



Title	Psychosocial Aspects of Genetic Screening of Pregnant Women and Newborns: A Systematic Review
Agency	NCCHTA, National Coordinating Centre for Health Technology Assessment Mailpoint 728, Boldrewood, University of Southampton, Southampton SO16 7PX, United Kingdom; Tel: +44 2380 595586, Fax: +44 2380 595639
Reference	Health Technol Assess 2004;8(33). August 2004. www.hta.ac.uk/execsumm/summ833.htm

Aim

To investigate how screening programs are likely to be experienced by recipients, and to learn lessons from psychosocial aspects of past screening programs to inform genetic screening in the future.

Conclusions and results

The review was structured around key questions, including: How well informed are screening program participants, and what factors are associated with different levels of knowledge/understanding? What are the aspects of screening programs that are associated with high/low levels of anxiety?

Knowledge: Levels of knowledge adequate for decision making are not being achieved. Information leaflets and videos have some effect, but large gaps in knowledge usually remain. Procedural aspects of testing are better understood than material related to the meaning of risk calculations. Substantial social and cultural inequalities exist in knowledge about testing. These findings probably underestimate the extent of the problem, since only limited aspects of knowledge have been studied. Also: *Knowledge is not the same as understanding*; public understanding of the basic concepts associated with screening is poor. *Knowledge that is only superficially acquired may not be retained*; informed consent for neonatal screening has not been well studied.

Anxiety: Studies that have succeeded in increasing knowledge have not observed a corresponding increase in anxiety. Anxiety is raised in women receiving positive screening results, but evidence is lacking of a beneficial (ie, reassuring) effect of a negative result. Anxiety in screen positive women falls on receipt of subsequent reassuring results, but some residual anxiety may remain. The way in which carrier screening is offered may affect anxiety in screen negative women. See full report for additional findings.

Recommendations

Levels of knowledge adequate for decision making are not being achieved. Substantial social and cultural inequalities exist in knowledge on testing. Considerations of efficiency that limit the time available to inform women may be misguided if achieved levels of understanding are inadequate. Anxiety is often an appropriate response. Much inappropriate anxiety can be traced to poor communication. Knowledge that improves decision making may not be the same as that which reduces anxiety.

Methods

See Executive Summary link above.

Further research/reviews required

As different genetic tests are introduced, the cumulative knowledge demands become substantial, increasing the possibility of inadequate or incorrect understanding.

More complicated testing scenarios may amplify inequalities in understanding, especially if time constraints mean leaflets are used as substitutes for face-to-face explanations. Future research needs to tackle these challenges, focusing particularly on: defining necessary and sufficient levels of knowledge, the needs of people with false positive results, the needs of male partners, and the resource requirements of providing satisfactory service. Policy developments and technological advances are likely to add new components to existing programs, eg, new conditions, new client groups, and new testing modalities. Research needs to incorporate these topics in mainstream work.