

13 April 2012

Ministry of Health

Consultation on updated guidelines for health practitioners for antenatal screening and brochure

Thank you for the opportunity to provide comment on the above document and for the extension of time provided. I trust the following brief comments are of assistance.

With regard to the guidelines and brochure, I refer to HDC's previous submissions of 18 August 2009 and 13 October 2011 to the National Screening Unit. These submissions included general comments about the screening programme and are not repeated here, but may be relevant.

This submission focuses specifically on issues that are particularly pertinent to the Code of Health and Disability Services Consumers' Rights (the Code). If you wish HDC to comment in detail on any other specific aspect of the publications, please let us know and we would be happy to assist.

Guidelines

Title

In our submissions of 18 August 2009 and 13 October 2011, it was submitted that, as antenatal screening is for a number of conditions, it would be more appropriate for the title to refer simply to "antenatal screening" and omit "for Down syndrome and other conditions". I repeat that point and refer you to those previous submissions for our rationale.

Informed consent

Page 15 of the guidelines correctly states that healthcare consumers have a legal right to appropriate information to enable them to give informed consent. However, as well as the information set out in the box on page 15, women considering entering the screening pathway also need other information, including information about:

- the conditions being screened for;
- the disadvantages of screening;
- the subsequent decisions that may have to be made; and
- the options available to the woman.

The most relevant parts of the Code state:

- 6(1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including -
 - a) An explanation of his or her condition; and
 - b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
 - c) Advice of the estimated time within which the services will be provided; and

- d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
 - e) Any other information required by legal, professional, ethical, and other relevant standards; and
 - f) The results of tests; and
 - g) The results of procedures.
- 6(2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.

In addition, Right 5 requires communication to be in a form, language, and manner that enables the consumer to understand the information provided.

The guidelines also suggest that if a woman initially decides not to participate, she is then unable to change her mind and undergo some level of screening later in her pregnancy. I recommend making it clear that this would not be the case, as presumably, a woman could refuse the first trimester combined screening, but decide later to have the second trimester maternal serum screening.

Training

As the information on screening is generally provided to a woman by her LMC, I consider that it may be useful for regular updated training to be provided to ensure each LMC's knowledge remains current and to provide an opportunity for LMCs to reflect on their practice, particularly regarding the manner in which screening is presented to pregnant women.

Brochure

The brochure does not point out that, in some cases, the effects of a condition on the baby may be minor. This information would assist in ensuring the brochure presents a balanced picture.

The brochure also does not warn that a baby may be born with a health condition despite the result of screening indicating a "low chance" of this. In addition, I note that many people do not understand that antenatal testing relates to some conditions only, and that there are many other health conditions not tested for that may affect their baby. Clarity around these issues would, in my view, be beneficial.