**National Cervical Screening Programme: Changing the primary laboratory test**

**List of consultation meetings**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Number | Date | Geographic Area | Meeting Location | Audience | Number in Attendance |
| 1 | 14 October 2015 | Wellington (Lower Hutt) | Kokiri Marae | Māori | 13 |
| 2 | 14 October 2015 | Wellington | Travelodge Wellington  | General Public | 7 |
| 3 | 14 October 2015 | Dunedin | Wakari Hospital  | Clinical | 8 |
| 4 | 15 October 2015 | Auckland | Papakura Marae | Māori | 8 |
| 5 | 15 October 2015 | Auckland | South Seas Healthcare  | Pacific | 8 |
| 6 | 15 October 2015 | Auckland | Potters Park Event Centre | General Public | 12 |
| 7 | 16 October 2015 | Christchurch | Russley Golf Club | General Public | 19 |
| 8 | 19 October 2015 | Wellington | Ministry of Health | Laboratories | 14 |
| 9 | 20 October 2015 | Wellington (Porirua) | Te Rauparaha Arena | Pacific | 8 |
| 10 | 21 October 2015 | Hawkes Bay | Hawkes Bay District Health Board | Clinical | 11 |
| 11 | 21 October 2015 | Gisborne | Hauora Tairawhiti Ko Matakerepo | Clinical | 23 |
| 12 | 23 October 2015 | Wellington | RANZCOG Teleconference | Professional College | 5 |
| 13 | 11 November 2015 | Wellington | RNZCGP Meeting | Professional College | 2 |

 Total attendance: 138

Meeting 1: Wellington hui at Kokiri Marae 14 Oct 2015

**Consultation attendees:**

1. Angela Davies CPHQ
2. Eileen Hollands Hutt Valley DHB
3. Louise Sanford The Cancer Society of New Zealand
4. Robyn Ingleton Te Awa Rarogi Health Network
5. Cassie Elley Mana Wahine Ora Toa
6. Eve Kaimoana Maraeroa Marae Health Clinic
7. Pungaerere Elaine Denton Mana Wahine
8. Josie Reivi-Rongonui Mana Wahine Whaiora
9. Sally Walker Mana Wahine Whaiora
10. Diane Chapman Kokiri Marae
11. Tracy Keelan Kokiri Marae
12. Kuini Puketapu Hutt Valley DHB

**The nine key themes for this consultation:**

1. Self-sampling
2. Starting age limit
3. Ending age limit
4. Screening intervals
5. Workforce impacts
6. Equity
7. Immunisation
8. Further research
9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

1. Self-sampling
	1. The cost associated with self-sampling or repeat testing in a doctor’s office may prevent Maori women from accessing a screening because of limited funds or bills owed at the doctor’s office. They may also have limited access to transportation or childcare, making repeat testing even more challenging.
	2. Self-sampling may increase inequity issues as wahine won’t do it or may get mokos to take it for them. The samples may also not be properly cared for or delivered after collection.
	3. Women who had a positive result may not do any follow up. How would the programme support them?
	4. Where would self-sampling results go and how will that affect test-taking?
2. Starting age limit
	1. There was strong resistance to the idea of pushing back the start date because it may adversely affect Maori women with earlier sexual debuts.
		1. “Missing even one Maori girl is a life lost.”
	2. There is a perceived risk of women who have cancer not being on the radar.
3. Ending age limit
	1. Older Maori women may not accept the need for screenings later in life, so they may not go.
4. Screening intervals
	1. Many in attendance felt that increasing the screening intervals would increase, rather than decrease, the equity gap.
	2. Increasing the time between screenings to five years may pose a risk for women who are difficult to locate for overdue screenings (i.e. if it takes 1+ years to track them down, it becomes 6+ years since their last screen).
	3. The register will need regular maintenance, because when attempts are made to contact women overdue for screens, their phone numbers and addresses have often changed.
5. Workforce impacts
	1. Will colposcopy facilities be able to cope with the increased workload?
6. Equity
	1. Maori experience unequal access to health services and disproportionately experience poorer health outcomes, including higher mortality rates from disease.
		1. Maori women with disabilities may face additional barriers (including financial) that need to be taken into consideration.
	2. There is a need to improve health literacy among Maori women.
		1. Many Maori women do understand the importance of screening.
		2. Young Maori women may conflate the HPV screen with getting tested for HIV.
		3. Older Maori women may not understand how to take swabs and may feel they can’t because they are “not a doctor.” They also may not understand the reason for getting screened at 65+ years.
	3. Fear and mistrust of the medical profession and associated institutions may be an additional barrier. For instance, Maori women may be embarrassed at owing money to the doctor or may be afraid of the results.
	4. Additional funding will be needed to enable additional community health/support workers to provide healthy literacy education and ensure Maori women get screened.
		1. Face-to-face interactions and korero are more effective than repeat letters about overdue screens. Korero will also empower women to share the information through their informal networks with whanau and other women.
	5. There is a significant need to focus on whanau ora when working with Maori women, and this should be reflected in the screening programme. It should be considered part of a multi-pronged approach.
		1. It is perceived that without this approach, the screening programme will increase rather than reduce the equity gap.
		2. NSU has the ability to encourage the government to provide access through increased funding for a whanau ora approach that addresses wider issues facing Maori women.
	6. The Treaty of Waitangi needs to be recognised in the new screening programme. Maori worldview and ways of working to reach Maori need to be specifically included. A different lens has to be applied when working with Maori. How will their status at treaty partners be respected?
7. Immunisation
	1. There is a need to improve immunisation rates across the board and participants queried whether HPV immunisation would be extended to boys.
8. Further research
9. Additional feedback

Meeting 2: Wellington general public at Travelodge Wellington 14 Oct 2015

**Consultation attendees:**

1. Rosie Stewart Family Planning
2. [name redacted] General public
3. Geraldine Walmsley Capital and Coast DHB
4. Karen Heine The Cancer Society
5. Bev Lawton Women’s Health Research Centre University of Otago
6. Pete Gootjies Southern Community Laboratories

**The nine key themes for this consultation:**

1. Self-sampling
2. Starting age limit
3. Ending age limit
4. Screening intervals
5. Workforce impacts
6. Equity
7. Immunisation
8. Further research
9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

* + - 1. Self-sampling
1. Self-sampling should be available to all women.
2. What is the sensitivity of self-sampling? Will it decrease the ability to identify and support priority group women?
3. Starting age limit
	1. Pushing back the start date may adversely affect Maori women, who disproportionately develop cancer before the age of 25.
	2. A later start date may also pose a risk for women between 20 and 25 years of age.
4. Ending age limit
5. Screening intervals
	1. Increasing the time between screenings to five years may pose a risk for women who are difficult to locate for overdue screenings (i.e. if it takes 1+ years to track them down, it becomes 6-10 years since their last screen).
	2. The longer period between screens may increase the equity gap with under-screened women, vulnerable women, or Maori and Pacific women.
	3. One attendee advocated for informed consent that allowed women to choose whether they wanted a screening every 5 years (if low risk) or 3 years (if higher risk).
6. Workforce impacts
	1. There is concern about women who are referred to colposcopy and nothing shows. Are continued tests necessary?
	2. Will labs be centralised?
7. Equity
	1. There is a need to re-frame the cervical screening narrative more positively.
		1. For example, using the phrase “exit smear” shifts the focus from women’s health to the programme, when it should be the other way around.
	2. There is a need to promote informed consent to support women’s control and decision-making abilities.
		1. Included within this is a need to provide information to young women before they start the screening programme.
	3. Support services may need to be increased to ensure proper follow up and care for women, especially if they self-sample.
8. Immunisation
	1. There is a need to get immunisation rates up across the board.
	2. There is concern about older women who may get hrHPV 16/18 and may not be covered by immunisation.
	3. There is a need for immunising young men in additional to young women.
9. Further research
	1. There is a need to examine the longevity of the vaccine because it is not currently known if the HPV vaccination will provide life-long protection.
	2. What is the evidence for other screening programmes? There were calls to slow the Ministry’s plans until more research is made available about the effectiveness of the Australia and Netherlands programmes.
10. Additional feedback
	1. The test is not 100% effective, so there are concerns about sensitivity.
		1. This includes women who receive a false negative and later develop cancer.
	2. Is there a screening plateau in terms of success rates, especially for some groups?
	3. Some commented that they were happy switching to an HPV screening, but had issues around the change in age range and screening interval.
	4. Women’s control over their bodies and what happens to it should remain a key focus of the programme.

Meeting 3: Dunedin meeting at Wakari Hospital 14 Oct 2015

**Attendees:**

1. Paul Spek Southern Community Laboratories
2. Jocelyn Arthur Southern Community Laboratories
3. Livia Hardy Southern DHB
4. Sharon Robson Service Manager, Population Health (Southern DHB)
5. Barron Brown ONG Consultant
6. Judith McCarty Lead Colposcopy Nurse
7. Pip Egerton Practice Nurse Medical Centre
8. Sue Smith Primary Care representative Cervical screening
9. Peter Fitzgerald Southern Community Laboratories

(Also people from Invercargill in attendance. Names not provided).

**Notes:**

* A question was raised about the reduction of cervical cancer from HPV screening.
* Concern was raised that 80% cancer is in under-screened women.
* Concerned that coverage will worsen if expanded from 3-yearly cytology screening to 5-yearly HPV screening. The NCSP needs to improve coverage.
* Issue was raised of adjunct cytology needed for HPV 29, 16 and 18.
* Concern was noted that sensitivity of LBC is understated and the sensitivity HPV is overstated.
* It was commented that LBC performance is expected to be closer to 90%.
* It was stated that cytology is better than expected.
* Concern was raised that moving to primary HPV screening might mean that fewer endometrial cancers are detected, compared with primary cytology screening that may detect endometrial cancer as side benefit.
* Attendees questioned whether strategy 2a is likely to result in decrease of cancers.
* Concern was raised about public perceptions linking the HPV vaccine to sexual activity.
* There was concern about girls under the screening age who have an STI. It was also noted that HPV can also cause oropharyngeal cancer.

Meeting 4: Auckland hui at Papakura Marae 15 Oct 2015

**Consultation attendees:**

1. Natasha Iotuo Te Hononga
2. Camilla Tuiraiti Te Hononga
3. Tapina Taniola Raukura Hauora o Tainui
4. Meena Narang Counties Manukau DHB (CMDHB)
5. Dianne Glenn CMDHB and National Council of Women NZ
6. Lorraine Busby Waiparera
7. Tania Pompallier Raukura Hauora o Tainui

**The nine key themes for this consultation:**

1. Self-sampling
2. Starting age limit
3. Ending age limit
4. Screening intervals
5. Workforce impacts
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8. Further research
9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

* + - 1. Self-sampling
1. Self-sampling could be an empowering experience by encouraging self-responsibility.
2. There is a need for an urban and rural trial for self-sampling before implementing.
3. Self-sampling would be great for women in rural areas. It’s the only way to engage wahine on the screening pathway.
4. Women may not perform the self-sample correctly, which happens with STI screens. Outreach workers will be needed to ensure self-sampling is done correctly.
5. The bowel screening programme is a good example of a screening process that works well.
6. Starting age limit
	1. Maori women are sexually active at 15 years of age. If the first screen is not until 25 years of age, there could be a risk.
	2. However, starting at 25 years of age is okay if the decision is based on evidence.
7. Ending age limit
	1. Is an exit smear necessary for low-risk women who have never had HPV?
8. Screening intervals
	1. New Zealand women travel back and forth to Australia quite a bit, which could pose problems with accessing screenings, especially if increased.
9. Workforce impacts
	1. There is a bottleneck with colposcopy clinics. Are there services to support the future increase in demand?
10. Equity
	1. The programme needs both Maori and Pacific responsiveness in terms of how it is delivered. This has been lacking for some time.
	2. The messaging around cervical screens needs to be done differently.
		1. Currently, the messaging is a scientific one and not a community message.
		2. It should be about men looking out for, and protecting, women.
			1. This can be very effective with Asian and Islamic men who can be very influential by encouraging women to get screened.
			2. An example for how this was done effectively was a recent advert with the Raukura Rugby League that encouraged men to take charge and get women in for a screen.
		3. Families should also be considered focus points as grandparents ask questions of moko.
		4. Social responsibility needs to be restored in a culturally-appropriate manner and be linked with restorative value.
	3. More information is needed about screening to address the knowledge gaps that surround it. A media programme could be used, but it needs to include men.
	4. We can’t get equity for women if men are not a part of it. This is especially true for Maori women.
11. Immunisation
	1. Boys should be vaccinated as well as girls. Girls are being picked on as the only targeted group.
	2. Immunisations could be done through Maraes or churches.
12. Further research
13. Additional feedback
	1. What is the accuracy of the data that’s been shared?
	2. Is information being collected with Islamic women? We may be missing an important group.

Meeting 5: Auckland fono at South Seas Healthcare 15 Oct 2015

**Consultation attendees:**

1. Kim Letford Alliance Health Plus
2. Lean Sanford Auckland DHB/Waitemate DHB
3. Vai Naseri Health Star Pacific Trust
4. Juanita To’o Health Star Pacific Trust
5. Alaviola Pomana South Seas Healthcare
6. Juliet Pati South Seas Healthcare
7. Aifai Taupule South Seas Healthcare
8. Irata Passi South Seas Healthcare

**The nine key themes for this consultation:**

1. Self-sampling
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3. Ending age limit
4. Screening intervals
5. Workforce impacts
6. Equity
7. Immunisation
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9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

* + - 1. Self-sampling
1. Self-sampling should be available to all women.
2. Self-sampling may help Pacific women who are not going in for a screen because they are shy. For example, if a Palangi/ European nurse is not available, they may be afraid to get a screen because they know a Pacific nurse through family, church, or other ties.
3. Focus groups with women from the community are needed in order to get their feedback.
4. Starting age limit
	1. Girls who are not immunised will be at a higher risk if the starting screen is pushed back to 25 years of age.
	2. Smears may still be needed at 20 years of age.
5. Ending age limit
6. Screening intervals
7. Workforce impacts
8. Equity
	1. Involving partners/men may help encourage some Pacific women to get screened.
		1. This may not work for Tongan or older Maori women, where the topic is tapu.
9. Immunisation
	1. Clinics/practices are not informed about the HPV immunisation status of their patients who are girls.
10. Further research
11. Additional feedback

Meeting 6: Auckland general public meeting at Potters Park 15 Oct 2015

**Consultation attendees:**

1. Lynda Williams Auckland Women’s Health Council
2. Ana dos Santos Roche
3. Lava Hashimoto Roche
4. Bill Neville Roche
5. Jen Barnes Roche
6. [name redacted] General public
7. Erin Retter International Accreditation New Zealand (IANZ)
8. Jane Grant Waitemate DHB
9. Lifeng Zhou Waitemate DHB
10. Holly Coulter Women’s Health Action
11. Christine Lipyeat Cairnhill Health
12. Marita Carman Roskill Union and Community Health

**The nine key themes for this consultation:**

* + - 1. Self-sampling
			2. Starting age limit
			3. Ending age limit
			4. Screening intervals
			5. Workforce impacts
			6. Equity
			7. Immunisation
			8. Further research
			9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

* + - 1. Self-sampling
	1. Will self-sampling be available to all women or a select few?
	2. Women less than 75 years of age may wish to self-sample.
1. Starting age limit
	1. Young women that have been sexually abused need to be considered for screening within the 20-25 year age.
	2. There needs to be a tailored programme for different ethnic groups. For example, tailored start times for screenings based on ethnicity.
2. Ending age limit
3. Screening intervals
	1. If women do not attend a screening, how will it be managed?
4. Workforce impacts
	1. How are the already stretched colposcopy services going to be managed?
	2. Will colposcopy wait time be longer?
	3. What is the timing of reporting between HPV and cytology tests? Will there be an increase in timeframe?
	4. Is the Ministry of Health looking at integrating the two registers (NCSP and NIR)?
		1. For example, if a woman presents with cancer, there may be questions around when she was immunised and what the length of time was between doses.
			1. There needs to be a proactive approach rather than a reactive one.
	5. Cytologists could be retrained to histology. It may be hard for them to change areas, though.
	6. Universities were not involved in the consultation process.
		1. If cytologist numbers are going to be reduced, conversations will need to happen with universities to alter the training programmes they provide.
5. Equity
	1. Better education in the schools about HPV, the vaccine, and screens is needed. This is important for informed consent.
		1. This includes how it is presented to parents, who are currently told it’s a vaccine for sexually transmitted infections, which is a negative framing.
	2. The rates of screening non-attendance are quite high for Maori and Pacific women, so how will the NSU cope with a potential increase?
	3. 80-90% of women clear the HPV infection, but most women do not understand that may occur naturally without treatment.
		1. Telling them they have the virus creates an environment that carries high anxiety, etc.
		2. Better education is needed to address this issue.
	4. Will screens be free?
		1. If the government was concerned about priority group women, their smears would be free.
	5. Categorising women as “priority women” based on their ethnicity might change to their HPV immunisation status. NSU needs to consider this.
	6. Language used within/about the programme needs to be careful. It won’t be a “smear” test anymore.
		1. It also is not a “cervical cancer vaccine,” which may cause women to think they’re fully protected against cancer.
6. Immunisation
	1. Why not vaccinate boys? Gardasil has been introduced for boys in Australia.
	2. Why not use a two-dose immunisation? Money saved by not administering the third dose could be used elsewhere.
7. Further research
	1. There is a need to examine the immunisation coverage rate for Maori and Asian women.
	2. It will be important to monitor different HPV types to see if there are any changes over a couple of years with increased immunisations, screenings, etc.
8. Additional feedback
	1. What about immune-suppressed women? Is there a different algorithm for them?
	2. With the specificity of the test, would the programme accept HPV tests from overseas?
	3. Will migrant women from overseas be screened as a part of the programme? Overseas smear tests are not currently accepted.
		1. Could this be part of an immigration medical check?
	4. If there is a significant rise in HPV, how will the NSU manage this?

Meeting 7: Christchurch general public meeting at Russley Golf Club 16 Oct 2015

**Consultation attendees:**

* + - 1. Helen Mcnab Canterbury DHB
			2. Jill Lamb Canterbury DHB
			3. Amy Carry Family Planning
			4. Kate Bridgeman-Smith Family Planning
			5. Sandra Hamilton Family Planning
			6. Allan Shao Canterbury Health Laboratories
			7. Jo Hackman-King Canterbury Health Laboratories
			8. Ruth Love-smith Canterbury Health Laboratories
			9. Hinarata Campin Screen South
			10. Angela Lee Screen South
			11. Jin Cho Screen South
			12. Natasha King Canterbury DHB
			13. Nancy Stewart Canterbury DHB
			14. Vivienne Back Screen South
			15. Julie Haywood Screen South
			16. Joan Miles Screen South
			17. Greg Devane Canterbury Health Laboratories
			18. Barbara Screen South
			19. Rachel Faatili Screen South
			20. Johanne Curtis Screen South

**The nine key themes for this consultation:**

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**Specific issues mentioned during the meeting in relation to broader themes:**

* + - 1. Self-sampling
	1. Ideally, self-sampling should be free.
	2. If utilised, the self-sample test must be extremely high quality.
		1. What is the validity and reliability of it?
		2. What is the evidence from self-sampling done in other countries?
	3. Self-sampling is not ideal for everyone, but may be beneficial for those who don’t show to their screens.
	4. Self-sampling could be a good first step to getting women on the screening pathway.
		1. It should be considered one tool in a toolkit for women who wouldn’t otherwise participate in the screening programme.
	5. Low vaginal swab would be a good starting point for women who have not previously participated to build confidence.
	6. There is value in visualising the cervix when conducting cervical smears, so would that be lost if self-sampled?
	7. The negative predicative value of self-sampling is still in the 90s, which is not as good as cervical smears.
1. Starting age limit
	1. Many in attendance did not like the idea of pushing back the start date to 25 years of age.
		1. People younger than 24 years of age have the most partners, potentially meaning their highest risk for contracting the virus is while they are younger than 25. A delayed start date would cut off these young people.
	2. How will the later start date affect women who have been sexually abused?
2. Ending age limit
	1. Doing a screen on a 69 year old woman is much more traumatic than doing it on a younger person.
	2. Is an end screen at 75 really necessary if cervical cancer is slow to develop, meaning they may not develop anything until their 90s?
	3. Women should have informed consent to participate or not at an older age.
3. Screening intervals
	1. Would be great if the test was every six years to tie into breast screening.
	2. What if the patient is not immunised? What is the validity of the 5 year testing?
	3. How will more aggressive types of HPV be affected by the longer screening intervals?
	4. Longer screening intervals may create less harm for women by decreasing their anxiety around so many tests, including unnecessary colposcopies.
4. Workforce impacts
	1. A two lab model has not been proposed by NCSP.
	2. How will colposcopy services be able to cope with the increased pressures?
	3. One cytoscientist in attendance was worried about staff attrition during the transition to the HPV primary screening and how that would affect the ability to manage the current liquid-based cytology workload.
	4. Not every cytologist will be able to be absorbed or re-trained, which is an issue.
	5. The benefit of cytology is that it can tell the difference between a low grade and a high grade lesions. It is important to remember it is more than a screening tool, it is a diagnostic tool.
	6. Workforce issues affect smear takers as well as lab staff. This needs to be taken into consideration.
	7. The register needs to be more functional, especially for health professionals.
		1. For example, it should include immunisation histories and even link to the NIR.
5. Equity
	1. Will the HPV primary screen be cheaper and/or free?
	2. A New Zealand focus must be maintained (and not just relying on Australian data) when considering a new screening programme.
6. Immunisation
	1. Some fully vaccinated women are showing up with high grade lesions. What are the implications of that?
7. Further research
	1. How many non-cervical cancers get detected through the current screening programme? Is that different from what the HPV screen would detect?
	2. With an increasing number of people who have the HPV vaccine, other strains (not 16 and 18) may become more prevalent. How will this be monitored?
	3. Are there any studies looking at a woman’s risk of developing cervical cancer if she had HPV in the past and then cleared it?
8. Additional feedback
	1. What is the reliability and sensitivity of the HPV screening test?
		1. There may be a difference between reliability studies done in a lab and real life experiences with reliability.
		2. Without broad “real life” experience studies, how do we know the true reliability? Should we rush into this?
	2. When women turn up for a cervical smear, staff also perform a sexually transmitted infection screen. Quite a few sexually transmitted infections are detected this way. How would this be taken into account with the new HPV testing programme?
	3. If a woman has been exposed to HPV, what is her risk for later developing cancer?
	4. There is a higher rate of hrHPV 52 in New Zealand. How will that be addressed in the new screening programme?
	5. Will the HPV test the same strains that are screened for now?
		1. Would we extend the range of testing (i.e. the number of strains)?

Meeting 8: Laboratory meeting in Wellington 19 Oct 2015

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| **Date:** | Monday 19 October 2015 |
| **Time:** | 12 – 4pm |
| **Location:** | G:04 Ministry of Health, Freyberg Building, 20 Aitken St, Thorndon Wellington |
| **Attendees:** | Marg Lovell-Smith - LabPlusMuna Bulbul, LabPlusLiz Pringle - APSRichard.Massey – PathLabHerman Ventor – MedLab Central Andrew Miller – Canterbury Health LaboratoriesAnya Werno – Canterbury Health LaboratoriesGreg Devane – Canterbury Health LaboratoriesPeter Fitzgerald – Southern Community Laboratories (VC)Paul Spek – Southern Community Laboratories (VC)Peter Gootjes – Southern Community Laboratories (VC)Margaret Sage – National Cervical Pathology Training ServiceChristopher Burke – Health Workforce NZCollette Bromhead – Technical Reference Group member, NZIMLS representative |

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| --- | --- |
| 1. | Meeting opened 12:15 |
| 2. | The group was updated on the progress the NSU has made to date on the HPV primary screening project. Included in the update was the process being following, the timelines for the project, the work to be done in future months and years, and how the laboratory workforce has been and will be involved in the project.Discussion covered:* The need for the Register to invite women to participate in the programme
* The need to closely consider the 2015 Kitchener paper on the UK NCSP as the UK is more comparable to NZ than other screening programmes because we both use LBC

Pilot study* Advocacy for a pilot study as a safety measure and to collect more NZ data comparisons between the new/old programme. Question asked whether NZ has the numbers for a proper pilot like the UK.
* Discussion of Compass NZ, and comment that the numbers in NZ Compass are too small to work out much more than HPV positivity rates.
* What are our outcomes of interest in terms of a pilot? – validation of the model, assessment of long-term risk, practicality in labs.
* Question asked “does NZ want to be first?” – we need to learn from other countries

Equity* The proposal won’t significantly improve the equity issue which is a key issue for the NCSP – we need to learn what went well with HPV immunisation for priority group women

Screening under 25 year olds * It was acknowledged that we are detecting cancers in the 20-24 group. Asked “what is the mean age of CIN 3 in NZ?”
* Agreement that HPV testing is not the best thing for U25s and support for cytology for under 25s being remodelled.
* Question asked if an overall co-testing regime would benefit a lot of women – discussed need for cytology result for all women being referred to colposcopy.
* Agreement that HPV testing is not the best thing for U25s and support for cytology testing for under 25s being remodelled
* Data – can look at the value of the second cytology 12mths after the first – what is compliance? What is the difference in results?
* Point made that there is a risk that the current programme will not be as effective over time as vaccination rates increase.
* Point made that NZ differs from other countries with STI and sexual behaviour – high chlamydia, low HIV (so people are not afraid).
* Princess study will provide info on how to reduce harms in under 25s.

Self-sampling* Support to not have self-sampling for all
* Supervision in taking sample required – potential for harm from false negatives
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| 3. | Cancer Council NSW led the group through a presentation and discussion on the HPV primary screening modelling evaluation  |
| 4. | Workshop: Laboratory Workforce implications with HPV primary screeningThe group discussed impacts of the proposed change on the lab workforce:* Did the Ministry want to have less contracts?
* Training requirements – what is required to maintain the workforce
* How do we best support clinicians – need to treat labs as a clinical support for the programme. Clinicians value pathologist and scientist input – recognise that cytology supports clinical decision-making
* cytology will be more diagnostic – abnormality rate will be higher - Staff won’t screen as many slides as the abnormality rate is higher
* Staff are really distressed
* Downsizing has already happened in some labs
* We need to rethink a laboratory strategy
* We need to give labs that do the work surety in the numbers of specimens – labs need this surety to invest in technology and staff
* Need labs of equal size
* There needs to be minimum funding of labs to run a cyto lab,
* APS has offered cytology staff training in histology, but none have accepted to date. Bowel screening programme will require additional histoscientists to process polyps
* Need a plan for supporting/ upskilling staff ahead of transition
* Don’t want to lose really expert people – need them to do the training
* Retention a big issue – offering financial incentives to stay is a temporary fix
* There are no new students coming through
* Consideration of making cytology post-grad training
* Consideration of impacts on non-gynae cytology workforce
* View that we don’t need a massive restructure of NCSP labs
 |
| 5. | Meeting closed 3:50pm. |

Meeting 9: Wellington fono at Te Rauparaha Arena 20 Oct 2015

**Consultation attendees:**

* + - 1. Kay Lavill Massey University
			2. Barbara Varday Compass Health
			3. Vaiata Mitchell Pacifica Women’s
			4. Katarina Crawford Department of Internal Affairs
			5. Kaopaerangi Ngatoko Cook Islands High Commission
			6. Tui Tarao Arthritis New Zealand
			7. Anne A-Moetara
			8. Akaiti Samuel CIM Porirua Community

**The nine key themes for this consultation:**

1. Self-sampling
2. Starting age limit
3. Ending age limit
4. Screening intervals
5. Workforce impacts
6. Equity
7. Immunisation
8. Further research
9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

1. Self-sampling
	1. Self-sampling may pose issues for older Pacific women who may experience difficulties with insertion of a tampon-based other similar test into the vagina.
		1. What is the uptake with older women and self-sampling?
	2. Self-sampling may be accepted by younger Pacific women, though.
		1. Marketing will need to encourage “taking responsibility.”
	3. There was hesitation around the idea of a two-stage self-sampling process.
	4. A key thing to consider will be a woman’s sense of safety when taking the test.
2. Starting age limit
	1. Pushing the start date to 25 years may be a risk for young women because it may mean connecting with a health professional later.
		1. For example, 16 to 20 year old women head into Family Planning for contraception, so it’s easier to get them to take a screen while in the office.
		2. If they aren’t starting to get screened until 25, they may come in less frequently and may find it challenging to develop relationships with health professionals.
3. Ending age limit
	1. A speculum exam may not be the most comfortable for older women.
4. Screening intervals
5. Workforce impacts
6. Equity
	1. Pacific women are struggling with the existing process. A two-stage process may be even more challenging.
	2. There is a need for health literacy to educate Pacific women about the screening process, risks, etc.
		1. It needs to be “de-mystified” for Pacific women.
	3. Education needs to begin much earlier, perhaps even 12 years of age (such as encouraging them to get ready for their future screening).
	4. Some Pacific women may fear the results and what that means for the next step.
		1. Reducing fear should be a priority with health literacy attempts.
	5. Support services within the community need to be improved so they can encourage participation in the programme. This is especially important for Maori and Pacific women, including older women.
		1. The support service providers need to be well-known, respected, information-sharing members of the community.
		2. The focus needs to be on relationship-building between the support service providers and the women, their families, and their friends.
	6. There is a need to explore the messages that will be used to educate.
		1. What will help the women themselves understand?
		2. What will help their providers understand?
		3. What is communicated is just as important as how it is communicated.
		4. There should also be a focus on the family, not just the individual woman.
	7. Marketing will be crucial for the effectiveness of the new screening programme.
		1. There is confusion around HPV, so “cervical screening” might be more effective.
		2. A social campaign would be a great way to reach younger people and their networks.
7. Immunisation
	1. Immunisation rates of Pacific women need to be improved and remain a key focus.
	2. Will boys be immunised, like in Australia?
		1. Immunising boys could remove the stigma young women feel by being the sole focus of immunisation efforts.
8. Further research
9. Additional feedback
	1. Women need to be fully-informed to be respectful of them and to empower them to make their decisions. In order to do this, it is important to give them lots of information.

Meeting 10: Hawkes Bay (Napier) meeting at Hawkes Bay DHB 21 Oct 2015

**Consultation attendees:**

1. Jenny Cawston Hawkes Bay DHB
2. Sandra Corbett Hawkes Bay DHB
3. Margaret Alexander Hawkes Bay DHB
4. Annette Davis Hawkes Bay DHB
5. Julia Glentworth Lead Colposcopy Nurse, Hawkes Bay DHB
6. Victoria Speers Health Hawkes Bay, PHO
7. Christine Le Geyt Central Health
8. Andrea Burton KHS “Choices”
9. Patrick Le Geyt Maori Health Hawkes Bay DHB
10. Lynda Croft Lead Colposcopist, Hawkes Bay DHB

**The nine key themes for this consultation:**

1. Screening interval
2. Starting age
3. Exit age
4. Self-sampling
5. Workforce impact- Colposcopy volumes and histology tests
6. Payment for testing
7. Register
8. Immunisation
9. Further research

**Specific issues mentioned during the meeting in relation to broader themes:**

1. Screening interval
	1. At present, we call women at 3 years, but they don’t come in for a smear until closer to 5 years. We don’t want this to happen if we move to 5 years – then women will delay until 7 years. Should we recall some groups earlier? We don’t want to increase risk for women who don’t have timely smears now.
	2. Need to consider application of longer screening interval for immunosuppressed women.
	3. There may continue to be women who want to have annual smears. Comment from the Maori Women’s Welfare League in previous meeting with Sandra that women will need to have confidence that the new test will keep them safe.
2. Starting age
	1. We need more research, and to reach herd immunity before we increase the starting age. Support for option of using cytology screening for under 25s.
	2. Understand the implications for increased referrals to colposcopy by using HPV to screen younger women, and the potential harms from over treating.
3. Exit age
	1. Older women at risk of HPV now – are seeing these cases in HB.
4. Self-sampling
	1. We need to be selective about who is offered self-sampling
	2. Informed consent is important – in that women need to understand that self-sampling is not the gold standard test.
	3. Women could be put off by knowing they may need to come back for another test (LBC or colp) – they would be better with one gold standard test
	4. Will all women want self-sampling when they hear about it? Would it be better to focus on why women are not wanting to have clinician collected smears now and how to encourage them to?
	5. Self-sampling could lead to a missed opportunity to take an holistic approach to health care
	6. Could be offered as a last-ditch attempt to get women into screening.
	7. Many women would jump at self-sampling, and may expect self-colposcopy too
5. Workforce impacts
	1. Will colposcopy facilities be able to cope with the increased workload? They are struggling to meet timeliness targets now.
	2. How will the pathologists cope with the increase in histology?
6. Payment for testing
	1. Question asked re who would pay for pathology tests under the new programme (ie any additional costs for DHB)
7. Register
	1. Our timelines for Register redevelopment are unrealistic and we need to be prepared for this. We need to read the “lessons learned” document prepared by Nick Winfield about the last register redevelopment. Choice of IT contractor is important.
	2. Don’t cut corners – make sure the new Register meets the needs of all going forward (particularly primary care).
	3. Whose role is it to invite women for testing – opportunity to have population health screening programme.
8. Immunisation
9. Timeline to implementation of new programme would give an opportunity to increase HPV imms coverage
10. Support for immunising boys equality issue at present
11. Further research
12. Get Register data on women with positive colposcopy findings after treatment
13. The number of woman who have been waiting following referral for a LG and have HG on biopsy
14. The issue where woman who are referred following a positive HrHPV test within three years of treatment, presenting, colposcopied and discharged as nothing to treat could this be an issue with HPV testing.

Meeting 11: Gisborne consultation at Tairawhiti DHB 21 Oct 2015

**Consultation attendees:**

1. Nicki Dever Tairawhiti DHB
2. Netta Kutia Community Clinic
3. Bill Weidermand Obstetrics and Gynaecology
4. Lynn Mackey Outpatients
5. Karen Staples Midlands Health Network
6. Evelyn Cross Hauora Tairawhiti
7. Missie Winiata Hauora Tairawhiti
8. Sean Pocock Obstetrics and Gynaecology
9. Sandi French Well Child
10. Clare Aitcheson Lead Colposcopy Nurse
11. Molly Para Hauora Tairawhiti MHS
12. Dewe Pawar Hauora Tairahiti MHS
13. Diane Van de Mark Obstetrics and Gynaecology
14. Connie Stephens Ngati Porou Hauora
15. Tiziana Manea Community Clinic
16. Chris Hannah Community Clinic
17. Jo Pere Cancer Society
18. Liz Mackenzie Turanga Health
19. Margaret Thorpe City Medical
20. Debra Bromley Puhi Kaiti – Ngati Porou Hauora
21. Rob Wilkes Uawa Clinic – Ngati Porou Hauora
22. Julia Wanoa Ngati Porou Hauora
23. One name not recorded.

**The key themes for this consultation meeting:**

1. Self-sampling
2. Starting age limit
3. Ending age limit
4. Screening intervals
5. Workforce impacts
6. Equity
7. Immunisation
8. Further research
9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

1. Self-sampling
	1. In general, a lukewarm response to self-sampling. Understood the limitations and the arguments for and against. General preference with clinician-collected cervical sample.
2. Starting age limit
	1. Will feel more confident about this change when the immunisation rates are better.
	2. Suggestion for cytology for under 25s.
3. Ending age limit
4. Screening interval
	1. Women may have anxiety about moving to 5 years – give them confidence that it’s okay.
	2. 5 years is great – will help encourage women to have smears as it is less frequent.
	3. There will be cost savings with the 5 yearly tests – can we use the savings to immunise boys?
5. Immunisation
	1. Want to see boys immunised.
	2. Immunisation rates are very good in Tairawhiti – have sent Kiawhina to homes to get consent forms signed – big focus on this.
6. Equity
	1. We need to carefully consider how to introduce the changes to the public – HPV immunisations was not sold well. We need education to give confidence to women about the changes.
7. Immunisation
8. Further research
9. Additional feedback
	1. How will the change effect post hysterectomy women – will they need smears? Will the guidance change?

Meeting 12: Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) teleconference 23 Oct 2015

**Consultation attendees:**

1. Jane Cumming RANZCOG
2. Lois Eva Auckland DHB
3. Gillian Gibson Gibson Medical
4. Peter Sykes University of Otago
5. Peter Stone University of Auckland

**The nine key themes for this consultation:**

1. Self-sampling
2. Starting age limit
3. Ending age limit
4. Screening intervals
5. Workforce impacts
6. Equity
7. Immunisation
8. Further research
9. Additional feedback

**Specific issues mentioned during the meeting in relation to broader themes:**

1. Self-sampling
	1. Conventional screening would be best, but self-screening is better than nothing.
	2. Good opportunity to include a hard-to-reach group but would be a negative step to over this as a universal option.
	3. Would need research in the New Zealand environment about how a positive self-sampling test is managed and consideration as to how these women engage with the health sector – suggestion is that a nurse is responsible for contacting women with negative results.
	4. Need to have pilot studies and not introduce this option until pilot studies have been conducted and evidence gathered.
2. Starting age limit
	1. Fully support epidemiology that screening under 25 years of age is not of any substantial benefit and has significant negative therapeutic effects.
	2. However, given there is still a risk to a small number there may be political issues if the impression is that women under 25 are being denied screening.
	3. There needs to be education and publicity about why screening under 25 years is not needed.
	4. There could be a big push in vaccination before the change takes place, especially given the increasing evidence of the benefit of vaccination to women in their 20s, not just younger women. Need strong recommendation for vaccination and explanation that this has evidenced-based protection against HPV whereas there is sketchy evidence of the benefits of screening for this group.
3. Ending age limit
	1. Exit age of 70 would seem appropriate but discretion should be used.
	2. RANZCOG is in favour of the exit test, as long as the screening interval is being followed.
4. Screening intervals
	1. There is good evidence that a five year interval is appropriate for HPV screening but need to consider the process if women miss a screening.
	2. Follow up process is needed.
	3. Education and monitoring will be important.
	4. High risk women needing shorter intervals between screening? Noted that the issue is that there is not a lot of data on this so monitoring will be important. RANZSCOG suggests the current normal screening intervals are maintained but are monitored and that this is included in research and evaluation in the future.
5. Workforce impacts
	1. Impact on workforce will be temporary and will reduce if vaccination rates increase.
	2. Needs to be resourcing for the expected initial increase – may be a greater than expected impact because there may be a higher than expected referral rate.
	3. Need to establish triaging methods after the changes. Suggest HPV 16/18 positive women are offered cytology before they come to the clinic. Need research on what is acceptable to the women.
	4. If self-testing is introduced, nurse supporting this group should be a smear taker who can offer cytology.
6. Equity
7. Immunisation
	1. RANZCOG supports the vaccination programme and ensuring it is successful and supports primary HPV screening but regards evaluating as very important.
	2. This is a good opportunity to strengthen and promote HPV vaccination.
	3. Guiding principles need to be adhered to and there needs to be prospective audit and monitoring (not retrospective)
	4. There needs to be a coordinated approach by the vaccination and the screening programmes.
	5. Education is needed for both primary care and the public.
	6. Will register of women who have been vaccinated be linked into the screening register? RANZSCOG feels strongly that this is an opportunity to revamp the registers so that they are linked and the information can be optimised. Should be population based.
	7. Combined information could be useful in the future if re-vaccination is needed for long-term immunity.
8. Further research
9. Additional feedback

Meeting 13: RNZCGP 11 Nov 2015



