



Down's Syndrome Scotland

helping people realise their potential

Monday 13th November 2017

To whom it may concern,

Consultation: Guidance for the development, production and review of information to support UK population screening programmes

Down's Syndrome Scotland (DSS) welcomes the opportunity to respond to this consultation from the UK National Screening Committee (UK NSC).

DSS is the only Scottish charity focused solely on the needs of people with Down's syndrome (Ds) and their family carers. We provide information, support and services for people with Ds, their families, carers and those with a professional interest in Scotland. We also seek to improve public knowledge and understanding of Ds and to champion the rights of people with Ds.

We agree that the issue of 'informed choice' is crucial to all screening programmes and we welcome the proposed guidance. Overall important points are addressed in the document. We have a couple of issues we would like to raise regarding 'Principles for information development'.

The principles outlined in bold in the document are relevant and essential criteria for delivering person-centred screening programmes. However we are of the view that the principles should address both written and verbal formats of information. More focus is needed on the key role of professionals (including training) and communication between them and their patients (including the importance of terminology and the language used by professionals). We believe that some of the points made in the second half of section 2.1 should be in bold too, especially the importance of understanding and health literacy as well as the need for consistency between professionals and public information.

We would also add additional criteria to some of the principles outlined in the guidance:

- *Information should be balanced and include accurate, evidence-based information on the condition being screened for, potential benefits and harms of taking the test and the possible outcomes and decisions that may ensue.*

It would be helpful to add that information should also include the offer of informed, broad and non-directive counselling with specialist and the support available to parents (within NHS and from organisations like DSS for example).

- *Information should make it clear that it is a personal choice to accept or decline screening.*



It would be helpful to add that people should be treated with sensitivity and dignity and that their decision regarding the screening process and its outcomes should be recorded and respected.

We trust these comments assist the Committee with its inquiry. Please do not hesitate to contact our office on 0131 442 8849 or by email at rachel@dsscotland.org.uk should you have any questions.

Yours sincerely,

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