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|  **National Screening Advisory Committee (NSAC)** **National Screening Unit (NSU)** |
| **Minutes Wednesday 10 April 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 AtmoreDr Karen Bartholomew Professor Barry BormanProfessor Mark Elwood John Forman Astrid Koornneef Dr Caroline McElnay Dr Deborah Rowe Dr Caroline Shaw Dr Pat Tuohy |
| Other attendees | **NSU** Anne McNicholas Principal Advisor Dr Bronwyn Rendle Public Health Physician Dr Nisha Nair Public Health Physician  Dr Emma Church Public Health Registrar  | **Item 5: Prostate Cancer Screening** Professor Ross Lawrenson, Waikato University Vi Vu, Senior Advisor, Cancer Services, Ministry of Health  **Item 6: Open Communication**Dr Margaret Sage, National Cervical Screening Programme (NCSP)Christine Nolan, Quality Manager, NSU **Item 7:** **BreastScreen Aotearoa (BSA) age extension**Chrystal O’Connor, Manager, BSA Jennifer Cox, Senior Advisor, BSA  |
| Apologies | Dr Joanne Dixon Professor Jackie Cummings  |

| **Item** | **Subject and summary** |
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| **1.** | **Welcome, apologies and introductions**  |
| **2.** | **Declaration of conflicts of interest** Conflict of interest register tabled.  |
| **3.** | **Minutes of 28 November 2018** Amended and confirmed as a true and accurate record.  |
| **4.** | **Matters arising from the minutes** * *Re-emergence of congenital syphilis*: Karen Bartholomew provided a report back on a metro-Auckland Region review of recent congenital syphilis cases.
	+ Since 2015 there has been a marked increase in cases in heterosexual women and in recent years an increase in syphilis cases in women of child bearing age, and as a consequence an increase in congenital syphilis.
	+ Syphilis is a curable infection with a short course of intramuscular penicillin. If detected and treated in early pregnancy, complications for mother and baby can be avoided.
	+ From 2013 to mid-2018, nine mothers had syphilis diagnosed in pregnancy requiring treatment, with one infant born with congenital syphilis.
	+ In 2017, between 1.5% and 2.6% of women who delivered did not have a syphilis screening result recorded. In general these same women also had no HIV or Hep B screening.
	+ The gap in syphilis screening was variable by DHB, age and ethnicity.
	+ There is also a gap in the epidemiology related to stillbirth as an outcome of syphilis infection during pregnancy.
	+ The review made a number of recommendations regarding maternity care providers undertaking screening for syphilis in pregnancy, including screening in early third trimester for all pregnant women not already screened, rescreening high risk women at 28 weeks (eg a new sexual partner) and screening women in the event of a stillbirth.
	+ The review also recommended development of a protocol for syphilis in pregnancy and the newborn period; and a full case review of all cases of congenital syphilis, including still births, to identify areas for improvement in order to prevent further cases, with findings shared nationally.
	+ Lack of early engagement with a lead maternity carer is regarded as a key driver for a woman not being screened. Also concern raised about the unbundling of antenatal infectious disease screening (HepB, HIV, Syphilis) with labs moving to a separate tick-box for each infection, resulting in some women choosing not to test for all. Concern whether women are truly fully informed about the risks of not being screened for a particular infection.
	+ NSAC also noted that chlamydia screening is important, with 1 in 1000 babies born with chlamydia, but only a 50% uptake of screening in pregnancy.
	+ A national plan related to congenital syphilis is anticipated.

Action: NSAC (via Pat Tuohy) will advise the Well Child Tamariki Ora (WCTO) review of its support for a comprehensive antenatal / well child monitoring framework, including real time monitoring of infectious disease in pregnancy. * *WCTO review:* Pat Tuohy outlined the adoption of a life course approach for the age group 0-24 years, ie, maternal, child and youth.
	+ The review will align with the Child Wellbeing Strategy.
	+ A phased approach will be followed, with the first iteration of the programme planned for July 2020.
	+ A range of screening opportunities are currently in place but with poor data collection and monitoring.
	+ Rapid evidence reviews are proposed related to maternity/child screening, noting importance of considering the entire screening pathway.
	+ The “early years’ approach includes brain development through to and including adolescence.
	+ Will look at including the Year 9 assessment, and will include consideration of the B4 School Check (noting concerns raised previously by NSAC).

Action: Pat Tuohy to provide a progress update, including the rapid evidence reviews, at NSAC’s July 2019 meeting.  |
| **5.** | **Prostate specific antigen (PSA) screening for prostate cancer** At its July 2018 meeting NSAC agreed it would reconsider prostate cancer screening, in particular recently published results from the UK Cluster Randomised Trial for PSA testing for Prostate Cancer (CAP) and the decision support tool Kupe which had been commissioned by the Ministry of Health’s Prostate Cancer Awareness Quality and Improvement Programme. **Caroline Shaw led the committee through a consideration of the harms and benefits of screening in general, the attributes of decision tools and the UK CAP study** *Harms & benefits of screening* * Health professionals and the public have a poor grasp of the harms and benefits, generally overstating the benefits.
* Harms of screening include
	+ false positives: anxiety
	+ false negatives: false reassurance
	+ overdiagnosis: detecting & treating diseases that were never going to be a problem
	+ complications: from the screening test, diagnostic testing or treatment.
* Benefits of screening include
	+ reduction in deaths from that cancer (not necessarily overall mortality)
	+ true negatives: reassurance
	+ lower levels/less invasive treatment with stage shift.
* Screening information is poor at presenting this information and rarely gives absolute effects for both benefits and harms so that the trade-offs can be directly compared. Such shortfalls are apparent across NSU cancer screening programmes resources.

*Decision aids** Decision aids provide information about screening to help people make decisions consistent with their own values and preferences. The aids are about the decision process not the outcome. They improve decision quality by improving knowledge, risk perceptions, the match between values and choices, patient provider communication, and decrease decisional conflict and passive decision making.
* Requirements of a high quality decision aid include describing positive and negative features of options, and presenting probabilities of outcomes in an unbiased and understandable way.

*Effect of a low-intensity PSA-based screening intervention on prostate cancer mortality. The CAP randomized clinical trial. JAMA, 2018:319(9):883-895* * The study examined whether a low intensity screening intervention changes the balance of benefits and harms of prostate cancer screening?
	+ Clustered randomised control trial (RCT) of 400,000 men aged 50-69 in the UK.
	+ Offer of a one-off PSA screen with 10 year follow up using intention to treat analysis.

*Results** + Prostate cancer mortality was low in both the intervention and control groups at 10 years (about 1%) and there was no difference between intervention and control group.
	+ No difference in all-cause mortality between the intervention and control group.
	+ Increase in detection of low risk prostate cancer cases in intervention group i.e. likely over diagnosis.
	+ Longer follow up is needed: high survival from prostate cancer in both groups may mean benefits will be seen after a longer follow up period.
	+ Conclusion: no evidence a one off screen useful as no apparent benefit and has harms in the form of overdiagnosis.

A new systematic review and meta-analysis was also published recently: *Prostate cancer screening with prostate specific antigen (PSA) test: a systematic review and meta-analysis. BMJ 2018;362:k3519* * Included five RCTs with a total of over 700,000 men. The meta-analysis found overall no evidence of benefit but substantial evidence of harm.
* All RCTs have methodological issues, however the European Randomized Study of Screening for Prostate Cancer (ERSPC) is thought to have the lowest risk of bias. It found 1/1000 men will have their life saved by screening after 13 years but many men will be harmed.

**Professor Ross Lawrenson presented on prostate screening in primary care** * The 2011 Health Select Committee Inquiry did not support organised national screening because there was not clear evidence that the benefits of screening outweigh the harms.
* An outcome of the Prostate Cancer Taskforce was establishment of a four year equity-focused Prostate Cancer Awareness and Quality Improvement Programme to help ensure men receive evidence-based information about prostate cancer testing and treatment. It has delivered management and referral guidance for GPs, the public facing decision aid KUPE and a version for use by GPs.
* Guidance is that men who want to know about screening should have an informed discussion with their GP before testing (consistent with US Preventive Services Task Force Guidelines), including that screening is not recommended at all if aged over 70 years.
* Public consultation findings reflect a community level environment that is very pro-screening and lacks a population/public health approach.
* Despite overall findings of the ERSPC, prostate cancer screening is well established in New Zealand with GPs, that is, defacto screening. GPs request ~450,000 PSA tests annually. The majority believe PSA screening reduces mortality rates and that the benefits outweigh the harms. Arguably the main reason GPs screen is driven by risk aversion.

**The Cancer Services team presented on the The Prostate Cancer Awareness and Quality Improvement Programme and development of the decision support tool KUPE** * The four-year programme was an action plan to deliver a range of new resources, tools, public information and system enhancements to improve the quality of prostate cancer care for all New Zealand men.
* A specific action was the development of a decision support tool to assist men and GPs in shared decision-making about early detection and treatment of prostate cancer. This action was a response to men receiving confusing information, variation in how GPs provide support and information, and variations across the treatment pathway.
	+ Phase One: initial design phase, May 2015 to November 2016 (Evidence base, assessment of IT systems and requirements).
	+ Phase Two: development and implementation, June 2017 to April/Nov 2018.
	+ During the October- December 2018 period ~8,000 accessed the web site and ~400 completed the decision tool.

*Discussion included* * Asymmetry in public and health professional expectations around the benefits of screening.
* Acknowledged underlying public pressure around men’s health and that this wider context limits the ability of GPs in the consultation room to influence a man’s decision when explaining risks and benefits of screening, with the public conversation already set in favour of PSA screening.
* Regarding harms of screening, need to recognise the impact of overdiagnosis with the distress a cancer diagnosis causes, and the degree to which it changes the view a person has of themselves.
* Noted UK advice to health professionals includes that a GP does not need to raise prostate screening as a topic with a patient.
* Noted that the College of Pathologists does not support PSA screening.
* NSU resources across its programmes should include infographics to help assessment of harms and benefits of screening.
* Purpose of the KUPE tool was to help decision making when men ask for information about prostate screening. It was also an attempt to move to more equitable access to information for Māori and Pacific men, hence the name KUPE.
* NSAC reiterated previous concerns regarding the content of the tool.
	+ Disappointed by the biased information it presents which results in the aid presenting a very pro-screening view.
	+ It does not state that population based screening is not recommended in New Zealand or that the harms of prostate screening outweigh the benefits.
	+ Digital rectal examination is not generally supported as a screening test.
	+ It does not quantify the risks. It is incorrect to describe the side effects as minor.
	+ While the tool could provide help for men who want information on screening, and not all the information is wrong, it is substantially more pro-screening than it should be.
	+ The brochure is particularly confusing, noting there was difficulty emulating the interactive tool on paper.
* Noted there is a general perception that PSA screening for prostate is a good thing to do. However, this is not the case and information for the public needs to honestly reflect this situation.
* Noting the recent US Preventive Services Task Force (USPSTF) recommendations, the UK CAP study findings and the most recent meta-analysis, all published in 2018, NSAC agreed it sees no advantage in undertaking a formal review of the evidence as it would come back to its current position of not supporting population wide screening.

*Concluding comments* * NSAC reiterated its position that it does not support population based screening for prostate screening.
* NSAC remains very concerned with content of the KUPE tool and the degree to which it is pro-screening. There is a disconnect between the evidence around prostate screening and the information promoted through the tool. Given the harms of prostate screening, it is important that this tool does a good job presenting balanced information to help men who may be considering a PSA screening test. It should include:
	+ a statement that screening is not recommended in New Zealand
	+ a clear statement that the harms of screening outweigh the benefits
	+ a quantification of the risks of screening.
* NSAC recommends that the Ministry looks to a mechanism for reviewing and updating the content of KUPE.
* NSAC supports an approach whereby GPs are advised that they are not obliged to initiate a conversation with a man about prostate screening. A process of shared-decision making would follow a patient seeking information and advice.
* NSAC supports the NSU more broadly disseminating the harms as well as the benefits of screening across all its programmes.
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| **6.** | **Open Communication**At its July 2017 and July 2018 meetings NSAC considered open communication, including a draft NSU open disclosure policy document, and NSU plans to develop open disclosure policies for each of its screening programmes. NSAC was also provided information on emerging screening issues in Southern Ireland and England which involved open disclosure of adverse events to screening participants. Ireland’s Inquiry into its cervical screening programme and the Independent Review of the English Breast Screening were completed in late 2018. The full reports were provided for NSAC’s information. * England’s Review looked at what was thought to be an IT error that had meant 450,000 women between the ages of 68 and 71 did not received their final breast screening invitation between 2009 and 2018. However the Review concluded that there had in fact been no incident, and Ministers and the public were incorrectly advised. Women were wrongly told they had missed a screening invitation, and were then unnecessarily re-invited for an additional screen.
* Ireland’s Inquiry followed controversy around the failure to disclose to women diagnosed with cervical cancer the results from retrospective audits of their cytology slides which indicated an abnormal result had been misread. The Inquiry has recommended that “a statutory duty of candour be placed on individual health care professionals and on the organisations for which they work”.

NSAC considered a presentation on how coverage of the Irish cervical screening incident played out in their media. It included how the impact of misunderstandings around the sensitivity of cervical cytology screening and shortfalls in their open disclosure processes saw the undermining of confidence in the screening programme. Dr Margaret Sage, the NCSP Pathology Clinical Lead, provided an update on the NCSP’s progress towards development and implementation of open communication and open disclosure polices. *Discussion included* * Public misunderstandings around the limitations of screening and misinterpretation of false negatives, which in turn creates risks to a programme and negative media coverage.
* There is often a conflation of acceptable error rates within a screening programme, noting the close monitoring/audit in place around these, and the impact of a false negative or false positive at an individual level.
* Open disclosure is a subset of open communication. A planned approach to providing information is important to help maintain confidence in screening programmes.
* Noted NSU is meeting with ACC and HDC as it progresses development of its open communication and disclosure policies.

*Concluding comments* * NSAC supported the direction the NSU is taking setting and implementing open disclosure policies.

Action: NSU will provide an updated draft open disclosure policy for the July 2019 meeting..  |
| **7.**  | **BSA – extending screening to women aged 70 to 74 years** NSAC has previously considered the BSA’s impact analysis of extending the eligible age range. (Meetings of Nov 2016, Mar 2017, Nov 2017 and Nov 2018). NSAC had previously noted that: * in 2004, when the age range was extended to 45-49 years, there was a decline in coverage for Māori women aged 50-69 years and an increase in the equity gap; and emphasised the importance of ensuring age extension does not negatively impact on equity of access to screening
* age extension will require an extra 42,000 mammograms annually and hence investment in IT infrastructure and programme capacity.

NSAC considered further work recently undertaken in relation to age extension and provided advice regarding the NSU’s preferred rollout approach. **NSAC considered a high level review of the epidemiological evidence for age extension** * The epidemiological evidence on breast cancer mortality benefit for screening women 70-74 years is limited and equivocal. There is a lack of consensus between international experts on the balance of benefits and harms in screening this age group.
	+ The WHO’s International Agency for Research on Cancer (IARC) concluded in 2016 that there was sufficient mortality benefit from screening women 70-74 years, but published data for this age group did not allow for the evaluation of net benefit i.e. benefits versus harms. In addition to IARC’s position, the Independent UK Panel on Breast Cancer Screening concluded in 2012 that the impact of screening outside the ages 50-69 is very uncertain. The US Preventive Services Task Force in 2016 acknowledge that trial data for women age 70-74 years was inconclusive and that their recommendation to screen this age was based on extrapolation of the benefit seen in women aged 60-69 years.
* There is also inconsistency internationally on screening women aged 70-74 years.
	+ BreastScreen Australia recently extended their age criteria to invite women aged 69 to 74 years to screening. The UK offer triennial screening to women aged 50 to 70 years. Women aged 70 and over are not actively recruited, but are able to self-request. France and the Netherlands screen up to age 74/75 years, but the majority of European countries do not include women aged 70 years and older. In Canada, women aged 70 years and over are eligible for free screening in some, but not all provinces.

New Zealand’s National Health Committee screening criteria have not all been met. * The existing evidence base from RCTs is unable to confirm a mortality benefit from offering breast screening to women aged 70-74. In addition, the potential harms for screening such as overdiagnosis are unclear for women aged 70-74 years.
* While the ongoing RCT in the UK (the AgeX trial) may help assess the benefits and harms of offering screening to women aged 70 years and over, the findings are not expected until the mid-2020s.
* In a situation of uncertainty, the National Health Committee guidance recommends a conservative position:
	+ “If a RCT is in progress, then formal assessment of a proposed programme should be deferred until that evidence is available. If RCT evidence is not available and is not likely to become available, then a programme should only be endorsed with caution and only if this endorsement is based on very strong evidence from other sources”.

Consideration of equity has been about access, particularly for Māori women, based on the following principles. * Maintaining and improving equity of access for women aged 45 to 69 years where there is clear New Zealand evidence that breast screening is effective in reducing mortality. Increasing participation in this group will have positive equity impacts for women aged 70 to 74 years.
* For women 70 to 74, women of all ethnicities have the same opportunity to make an informed decision about participation in screening, including the current state of the evidence.

The BSA Technical Reference Group and the NSU’s Māori Monitoring and Equity Group (MMEG) have indicated a strong preference for minimising any disruption to current breast screening services for women aged 45- 69 years, supporting implementation of a gradual roll out of age extension. * + Alongside broader equity issues and life expectancy for Māori, the net benefit of age extension to 74 years for Māori women is likely to be less than for non-Māori.
	+ MMEG advised that equity for women over 70 years of age would be best achieved through achieving equitable access for priority women aged 45-69, as these women would in turn be offered screening as they aged through.

*Discussion included* * Noted concerns regarding uncertainty that the benefits of age extension outweigh harms.
* Noted that while the risk of breast cancer increases with age, more favourable biology of breast cancer and competing mortality risks may mean that the risk of overdiagnosis is greater than at younger ages.
* However, one view expressed was that the extrapolation of the benefit seen in women aged 60-69 years was an acceptable approach, i.e. the argument that there would need to be a plausible biological reason as to why women aged 70-74 would not benefit in the same way as women less than 70 years would.
* Awaiting the Age X trial results before implementing age extension was generally viewed as a preferred approach.
* Noted that the coalition agreement between the New Zealand Labour Party and New Zealand First includes progressively increasing the age for free breast screening to 74 years.
* Noted that investment in equity is critical, and that sufficient IT, infrastructure and workforce capacity are also pre-requisites for age extension. Given these current constraints, age extension cannot not start within the short term and the future rollout would be progressive.
* The most manageable implementation strategy is based on re-invitation of women who are already enrolled in BSA.
	+ Providers can predict and plan for the number of women they need to screen and provide assessment appointments for and maintain access for priority group women.
	+ Priority would be given to existing and new initiatives to reach equitable coverage for women aged 45 to 69.
	+ Invitations would also be uninterrupted so there was less chance the women would be lost to service.

**NSAC endorsed the BSA programme’s preferred option to implement a gradual rollout of age extension through the progressive extension of invitation*** Women who turn 70 after a specific date, for example, 1 January 2022, would be eligible to continue screening up to 74. These women would be invited when two years have elapsed since their last mammogram.
* During the transition period, the programme will not invite women to screening who were already aged 70-74 at the pre-specified start date for age extension.
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| **8.**  | **National Bowel Screening Programme (NBSP) - update****The National Screening Unit hosted a hui attended by Māori health sector experts in February 2019** * Meeting attendees reviewed the evidence around achieving equity for Māori in the NBSP.
* The latest cancer incidence data for Māori show an increase in colorectal cancer incidence and a younger age distribution. The incidence is now similar between Māori and non-Māori. The primary concern from this evidence was that the NBSP in its current form is increasing inequities for Māori.
* Attendees’ highest priority recommendation was to extend the age range for bowel screening eligibility for Māori to 50 years old.
* The Ministry will continue to review the evidence so as to achieve equitable outcomes for Māori, including more work on when and how the screening age can be extended for Māori in a safe and effective manner. However, significant changes will not be introduced until after the national rollout has been completed in 2021 and when there is sufficient colonoscopy capacity to accommodate increases in demand associated with an age range change.

In discussion, NSAC supported implementation of the lowering of age eligibility for Māori earlier than 2021 to maximise equity of outcomes. Action: Suggested that NSAC look at equity across the NSU programmes at its next meeting.**NBSP rollout** * In January 2019, the Ministry contracted Deloitte to build the National Screening Solution (NSS). The build is due to be completed by early October 2019. The NSS provides a centralised invitation and recall system which tracks the participant’s journey along the screening pathway. It is also critical in the ongoing monitoring and evaluation of the programme.
* The NBSP is operational in eight district health boards covering over 40 percent of the eligible 60 to 74 year olds across New Zealand. In 2019/20 the programme will be implemented in six more DHBs, subject to the delivery of the NSS. The last six DHBs will be implemented by June 2021.
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| **9.** | **Other business** 2019 meetings dates: Thurs 25 July, Thurs 28 Nov Meeting closed at 1600hrs. |