National Screening Advisory Committee (NSAC) National Screening Unit (NSU)		
Minutes Wednesday 25 July 2019		
Venue	Ministry of Health, 133 Molesworth St, Wellington	
Start time	1000hrs	
NSAC members present	Professor John McMillan (Acting Chair) Dr Jane O'Hallahan (Deputy Chair) Dr Carol Atmore Dr Karen Bartholomew Professor Jackie Cummings Professor Mark Elwood John Forman Dr Deborah Rowe Dr Caroline Shaw	
Other attendees	**NSU** Anne McNicholas Principal Advisor Dr Bronwyn Rendle Public Health Physician Dr Nisha Nair Public Health Physician Dr Sally Thomas Public Health Registrar	**Item 6: Well Child Tamariki Ora (WCTO) Review, Ministry of Health** Dr Janine Ryland, Clinical Advisor, Child and Youth Health Christine Stewart, Senior Portfolio Manager, Child and Family Investment Alison Hussey, Principal Advisor, WCTO Review **Item 7: National Cervical Screening Programme (NCSP)** Nicki Martin, Manager, NCSP Leanne Blinkhorne, Senior Portfolio Manager, NCSP Laetitia O'Connell, Senior Advisor, NCSP Dr Kerry Sexton, Public Health Physician, NSU **Item 8: Open Communication** Christine Nolan, Quality Manager, NSU
Apologies	Dr Joanne Dixon Professor Barry Borman Astrid Koornneef Dr Caroline McElnay Dr Pat Tuohy	

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1.	**Welcome, apologies and introductions** The Chair noted that Dr Deb Rowe's term on NSAC ends after the current meeting, with the appointment of a new Chair to the Maori Monitoring Equity Group (MMEG). The Chair thanked Deb for her contribution and dedication to NSAC over the last four years.
2.	**Declaration of conflicts of interest** Conflict of interest register tabled.
3.	**Minutes of 10 April 2019** Amended and confirmed as a true and accurate record.
4.	**Matters arising from the minutes** Re-emergence of congenital syphilis • The Ministry of Health has recently released a National Syphilis Action Plan. • Concern raised that the plan inadequately addresses the monitoring of antenatal screening for syphilis. Action: Proposed that Dr Caroline McElnay update NSAC on the national plan at the next meeting.
5	**Correspondence** NSAC has received a request from a member of the public for it to consider preconception genetic screening for rare and debilitating birth disorders including spinal muscular atrophy (SMA). NSAC will maintain a watching brief of this area, including an Australian reproductive carrier screening study (pre-natal screening) to be piloted from late 2019 to the end of 2021. NSAC noted that the recent UK National Screening Committee evidence review and recommendation that does not currently support a national screening programme for carrier or new-born screening for SMA.
6.	**Well Child Tamariki Ora (WCTO) Review** Dr Janine Ryland presented on the WCTO Review. The WCTO programme is the universal health service responsible for protecting and improving the health and wellbeing of children between the ages of zero to five years. This is achieved through health and development screening and surveillance, family and whānau care and support, and health education. The Ministry is undertaking a review of the WCTO programme to ensure that it is financially sustainable and more effectively contributes to child and youth wellbeing. • The Review forms part of the Ministry's work programme to transform its approach to supporting maternal, child and youth wellbeing. • To support this work, a Health Contact workstream has been established to develop an integrated framework of universal wellbeing contacts for the pregnancy to 24 years of age lifecourse. The initial focus of the Review is on the zero to five years age group and the delivery of the WCTO Schedule of Universal Contacts to be delivered. The Review is considering the timing, content and intensity of these contacts. The National Science Challenge *A Better Start E Tipu Rea,* through the University of Auckland, is managing a series of rapid evidence reviews.

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	• The rapid reviews are modelled on the UK National Screening Committee question-led evidence review process and it is intended that the reviews will inform the future WCTO Schedule of Universal Contacts.
	• The project commenced on 1 July 2019 with the first tranche of priority research expected by 30 September 2019 and the second by 30 November 2019.
	
	Dr Ryland sought advice on the extent to which New Zealand's screening criteria are appropriate for the assessment of the current / future WCTO health check programme components; and how NSAC would like to be kept informed of progress with the health contact workstream's review of the WCTO Schedule.
	
	The following issues were discussed
	
	• The current phase of rapid evidence review topics are for the six weeks to four year age group.
	• There are difficulties in establishing an overall picture of the well child programme with WCTO Schedule's delivery through different contracts (eg birth checks by midwives are under Section 88 of the Public Health and Disability Act).
	• The current WCTO schedule does not have a central repository for information (apart from the B4 School Check) or clear referral and treatment pathways, or a consistent consent process – the current review could be an opportunity to achieve these.
	• It is important a standard definition of population level screening and surveillance is used and it was noted that:
	  • organised population level health screening applies to an asymptomatic population
	  • consideration of new population level screening programmes requires an analysis of how expected "programme" features can be met such as audit, monitoring and quality assurance
	  • having multiple contacts over time is not a distinguishing feature of screening or surveillance
	  • surveillance is generally associated with a known risk factor
	  • the term surveillance has negative connotations for Māori.
	• A systematic approach to the rapid evidence reviews is important, eg same criteria and formatting to allow comparable grading such as for United States Preventive Services Task Force (USPSTF) grading.
	  • It was noted that subsequent longer reviews may be done with an iterative process identifying further review questions.
	• There was concern that only some National Health Committee screening criteria were used for the evidence reviews, and that there is no or an insufficient Māori lens across the reviews (equity/access to care). Other voices also should be considered, eg voice of professions, and peer review by experts in a field to establish consistency with practice.
	• While effectiveness or cost effectiveness is a focus, other issues are important, eg access to services.
	• As well as a Treaty/equity lens, consideration of Pacific peoples and other population groups needs to be included.
	• How the review will examine the implementation of the current WCTO schedule was questioned, including who is delivering it and what will happen if the scope is expanded. Related questions included:
	  • What works well in other jurisdictions?
	  • What do we currently do and what can we do better?
	  • What are the markers to identify/differentiate children who need a "light touch" versus those who need more support?
	  • Current system sees benefits accrue to certain groups (related to educational level, confidence and knowledge of the system, and ability to cope.)
	• It was noted that other workstreams within the wider WCTO review are looking at models of care for Māori and Pacific families.

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	• The view that the current WCTO health programme is disconnected from GPs/primary care was expressed.
	• Additional sources of information that could usefully inform the review were suggested, e.g.,
	  • PhD theses - a very good source of information on health system reviews
	  • current national Health System Review - has considered written work on Pacific experience (GP services, access etc.)
	  • DHB General Managers - information from audits/reports of vision and oral health screening activities.
	• The review could be taken as an opportunity for transformational change; and there was a need to think radically about which families need support and how best to interact with them, noting the importance of not "labelling" different groups.
	• It is important to identify explicitly what is screening and any new screening that could be added.
	• Accountability about the pathway post screening was noted as important, along with the difficulty of monitoring this without a national WCTO database.
	• It was noted that many current problems relate to poor co-ordination between services.
	• Concern was expressed about the absence of consumer voice on the WCTO Review Advisory Group and the importance of this conversation being held at the top table (it was advised there are plans to build consumer engagement/feedback into the process)
	• The concept of the overall 0-24 year framework is important, and it should include newborn and antenatal screening, including for infectious diseases.
	
	Concluding comments
	
	• All the rapid evidence reviews should be consistent in approach and use all the screening criteria. They should all, for example:
	  • establish the prevalence of condition
	  • include consideration of cost effectiveness
	  • separate New Zealand practice from overseas approaches.
	• Equity criteria should be a threshold component for any new programme.
	• A truly programmatic approach requires accountability with a central repository and monitoring data.
	• Concern was expressed that a transformational change to the model of care is unlikely if activities occur within silos.
	• NSAC have an interest in the outcomes of the rapid evidence reviews (and possible assistance with assessing the evidence reviews) because this aligns with NSAC's remit to consider the evidence for screening programmes.
	• If a new national screening element/programme is proposed it must be considered by NSAC.

7.	**National Cervical Screening Programme** At its November 2015 meeting NSAC agreed that the NCSP would move to five yearly cervical screening for women aged 25-69 years using primary human papillomavirus (HPV) testing. Primary HPV screening is more sensitive than current liquid-based cytology screening, and with better protection from a negative screening result, allows the extension of the interval between screens to five years. **Change in cervical screening starting age to 25 years - update** In July 2016 NSAC endorsed the cessation of cervical screening in women aged 20 to 24 years at the same time primary HPV screening was to be introduced. In March 2018 NSAC endorsed the cessation of screening in women aged 20 to 24 years prior to primary HPV screening implementation. This change in timing is because the introduction of primary HPV screening is

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	now not likely until 2021 as the NCSP register must first be moved across to a new population screening register.
	• The NCSP wishes to avoid delaying changing the starting age for cervical screening from 20 to 25 years as the harms of screening this age group outweigh the benefits. The evidence base for this change is viewed as strong and separate to the introduction of primary HPV screening.
	• International evidence shows that screening women aged 20-24 years has had little or no impact on rates of cervical cancer in this age group or up to age 30. Investigating and treating common cervical abnormalities in young women, of which the majority resolve without treatment, can lead to over-treatment with associated risks.
	• International guidelines recommend against screening women under 25, and a number of other countries have implemented these recommendations.
	
	A literature review and information from focus groups, particularly Māori, Pacific and Asian women, are being used to help develop the approach to communicating the importance of young women starting to screen at 25 years, with a social media focused media campaign planned. For example, targeted mobile phone messages to women as they turn 25 years.
	
	Focus groups have highlighted a number of issues including:
	• a lack of knowledge about cervical screening
	• the current information does not make it clear why young women should participate
	• the need to use the term "cervical screening" ie, stop calling the test a "smear"
	• the importance of positive messaging and a trusted source of information.
	
	A steering group is being created which includes representatives from the sector, Māori, Pacific, GPs and Support to Screening services.
	
	Discussion included
	
	• The importance of monitoring the change of practice, noting three key indicators:
	  • The uptake of first screen in 25 year olds not already in the programme
	  • The first screen in women less than 24.5 years (i.e. non-recommended screening)
	  • The monitoring of cervical cancer incidence trends in 20-24 and 25-29 year age groups.
	• Potential opportunities for the NCSP to provide information to the sector include upcoming GP conferences.
	
	Primary HPV screening: self-testing
	
	A range of evidence was presented regarding the accuracy and acceptability of primary HPV self-testing. Dr Bronwyn Rendle gave a presentation summarising recent evidence for self-testing including international and New Zealand research, and the approach the NCSP proposes for introducing self-testing.
	• Self-testing will ultimately be an option for all women (as an alternative to a clinician collected sample).
	• Initially this change would involve the offer of self-testing being made face-to-face to women (ie, no intention for mail out).
	• Ongoing collaborative work is anticipated with stakeholders to implement self-testing, particularly service design and communications.
	
	Key international evidence
	
	Recent international research includes a 2019 randomised trial and a 2018 meta-analysis showing that tests performed on self-samples are similarly sensitive to those taken by clinicians when an HPV assay based on polymerase chain reaction (PCR) is used. These studies are summarised briefly below.

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	• *Polman N, Ebisch R, Heideman D, et al., Performance of human papilloma virus testing on self-collected versus clinician-collected samples for the detection of cervical intraepithelial neoplasia of grade 2 or worse: a randomised, paired screen positive, non-inferiority trial. Lancet Oncology 2019.*
	  • The IMPROVE study was undertaken within the Netherlands organised screening programme environment (women aged 29-61 years) to assess HPV self-sampling as a potential primary screening method in the general screening population.
	  • It compared 7643 women who had collected their own samples for HPV testing and 6282 women whose samples were collected by a clinician.
	  • In the regular screened population HPV testing done with a PCR-based assay and an adequate self-sampling device has clinical sensitivity and specificity for the detection of CIN2+ and CIN3+ similar to that of clinician collected samples.
	  o 569 (7.4%) self-collected samples and 451 (7.2%) clinician collected samples tested HPV positive (relative risk 1.04, 95% CI 0.92-1.17).
	  o The CIN2+ sensitivity and specificity of HPV testing did not differ between self-sampling and clinician samples: relative sensitivity 0.96 (0.90-1.03); relative specificity 1.00 (0.99-1.01).
	  o For CIN3+ relative sensitivity was 0.99 (0.91-1.08) and relative specificity was 1.00 (0.99 -1.01).
	  • The study authors concluded that these findings suggest that HPV self-sampling could be used as a primary screening method in routine screening.
	
	• *Arbyn M, Smith S, Temin S, et al. Detecting cervical pre-cancer and reaching underscreened women by using HPV testing on self-samples: updated meta-analyses. BMJ 2018:363;k4823.*
	  • Separately pooled the accuracy of signal amplification and PCR based assays.
	  • The hrHPV PCR based assays were as sensitive on self-samples as clinician collected samples to detect CIN2 or CIN3+ (pooled ratio 0.99, 95% CI 0.97-1.02); and the specificity to exclude CIN2+ was 2% lower on self-samples than on clinician samples.
	  • The study authors suggest self-sampling could become the new paradigm for cervical screening in the general population.
	
	New Zealand research
	
	The NCSP's consideration of primary HPV self-testing has also been informed by Australian and New Zealand-based research. New Zealand research has focused on different aspects of the acceptability of self-testing, including specific consideration for programme priority groups, and are outlined below.
	
	He Tātai Hauora O Hine, Victoria University of Wellington
	
	The first phase of the He Tapu Te Whare Tangata research programme investigated Māori women's knowledge and attitudes to self-testing using a Kaupapa Māori mixed methods approach. The research was funded by Te Kete Hauroa, Ministry of Health, with recently published results as follows.
	
	• *Adcock A, Cram F, Lawton B, et al. Acceptability of self-taken vaginal HPV sample for cervical screening among an under-screened indigenous population, Aust NZ J Obstet Gynaecol 2019; 59: 301-307.*
	  • The survey of 397 un- and under-screened Māori women showed 77.3% were likely/very likely to do a self-test if offered. Reasons for not attending regular cervical screening were also identified, with whakamā/shyness, lack of time/other commitments, fear of pain or discomfort and cost/financial barriers the top four.

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	The second phase of this research, funded by the HRC from 2017, is a randomised community trial in Northland primary care clinics that have a high proportion of Māori women enrolled.
	• In intervention clinics, women who are unscreened or have not been screened for four years or more are offered self-testing alongside a range of active follow-up strategies and wrap-around care to support their participation. Control clinics offer usual care.
	  • Preliminary results showed a 41.7% uptake of self-testing among women in the intervention clinics, with higher uptake for Māori women at 47.6%.
	  • Qualitative work is being undertaken to understand the experience of referral to colposcopy after a positive self-test.
	
	Waitemata DHB, Auckland DHB and Massey University
	
	This research programme is looking at the acceptability and uptake of self-testing for women who don't participate in the current cervical screening programme (never screened or more than 10 years since last screened) with a strong focus on operational aspects. The DHB initially led and funded three projects.
	• Focus groups with Māori, Pacific and Asian women; self-tests were also offered. The invasiveness of current cervical screening was the primary barrier for many women.
	• A feasibility study offering self-testing to Māori women through a GP clinic.
	• An evaluation by a Māori provider to understand women's experiences and the cultural appropriateness of the approach.
	
	An HRC funded randomised control trial (RCT) s currently underway, aiming to recruit 5000 Māori, Pacific and Asian women who are unscreened or who have not been screened for at least eight years. There are four arms; mail out, clinic based, usual care and opportunistic offer. Dr Karen Bartholomew presented the preliminary study findings.
	• There was a likely small absolute coverage improvement, but with important equity benefits and also clinical outcomes for participating women (case studies presented). Of note, Maori women had high uptake in the mail out arm, and the uptake for the opportunistic approach undertaken in a number of clinics after the RCT was also high, particularly for Pacific women.
	• High resource requirements and a skilled workforce are required to provide a positive supportive experience for women who test positive through diagnosis and also treatment pathways. It was recommended that support for this element of the pathway was appropriately resourced to ensure equitable benefit to self-testing implementation.
	
	Massey University
	
	This small study involved 56 un- and under-screened women, predominantly Pacific. It surveyed participants about their preferences around self-testing. Participants were also given the opportunity to try up to three different self-testing devices. Recently published results are briefly summarised as follows.
	• *Brewer N, Foliaki S, Bromhead C, et al. Acceptability of human papilloma virus self-sampling for cervical cancer screening in under-screened Māori and Pacifica women: a pilot study. NZMJ 2019; 132 (1497):21-39.*
	  • There was a greater preference for self-testing compared to clinician taken samples indicated in the initial questionnaire (78%), though this fell a little after the devices were used. Comparison of acceptability of different devices is limited by small numbers and a stated bias in how the devices were offered to participants.
	
	NCSP HPV self-testing policy approach
	
	The recent evidence that self-testing, when a PCR assay is used, is similar to a clinician collected specimen reduces concerns (also previously expressed by NSAC) that a self-test may be a lower quality test than a clinician taken test.

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	Most research on HPV self-testing has been undertaken in under-screened populations with a view to increasing the acceptability and accessibility of screening. Recent research in the Netherlands indicates that self-testing may be successfully incorporated into a national screening programme as an option for all women. To date, programmes in Australia and the Netherlands, which introduced primary HPV screening in 2017, offer self-testing only to under-screened women. The UK is taking a more conservative approach and is not yet offering self-testing within its primary HPV screening programme (with completion of their programme rollout anticipated by the end of 2019). Given the latest international research, the NCSP has recently considered options for offering self-testing to all participants when primary HPV screening is introduced. In March 2019, the NCSP's Technical Reference Group gave support to the NCSP adopting a universal self-testing approach from the outset of the introduction of primary HPV screening, providing a less invasive collection option for any women to choose if they prefer. With the introduction of primary HPV testing not expected before 2021, the NCSP has the opportunity to learn from other countries' experiences and evaluate emerging evidence on offering self-testing to all women. Anticipating that universal self-testing will ultimately become a clear option, planning will be undertaken for its implementation as part of the introduction of primary HPV testing. Full consideration will be given to unintended consequences and risk mitigation. Self-testing remains a key strategy to achieve equitable access and outcomes for priority populations and will be implemented from the outset of the NCSP's change to HPV primary testing. To assist in achieving the programme's equity aims, the NCSP also intends to offer an increased support service for Māori and Pacific women and a wider package of targeted free screens. These initiatives are subject to successful funding bids. *Discussion included* • Clarification that clinic based self-testing is proposed at this stage not postal of self-testing kits. • Ultimately multiple approaches are likely in the future with for example self-testing and clinician taken samples in primary care based clinics, as well as mail out to those who prefer this approach or those who do not attend following a screening invitation. • Potential issues with decreases in mail services and more limited courier services in rural areas, although there is good evidence of high stability of specimens over lengthy periods. • Initial focus is building on the current cervical screening approach and maintaining a high level of primary care involvement, noting in particular the importance of follow up cytology and 12 month recall for women with "other" hrHPV strains identified (non-HPV16/18). • There are lessons from primary care involvement in the national bowel screening programme, with their important provision of a safety net for follow up. • The advantages self-testing will bring with the freeing up of primary care time when self-testing is offered as an option to all women. • The exemplary approach the NCSP has taken regarding the development of options for self-testing, including the timely consideration of a strong international and New Zealand evidence base. **HPV self-testing recommendations** NSAC endorsed: 1. The offer of self-testing for priority groups when primary HPV screening is introduced. 2. In principle, the implementation of the offer of primary HPV self-testing to all women.

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	NSAC noted: 1. The NCSP will undertake active assessment of international programme developments and related research on primary HPV self-testing to inform final policy decisions on a programme change to include the offer of the self-testing option to all women. 2. The NCSP will seek NSAC's endorsement of the timing of a programme change to include the offer of self-testing to all women.
8	**Open Communication** At its July 2017 and July 2018 meetings NSAC considered open communication, including Public Health England's 2016 guidance document on how screening programmes should apply duty of candour and disclose audit results; and requirements under the New Zealand Health and Disability (HDC) Code of Health and Disability Services Consumers' Rights. NSAC also reviewed a draft NSU open communication policy document which specifically considered requirements within the context of screening. At this July 2019 meeting the NSU provided an updated open communication policy document for NSAC's consideration. NSAC feedback on the current version indicated the need for a re-positioning of the policy to better articulate the principles and issues specifically related to screening programmes. These include greater clarity around screening programme limitations, rather than the more generic approach currently adopted. • Screening programmes by their nature have known/acceptable error rates, with false positives and false negatives inherent to all screening tests. • There is a need to reflect the importance of communicating screening programme limitations to participants - screening can never be perfect and may create risks that cannot always be avoided. • The duties under the HDC Code as well as the force of the rights should be explicitly included in the document, including that these rights may be tempered eg by resource constraints. • It is important that any investigation is required to provide feedback to the person and family/whānau in a manner and frequency that has been agreed will work best for them.
9.	**Programme Updates** *Antenatal and Newborn Screening* • NSAC has previously endorsed the NSU undertaking public consultation on the potential introduction of non-invasive prenatal testing (NIPT) as a contingent test within the current screening pathway for trisomies 21, 18 and 13. • The Ministry has decided not to progress public consultation at this stage because the NSU does not currently have the resources to implement the proposed change. *National Bowel Screening Programme (NBSP)* • At the April 2019 meeting, NSAC indicated support for the proposal to lower the eligible age for screening in Māori to 50 years, in line with the key recommendation from the February 2019 hui on achieving equity for Māori in the NBSP. • A Pacific Fono is being held this month which will examine achieving equity for Pacific people in the NBSP. Similar to Māori, evidence indicates that around half of bowel cancers are diagnosed in Pacific before 60 years of age (compared with around 30% for "other" ethnic groups).

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	National Cancer Plan • Release of plan anticipated shortly. *BreastScreen Aoteoroa - age extension* • Project work progressing. Action: Proposed that NSAC will look at equity across the NSU programmes at its next meeting, noting also the need to consider equity for other population groups eg Asian. The Chair invited Dr Deb Rowe to attend the next meeting alongside the incoming MMEG Chair.

10	**NSAC Work Programme Review**
	Work programme priorities were reviewed with a watching brief and/or further information to be sought in the following areas:
	• abdominal aortic aneurysm (AAA) screening
	  • progress with primary care case detection/screening approach with potential NSAC reconsideration
	  • retrospective application of AAA screening algorithm underway in Waitemata/Auckland
	  • Pacific AAA screening project in Auckland
	• atrial fibrillation case finding in two Auckland trials (not a screening approach)
	• a rheumatic heart disease screening project proposed in pregnant women
	Action: Dr Caroline McElnay to report back
	• concern that inappropriate screening for HPV throat infection was being undertaken by some clinicians
	• a qualitative study of lung cancer in Māori
	• Australian pre-natal genomics screening trial
	• HRC funded screening related research, with potential for NSAC oversight/review
	• chlamydia screening in reproductive aged women.

	Other business *Lung cancer screening in Māori.* Dr Karen Bartholomew advised committee members of: • equity focused work underway to assess the feasibility and cost-effectiveness of lung cancer screening in Māori, with a RCT proposed (noting her declared conflict of interest as the study's Principle Investigator) • an equity review of the BODE model originally used to assess cost-effectiveness of lung cancer screening (and previously considered by NSAC) has identified potential errors in the model which impacted that assessment, and new analysis indicates screening is likely to be cost-effective for Māori • publication of the re-worked analysis is expected later in the year and will be shared with NSAC.
11	Next meeting Thursday 28 November 2019. Meeting closed at 1600hrs.