Women’s Health Action Trust

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 31st 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 this feedback.

National Screening Unit Quality Framework: Feedback Form

Thank you for taking the time to provide feedback.

Grouped under five essential components of organised screening programmes, the Quality Framework describes the quality requirements for the NSU's national screening programmes.

The project team is particularly interested in your comments on what has been included in each of the five main sections and also on any areas that may have been omitted.

Essential Component: Central agency to lead and coordinate the screening pathway
Central Agency: We agree that a central agency should be responsible for screening. However, we continue to have concerns about this agency sitting within the Ministry of Health and with clarity of the roles of the NSU and the screening programmes particularly NCSP. Leadership on equity: We think more substance has to be put into the requirements around leadership on population equity. While progress is being made with some groups, others are not taking up screening programmes. There is a need for research amongst certain communities such as some migrant groups, women with disabilities and lesbians for example. Standards and Indicators and policy framework: We agree with regular and transparent revision of standards and policies. These reviews must involve a diverse range of consumers and be transparent and accessible to the public. Research: Research contributes valuable information to health care consumers and providers. However, research must be independent and ethical and the results published widely. Given the problems and mistakes that have occurred in the past (Cartwright, Gisborne) we would like to see clearer guidelines for research and data collection within this framework. Quality management: The section on quality management systems is not clear about what systems you are proposing to use. This section requires more information. Evidence based information: We agree evidence based information is extremely important. We believe this section should contain commitment to proper informed consent processes, confidential data collection and the provision of culturally appropriate information to the public and transparent processes for establishing an 'evidence base'. Use of resources: We also agree that coverage and resources must be appropriate and equitable. We believe this must include provision of specific services or programmes for certain groups and that assessing 'value' should entail analysis of more than just cost. We agree with the workforce development requirements and support in particular the need for 'cultural competence' so services can target a range of diverse cultures and communities.

Uptake of new technologies:
We believe that when considering new technologies, patient safety should be paramount and processes surrounding these developments should be transparent.

Essential Component: Clinical governance

Partnership with management:
It is essential that clinical safety is a paramount consideration and believe this section leaves the relationship between clinical and operational governance unclear which could give rise to operational requirements being given precedence.

Consumer centred partnership:
Consumer input into how programmes are delivered must include consumers and clinicians from diverse population groups and advisory groups should always include more than one consumer. We would also expect both Māori and Pacific populations would be represented on all such groups. Research indicates that often programmes also fail to target minority populations such as LGBTI or migrant groups. We would expect consumer centred partnerships would include representatives from diverse population groups.

National clinical governance:
The national screening advisory authority and the programme advisory groups need to be representative groups that reflects the diversity of Aoteroa’s population.

Service provision Governance:
This section does not clearly identify the role of the NSU should a service provider fail to provide safe or effective services or fail in their own governance systems.

Essential Component: Infrastructure and systems

Comments on requirements:
Privacy and Confidentiality:
Consumers must be sure that the information is private and confidential and must also have the option of opting out of data collection. This section needs to ensure that the public benefits from and understands any data collection and there are robust consent processes. 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.

Recruitment and retention:
We agree that programmes to support increased participation must be funded. Some population groups will require specific programmes and expertise.

Fit for purpose registers:
We would like to have more detail regarding registers and note again that confidentiality, privacy and informed consent issues must be addressed.

Information across agencies:
We do not see any reason why screening information would be shared across social sector agencies.

Information system platforms and tools:
We believe confidentiality and security issues should be addressed here. 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.

Essential Component: Monitoring and evaluation

Programme evaluation:
We agree all programmes must be evaluated. Importantly this information should be made available to the public. In addition, information repositories must also 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).

Individual performance monitoring:
We agree this is extremely important. The benefits of any health intervention should always outweigh the harm. We would add that any possible adverse effects from any screening program should be made clear to consumers so they can make an informed choice. 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.

Programme monitoring:
Again we note that the results of programme monitoring must be made available and accessible to the public.
Ethnicity data accuracy:
No comment

Provider relationships and contract monitoring:
No Comment

Essential Component: Quality cycle

Consumer feedback:
This section is vague about what mechanisms would be used to obtain feedback at various levels and how complaints would be dealt with particularly those where patient safety is compromised. We believe there must be some mandatory aspects applied to agencies in relation to both informed consent and consumer feedback processes.

Risk and incident Management:
These sections are both vague and do not give any clear responsibilities or guidelines. We believe there must be a de-identified record kept regarding any incident which are made available to the public.

Monitoring reviews:
These must be also placed in the public domain.

Public reporting:

We agree transparent public reporting of activities and results including challenges is extremely important.

Audit:
We agree auditing is also important and that the results must be available to the public.

General Comments:
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 give this feedback.

Please return your feedback by **Friday 30 January 2015** to:

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