

NATIONAL SCREENING ADVISORY COMMITTEE

Advice to the Director-General of Health

Title	Antenatal Down Syndrome Screening
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Statement No.	4

1. Background

From its inception, NSAC has raised concerns about the safety and quality of antenatal screening. In 2006, NSAC reviewed Professor Peter Stone and Dr Nicola Austin's report on the Assessment of Antenatal Screening for Down Syndrome in New Zealand. As a result of that report, Members of NSAC met with the then Director-General of Health to discuss its concerns in greater detail. Following that meeting, the Ministry agreed that the National Screening Unit would carry out a detailed review of antenatal screening for Down syndrome.

The National Screening Unit's review included the establishment of the Antenatal Down Syndrome Screening Advisory Group ("the Advisory Group"), which developed a report to the National Screening Unit. NSAC was provided an opportunity to review both the report of the Advisory Group and, with the Director-General's agreement, a draft version of the Ministry of Health's proposed advice.

2. Reliable screening tests

The NSAC shares the concerns of the Advisory Group and the wider health sector that that screening tests in current use are not the most reliable tests available internationally. In NSAC's view, the high-false positive rate of the current tests is not acceptable.

NSAC supports the technical recommendations of the Advisory Group as a reasonable way to introduce more accurate forms of screening. Given the widespread concerns about the safety of current screening practice, NSAC recommends that further steps be taken to introduce the better forms of screening as soon as possible. However, the technical recommendations cannot be implemented without also taking steps to address the social and ethical implications of screening. It is recommended that the Ministry develop a detailed implementation plan, which would describe how the technical, social and ethical recommendations will be implemented.

NSAC considers that implementation of the most accurate forms of screening will require specific mechanisms and structures to organise and co-ordinate the screening pathway and deliver high quality screening. Detailed planning will need to be carried out.

3. Social and ethical considerations in screening

Inequalities

Steps need to be taken to ensure that Māori women have the same opportunity to access quality screening that non-Māori women have. This may impact on the way that a safer form of screening is funded, provided and implemented. For example, the Ministry of Health will need to consider how the services can be funded in a way that ensures women are not denied an opportunity to access the screening due to the charging of co-payments for some services. Consideration will also need to be given to how best to provide high-quality access to screening for women who live in rural areas.

As discussed further below, adequate informed consent processes are going to be key to ensuring that a safer form of screening is implemented in a way that addresses many of the social and ethical considerations. The Ministry of Health will need to ensure that the informed consent process is supported by adequate balanced information in a range of formats including for people with limited education, and in a range of languages including Te Reo Māori, and the most commonly used Pacific languages.

Informed consent

Adequate informed consent processes are a key element of offering antenatal screening for Down syndrome in a way that is socially and ethically responsible. Many of the social and ethical considerations would be addressed if the Ministry could implement nationally a clear process for informed consent, with the requisite training for health practitioners, information resources for consumers, and a robust system to audit and evaluate this process. It is recommended that as part of the detailed implementation planning, the Ministry describes how the informed consent process would be supported at each stage of the screening pathway.

For many medical practitioners, it will be difficult to help prospective parents understand what their child's life might mean beyond a clinical view of impairment. NSAC proposes that the materials produced to improve the likelihood of genuinely informed consent include perspectives of young people and adults with Down syndrome, along with those of parents who are raising children with varying degrees of impairment and diversity of circumstances. NSAC suggests that this could be achieved using recorded video and other accessible methods of conveying those perspectives. Consideration needs to be given to the most appropriate point in the screening pathway at which to provide these resources to women.

Support and counselling services

If a national screening programme is to be implemented, the health sector must invest in good-quality non-directive support for decision making. It will be important that women who received a high-risk result and a positive diagnosis are offered a referral to services that can provide appropriate support for decision making. This will have workforce implications.

Disability support services

Expectant parents must be presented with options other than termination of pregnancy. This emphasises the need for disability support services to be available. NSAC strongly supports the need for continuing investment in disability support services and recommends that the Director-General of Health consider advice from the current Office for Disability Issues review of Long-Term Support Services about ways of improving access to, and quality of, services.

Attitudes towards disability

Some Members of NSAC are concerned that screening for disability invites the conclusion that Down syndrome is a 'harm', and that the treatment for this 'harm' is termination of the pregnancy. Publicly funding a programme that is likely to result in a reduced number of children born with disabilities is likely to give the impression that the Government does not consider disabled people to be socially valuable. It is suggested that the Government consider ways to actively counter this perception. One option that would have wider benefits is a significant public mass-media anti-discrimination campaign along the lines of the internationally renowned "Like Minds, Like Mine" mental health initiative. This would be support the intention of the New Zealand Disability Strategy.

4. Consultation with consumers, disability sector and the public

NSAC notes that, to date, there has not yet been formal consultation with consumers of maternity services, the disability sector or the general population, in relation to antenatal screening for Down syndrome.

Consumer consultation

Consumer consultation would assist in identifying the values and acceptability of the screening tests to women and their partners. This would assist in determining how many women are likely to participate in screening, and whether there are forms of screening that are more or less acceptable than others. Some members of NSAC believe that information on consumer preferences may usefully be obtained by implementing a programme in a staged manner, accompanied by rigorous monitoring and evaluation, with the potential to make changes as necessary.

Disability sector consultation

Some members of NSAC consider that more work should be carried out in future to incorporate the views of disability stakeholders. In particular, disability stakeholders should be engaged in developing suitable information materials and resources as part of implementing a national programme.

Public consultation

Some members of NSAC consider that the Ministry should engage the public in a way that can add to public acceptance of screening. This would need to be carried out in a way that would not unduly delay the implementation of safer screening.

Given the risks of the present screening activities, NSAC considers it is important to introduce the better forms of screening tests as soon as possible.

5. NHC committee criteria to assess screening

NSAC notes the comments of the Antenatal Down Syndrome Screening Advisory Group in relation to the National Health Committee's criteria to assess screening programmes.¹ NSAC has previously indicated that it would like to review these criteria at some point in the future, and develop criteria that could be more usefully applied across the wide range of screening activities, including disability. As a starting point, NSAC's work programme over the next two years includes the development of a framework to guide the consideration of social and ethical matters in screening.

6. Antenatal Screening

As noted earlier, NSAC has raised concerns about antenatal screening over a number of years. A project on antenatal screening is the first priority on NSAC's work programme for the next two years. We hope that this will go some way to providing an overview of the broad issues in antenatal screening.

RECOMMENDATIONS

NSAC makes the following recommendations in relation to antenatal Down syndrome screening:

1. That the recommendations of the Antenatal Down Syndrome Screening Advisory Group on social and ethical issues be accepted and incorporated into the detailed implementation planning.
2. That the technical recommendations of the Antenatal Down Syndrome Screening Advisory Group be implemented as soon as possible, taking into account the need for detailed implementation planning and the responsibility to organise all elements of the screening pathway.
3. That the Ministry of Health give consideration to the mechanisms and structures that are required to organise and co-ordinate 'best practice' screening pathway and deliver high quality screening.
4. That the Ministry of Health gives consideration to implementing the technical recommendations in a way that ensure Māori, Pacific and rural women are provided the same opportunity to access screening as non-Māori, non-Pacific, and non-rural women.
5. That the Ministry of Health gives consideration to the informed consent process and how it will ensure that all women are given an opportunity to provide a fully

¹ Ref NHC criteria

informed consent to the screening pathway, and how this will be monitored and evaluated. As part of the detailed implementation planning the Ministry should:

- describe how the informed consent process would be supported at each stage of the screening pathway
 - consider the development of materials using video and other accessible methods to convey a variety of disability perspectives including the views of young people and adults with Down syndrome.
6. That as part of implementing better forms of screening, the health sector should invest in good quality, non-directive support for decision making by health care professionals and families. The workforce implications should be considered during the planning phase.
 7. That the Director-General of Health consider the recommendations of the current Office for Disability Issues review of Long-Term Support Services about ways of improving access to, and quality of, services.
 8. That the Ministry should plan for ways to involve consumers of maternity and disability services in the implementation phase.

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National Screening Advisory Committee