Supplementary Online Content


eAppendix 1. Values Clarification Questions
eAppendix 2. Knowledge Questionnaire

This supplementary material has been provided by the authors to give readers additional information about their work.

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eAppendix 1. Values Clarification Questions

Questions to help decide whether or not to have any testing (presented to all women):

How important to you is knowing whether or not your baby will be born with a birth defect such as Down syndrome?

1 = very important, 2 = somewhat important, 3 = I am not sure, 4 = not very important, and 5 = not important at all

Would you choose to have a diagnostic test that would tell you for sure whether or not your fetus has Down syndrome, even if it could cause a miscarriage?

1 = definitely, 2 = probably, 3 = I am not sure, 4 = probably not, and 5 = definitely not

Which would be worse for you, having a child with Down syndrome or having a miscarriage caused by a prenatal test?

1 = definitely worse to have a child with Down syndrome, 2 = probably worse to have a child with Down syndrome, 3 = I am not sure, 4 = probably worse to have a miscarriage, and 5 = definitely worse to have a miscarriage

Questions to help choose between starting with screening or going straight to invasive testing (presented only to women who were considering having testing)

How important is it to you to avoid a false positive screening result?

1 = very important, 2 = somewhat important, 3 = I am not sure, 4 = not very important, and 5 = not important at all

How important to you is knowing for sure whether or not your fetus has Down syndrome?

1 = very important, 2 = somewhat important, 3 = I am not sure, 4 = depends on my risk, and 5 = not important

Would it help you to know your personal chance of having a baby with Down syndrome before deciding whether or not to have a diagnostic test (CVS or amniocentesis)?

1 = definitely would help me, 2 = probably would help me, 3 = I am not sure, 4 = probably would not help me, and 5 = definitely would not help me.

Questions to help decide which screening or diagnostic test to undergo (only presented to women who were considering having testing)

When would you prefer to receive results?

1 = definitely during my 1st trimester, 2 = probably during my 1st trimester, 3 = it doesn’t matter, 4 = probably during my 2nd trimester, and 5 = definitely during my 2nd trimester

Would you be willing to go to another facility to have a nuchal translucency ultrasound?

(presented only to women who preferred to start with screening)

1 = definitely would not, 2 = probably would not, 3 = I am not sure, 4 = probably would, and 5 = definitely would
eAppendix 2. Knowledge Questionnaire*

1. Amniocentesis involves taking blood from a pregnant woman’s arm.
2. All people with Down syndrome have mental retardation.
3. Women who have a “negative” or “low risk” result on a screening test can be sure that their baby will not have Down syndrome.
4. Amniocentesis is used to test for diabetes.
5. Nuchal translucency screening is a type of blood test.
6. Screening tests tell you for sure whether your fetus has Down syndrome.
7. Amniocentesis can tell you about the severity of mental disabilities that a baby with Down syndrome will have.
8. The chance of having a baby with Down syndrome increases with the age of the mother.
9. If a woman receives a “positive” or “increased risk” result on a screening test, further tests are needed to tell if anything is wrong.
10. Amniocentesis can cause a miscarriage.
11. Amniocentesis can tell you for sure whether or not your fetus has Down syndrome.
12. Down syndrome can be cured.
13. The Quad Marker Screening test only detects Down syndrome.
14. Amniocentesis is done later in pregnancy than chorionic villus sampling (CVS).
15. The Quad Marker screening test can cause a miscarriage.

*Adapted from Maternal Serum Screening Knowledge Questionnaire.14 Response options for each item included “true,” “false,” and “not sure/don’t know.” The correct response to items 2, 8, 9, 10, 11, and 14 was “true”; the others were false. Scores range from 0 to 15, reflecting the number of correct responses.