The proposed amendments are to ensure the Register can both fulfil its statutory functions and continue to safeguard women's health.

#### **Q4: What will be the new name of the Register and when will the legislation take effect from?**

**A:** The name of the Register will be changed from the Cervical Cytology Register to the Cervical Screening Register which more accurately represents the role of the Register. The Register records the results of all cervical cancer tests, not just cervical cytology tests. It is planned for the amendments to take effect from 1 January 2010.

#### **Q5: What does the Cervical Screening Register do?**

**A:** The Register records the results of cervical cancer tests. Its role is to ensure a woman and her doctor or nurse is notified:

- if the woman's next cervical cancer test is overdue,
- if a cervical cancer test needs to be repeated, or
- if appropriate medical investigation and intervention is required.

Women are recommended to continue having pap smears (also referred to as 'pap tests') every two years so that abnormal changes to cells in the cervix can be detected so treatment can start before cancer develops. A woman may choose not to have her cervical cancer test results provided to the Register.

#### **Q6: Why does a woman's personal information have to be shared?**

**A:** The sharing of a woman's personal information and screening history is to ensure appropriate follow-up occurs and to improve health outcomes for women.

When a woman has an abnormal cervical cancer test result, it is important she receive appropriate investigation and intervention. For this to occur, the pathology laboratory and the doctor or nurse who have performed the test need to know the woman's screening history. This will determine what management or treatment is required.

Sometimes, a woman moves interstate or even changes her doctor within Tasmania. The Register needs to be able to share the woman's test results or screening history with the woman's new doctor or nurse or with the corresponding Register interstate.

#### **Q7: How will you let women know about this sharing of information?**

**A:** A range of communication materials explaining the changes will be made available to women on the Register. Information explaining the role and function of the Register and the use and collection of the information will be forwarded when a woman's first cervical cancer test is recorded on the Register. Information will also be provided through health practitioners and health centres across the State. Relevant information will also be published on the Cervical Cancer Prevention Program (CCPP) webpage at:

[http://www.dhhs.tas.gov.au/health\\_and\\_wellbeing/womens\\_health/related\\_topics/cervical\\_cancer\\_prevention\\_program](http://www.dhhs.tas.gov.au/health_and_wellbeing/womens_health/related_topics/cervical_cancer_prevention_program)

### **Q8: Does my Doctor know about this change?**

**A:** Medical Practitioners across the state will be provided with information about the changes through their professional organisations and will also be able to access information through the CCPP webpage.

### **Q9: Will you be discussing this change with other people?**

**A:** There will be a broad range of community and clinical consultation including:

- Letters to key advisory clinicians and interstate stakeholders;
- Face to face meetings with members of the community;
- Focus group meetings;
- Information on the CCPP webpage

### **Q10: What is the HPV Vaccination Program Register?**

**A:** The Human Papilloma Virus (HPV) is known to cause the majority of cervical cancers and a vaccine has been developed to prevent some of the common, high-risk HPV types. The HPV Vaccination Program Register (HPV Register) is a database that collects details about HPV vaccinations given in Australia. Further consumer information about the HPV Register can be obtained from <http://www.hpvregister.org.au/consumer-info/>

### **Q11: Do vaccinated women need to continue with Pap smears?**

**A:** Yes. The HPV Vaccination will not prevent all cervical cancers and women are recommended to continue having Pap smears every two years so that abnormal changes to cells in the cervix can be detected, and treatment can start before cancer develops.

### **Q12: Why does the Tasmanian Register want to share information with the HPV Vaccination Program Register?**

**A:** Legislation was passed by the Australian Government in 2007 to enable the National HPV Vaccination Program Register to share and correlate data with state and territory cervical cancer screening registries. HPV immunisation status is important in determining the appropriate follow-up and management for all women.

Sharing (cross referencing) personal and vaccination information held on the HPV Immunisation Program Register is for the purposes of monitoring the impact of immunisation on cervical cancer incidence. This can be done by matching the immunisation status of a woman with her individual cervical cancer test results.

### **Q13: Why does the Tasmanian Register want to share information with Medicare Australia?**

**A:** The Register sends overdue reminder letters to the woman's last known address. On occasion, these letters are 'returned to sender'. If updated contact information cannot be obtained from the woman's medical practitioner or a corresponding register, then the Register will contact Medicare Australia to request a current address so the woman can be sent her overdue reminder letter.

### **Q14: What safeguards exist to make sure my information is not publicly available?**

**A:** The Register is only permitted to share your personal information with certain persons or organisations and for very limited purposes. Your information is otherwise protected by the provisions of the *Personal Information Protection Act 2004*. Information shared with the National HPV Vaccination Program Register or Medicare Australia is protected by the *Commonwealth Privacy Act 1988*.

Information shared with a corresponding Register in another State or Territory is protected by that jurisdiction's corresponding privacy legislation.

Information shared with a health practitioner or a laboratory, are covered by professional confidentiality.

### **Q16: What happens if no changes are made to the legislation?**

**A:** If the amendments are not made, there is a risk that the Register will be unable to offer follow-up to a woman in the event that she cannot be located. It is possible that a woman may not receive appropriate follow-up medical treatment if her information cannot be shared with those people proposed by the amendments. In that case the woman's health may be put at risk.

### **Q17: What if a woman does not wish to participate?**

**A:** These changes to the *Public Health Act* will have no effect on a woman's ability to opt-off or opt back on to the register at any time.

### **Q18: Where can I get further information?**

**A:** You can get further information about the register and the proposed changes to the legislation by:

Phone: 13 15 56

Email: [canscreen@dhhs.tas.gov.au](mailto:canscreen@dhhs.tas.gov.au)

[http://www.dhhs.tas.gov.au/health\\_and\\_wellbeing/womens\\_health/related\\_topics/cervical\\_cancer\\_prevention\\_program](http://www.dhhs.tas.gov.au/health_and_wellbeing/womens_health/related_topics/cervical_cancer_prevention_program)