Women’s views on human papillomavirus self-sampling: focus groups to assess acceptability, invitation letters and a test kit in the Australian setting


Centre for Epidemiology and Biostatistics, Melbourne School of Population and Global Health, Level 3, 207 Bouverie Street, The University of Melbourne, Vic. 3010, Australia.
B Cancer Council Victoria, 615 St Kilda Road, Melbourne, Vic. 3004, Australia.
CMichael Murphy Research, 5/8A Dickens Street, Elwood, Vic. 3184, Australia.
DVCS Inc., 265 Faraday Street, Carlton, Vic. 3053, Australia.
ERoyal Women’s Hospital, Locked Bag 300, Corner Flemington Road and Grattan Street, Parkville, Vic. 3052, Australia.
FDepartment of Obstetrics & Gynaecology, Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne, 7th Floor, Royal Women’s Hospital, Corner Flemington Road and Grattan Street, Parkville, Vic. 3052, Australia.
GNational HPV Vaccination Program Register, Victorian Cytology Service, PO Box 310, East Melbourne, Vic. 3002, Australia.
HVictorian Cervical Cytology Registry, PO Box 161, Carlton South, Vic. 3053, Australia.

Corresponding author. Email: dgertig@vcs.org.au
SAMPLE PRE-INVITATION LETTER

<Date>

<Salutation> <First name> <Surname>
<Street number and name>
<Suburb, State, postcode>

Dear <Salutation> <Surname>,

There is now a free screening test you can do at home to find out if you are at increased risk of cervical cancer.

In Victoria, a woman is diagnosed with cervical cancer every two days, but nine out of ten of these women have not had regular Pap tests.

There is now an alternative, self-sampling test that is as accurate as a Pap test performed by a health professional. It is now being offered to some Victorian women.

We are writing to you because you are 30 years or older and our records indicate that you have never had a Pap test. This means that your health may be at risk. The Victorian Electoral Commission (VEC) has provided the enrolment details of Victorian women to the Victorian Cervical Cytology Registry strictly for the purpose of this health screening program. For more information please refer to the text box on the next page.

An invitation package including a test kit with instructions and an information booklet will be sent to you in the next few weeks by the Victorian Cervical Cytology Registry, which is a not-for-profit Pap test Registry, funded by the Victorian Government. The test is free, simple and taking the sample will take just a few minutes. In the meantime, if you would like more information go to www.vccr.org/HPVselfsample.

Cancer of the cervix often has few, if any, early warning signs. If cervical cancer is found early it can be treated.

Please call the Victorian Cervical Cytology Registry on (03) 9250 0399 to update your record if you:

- Have recently had a Pap test
- Have had your cervix removed at hysterectomy
- Do not want to receive the kit, or be contacted for health screening purposes in the future, or
- Are pregnant. If you are pregnant, you should not take this self-sample.

We hope you choose to take part in this important Program: having a screening test for cervical cancer might save your life.

Yours sincerely,

[Signature]

Associate Professor Dorota Gertig
Medical Director

© VCS Inc. 2014
Where did my contact details come from?
The Victorian Electoral Commission (VEC) has provided the enrolment details of Victorian women born between 1 January 1944 and 31 December 1983 (excluding silent electors) to the Victorian Cervical Cytology Registry for the purpose of a health screening program. This information is made available under section 34 of the Electoral Act 2002, on certain conditions including that the information will only be used for the approved purpose and will be treated in accordance with the terms of the release and the Information Privacy Act 2000. Severe penalties apply for any misuse of this information. For information about the provision of enrolment information under section 34 of the Electoral Act 2002 please call the VEC on 131 832.

Translations?
For information on cervical screening tests and cervical cancer in your language, please call an interpreter at the Translation and Interpreting Service on 131 450, ask them to phone Victorian Cervical Cytology Registry on (03) 9250 0399.

Arabic:
لمزيد من المعلومات حول اختبارات فحص عنق الرحم وسرطان عنق الرحم في لغتك، يمكنك الاتصال بخدمة الترجمة الكاملة (03) 9250 0399.

Cantonese:
要用您自己的語言了解宮頸瘤篩查及宮頸癌的資訊，請聯絡筆譯及傳譯服務處電話 131 450，並請他們轉接維州宮頸瘤細胞學登記處電話(03)9250 0399。告訴他們您說哪一種語言，傳譯員會幫助您打電話。

Greek:
Για περισσότερες πληροφορίες στις εξετάσεις προληπτικού ελέγχου του τραχείου της μήτρας και του τραχείου της μήτρας στη γλώσσα σας, παρακαλούμε επικοινωνήσετε με την Υπηρεσία Μεταφραστών και Διερμηνεύσεων στο 131 450 και ζητήστε τους να περιγράψουν το Γραφείο Κυτταρολογίας του Τραχείου της Μήτρας της Βικτορίας (Victorian Cervical Cytology Registry) στο (03) 9250 0399. Πείτε τους ποια γλώσσα μιλάτε και διερμηνεύσεις θα σας βοηθήσει με την κλήση σας.

Italian:
Per maggior informazioni in italiano sulle visite di controllo della cervice uterina e per il cancro della cervice contattare il Servizio di traduzione ed interpretazione telefonando ad 131 450 e chiedendo il collegamento con il Victorian Cervical Cytology Registry al numero (03) 9250 0399. Spiegate che parlare italiano e chiameranno un interprete ad aiutarti.

Macedonian:
За повеќе информации за проверка за сомнение на грлото на мачката и рак на грлото на мачката на македонски јазик, ве молиме јавете се на Преведувачката служба на 131 450 и јамолете да телефонираат на Victorian Cervical Cytology Registry (Викторииски регистар за рак на грлото на мачката) на (03) 9250 0399. Каквото и кој јазик го зборувате и преведувачот ќе ви помогне со вашите поживи.

Mandarin:
要用您自己的语言了解宫颈瘤筛查及宫颈癌的信息，请联系翻译服务处电话 131 450，并请他们转接维州宫颈瘤细胞学登记处电话(03)9250 0399，告诉他们您说哪一种语言，翻译会帮助您打电话。

Sinhalese:
කඳුකාගේ ආවරණ කරුණක්ට කියන් කර ඇති මෙන්ඩ් කුංජ ආවරණය කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කුංජ කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කරමු. මෙන්ඩ් කුංජ කරුණක් සඳහා කරමු.

Spanish:
Para obtener más información en su idioma sobre exámenes de control de cuello uterino y de cáncer de cuello uterino, por favor, póngase en contacto con el Servicio de Traducción e Interpretación llamando al 131 450 y pídale que llamen al Victorian Cervical Cytology Registry al (03) 9250 0399. Dígalas qué idioma habla y un interpréte le ayudará con su llamada.

Turkish:
Rahim boynu tarama testi ve rahim boynu kanserine iliklik olan kendi dilinize daha fazla bilgi için lütfen 131 450’den Yazi ve Sözlük Servisi ile iletişime geçin ve onlardan Victoria Rahim Boyun Sitoğlu Sicili’nin (03) 9250 0399 numaralı telefondan araçlanmanızı isteyin. Onlara, konuştugunuz dili söyleyin, terciham size yardımcı olacaktır.

Vietnamese:
Để có thêm thông tin về xét nghiệm cổ tử cung và bệnh ung thư cổ tử cung bằng ngôn ngữ của quý vị, Xin hãy liên lạc với Dịch vụ Thông tin Phòng dịch theo số 131 450 và yêu cầu họ gọi cho Cơ quan Tể bảo hộ Cổ tử cung Victoria theo số (03) 9250 0399. Hãy cho họ biết quý vị nói ngôn ngữ nào và thông dịch sẽ giúp quý vị nói chuyện.
SAMPLE INVITATION LETTER

<Date>

<Salutation> <First name> <Surname>
<Street number and name>
<Suburb, State, postcode>

Dear <Salutation> <Surname>,

Most women who develop cervical cancer have not had regular Pap tests. A screening test could save your life.

We recently wrote to you about a free alternative to a Pap test that you can easily take at home.

We are now sending you a kit and instructions so you can take the sample. Taking the sample is quick and easy. We have also included a detailed booklet to explain the test, or you can go to www.vccr.org/HPVselfsample for online information.

Once you have taken your sample, please mail it to the laboratory in the envelope supplied, along with the completed pathology information form. Your sample will be tested for certain strains, or types, of Human Papillomavirus (HPV), the virus that causes cervical cancer. You will get a letter about your results in about two weeks. If your test is positive you will be asked to see your doctor to discuss if any further tests are needed. If you give permission, your doctor will be informed of your results.

**A positive test does not mean that you have cancer or you will develop it, but it does mean you need follow-up**

We strongly encourage you to take the sample because:
- This is a simple alternative to a Pap test and has been shown to be just as accurate
- Nine out of ten women diagnosed with cervical cancer have not had regular Pap tests
- This test will help to identify if you are at increased risk for cervical cancer
- Follow-up of positive test results can detect early changes in the cervix which can be treated before they develop into cancer.

You should not take this self-sample if you are pregnant, or have had your cervix removed at hysterectomy. However, please return the completed information form. If you don't want to take this sample yourself, please see your nurse or doctor to talk about having a Pap test.

Please note that your test results will be completely confidential to you and, if you wish, your doctor. We are a not-for-profit Pap test Registry, funded by the Victorian Government. If you need further information call the Registry on (03) 9250 0399.

Yours sincerely,

[Signature]

Associate Professor Dorota Gertig
Medical Director

© VCS Inc. 2014
**Where did my contact details come from?**

The Victorian Electoral Commission (VEC) has provided the enrolment details of Victorian women born between 1 January 1944 and 31 December 1983 (excluding silent electors) to the Victorian Cervical Cytology Registry for the purpose of a health screening program. This information is made available under section 34 of the Electoral Act 2002, on certain conditions including that the information will only be used for the approved purpose and will be treated in accordance with the terms of the release and the Information Privacy Act 2000. Severe penalties apply for any misuse of this information. For information about the provision of enrolment information under section 34 of the Electoral Act 2002 please call the VEC on 131 832.

---

**Translations?**

For information on cervical screening tests and cervical cancer in your language, please call an interpreter at the Translation and Interpreting Service on 131 450, ask them to phone Victorian Cervical Cytology Registry on (03) 9250 0399.

---

Arabic:
لمزيد من المعلومات حول اختبارات فحص عنق الرحم وسرطان عنق الرحم في اللغة العربية، يرجى الاتصال بخدمة الترجمة وتسجيل النسخة الورقية على رقم 131 450 أو طلبهم سجلهم عنق الرحم في فيكسيو على (03) 9250 0399.

Cantonese:
要用您的语言了解宫頸癌篩查及宮頸癌的資訊，請聯絡筆譯及傳譯服務處電話 131 450 并請他們轉接維州宮頸癌細胞學登記處電話 (03) 9250 0399，告訴他們您說哪一種語言，傳譯員會幫助您打電話。

Greek:
Για περαιτέρω πληροφορίες στις εξετάσεις προληπτικού ελέγχου του τραχήλου της μήτρας και καρκίνου του τραχήλου της μήτρας στη γλώσσα σας, παρακαλούμε επικοινωνήσετε με την Υπηρεσία Μετάφρασεων και Διερμηνευτών στο 131 450 και ζητήστε τους να τηλεφωνήσουν στο Γραφείο Κυτταρολογίας του Τραχήλου της Μήτρας της Βικτώριας (Victorian Cervical Cytology Registry) στο (03) 9250 0399. Πείτε τους ποια γλώσσα μιλάτε και διερμηνευτής θα σας βοηθήσει με την κλήση σας.

Italian:
Per maggiori informazioni in italiano sulle visite di controllo della cervice uterina e per il cancro delle cervice contattare il Servizio di traduzione ed interpretazione telefonando a 131 450 e chiedendo il collegamento con il Victorian Cervical Cytology Registry al numero (03) 9250 0399. Spiegate che parlate italiano e chiameranno un interprete ad aiutarvi.

Macedonian:
За повеќе информации за проверка за снимање на грлото на матката и рак на грлото на матката на македонски јазик, вие можеме ја вклучите на Праведувачката служба на 131 450 и замолете да телефонираат на Victorian Cervical Cytology Registry (Викториски регистар за рак на грлото на матката) на (03) 9250 0399. Кажете им кој јазик го зборувате и праведувачкот ќе ви помогне со вашот повик.

Mandarin:
要用您的语言了解子宫颈癌筛查及子宫颈癌的信息，请联系翻译服务处电话 131 450 并请他们转接维州子宫颈细胞学登记处电话 (03) 9250 0399，告诉他们您说哪一种语言，翻译会帮助您打电话。

Sinhalese:
කොළඹ නිදසුන් මෙහෙයින් අපේනාව මත ආකටි සතුටා පෙන්නෙන්ම, මත අතික්ෂේෂණය කළ නිදසුන් (03) 9250 0399 මත ගමතිය. මෙය අතික්ෂේෂණය කළ පිළිතුරුව අපේනාව මෙහෙයින් මෙහෙයින් පෙන්නෙන්ම. කොළඹ නිදසුන් (03) 9250 0399 මත අපට මෙය මෙහෙයින් පෙන්නෙන්ම. මෙය කොළඹ නිදසුන් (03) 9250 0399 මත අපට මෙය මෙහෙයින් පෙන්නෙන්ම.

Spanish:
Para obtener más información en su idioma sobre exámenes de control de cuello uterino y de cáncer de cuello uterino, por favor, póngase en contacto con el Servicio de Traducción e Interpretación llamando al 131 450 y pidales que llamen al Victorian Cervical Cytology Registry al (03) 9250 0399. Dígales qué idioma habla y un intérprete le ayudará con su llamada.

Turkish:
Rahim boyunu tarama testi ve rahim boyunu kanseri ilgili olarak kendi dilinize daha fazla bilgi için telefon 131 450’den Yazılı ve Sözlü Servis ve ile ilgiliye geçin ve onlardan Victoria Rahim Boyunu Sitoğlu Sichilli’ni (03) 9250 0399 numaralı telefondan aramaalarnı isteyin. Onlara, konuştugunuz dili söyleyin, tercihinden size yardımcı olacaktır.

Vietnamese:
Để có thêm thông tin về xét nghiệm cổ tử cung và bệnh ung thư cổ tử cung bằng ngôn ngữ của quý vị, xin hãy liên lạc với Dịch vụ Thông phòng Phân tích theo số 131 450 và yêu cầu họ gọi cho Cơ quan Thể báo Học cổ tử cung Victoria theo số (03) 9250 0399. Hãy cho họ biết quý vị nói ngôn ngữ nào và thông điệp sẽ giúp quý vị nói chuyện.
INSTRUCTIONS
HOW TO TAKE A VAGINAL SWAB

Simply follow the step-by-step instructions below:

WHAT DOES THE KIT CONTAIN?
• A cotton swab in a plastic tube
• A plastic ziplock bag
• This instruction sheet
• Pathology information form
• A padded ‘Reply paid’ envelope

TAKING THE SAMPLE:
• Gently spread open the folds of skin at the vaginal opening with your other hand.
• Insert the swab into your vagina directed towards your lower back about two inches (5cm), half the length of a finger. This is similar to how you would insert a tampon.

SWAB:
• Remove the swab out of its plastic tube, just twist and pull it
• If possible, avoid taking the sample during your monthly period

TAKING THE SAMPLE (CONTINUED):
• Rotate the swab gently for 10-30 seconds. There should be no pain or discomfort

POSITION:
• Undress from the waist down
• Get into a comfortable position as shown above while holding the swab in your hand

WHAT IF I MAKE A MISTAKE?
It is okay to continue with the vaginal sample if you:
• Have touched it with your fingers
• Have dropped the swab onto a dry surface

If you have inserted the swab into your vagina but are unsure if the distance is correct, please return the completed kit.
We will send another kit if we cannot get a result from your swab for any reason.

WHAT IF I MAKE A MISTAKE?
Please call the Registry on (03) 9250 0399 to request a kit to be re-sent if it:
• GETS WET/OR
• IS DAMAGED

DO NOT COLLECT THE SAMPLE IF YOU ARE PREGNANT

Instructions overleaf on how to pack and post the sample...
Simply follow the step-by-step instructions below:

**RETURN TO PLASTIC TUBE:**
- Place the swab into the plastic tube
- Tightly screw the cap onto the tube
- Finish by washing your hands with soap and water

**COMPLETE FORM AND CHECK LABEL:**
- Complete the Pathology information form and check the details. Ensure you write the date of the collection.
- Check the label on the plastic tube is correct
- Your sample does not require refrigeration, even on a hot day. Just keep at room temperature.

**PACKAGING:**
- Place the plastic tube into the ziplock bag
- Then pack the tube and the Pathology information form into the padded reply paid envelope
- Seal the envelope firmly

**POST:**
- Deposit the reply paid envelope into an Australian Post mail box

**IMPORTANT INFORMATION**
- Your swab should be posted as soon as possible, preferably within 24 hours of collection
- Store the swab at room temperature until delivery
- Please read the information brochure for information on HPV and cervical cancer
- If possible, avoid taking the sample during your monthly period

**IF YOU REQUIRE A REPLACEMENT KIT, OR FOR MORE INFORMATION CONTACT THE VICTORIAN CERVICAL CYTOLOGY REGISTRY ON**
**PH: 03 9250 0399**

>> Instructions overleaf on how to take a vaginal swab - **DO THIS FIRST...**
I have had the ‘cervical cancer’ vaccine, do I still need screening?
Yes, the vaccine only protects against two of the 15 high-risk HPV types. Although these two types caused the majority of cervical cancers, you could be infected with other high-risk types. This is why you need to have routine screening tests even after vaccination. More information is available at www.hpvvaccine.org.au

If I have had a hysterectomy do I still need to be screened for cervical cancer?
This depends on why you had your hysterectomy, and if you still have your cervix. If you had your entire uterus removed for reasons other than cancer, you may not need cervical cancer screening. Talk to your doctor to find out if you still need to be screened.

What if I am pregnant?
There have not been any problems with self-sampling in pregnant women. However just to be safe do not do the test if you are pregnant.

What information will be recorded?
Your name, date of birth, address, HPV test result, and doctor’s name and address will be recorded (if provided), your country of birth, indigenous status, any screening performed in the past, history of hysterectomy or pregnancy status. Results of further investigations such as Pap tests, colposcopies, biopsies and further HPV tests will also be recorded as they can affect how often you need Pap tests in the future.

Do my results have to go to the Registry?
- Your test results will be recorded with the Victorian Pap test Registry (the VCCR). When you have your HPV test, your results will be sent to the Registry by the laboratory that reported your test.
- The Registry is a voluntary ‘opt-off’ confidential database or register of Victorian women’s Pap test results. However, if you wish to send in a self-collected sample for HPV testing, your results will have to be recorded by the Registry for monitoring purposes.

Who has access to my information?
The Cancer Act allows you, your doctor and the laboratory that is reporting your screening test results to have access to your details.

How is my privacy protected?
- The Registry is committed to protecting your privacy and has policies and procedures in place to ensure this is maintained. These comply with all applicable Privacy legislation. Information is also used for research to improve our knowledge about preventing cervical cancer. No research information identifies an individual person.
- Our full privacy policy can be viewed at: www.vccr.org/privacy.html

Want more information?
For more information about Pap tests and preventing cervical cancer visit www.vccr.org or www.papscreen.org.au or call the Registry on (03) 9250 0399 for more information or to update your details.
What is HPV?
- HPV (Human Papillomavirus) is a virus.
- Being infected with HPV is very common. Four out of five men and women will have HPV at some point in their lives.

How do you get HPV?
- HPV is spread by genital skin-to-skin contact during sex.
- It is very common in men and women who have ever had sex even if you are in a long-term relationship with one person, or not currently having sex, you could have HPV.
- The virus can hide in your cervix (the lower part of the uterus) for many years before cell changes on the cervix are found.

How is HPV linked to cervical cancer?
- Infection over many years with certain types or strains of HPV (known as ‘high risk’ types) causes cervical cancer.
- Having HPV does not mean you have or will get cervical cancer. For most women, HPV goes away before it causes anything serious. A Pap test is not a check for ovarian cancer or for sexually transmitted infections.

What do the different types of HPV mean?
- The HPV types affecting the cervix are called low-risk or high-risk.
- Some high-risk HPV types take longer to clear from the body. This may increase a woman’s risk of developing cervical cancer. Of all the different high-risk HPV types, infection with HPV types 16 and/or 18 are the most likely to cause significant cell changes.
- Low-risk types can cause minor changes to the cells of the cervix, or sometimes genital warts. Low-risk types are usually cleared by the body within one to two years and do not cause cervical cancer.

How can cervical cancer be prevented?
- We can never prevent all cases of cervical cancer. But the best protection comes from:
  - Vaccinating adolescent girls and boys with the HPV vaccine.
  - Having regular screening tests.

How is HPV linked to cervical cancer?
- Infection over many years with certain types or strains of HPV (known as ‘high risk’ types) causes cervical cancer.
- Some high-risk HPV types take longer to clear from the body. These changes are usually caused by HPV and are usually not serious. However, if left for many years they could develop into cervical cancer. Finding these changes early means they can usually be treated before anything serious happens. A Pap test is not a check for ovarian cancer or for sexually transmitted infections.

What is an HPV test?
- In an HPV test a sample of cells from the cervix or vagina is sent to a laboratory where tests are done to look for high-risk types of HPV. An advantage of an HPV test is that, unlike a Pap test, it can be done by the woman herself, or by a nurse or doctor.

What is self-sampling for HPV?
- A woman can take a sample herself from her vagina (using a cotton swab) in the privacy of her own home. This is called self-sampling. The swab is then posted to the laboratory for HPV testing. For details please see the instruction sheet enclosed with the kit.

Why should I do self-sampling?
- Scientific studies have shown that:
  - Self-sampling is simple to perform at home
  - The majority of cervical cancers occur in women who do not have regular screening

Is it accurate?
- Vaginal self-sampling is as accurate as a doctor collected Pap test.

How can I do self-sampling?
- Please see the instruction sheet enclosed with the kit.

What type of follow-up is required?

<table>
<thead>
<tr>
<th>HPV Results</th>
<th>Follow-up required*</th>
</tr>
</thead>
<tbody>
<tr>
<td>You do not have HPV</td>
<td>Have regular Pap tests</td>
</tr>
<tr>
<td>You have a high risk HPV type but not types 16 or 18</td>
<td>Your doctor or nurse will do a Pap test</td>
</tr>
<tr>
<td>You have HPV types 16 or 18</td>
<td>Your doctor will refer you to a specialist for further examination</td>
</tr>
</tbody>
</table>

*These recommendations apply to women 30 years and over

Are there any possible risks with self-sampling?
- Performing self-sampling for HPV does no physical harm. However, it is possible that you may become upset or embarrassed if you find out that you have HPV infection. Remember most women get HPV at some time in their lives.
- If you would like to speak to a female doctor about your result, phone VCS Pathology on (03) 9250 0300 and ask to speak to one of the Liaison Physicians. Let them know you have self-tested for HPV. You can also call the Registry on (03) 9250 0399 for more information in your language.

Is there any treatment for HPV?
- There is no treatment for the virus (HPV) as your body’s immune system usually clears it over time.
- However, the serious cell changes caused by HPV can be treated, which is why it is important for you to have further tests if you are found to have high-risk HPV. Treatment of these cells to stop them becoming cervical cancer is very successful.

What do my results mean?
- The HPV test will detect if you have the virus that can cause abnormal cells in the cervix. If you are found to have the high-risk HPV, your doctor will advise you what type of follow-up is needed to prevent cancer from developing, so it is important that you complete the pathology information form with the invitation letter and return it to us so that we can contact you, your doctor if necessary. Please remember that testing positive for high-risk HPV does not mean that you have cancer. Most women with HPV will NOT develop cervical cancer (as the virus clears by itself).

What is a Pap test?
- In a Pap test cells from the cervix are collected by a health practitioner and placed onto a glass slide. This is sent to a laboratory where a specially trained scientist looks for cell changes using a microscope. These changes are made early means they can usually be treated before anything serious happens. A Pap test is not a check for ovarian cancer or for sexually transmitted infections.