



Submission on NSU Quality Principals-draft for comment.

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Women's Health Action is a women's health promotion, information and consumer advisory service. We are a non-government organisation that works with health professionals, policy makers and other not for profit organisations to inform government policy and service delivery for women. Women's Health Action is in its 30th year of operation and remains on the forefront of women's health in Aotearoa New Zealand.

We provide evidence-based analysis and advice to health providers, NGOs and DHBs, the Ministry of Health, and other public agencies on women's health (including screening), public health and gender and consumer issues with a focus on reducing inequalities. We have a special focus on breastfeeding promotion and support, women's sexual and reproductive health and rights and body image.

Thank you for the opportunity to provide our views on the NSU Quality Framework

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National Screening Unit Quality Framework

Draft Principles – request for feedback

The six principles below are derived from a paper produced for the World Health Organisation (WHO).¹ They have been adapted to incorporate themes derived from key stakeholder interviews, and feedback to date from National Screening Unit advisory and senior management groups.

1. The overall benefits of screening must outweigh the harm

- The condition should be an important health problem
- There should be an accepted treatment for those identified with the condition
- There should be an agreed policy on whom to treat
- There must be treatment available within an agreed timeframe.

Comment:

Women's health action believes that benefits of any health intervention should always outweigh the harm. We agree with principal one and would add that any possible adverse effects from any screening program should be made clear to consumers so they can make an informed choice.

2. National screening programmes are people centred

- The screening test should be suitable and acceptable to whānau and the populations concerned
- Advisory groups should include at least one consumer with experience in the condition screened for
- Screening programmes must use appropriate methods of service delivery that operate in line with ethical obligations and cultural safety.

Comment:

We agree with principal two and would add that consumer input into how programs are delivered must also include consumers and clinicians from diverse population groups and that advisory groups may therefore need to include more than one consumer. Research indicates that often programs fail to target minority populations such as LGBTI or migrant groups. We would also expect both Māori and Pacific populations would be represented on such groups and that screening programs would ensure that they are specifically targeted to all age groups they are expected to cover.

¹ Andermann, A., Blancquaert, I., Beauchamp, S. and Dery, V. *Revisiting Wilson and Jungner in the genomic age: a review of screening criteria over the past 40 years.* Bull World Health Organ. 2008 April; 86(4): 317–319.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2647421/>

3. National screening programmes will achieve equity and access to screening and in screening outcomes for all populations

- Screening programmes should aim to reduce inequities and deliver equitable screening services by incorporating the principles of The Treaty of Waitangi
- Information repositories, including population registers, support achieving equity
- Solutions to access are focused on changing systems rather than changing individuals.

Comment:

Women's health action agrees with principal three and would add the comments already made above in relation to this principal and that information repositories must collect information about the participation and outcomes for minority populations, in particular those about which little data is currently known. For example data relating to lesbian and transwomen is not currently routinely collected by Breastscreen Aotearoa.

4. Informed consent is a priority throughout the screening pathway and must ensure confidentiality and respect for autonomy

- Screening programmes should provide full information to people; this includes detail on harms and benefits
- Screening programmes must ensure that ethnic, demographic and literacy differences are addressed when providing information to support informed consent.

Comment:

Women's Health Action agrees with principal four. We would add that as well as providing full information consumers should be given time to process and understand it in order to fully consent.

5. Screening programmes are monitored and evaluated on a regular basis

- There should be scientific evidence of the effectiveness of the screening programme
- Information systems should be set up to enable monitoring in real time, audit and evaluation of screening programmes and providers.

Comment:

We agree with this principal but believe it should say “independent scientific evidence”.

It should also include a process by which consumers can be informed of where their information is stored and what access researchers and evaluators have to it.

6. National screening programmes are committed to continuous quality improvement

- Screening programmes should integrate continual learning, improvement of care, clinical services and programme management.
- Policy makers, providers and all those involved in screening programmes are accountable and responsible for maintaining capacity and capability in delivering screening programmes / services of the highest possible quality.
- Screening programmes should be transparent and consistent with public reporting of outcomes and incidents

Comment:

Women’s health Action agrees with principal six, in particular that the outcomes and effects and any adverse incidents relating to screening programmes be widely reported to the public. This includes incidents with the storage of information or reports as well as any incidents related to adverse effects from the screening itself. We also believe the public should be kept well informed about the health benefits (or lack of them) from screening including issues such as false positives in diagnosis.

Thank you for the opportunity to provide this feedback.

Please send feedback by Monday 31 March 2014 to:

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Please also feel free to provide further general comment.

Thank you

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