

IMPROVING CANCER SCREENING PARTICIPATION IN
UNDER-SCREENED, NEVER-SCREENED AND
HARD-TO-REACH POPULATIONS:

ENVIRONMENTAL SURVEY RESULTS FOR PARTICIPANTS



Victorian Cytology Service

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Victoria's Cancer Action Plan

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1. Executive Summary

In 2009 the Victorian Cytology Service (VCS) conducted a survey of cancer screening programs around Australia and New Zealand to obtain information about the strategies and approaches being used to capture under-screened, never-screened and hard-to-reach populations. This work was commissioned by the Victorian Department of Health (DH) in response to the Victoria's Cancer Action Plan 2008-2011, which aims to increase cancer screening participation in communities with lower than average rates such as Indigenous and culturally and linguistically diverse (CALD) groups.

Responses were collected from 39 contacts across government, the research sector and cancer councils in Australia and New Zealand. All screening programs were well represented, with breast screening recording the highest number of respondents.

State level and postcode areas were the geographic regions for which data was most widely available within the programs, while Indigenous status and language spoken at home were the data most commonly collected reflecting cultural diversity, although they are not collected within the Australian cervical screening program. Around one-fifth (22%) of respondents routinely collect socio-demographic data, while a greater proportion (38%) conducted special studies to collect this information at some point.

The majority of respondents had evidence of either participation decreasing over time for the program as a whole, or decreased participation among specific population groups such as: Indigenous and culturally and linguistically diverse populations, older women, men, lesbians, disability groups and rural or remote communities. A diverse range of strategies are employed in an attempt to increase participation in these groups, ranging from community and grass-roots activities, to the development of culturally appropriate information and advertising, the use of bilingual interpreters, media campaigns, grant funding, working with local health workers, mails outs and reference groups. A large amount of literature, both published and unpublished, is produced, describing the programs and interventions, however as many are not formally evaluated, it can be difficult to assess the impact of certain strategies. The literature highlights the successes, but also the many challenges and, at times, ineffective strategies that have been trialled in an attempt to reach under-screened and never-screened groups.

2. Introduction

In 2008 the Victorian Government released a comprehensive Cancer Action Plan with measurable targets across four key action areas as a commitment to cancer care, prevention and research (Department of Health Victoria, 2008). The Plan includes targets to increase participation rates in population-based cancer screening programs. In particular the targets strive to:

- Increase by 10 percent breast cancer screening participation rates in Aboriginal and Torres Strait Islander (ATSI) and culturally and linguistically diverse groups (CALD) by 2013.
- Develop systems to measure baseline participation rates for Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse groups.
- Increase cervical and bowel cancer screening participation rates in Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse groups by 10 percent from a measured baseline by 2013.
- Increase breast cancer screening participation rates by offering 20,000 additional screening tests per annum by 2013.
- Work with the Commonwealth Government to enhance the overall bowel cancer screening program and agree on a target participation rate of 60 percent in the eligible population (currently 50, 55 and 65 year olds) by 2011.

To help inform activities to deliver on this Plan, the Victorian Department of Health (DH) commissioned the Victorian Cytology Service (VCS) to collate and review work already undertaken to identify hard-to-reach groups within cancer screening programs as well as examine strategies to increase participation. A literature review was conducted to look at the factors and barriers associated with participation in organised programs, with an emphasis on population-based screening programs. In addition, the present survey of program managers and organisations involved in breast, bowel and cervical cancer screening programs in Australia and New Zealand was conducted in parallel to the literature review to complement the findings and as a means to collect unpublished material on participation within these programs. The unpublished material and reports collected have been considered and included as part of the literature review.

There are three national cancer screening programs in Australia: the National Cervical Screening Program, established in 1991; the BreastScreen Australia Program which also commenced in 1991; and the National Bowel Cancer Screening Program, implemented in 2006. The aim of these screening programs is to detect cancer or pre-cancerous changes at an early stage, when treatment is more effective.

The Australian government are responsible for the policy formulation, national data collection, quality control and monitoring and evaluation of the BreastScreen Australia program, with the State and Territory governments having primary responsibility for the overall co-ordination and implementation of the program at their local level, including the recruitment of women.

In Australia, the National Cervical Screening Program is also a joint program of the Australian, State and Territory governments. As with the Breast Screening program, policy, quality control, monitoring and evaluation occur at the national level while the coordination of screening activity is the responsibility of the individual state or territory. Each jurisdiction also plays a key role in performance and monitoring of the program through the activities of its Pap test Registry which collects screening histories, sends reminder letters, follows up abnormal results and provides data for national monitoring of the program.

The National Bowel Cancer Screening Program (NBCSP), currently in its second phase, is administered by the Commonwealth Department of Health and Ageing, working in partnership with Medicare Australia. Medicare Australia has been engaged by the Commonwealth to establish and maintain a National Bowel Cancer Screening Program Register and associated support services, including the issuing of reminder letters to program participants and their nominated health professionals as well as maintaining and administering the Program Information Line. The Commonwealth Department of Health and Ageing (DoHA) has overarching policy development and program implementation responsibility for the Program. The State and Territories are responsible for the local coordination, planning and implementation of the NBCSP in their jurisdiction and also have responsibility to provide telephone follow-up of participants in the Program.

The Australian Institute of Health and Welfare produce monitoring reports outlining participation within each of the three cancer screening programs at the national and state and territory level.

New Zealand operates two cancer screening programmes: the National Cervical Screening Programme (NCSP), which began operations in 1991, and BreastScreen Aotearoa (BSA), established in 1998. The National Screening Unit (NSU) within the Ministry of Health is responsible for the national coordination and funding of these programs. A New Zealand bowel screening program is being established and is currently in the early stages of development.

In Australia, the target age group for breast screening within the BreastScreen Australia Program is 50 to 69 year olds. Women aged 40 to 49 and 70 years and over are also able to attend for screening. At BreastScreen Aotearoa in New Zealand free screening is provided to women aged 45 to 69 years.

The National Bowel Cancer Screening Program in Australia targets males and females turning 50, 55 or 65 years of age between January 2008 and December 2010.

The National Cervical Screening Program targets females aged 20 to 69 years, although females aged 18 to 20, and over 70 years can also attend for a Pap smear. Similarly, the target age group for the New Zealand National Cervical Screening Program is 20 to 70 years.

3. Method

In July 2009 a survey on participation within cancer screening, focused on under-screened, never-screened and hard-to-reach groups, was distributed by the Victorian Cytology Service to government run and funded cancer screening programs throughout Australia and New Zealand.

In June 2009 the Victorian Department of Health made initial contact with program managers across Australia and New Zealand informing them of the purpose of the survey and notifying them that the VCS would be conducting the survey.

The survey was developed by VCS in consultation with the Victorian Department of Health, with input from the Under-screened Working Group coordinated by the Department. The group included membership from PapScreen Victoria, BreastScreen Victoria, the Cancer Council Victoria and the VCS. A pilot of the survey was circulated to the working group in early July 2009 inviting feedback and comments.

The survey was forwarded to approximately 45 people across Australia and New Zealand operating within the breast, bowel and cervical screening programs in July 2009. These contacts were identified by the Victorian Department of Health, BreastScreen Victoria, The Cancer Council Victoria, PapScreen Victoria and the VCS. Participants were also invited to forward the survey to relevant contacts. Names of approximately ten additional contacts were provided to VCS in order to forward the survey directly; however there were also a number of instances where the original email was forwarded on by survey recipients. The survey was broadly distributed in order to obtain the most information, particularly from the “grey” literature.

The online survey tool *QuestionPro Professional* was used to conduct the survey and collect responses, with an option to complete via phone, email or hard copy if preferred. The survey was followed up with reminder emails several days before the due date to contacts who had not yet replied. A number of responses were received via email, with the majority of responses submitted directly online.

Given the structure of the various cancer screening programs, it was recognised that the survey may need to be completed by multiple representatives within an organisation. To cater for this, the survey was split into two parts, the first section relating to *data on participation* while the second section focussed on *strategies to improve participation*. The survey questions are listed in Appendix A: List of survey questions.

4. Results

4.1. Survey Respondents

The core group of survey participants targeted included representatives from each of the three screening programs in Australia by each of the eight Australian jurisdictions, plus responses from DoHA for each of the three cancer screening programs. In addition, a response was sought from each of the New Zealand Breast and Cervical Screening programs, resulting in a minimum target group of 29 participants to cover each jurisdiction and each program.

The majority of responses were from program administrators, with a handful of other responses received from cancer councils, universities and hospitals conducting research on participation within breast, bowel or cervical screening. All Australian States and Territories were represented within the survey responses, which also included Commonwealth responses from the Department of Health and Ageing (DoHA), the Australian Institute of Health and Welfare (AIHW) and Medicare, as well as responses from the Ministry of Health, New Zealand. A number of respondents reported on more than one screening program.

In total, surveys were received from 39 respondents. As shown in Table 1, this consisted of 23 participants completing both sections, an additional 14 respondents completing the first section only (data) and 2 participants completing only the second component (strategies). For the purposes of the statistical analyses, the 37 people completing the first section and 25 completing the second section formed the denominator for the respective sections.

Table 1: Number of survey responses by section completed

	No. completing part of survey only	No. completing whole survey	Total responses
Part 1: data	14	23	37
Part 2: strategies	2	23	25
Total	16	23	39

A number of participants reported on more than one screening program. Breast screening received the highest number of responses (21 responses or 54%) followed by bowel screening (16 responses or 41%) and cervical screening (13 responses or 33%) (Table 2).

Table 2: Number of survey responses by screening program

What screening program is your organisation involved in? (select all that apply)	Part 1		Part 2		Total responses	
	no.	%	no.	%	no.	%
Breast Screening	19	51	15	60	21	54
Bowel Screening	15	41	10	40	16	41
Cervical Screening	12	32	9	36	13	33
All programs	37	100	25	100	39	100

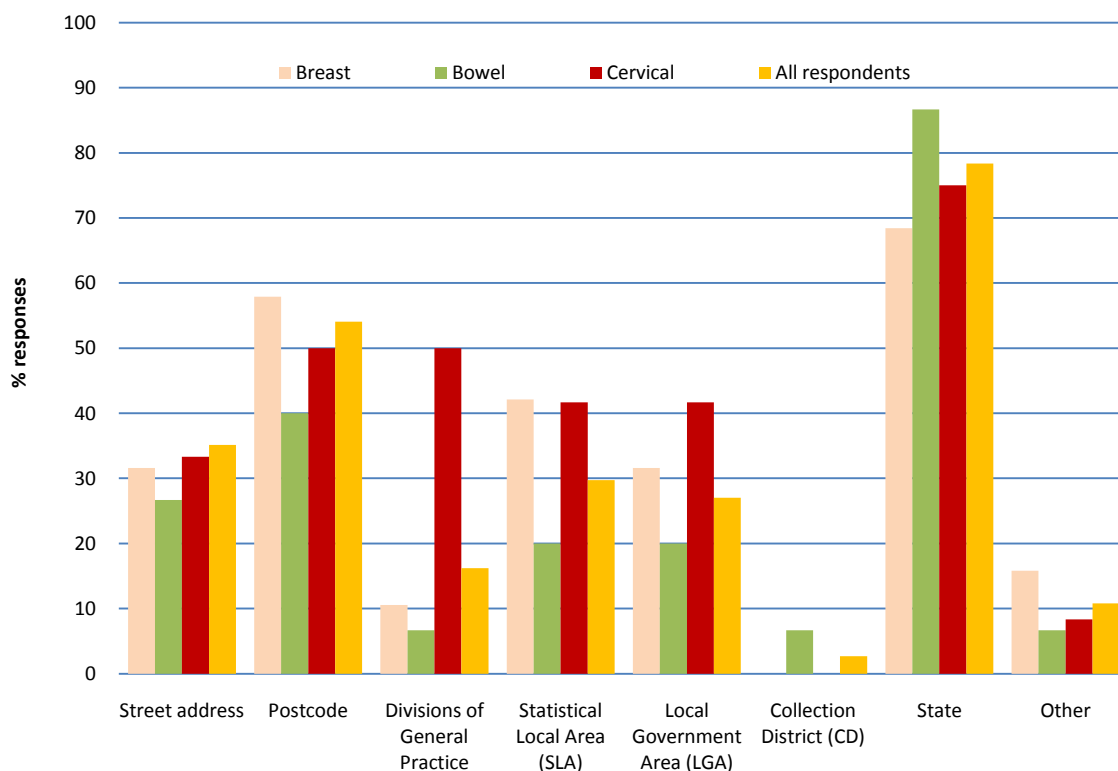
Note: The sum of responses for breast, bowel and cervical combined is greater than 'total responses' due to a number of people reporting on more than one screening program.

4.2. Participation data

4.2.1. Data collected on geography

Survey participants were questioned on the geographic level at which data was available. The geographic region most widely available was state-wide data, reported by 78% of respondents. Postcode was the next most widely available region with 54% having access to data at this level, followed by street address (35%), Statistical Local Area (SLA) (30%) and Local Government Area (LGA) (27%). Fewer indicated that data is available at Divisions of General Practice level (16%), while others had program data analysed by electoral divisions, the Accessibility/Remoteness Index of Australia (ARIA), and for New Zealand, District Health Boards and Territorial Local Authority Boundaries. Figure 1 illustrates geography type as a proportion of the responses received by screening program.

Figure 1: Client data by geographic region and screening program



Note: The sum of responses for breast, bowel and cervical combined is greater than 'all respondents' due to a number of people reporting on more than one screening program.

4.2.2. Data collected on cultural diversity & socio-economic status

As each of the cancer screening programs in Australia and New Zealand are coordinated at a national level, in the majority of cases the information collected reflecting cultural diversity is the same for each of the jurisdictions. As a general rule, Indigenous status is not collected by the cervical screening programs in Australia, whereas it is collected in New Zealand. Place of birth, year of arrival and language spoken at home are not collected in Australia or New Zealand for cervical screening.

The Australian and New Zealand breast screening programs collect Indigenous status, place of birth and language spoken at home. The Australian bowel screening program records Indigenous status

and language spoken at home. In addition, the bowel screening program records information relating to disability status.

Table 3: Minimum standards of data collected regarding CALD/ATSI status by screening program

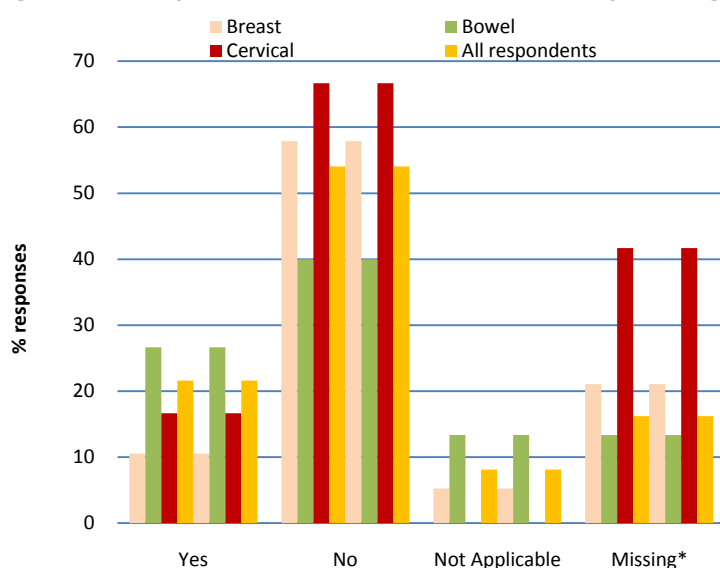
	Indigenous Status	Place of Birth	Year of Arrival	Language Spoken at Home
Australia				
Breast Screening	✓	✓	x [#]	✓
Bowel Screening	✓	x	x	✓
Cervical Screening	x*	x	x	x
New Zealand				
Breast Screening	✓	✓	x	✓
Cervical Screening	✓	x	x	x

* Not collected in the majority of jurisdictions however Victoria is conducting a pilot project to collect Aboriginal and Torres Strait Islander Status & CALD information on Pap smear forms.

[#] Year of arrival is not collected by the majority of breast screening programs however it is collected by the NT and ACT.

Approximately 22% of respondents indicated that they routinely collect some type of information relating to socio-economic status. Some examples include; disability information, use of address information to match up with the ABS SEIFA Index of Relative Socioeconomic Disadvantage, education level and employment. Half of those indicating that they collect this type of information were from bowel screening (4 respondents out of the total 8). Two participants replied in the affirmative from each of the breast and cervical screening programs, as indicated in Figure 2.

Figure 2: Routinely collected data on socio-economic status by screening program



* No response given.

In addition, 14 (38%) respondents indicated that they have conducted special studies to examine the characteristics of their clients. As shown in Table 4, at least one third of respondents from the breast, bowel and cervical screening programs had carried out special studies to look at clients' characteristics (42%, 33% and 42% respectively).

Socio-demographic information collected through these special studies included; occupation, employment status, income, education, marital status, household structure, home ownership, parent's country of birth, cultural associations, private insurance status, ABS SEIFA Index of Relative

Socioeconomic Disadvantage and population statistics. Surveys were also conducted to collect information on the beliefs and knowledge of breast, bowel and cervical cancer, awareness of the Australian National Bowel Cancer Screening program, and client satisfaction.

Table 4: Special studies to examine client characteristics

<i>Have you conducted any special studies to examine the characteristics of your clients?</i>	Breast screening		Bowel screening		Cervical screening		All respondents	
	no.	%	no.	%	no.	%	no.	%
Yes	8	42	5	33	5	42	14	38
No	6	32	4	27	6	50	14	38
Not Applicable	0	0	1	7	0	0	1	3
Missing*	5	26	5	33	1	8	8	22
Total	19	100	15	100	12	100.0	37	100

Note: The sum of responses for breast, bowel and cervical screening combined is greater than 'all respondents' due to a number of people reporting on more than one screening program.

** No response given.*

4.3. Strategies to Improve Participation

4.3.1. Evidence

Eighty-four percent of respondents reported evidence of either participation decreasing over time for the program as a whole, or decreased participation among specific population groups. This was indicated by all cervical screening respondents, 87% of those reporting on breast screening programs and 80% of bowel screening respondents. Overall, only three participants (12%) indicated they had no evidence or references showing decreased participation in the program amongst certain groups of clients.

Table 5: Evidence of decreased participation by screening program

Does the program have any evidence or references showing decreased participation overall or among specific groups?	Breast screening		Bowel screening		Cervical screening		All respondents	
	no.	%	no.	%	no.	%	no.	%
Yes	13	87	8	80	9	100	21	84
No	2	13	1	10	0	0	3	12
Not Applicable	0	0	1	10	0	0	1	4
Missing*	0	0	0	0	0	0	0	0
Total respondents	15	100	10	100	9	100	25	100

Note: The sum of responses for breast, bowel and cervical screening combined is greater than 'all respondents' due to a number of people reporting on more than one screening program.

** No response given.*

Most commonly the evidence was provided by: AIHW monitoring reports, participation measured using ABS population data, population surveys and the Report on Government Services (ROGS). Specific groups identified with decreased participation included Indigenous populations, CALD communities, lower socio-economic groups, people living within rural and remote areas and women aged under 40 years (for cervical screening).

4.3.2. Strategies for target groups

The survey queried the use of strategies to increase participation among several groups including:

- the Indigenous population;
- Culturally and Linguistically Diverse communities;
- Older women;
- Men;
- Lesbians;
- Disability groups; and
- Rural/Remote populations.

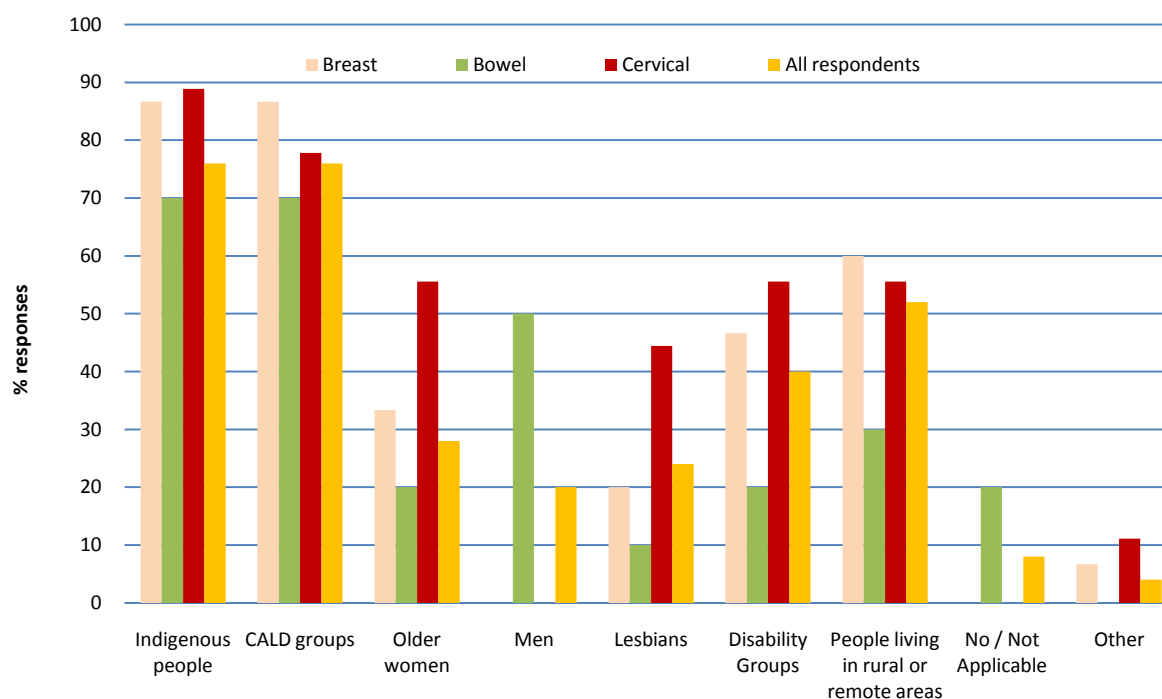
Responses were invited for more than one group where applicable. Most responses highlighted strategies for CALD groups and Indigenous populations (both with 19 responses or 76%). Rural and remote populations also featured (52% had strategies for this group, N=13). Forty percent of respondents have strategies relating to disability groups, while strategies for older women, lesbians and men were also reported by 28%, 24% and 20% respectively (Table 6 & Figure 3).

Table 6: Strategies to increase participation in selected groups by screening program

Does the program have strategies to increase participation among any of the below groups?	Breast screening		Bowel screening		Cervical screening		All respondents	
	no.	%	no.	%	no.	%	no.	%
Indigenous people	13	87	7	70	8	89	19	76
CALD groups	13	87	7	70	7	78	19	76
Older women	5	33	2	20	5	56	7	28
Men	n/a	n/a	5	50	n/a	n/a	5	20
Lesbians	3	20	1	10	4	44	6	24
Disability Groups	7	47	2	20	5	56	10	40
People living in rural or remote areas	9	60	3	30	5	56	13	52
No / Not Applicable	0	0	2	20	0	0	2	8
Other	1	7	0	0	1	11	1	4
Total	15	100	10	100	9	100	25	100

Note: The sum of responses for breast, bowel and cervical screening combined is greater than 'all respondents' due to a number of people reporting on more than one screening program.

Figure 3: Strategies to increase participation in selected groups by screening program



The types of strategies used for Indigenous communities ranged from those centred on information and education to community interventions. Examples of information and education included:

- information sessions;
- teaching kits and education resources;
- culturally appropriate information and advertising (e.g. designated Indigenous Program Officers who conduct information sessions);
- media campaigns;
- pilot projects exploring alternative screening pathways; and
- collecting locally specific information about Aboriginal Medical Services and communities to determine how programs would best work within existing structures to provide greater access to screening and improve information provision.

Strategies which engaged the Indigenous community included:

- community consultation;
- presentations;
- group bookings;
- Indigenous program and community liaison officers;
- Aboriginal and Torres Strait Islander reference groups (e.g. to provide information regarding Indigenous barriers and issues in screening, as well as to promote it within their own communities);
- networking with Indigenous Health workers;
- grant funding for Aboriginal Health Services (e.g. grant funding provided for nurses to target clinics for Aboriginal women); and
- an Indigenous Bowel Cancer Screening pilot program which utilised local educators and Indigenous radio.

Indigenous communities:

In 2006 in Queensland a Cervical Screening Community Education Kit for Aboriginal and Torres Strait Islander Health Workers was developed to assist health workers promote cervical screening in their communities.

Source: Queensland Cervical Screening Program, Environmental Scan – Culturally and Linguistically Diverse Women (CALD), Queensland Health, Brisbane.

Targeting CALD groups is achieved through:

- the provision of resources in appropriate languages, including advertising and media campaigns in various languages and on ethnic radio stations (for example radio interviews on CALD radio programs, multilingual Pap smear brochures or articles in CALD newspapers);
- use of interpreter services;
- use of multilingual cancer information line (available through the Victorian Cancer Council this service provides callers with information about cancer from oncology trained nurse counsellors, with the help of an interpreter. The service is available in eighty languages);
- utilising health promotion officers targeting CALD groups;
- conducting workshops to educate and motivate CALD groups to attend screening;
- practical assistance to people without the English language skills to assess screening (e.g. appointments, location, maps, transport, interpreters, support);
- liaison with peak bodies and national strategic working groups;
- grant funding for community health services and migrant resource centres to undertake community development;
- community presentations and displays (e.g. within breast screening particular communities are targeted with educational sessions provided to women from those communities who are, or soon will be, eligible for mammography screening. Displays promoting screening are also organised at suitable CALD community events. A multicultural women's craft day was held to promote screening); and
- the National Bowel Cancer Pilot Program had a focus on CALD groups and used bilingual educators.

Lower participation of older women was addressed by:

- media campaigns including print, TV and radio formats;
- information sessions; and
- reminder letter campaigns.

Strategies to reach men included:

- media campaigns;
- information sessions; and
- focus groups to better understand enablers and barriers to participation.

Culturally & Linguistically Diverse Populations:

The Cancer Council South Australia, BreastScreen SA and the SA Cervix Screening Program jointly fund and administer a Small Grants Scheme. In operation for seven years, it provides small funding grants to culturally and linguistically diverse (CALD) communities for the promotion of health information about breast and cervical screening services. The scheme has been very successful in providing financial support for the promotion of breast and cervical screening services to approximately 700 CALD women each year. It provides an attractive incentive as well as needed financial assistance to CALD communities, contributing significantly to raising awareness among CALD women of the importance of regular Pap smears and screening mammograms.

Source: BreastScreen SA, 2009, CALD Recruitment Plan for 2009, BreastScreen SA, Adelaide.

Increasing participation among lesbians involved:

- specific information resources and brochures used to target lesbians' involvement in cancer screening (e.g. *"Lesbians need Pap Tests too"* brochure);
- conducting surveys;
- utilising reference groups; and
- attendance at Lesbian festivals to promote education and awareness.

Strategies targeting disability groups were:

- health promotion officers on various disability stakeholder groups;
- the promotion of accessible screening services for women with disabilities, emphasising additional time and assistance for appointments when required;
- making TTY services available to women with hearing and speech difficulties;
- providing interpreters for people who use Australian Sign Language (AUSLAN);
- training for support workers; and
- funding local council and community health services to develop community development initiatives and the use of tailored information resources.

Participation among people living in rural and remote areas is addressed by:

- providing funding to area health services;
- networking with local health workers, GPs and community organisations;
- media campaigns;
- information sessions;
- mail outs;
- providing free transport and additional clinics in rural and remote areas; and
- the use of mobile screening vans.

Women with Disabilities:

The NSW Cervical Screening Program aims to improve the quality of, and access to, cervical screening services provided by general practitioners to women with disabilities. Women with disabilities have similar or greater risks for cervical and breast cancer as their peers. However, population research across various diagnostic groups has demonstrated that women with disabilities do not receive the same level of preventative health care as the general female population.

The following factors have been identified as contributing to lower screening rates:

- general practitioners have limited knowledge and training about the preventative health care needs of women with disabilities;
- women with disabilities have limited knowledge about their preventative health care needs; and
- general practitioners' premises and examination equipment are frequently inaccessible.

To overcome some of these barriers, the NSW Cervical Screening Program, in conjunction with the Centre for Developmental Disability Studies (CDDS), have developed guidelines for GPs to follow when providing preventative women's health care for women with disabilities.

The guidelines were based on a review of the research in this area, and in consultation with general practitioners, disability organisations, a women's advisory group and a focus group of women with disabilities. They provide GPs with practical information on how best to provide preventative women's health care for women with disabilities, including:

- Communication strategies;
- Consent requirements;
- Recommendations for improving physical access;
- Practical tips for doing Pap tests for women with disabilities, including the use of alternative positions and instruments; and
- General guidelines on breast screening, menstruation, sexual health, pregnancy choices and menopause.

Source: Preventative Women's Health Care for Women with Disabilities,
<<http://www.csp.nsw.gov.au/women/disabilities.html>>

4.3.3. Evaluations and project reporting

As show in Table 7, just over half of participants (56%, N= 14) carried out evaluations on strategies to increase participation in the above mentioned groups. Bowel screening had the lowest response for carrying out evaluations (30%) compared with the other screening programs which could be related to the relatively recent establishment of the program. Similarly, 60% (N=15) had produced reports, publications or evaluations on participation either overall or among specific target groups (Table 8).

Table 7: Evaluations on strategies to increase participation by screening program

Have any evaluations been carried out on any of the above mentioned strategies?	Breast screening		Bowel screening		Cervical screening		All respondents	
	no.	%	no.	%	no.	%	no.	%
Yes	10	67	3	30	6	67	14	56
No	3	20	6	60	2	22	7	28
Not Applicable	0	0	1	10	0	0	1	4
Missing*	2	13	0	0	1	11	3	12
Total	15	100	10	100	9	100	25	100

Note: The sum of responses for breast, bowel and cervical screening combined is greater than 'all respondents' due to a number of people reporting on more than one screening program. * No response given.

Table 8: Project reporting on participation by screening program

Have you produced any reports, publications or evaluations on participation within your program either overall or among under-screened and never screened groups?	Breast screening		Bowel screening		Cervical screening		All respondents	
	no.	%	no.	%	no.	%	no.	%
	Yes	11	73	5	50	6	67	15
No	2	13	3	30	2	22	5	20
Not Applicable	0	0	2	20	0	0	2	8
Missing*	2	13	0	0	1	11	3	12
Total	15	100	10	100	9	100	25	100

Note: The sum of responses for breast, bowel and cervical screening combined is greater than 'all respondents' due to a number of people reporting on more than one screening program.

** No response given.*

A wide variety of documentation was submitted by participants as additional resources to survey answers. This included literature available on the internet as well as unpublished material such as evaluations, project reports, communication strategies, business and work plans, discussion papers, monitoring and statistical reports. In some instances respondents indicated that evaluations had been conducted, but these were not forwarded with the survey response.

4.3.4. Participants' ideas and strategies

Participants shared the following ideas from their various strategies:

- Using existing ethnic and multicultural groups as a means to recruit women requires time and sensitivity to develop trusting partnerships, and understanding of the reciprocal nature of the relationship. This can be a slow process in some communities – expecting to achieve successful outcomes quickly is unrealistic.
- Relationship-building and persistence over time is required to gain the trust of ATSI and CALD communities and educate about cancer screening.
- Men also require knowledge about cervical screening. In some communities, where men's permission is required for women to take part, it is essential that men are included in education.
- Isolated women with low English language proficiency are unlikely to attend education groups unless offered transport and, if necessary, childcare.
- Use of Chinese Language Clinics in Box Hill, Victoria has been well received. It is a cost effective way of increasing the number of women receiving a Chinese interpreter and improving equity of access.
- Women from CALD backgrounds face barriers similar to those of Anglo-Australian women such as knowledge about cervical screening, fear, embarrassment, discomfort, pain and fear of outcome. Additional barriers identified for women from CALD background included language, cost, knowledge and understanding of the disease, motivation for prevention, the higher priority that women give to the health of their children and family, as against their own health, taboos on the discussion of sexual matters, beliefs and cultural practices and lack of linguistically and culturally appropriate services.
- The use of bilingual assistants recruited from within their communities is an effective way of reaching isolated women who might otherwise remain uninformed. It is also essential to

engage women about educational opportunities and assist them to overcome barriers to attend. Trained and more knowledgeable bilingual workers were better able to inform and motivate women.

- Bilingual workers who are known to and part of the community and are able to pass on information in an appropriate manner, without bias, have proved their value, particularly in dealing with HIV/AIDS issues, chronic diseases and immunisation. They know the culture, customs and values of the particular communities. Funding bilingual workers which would include their training and maintenance of competence would go a long way towards creating awareness about cervical screening.
- It is important that the medical profession, particularly GPs are involved in education, awareness, and delivery of screening to CALD groups where relevant.
- There is an emerging role for Refugee Nurses. These nurses would have a very important role to play in creating awareness about cervical screening.
- Identifying lapsed attendees and developing strategies to encourage them back for screening, such as further reminder letters is a strategy in use within breast screening.
- Money needs to be allocated nationally to CALD issues. Nationally funded CALD coordinators for each jurisdiction, who could work with health promotion officers and other relevant health workers to assist in awareness of and participation within screening, would be helpful.

The range of strategies in place to capture under-screened, never-screened and hard-to-reach populations are numerous and diverse. Participants reported many successes, particularly in the use of reminder letters, media campaigns, use of interpreters and grass roots work within the community. However, many of these programs were not formally evaluated and therefore conclusions about their effectiveness cannot be made. They also emphasised the many challenges, and that there are no quick fixes. Part of the complexity highlighted is that the hard to reach groups themselves are so diverse, often requiring different approaches.

4.4. Examples of Media Campaigns

While You're Here, Book Your Smear: New Zealand National Cervical Screening Program

On 18 September 2007, a campaign to encourage women to have regular cervical smears as part of the National Cervical Screening Program was launched.

The campaign, which included eight television commercials, had a strong focus on Māori and Pacific women because of their higher rates of cervical cancer and lower rates of cervical screening. Information was also provided to Asian women.

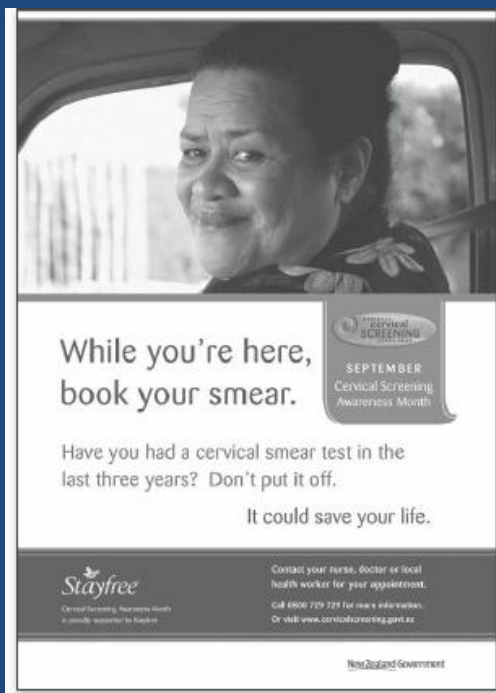
The campaign was developed to complement existing work carried out by Providers, with the overall aim of increasing the number of Māori and Pacific women who have regular cervical smears as part of the Program.

There has been a clear and direct link between the campaign and the number of women going for a cervical smear. Figures to June 2008 showed that since the previous year, screening coverage increased by:

- 4% for Maori women *
- 9.9% for Pacific women
- 5.3 % for Asian women
- 2.4% overall

These are statistically significant changes for all ethnic groups which has been very encouraging

**(Note: figures for Maori women to April only).*



In September 2009, a variety of advertising took place including: television, radio, ad shells, magazines, on-line, in medical centres, and in Maori, Pacific and Asian media, to coincide with Cervical Screening Awareness Month.

Promotional items included “*While you're here, book your smear*” cards for display on reception counters at clinics, free hand and body lotion samples to women having their smear test during September, and a partnership with Johnson & Johnson to place stickers on Stayfree pads packets carrying cervical screening messages.

Source: National Cervical Screening Program – Communications Campaign <http://www.nsu.govt.nz/Health-Professionals/2376.asp> and http://www.nsu.govt.nz/Files/SM_Issue19_Sep09_final.pdf

Don't Just Sit There: PapScreen Victoria

In 2004 PapScreen Victoria ran a mass media campaign titled "Don't Just Sit There". The campaign involved TV ads and mail campaigns.

The result was **8000 more Pap tests in 3 ½ weeks** – the majority of these were older unscreened & under-screened women.



The campaign had a significant positive effect on screening behaviour, with an 18% increase during the campaign. The campaign was repeated in 2005, and materials were also translated to reach Chinese, Arabic, Greek and Italian women.

A similar campaign was run in New South Wales in 2007 resulting in an increase in the number of Pap tests across all ages by 22 percent during the campaign, compared to the same period in 2006.

These evaluations of Australian media campaigns indicate that they have an effect, at least in the short-term.

Source: PapScreen Victoria, Communications & Recruitment Program 2000-2005 Final Report

Cherry & Pea TV Campaign: BreastScreen NSW

The Cherry & Pea TV commercial emphasises the importance of early detection of breast cancer by comparing the size of a breast cancer detected by physical examination (represented by a cherry) to that of a breast cancer detected by a screening mammogram (represented by a pea).

Evaluation of the campaign in February 2009 found that for 68% of women it “makes me more likely to call BreastScreen NSW for an appointment” while 86% agreed that it “makes me more aware of why I should have a mammogram every 2 years”.



Source: BreastScreen NSW, http://www.cancerinstitute.org.au/cancer_inst/campaigns/breastcancer.html

4.5. Partners and Other Agencies

More than three-quarters (80%) of respondents collaborate with partners and other agencies to target under-screened and never-screened populations, as shown in Table 9.

Table 9: Partnerships by screening program

<i>Do you work with health professionals or service providers to target the under-screened and never screened groups?</i>	Breast screening		Bowel screening		Cervical screening		All respondents	
	no.	%	no.	%	no.	%	no.	%
Yes	13	87	8	80	8	89	20	80
No	0	0	2	20	0	0	2	8
Not Applicable	0	0	0	0	0	0	0	0
Missing*	2	13	0	0	1	11	3	12
Total	15	100	10	100	9	100	25	100

Note: The sum of responses for breast, bowel and cervical screening combined is greater than 'all respondents' due to a number of people reporting on more than one screening program.

** No response given.*

The types of partners listed included:

- Cancer councils;
- Migrant resource centres; multicultural community groups, CALD radio programs;
- Indigenous bodies and organisations, Indigenous health workers;
- Disability services;
- Women's health centres, Rural Women's GP services, Women's health nurses;
- Community Health Services;
- Non-Government Organisations;
- Family Planning Organisations;
- Divisions of General Practice, The Royal Australian College of GPs (RACGP), General Practice Division Victoria (GPDV);
- Royal College of Nursing Australia;
- Sexual Health Centres;
- State and Territory Government Departments;
- AIHW; and
- The Electoral Commission

4.6. Future Steps

Twelve respondents (48%) reported particular strategies or innovative tactics that they found to be successful in improving participation among under-screened and never-screened groups. Table 10 illustrates the results stratified by screening program.

Table 10: Successful strategies by screening program

<i>Do you have any particular strategies or innovative tactics that you have found to be successful in improving participation among under-screened and never screened groups?</i>	Breast screening		Bowel screening		Cervical screening		All respondents	
	no.	%	no.	%	no.	%	no.	%
Yes	7	58	4	40	3	38	12	48
No	3	25	4	40	4	50	7	28
Not Applicable	0	0	1	10	0	0	1	4
Missing*	2	17	1	10	1	13	5	20
Total	12	100	10	100	8	100	25	100

Note: The sum of responses for breast, bowel and cervical screening combined is greater than 'all respondents' due to a number of people reporting on more than one screening program.

** No response given.*

A number of the strategies mentioned focussed on ATSI and CALD clients. These involved the use of Aboriginal Health Workers, representation on ATSI or CALD specific reference groups, bilingual educators, providing free transport for women (mainly Aboriginal) living in remote areas to attend mobile screening units, and providing group bookings.

Peer education was seen to be effective, as was communication, media and reminder letter campaigns. Joint strategies implemented through the government and cancer councils, stakeholder interviews and combining strategies across programs such as breast and cervical were options being explored. Identifying high priority local government areas (LGAs) based on the proportions of women from culturally and linguistically diverse and/or low socioeconomic backgrounds with low screening participation was another method used to identify and target participation among under-screened and never-screened groups.

Participants were invited to list any suggestions they had for improving data quality or participation by under-screened and never-screened groups. Some of these included:

- the use of media supported by local education strategies;
- access to Indigenous and CALD identifiers;
- improved education regarding data collected by practitioners, in particular the self-identification of ethnicity;
- Use of electoral role for matching;
- Collection and use of Medicare numbers; and
- GP liaison and health promotion liaison.

More specific suggestions relating to bowel screening included easier access to National Bowel Cancer Screening Program data from the Department of Health and Ageing and Medicare, particularly to look at data analysed by special needs groups as well as to evaluate participation by under-screened and never-screened groups.

In terms of cervical screening, the need for a national identifier for women who participate was suggested, particularly to assist in work planning as well as applying for funding to reach CALD communities. One suggestion to improve participation of those in the breast screening 'under-screened' group was to examine women who were lapsed attendees

5. Conclusions

There are a variety of spatial levels at which programs collect and report data by, with many finer spatial units such as postcode and street address available. Information on the cultural diversity of the population participating in cancer screening exists, although it is quite limited for cervical screening. Indigenous status and language spoken at home are the most widely collected items indicating cultural diversity, most commonly collected by the breast screening programs. Around 20 percent of respondents routinely collect additional data relating to socio-economic status while over one third conducted special studies to examine client characteristics.

Almost 85 percent of respondents had some evidence of decreased participation either for the program as a whole or among specific groups. In response to this evidence a range of population groups have been targeted by screening programs. Strategies to reach Indigenous and CALD groups were common to all three screening programs, with rural and remote populations and disabled groups also targeted. Media campaigns, education, the provision of funding, engaging with communities, health care professionals, peak bodies and advisory groups are key strategies across programs and jurisdictions to increase participation. Only about half the respondents carried out evaluations of these strategies, to varying degrees.

A wide variety of documentation was submitted by participants as additional resources to survey answers. This included literature available on the internet as well as unpublished material such as evaluations, project reports, communication strategies, business and work plans, discussion papers, monitoring and statistical reports. The volume and diversity of information is evidence not only of the amount of work happening in this area, but also the degree to which many programs and organisations grapple with this issue. A 'one size fits all' approach is not suitable due to the diverse, and at times changing nature, of the various target groups, such as culturally and linguistically diverse populations, whose composition may be altered over time by changing migration patterns. In addition, relatively few formal evaluations were conducted of interventions to improve participation in under-screened groups and this limits the assessment of the effectiveness of interventions.

Survey participants highlighted that capturing never-screened populations is a challenge, sometimes due to logistical issues or lack of funding, but more often due to a lack of data regarding who the under-screened and never-screened groups are and where they are located. However, there is significant effort attempting to identify and reach these groups within each screening program. There was a high degree of collaboration evident in approaches to improve cancer screening rates, with more than three quarters of respondents reporting working with partners and other agencies to target hard-to-reach populations. There was some evidence of collaboration across cancer screening programs, particularly where they are administered jointly, but there is potential for improved collaboration and leveraging off work conducted in different screening programs.

6. Acknowledgements

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7. Appendices

7.1. Appendix A: List of survey questions

Dear Colleagues,

Why a survey?

Victoria's Cancer Action Plan 2008-2011 (<http://www.health.vic.gov.au/cancer>) aims to increase cancer screening participation in communities that have lower than average participation rates such as Indigenous and culturally and linguistically diverse communities. In order to inform the Cancer Action Plan, the Victorian Department of Human Services (DHS) has commissioned the Victorian Cytology Service (VCS) to collate and review work already undertaken to identify hard-to-reach groups within cancer screening programs as well as examining strategies to increase participation.

Who is it being sent to?

This survey has been sent to government run and funded cancer screening programs throughout Australia and New Zealand. We are aware that there are many other groups working within the area of cancer screening and promotion, so please feel free to include details of work you may be doing in conjunction with other organisations, or to add relevant information that you are aware of in the non-government sector. Additionally, you are welcome to forward the survey to other contacts not included in our distribution where you think they have relevant information relating to participation in cancer screening.

How long will it take?

The survey will take approximately 10-15 minutes to complete. The 1st section of the survey relates to data identifying under-screened and never screened groups while the 2nd section relates to methods for improving participation in screening programs.

What information are we interested in?

Of particular interest are evaluations or reports from the year 2000 onwards, including unpublished information, report write-ups, project summaries or overviews on unsuccessful strategies as much as the successful ones. Please note that there are several questions asking for relevant reports or documentation throughout the survey (e.g. Strategic plans, program or statistical reports) so it may be useful for you to gather these documents before commencing.

Is the information confidential?

Your survey responses will be strictly confidential and data from this research will be reported only in the aggregate. The information will be used for internal reporting purposes and in a de-identified aggregated format when providing feedback on the survey results to participants. Respondent contact information is collected so we can contact you if we require further information, and to provide feedback on the survey.

Prefer the phone?

Please let us know if you would prefer to complete the survey via phone and we will arrange for a convenient time to call you.

Questions?

If you have questions about the survey or the procedures, you may contact Bianca Barbaro on 03 8417 6817 [international callers ph. +61 3 8417 6817] or by email [bbarbaro@vcs.org.au].

Feedback

Please note that the Victorian Cytology Service will provide participants with feedback on the results of this survey. Thank you very much for your time and support. Please start with the survey by clicking on the Continue button below.

Respondent Details

First and Last Name

Address

Suburb

State

Postcode

Country

Phone

Email Address

Name of organisation:

What screening program is your organisation involved in? (circle all that apply)

1. Breast Screening
2. Bowel Screening
3. Cervical Screening
4. Other

Data on Participation

What is the target population for your screening service? (circle all that apply)

1. Male
2. Female

What is the target age group?

Is client data available by any of the following geographic regions? (circle all that apply)

1. Street address
2. Postcode
3. Divisions of General Practice
4. Statistical Local Area (SLA)
5. Local Government Area (LGA)
6. Collection District (CD)
7. State
8. Other

Do you collect information on any of the below? (circle all that apply)

1. Indigenous Status
2. Place of birth
3. Year of arrival to Australia / New Zealand
4. Language(s) spoken at home

If you do collect information on any of the above, please provide the exact question and response options you use:

Indigenous Status

Place of birth

Year of arrival to Australia / New Zealand

Language(s) spoken at home

Do you routinely collect any information relating to socio-economic status? (e.g. disability, income, education, employment status, whether receiving government benefits etc.)

1. Yes
2. No
3. Not Applicable

If yes, please provide information on the question(s) and response options you collect relating to socio-demographic information:

In addition to routine data, have you conducted any special studies to examine the characteristics of your clients? (e.g. population based collections or client satisfaction surveys)

1. Yes
2. No
3. Not Applicable

If yes, please list any socio-demographic information collected through these:

Strategies to Improve Participation

Does the program have any evidence or references showing decreased participation overall or among specific groups?

1. Yes
2. No
3. Not Applicable

If yes, please list below further information on the type of evidence or a link to the literature if available:

Does the program have strategies to increase participation among any of the below groups? (circle all that apply)

1. Indigenous people
2. Culturally and Linguistically Diverse (CALD) people
3. Older women
4. Men
5. Lesbians
6. Disability Groups
7. People living in rural or remote areas
8. No / Not Applicable
9. Other

If yes, please list details on the types of strategies used for each group (e.g. information sessions, surveys, TV/Radio/Print campaign, mailouts etc.)

Indigenous people

Culturally and Linguistically Diverse (CALD) people

Older women

Men

Lesbians

Disability Groups

People living in rural or remote areas

Other

Have any evaluations been carried out on any of the above mentioned strategies?

1. Yes
2. No
3. Not Applicable

If yes, please list which strategy the evaluation referred to or the title of the report:

Have you produced any reports, publications or evaluations on participation within your program either overall or among under-screened and never screened groups?

1. Yes
2. No
3. Not Applicable

If yes, please list below further information on the literature or email relevant reports, publications or evaluations to bbarbaro@vcs.org.au or post to Cancer Screening Survey, Victorian Cytology Service, PO Box 310, East Melbourne, 3002:

Partners & Other Agencies

Do you work with health professionals or service providers to target the under-screened and never screened groups? (e.g. holding education sessions, providing information resources, providing funding, scholarships, telephone support etc.)

1. Yes
2. No
3. Not Applicable

If yes, please provide summary information regarding your work in this area, as well as the names of the partners/agencies that you work with:

Future Steps

Do you have any particular strategies or innovative tactics that you have found to be successful in improving participation among under-screened and never screened groups?

1. Yes
2. No
3. Not Applicable

If yes, please list some summary information regarding this strategy or innovative work:

Please list any suggestions you may have for improving data quality about and/or participation by under-screened and never screened groups:

We would appreciate copies of your most recent strategic plan or program reports. Please email these to bbarbaro@vcs.org.au or alternatively mail to Cancer Screening Survey, Victorian Cytology Service, PO Box 310, East Melbourne, 3002.

Please feel free to list any other comments below:

Are you happy to be contacted by the Victorian Cytology Service for further information if required?

1. Yes
2. No
3. Other

We thank you very much for your time.

7.2. Appendix B: References provided or referred to by survey participants¹

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