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|  **National Screening Advisory Committee (NSAC)** **National Screening Unit (NSU)** |
| **Minutes Tuesday 14 July 2015** |
| Venue | Wellington Airport Conference Centre |
| Start time | 10.00am |
| NSAC Members  | Professor Ross Lawrenson (Chair)Dr Jane O’Hallahan, Clinical Director, NSU (Deputy Chair) Dr Carol AtmoreAssociate Professor Brian CoxDr Joanne DixonJohn Forman Professor John McMillan Dr Deborah Rowe Dr Pat Tuohy, Chief Advisor, Child and Youth Health, Ministry of Health (MOH) Astrid Koornneef, Group Manager, NSU |
| Ministry of Health Attendees | Anne McNicholas, NSAC Secretariat, NSUDr Bronwyn Morris, Public Health Physician, NSU Welcome:Jill Lane, Director, National Services Purchasing, National Health Board Dr Don Mackie, Chief Medical Officer, Clinical Leadership, Protection and Regulation Stephanie Chapman (HPV primary testing agenda item) |
| Other Attendees | Dr Dianne Webster, Auckland DHB (SCID & pulse oximetry presentations)Dr Jan Sinclair, Auckland DHB (SCID presentation)Dr Elza Cloete, Starship Children’s Hospital (pulse oximetry presentation) |
| Apologies | NSAC members: Associate Professor Diana SarfatiDr Andrew Simpson, National Clinical Director, Cancer Programme, MOH Dr Bryn Jones, Chief Advisor, Community Health Service Improvement, MOH  |

| **Item** | **Subject and summary** | **Action**  |
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| **1** | **Welcome, apologies and introductions** Ross Lawrenson, Jane O’Hallahan, Jill Lane and Don Mackie: * Welcomed the NSAC members, noting in particular the important role of clinical leadership and governance.
* Acknowledged contribution of previous NSAC members and secretariat.
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| **2** | **Declaration of Conflicts of Interest (COI)**Members provided completed COI declaration forms. COI will be tabled at each meeting and the NSU will maintain a COI register.  |  |
| **3** | **Terms of Reference (TOR)*** TOR were confirmed noting the following:

*TOR Principles** Discussion regarding where considerations about costs and value for money sit:
	+ views expressed included that need to keep the evidence base wide with cost issues not included too early; that broader social and ethical considerations are also required in addition to cost analyses; and that recommendations will need to be realistic therefore value for money consideration will ultimately come into play
	+ suggested that NSAC look at the National Health Committee (NHC) principles around value for money
	+ suggested that NSAC membership could include health economic expertise.
* Discussion around a request that the third principle, related to equitable access and outcomes for all population groups, be amended to explicitly emphasise increasing Māori and Pacific engagement:
	+ noted that the principles used in the TOR are the same as the NSU Quality Framework principle. Further details around outcomes for different population groups are included in the full version of this Quality Framework principle
	+ agreed that NSAC will review the full version of the Quality Framework principle at NSAC’s next meeting. They will then consider potential amendments to the TOR text or whether a minute note about increasing Māori and Pacific engagement is sufficient.

*TOR Role** Discussion about NSAC’s role regarding screening programmes or initiatives which the NSU does not currently manage:
	+ NSAC can provide some support to other work areas, some of which are captured through the work programme prioritisation table. However, with a small secretariat and substantial demands from current NSU programmes, it will be challenging to broaden the scope beyond consideration of proposed central agency led screening programmes and major changes to current NSU programmes.

*TOR Purpose** Noted the apparent constraint in the purpose statement in that NSAC advice will relate in particular to the evidence for new national screening programmes:
	+ NSAC will review the purpose statement in 12 months.

**Other*** Noted that the NSAC minutes will be posted on the NSU website, with a link also through to the NSAC site.
* Noted the list of NSU Advisory Groups tabled.
* Noted that governance for the proposed national bowel screening programme will ultimately sit with NSAC.
 | The NSU will table the NHC principles at next meeting.The NSU will consider addition of member with health economic expertise. The NSU will table the full text of the NSU Quality Framework Principle related to equity at next meeting. The NSAC will review the purpose statement in 12 monthsThe NSU will check NSAC and NSU website links  |
| **4** | **NSAC work programme and priorities** Members reviewed a table summarising the NSAC’s potential work programme and priority areas. Members noted in addition: * Non-invasive prenatal testing (NIPT) for T21, T18 & T13
	+ potential for major improvements in screening for these genetic disorders, but requires a planned and moderated introduction to ensure benefits outweigh harms in face of increasing direct marketing of the technology as a screening test.
	+ GPs and LMCs require information about NIPT as patients are increasingly likely to ask about the test and there is a risk of health professionals not understanding the test or the test results, e.g., the future potential for reporting of non-disease causing mutations.
	+ NSU to provide a background paper for NSAC when the website is updated and the issue is receiving more attention
* Gestational diabetes
	+ NSAC should consider the screening components of the Ministry of Health’s Diabetes in Pregnancy guideline at some point
* Breast cancer age extension (70-74years)
	+ International Agency for Research on Cancer (IARC) published assessments and recommendations anticipated Nov 2015; with NSAC consideration possibly early 2016.
* Lung cancer screening
	+ UK decision expected this year
	+ issues around work force upskilling are anticipated.
* Abdominal aortic aneurysm (AAA) screening using ultrasound
	+ The NHC is currently reviewing this topic area.
* Rheumatic heart disease screening using echocardiography
	+ focus remains on prevention and reducing secondary cases
	+ there is insufficient known about the condition’s natural history, especially “grey” cases which comprise about half of screen positive cases using echocardiography.
* Genomic technologies
	+ increasing impact of these technologies on many screening conditions which will ultimately see requirement for an overarching plan re workforce, laboratory protocols & diagnoses alongside complex bioethical considerations.
	+ Australia’s Health Ministers’ Advisory Council (AHMAC) has directed establishment of a Genomics in Clinical Practice Working Group (GCPWG) under the auspices of the Department of Health, Western Australia. The GCPWG has to report to the Hospitals Principal Committee (HPC) after every meeting. Those reports then are collated and go to AHMAC 6 monthly
	+ Dr Joanne Dixon is on the working group by virtue of her current presidency of the Human Genetics Society of Australasia. NZ participation was sought from the Ministry of Health (Chief Medical Officer)
	+ noted value in raising increasing importance of genomics generally in the health system generally and its likely future impact on screening, and that this issue should be raised with the MOH Chief Medical Officer
 | NSAC to raise importance of genomics with Chief Medical Officer  |
| **5** | **NSU Update (for information)**The NSU tabled a written summary of recent programme activities.  |  |
| **6** | **HPV testing for primary screening in the National Cervical Screening Programme** The NSU provided a high level overview of the proposed introduction of HPV testing for primary screening including the: * governance structure for the HPV project and formation of a technical reference group and a steering group
* policy development process
* project timelines working towards potential implementation in 2018
* development of a rapid assessment document for wider sector consultation.

NSAC agreed that: * their role for the HPV primary screening project is to endorse the recommendations of the rapid assessment before it goes to the project sponsor (submission to the sponsor is proposed for early December 2015)
* the rapid assessment will be released for sector consultation subject to endorsement by other key NSU groups (release proposed mid-Aug 2015); with the proposed primary screening strategy being HPV testing (with partial genotyping) with cytology triage for non-16/18 HPV positive samples in women aged 25 to 69 years every 5 years
* NSAC will review the draft rapid assessment around the same time that sector consultation is under way.

Given the priority of NSAC’s strategic advice and the importance of their being confident with the science that the NSU and the HPV Technical Reference Group present, NSAC also agreed to: * attend an additional meeting in September for a preliminary consideration of the supporting science and the draft rapid assessment
* consider the final draft rapid assessment at their November 2015 meeting.
 | The NSU will schedule an additional NSAC meeting to consider HPV primary screening  |
| **7** | **Severe Combined Immunodeficiency Disease (SCID)** NSAC considered the NSU’s request to add SCID to the Newborn Metabolic Screening Programme (NMSP) NSAC member had received the following papers: * NSU memo detailing the proposal and analysing screening for SCID against the NHC screening criteria
* NSU commissioned cost effectiveness study undertaken in 2014
* UK National Screening Committee 2012 external review of screening for SCID

Drs Dianne Webster and Jan Sinclair gave a presentation on SCID screening. Discussion included: * the benefits of early diagnosis and high success rate with the only life-saving treatment option available i.e., bone marrow transplant
* the information provided to families and their overall level of under-standing about the range of conditions tested for by the NMSP. It was noted that Lead Maternity Carers (LMCs) are believed to be skilled at explaining the purpose of the collecting the blood spot card; that the NSU has recently produced new information resources; and that the NSU will ultimately need to update NMSP resources in relation to SCID
* whether there were risks to the uptake of the overall NMSP given the impact on families that face the complex life-saving treatment required for SCID. However, it was noted that the same treatment is offered for diagnoses made later in infancy; and that other conditions with significant implications are also identified though NMSP e.g., cystic fibrosis.

NSAC endorsed the inclusion of SCID on the NMSP panel of disordersNext steps:* NSAC Chair Ross Lawrenson, NSU Clinical Director Jane O’Hallahan and NSU General Manager Astrid Koornneef will meet with the Ministry of Health’s Director of National Services Purchasing Jill Lane and Chief Medical Officer Don Mackie to advise them of NSAC’s recommendation, and will report back at the next NSAC meeting
* John McMillan offered to provide additional comments related to quality of life information that could be added to the paper
* the NSU will report back on implementation timeframes
* NSAC will review outcomes NSAC in approximately two years
 | The NSU will provide NSAC a copy of updated NMSP resources The NSU will arrange a meeting between NSAC Chair and MOH. The NSU will report back on implementation timeframes NSAC to review outcomes in approximately two years  |
| **8**  | **Screening for critical congenital heart disease (CCHD) using pulse oximetry** NSAC considered the NSU’s preliminary assessment of screening for CCHD using pulse oximetry. NSAC member had received the following papers: * NSU memo detailing the proposal and analysing screening for CCHD against the NHC screening criteria
* UK National Screening Committee 2014 external review of screening for CCHD

Dr Elza Cloete gave a presentation on CCHD which assessed the use of pulse oximetry against the NHC screening criteria and described the Auckland region’s planned three year pilot. The pilot will also include a provincial DHB to test the feasibility and referral pathways in this setting. Discussion included: * option of integrating introduction of pulse oximetry screening with improvements to the wider foetal anomaly screening e.g., improved quality measures for antenatal scans
* whether the three year Auckland pilot was actually a feasibility study as it was unlikely to be powered to show a difference in outcome, in which case results could potentially be available in a shorter period of time
* potential quality issues, particularly for provincial / rural settings of implementing screening without guidelines and monitoring
* the need to address logistics e.g., early discharge of many newborns given screening is planned to be undertaken 4 to 24 hours post birth; LMC training requirements; and rural transfers
* the importance of midwifery / LMC involvement for successful implementation
* the importance of equitable provision of screening so that as many babies as possible are screened, maximising anticipated reductions in late diagnoses and deaths (current estimates indicate that 15 cases of CCHD are diagnosed late each year with four deaths)

The NSAC was supportive of CCHD screening using pulse oximetry but was undecided as to which implementation approach would work best, with options including:* a nationally led screening programme, with all aspects of the screening pathway implemented and monitored by the NSU (as proposed by the Paediatric and Congenital Cardiac Service at Starship Children’s Hospital)
* a nationally led quality improvement programme with for example the development of national guidelines alongside DHB led implementation and monitoring
* sector led implementation with screening framed as being part of improvements in routine care, with a focus also on raising the quality of foetal anomaly screening by incorporating improvements in the 18-20 week antenatal ultrasound scan and the newborn clinical examination

NSAC is very supportive of the Auckland led pulse oximetry pilot. The pilot will help address a number of unanswered questions regarding the feasibility of implementing pulse oximetry as a national screening programme. NSAC agreed it would look at available screening options once the study results are in.  | NSU to maintain watching brief of developments and NSAC to review screening options once Auckland led pilot results are available.  |
| **9** | **Other business** - **horizon scanning**Brian Cox noted that:* The results of the randomised introduction of bowel screening using FOBT in Finland has not reduced bowel cancer mortality; mortality ratio 1.04 (95% CI 0.84-1.28) for the bowel cancer mortality in the screening arm versus those not offered screening.  Median length of follow-up 4.5 years; maximum follow-up 8.3 years.
* The research study of the assessment of breast density in the Netherlands breast screening programme, using the Volpara density measurement system for digital mammography developed in Wellington, has found considerable geographic variation in breast density within their population.
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|  | The meeting closed at 4.30pm |  |