Appendix.

I. Screen Shots From the Prenatal Testing Tool

Background Information and Issues to Consider

The goal of this program is to give you the information you need to make informed decisions about prenatal testing that reflect your preferences.

Information about Prenatal Testing and Down Syndrome

. . . most women give birth to healthy babies. However, about 3 to 4% of babies are born with a birth defect. For some of these conditions, there are prenatal tests that can tell you whether the fetus is affected.
II. Values Clarification Exercises Included in Prenatal Testing Tool

1. Test results for many women are normal, and most women are reassured by such results. How important is receiving test results that suggest that your fetus is at low risk?

2. How important is it to you to get information about birth defects other than Down syndrome as part of your initial screening test?

3. How important is it to you to get information about birth defects other than Down syndrome as part of your diagnostic test?

4. Overall, how important is it for you to get information about whether or not your fetus has Down syndrome?

5. How important is it for you to know FOR SURE whether or not your fetus has Down syndrome or another chromosomal abnormality?
6. A screening test is called "positive" or "increased risk" when it indicates that your risk of having a fetus with Down syndrome is at least as high as the risk of an average 35- or 37-year-old. Even with "increased risk" results from a screening test, most of the time the fetus will turn out NOT to have Down syndrome or another chromosomal abnormality. This situation is sometimes referred to a "false alarm." How important would it be to avoid a false alarm?

7. Even with normal results from a screening test, it's possible that your fetus will have Down syndrome or another chromosomal abnormality. This situation is sometimes referred to as false reassurance. Typically, the fact that the fetus has Down syndrome will not be known unless a diagnostic test (i.e., CVS or amniocentesis) is performed, or until the baby is born. How important is it to you to avoid such false reassurance?

8. How important is it to you to receive prenatal testing results early in your pregnancy?

Response options (questions 1–8): Absolutely crucial; Very important; Somewhat important; Barely important; Not important at all

9. Which of these outcomes would be worse for you: giving birth to a child with Down syndrome, or having a miscarriage due to diagnostic testing?

Response options: Definitely giving birth to a child with Down syndrome; Probably giving birth to a child with Down syndrome; Both are about the same to me; Probably having a miscarriage due to diagnostic testing; Definitely having a miscarriage due to diagnostic testing
10. How would raising a child with Down syndrome impact your life and that of your family?

Response options: An impossible burden; A difficult burden; A manageable burden; A minor burden; No burden at all

11. Would you take an additional 0.75% (about 7 in 1,000) risk of miscarriage to get your test results at week 12 instead of week 18?

12. Do you think you would have an abortion if you found out for sure that your fetus was affected by Down syndrome?

Response options (questions 11–12): Yes, definitely; Leaning toward yes; Not sure; Leaning toward no; No, definitely not

III. Measures Used in Study (all were interviewer-administered)

A. Prenatal Testing Inclinations

1. If you were offered nuchal translucency screening free of charge in your current pregnancy, would you choose to have it?

2. If you were offered an expanded alpha fetoprotein test free of charge in your current pregnancy, would you choose to have it?

Response options (questions 1–2): I don’t know what [the test] is; No I definitely would not have [the test]; I probably would not have [the test]; I am unsure whether or not I would have [the test]; I probably would have [the test]; Yes I definitely would have [the test]
3. If you were offered chorionic villus sampling (CVS) free of charge in your current pregnancy, would you choose to have it?

4. If you were offered amniocentesis free of charge in your current pregnancy, would you choose to have it?

Response options (questions 3–4): I don’t know what [the test] is; No, I definitely would not have [the test]; I probably would not have [the test]; I am unsure whether or not I would have [the test]; I would consider having [the test] depending on the results of [the screening test]; I probably would have [the test]; Yes, I definitely would have [the test] Scoring: Women who answered they would definitely or probably have the test were considered to be inclined toward undergoing the test.

B. Knowledge

1. The chance of having a fetus with a neural tube defect does NOT increase with the age of the mother.¹

2. The expanded alpha fetoprotein (AFP) test detects only Down syndrome.¹

3. Women who have normal expanded AFP test results can be sure that they will have a normal baby.¹

4. Pregnant women of all ages are routinely offered CVS and amniocentesis.

5. Amniocentesis is done later in pregnancy than CVS.

6. Amniocentesis is a diagnostic test for Down syndrome and some other birth defects.

7. Amniocentesis involves taking blood from a pregnant woman’s arm.

8. An amniocentesis can tell you about the severity of mental disabilities that a baby with Down syndrome will have.

9. Nuchal translucency screening is a type of ultrasound test.

10. The chance of having a baby with Down syndrome increases with the age of the mother.¹

Response options (questions 1–10): Strongly agree; Agree; Not sure; Disagree; Strongly disagree

Scoring: Scored as the percent of the items answered correctly; items 1, 5, 6, 9, and 10 are true.

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C. Risk awareness

Please give us your estimate (in numbers) of the chances that an amniocentesis will cause a miscarriage in the average woman.

Note: The outcomes questionnaire that was administered to women in the Prenatal Testing Tool group differed from that administered to controls only with respect to the response items offered for the two risk awareness questions, as the two interventions differed in the way they presented the risks of procedure-related miscarriage and the chance that the women was carrying a fetus affected by Down syndrome. The Prenatal Testing Tool presented the risk as 7 in 10002,3 and the control intervention listed it as “generally less than 1 in 100.”4

<table>
<thead>
<tr>
<th>Prenatal Testing Tool Viewers</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 1 in 1,000</td>
<td>less than 1 in 1,000</td>
</tr>
<tr>
<td>7 in 1,000</td>
<td>1 in 100</td>
</tr>
<tr>
<td>52 in 1,000</td>
<td>1 in 20</td>
</tr>
<tr>
<td>201 in 1,000</td>
<td>1 in 5</td>
</tr>
<tr>
<td>Don’t know</td>
<td>Don’t know</td>
</tr>
<tr>
<td>Other _______</td>
<td>Other _______</td>
</tr>
</tbody>
</table>

Correct response: 7 in 100 Correct response: 1 in 100

Please give us your estimate (in numbers) of the chances that a pregnant woman your age is carrying a fetus that is affected by Down syndrome.
Note: The Prenatal Testing Tool provided the chances as X in 1000, while the control intervention presents them as 1 in X, hence the two randomization groups were given the following response options:

**Prenatal Testing Tool viewers:** ________ in 1,000

**Controls:** 1 in ________

Don’t know

Other:  

Correct Ranges for Chance that a Fetus has Down Syndrome\(^5,6\)

<table>
<thead>
<tr>
<th>Age</th>
<th>Correct range</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤30</td>
<td>0.0008 - 0.001</td>
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<tr>
<td>31</td>
<td>0.001 - 0.002</td>
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<tr>
<td>32</td>
<td>0.001 - 0.002</td>
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<tr>
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<td>36</td>
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</tr>
<tr>
<td>48</td>
<td>0.040 - 0.125</td>
</tr>
</tbody>
</table>

D. Intervention Satisfaction

(Data from Barry MJ, Fowler FJ, Jr., Mulley AG, Jr., Henderson JV, Jr., Wennberg JE. Patient reactions to a program designed to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. Med Care 1995;33:771–82.)

1. How would you rate the amount of information you received about prenatal testing?

Response options: Much more than I needed; A little more than I needed; About right; A little less than I needed; A lot less than I needed

Response coded as follows:

Much more than I needed or A lot less than I needed = 0

A little more than I needed or A little less than I needed = 2

About right = 4

2. How clearly was that information presented?

Response options: Everything was clear; Most things were clear; Some things were unclear; Many things were unclear

Responses coded as follows:

Everything was clear = 4

Most things were clear = 2.67

Some things were unclear = 1.33

Many things were unclear = 0

3. How balanced was that information?

Response options: Clearly slanted toward prenatal testing; Slightly slanted toward prenatal testing; Completely balanced; Slightly slanted away from prenatal testing; Clearly slanted away from prenatal testing

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Responses were coded as follows:

Clearly slanted toward prenatal testing or Clearly slanted away from prenatal testing = 0
Slightly slanted toward prenatal testing or Slightly slanted away from prenatal testing = 2
Completely balanced = 4

4. Would you recommend the program you viewed to a friend of yours who was pregnant?

Response options: Yes, I would definitely recommend it; I would probably recommend it; Maybe I would recommend it; I doubt that I would recommend it; No, I definitely would not recommend it

Responses were coded as follows:

Yes, I would definitely recommend it = 4
I would probably recommend it = 3
Maybe I would recommend it = 2
I doubt that I would recommend it = 1
No, I definitely would not recommend it = 0

Scoring: Four item codes were averaged and rescaled to generate a 0-to-10 score, with higher scores denoting greater satisfaction.

E. Intervention impact

Viewing the program affected my prenatal testing plans.

Response options: Strongly agree; Agree; Not sure; Disagree; Strongly disagree

Scoring: Those who strongly agreed or agreed were categorized as reporting that the intervention had affected their plans.
F. Decisional conflict


1. I have [had] enough information to make this decision. (R)

2. The decision is [was] hard for me to make.

3. I know [knew] the benefits of prenatal testing. (R)

4. I am [was] sure what to do in this decision. (R)

5. I know [knew] the risks of prenatal testing. (R)

6. I am [was] aware of the choices I have [had] for prenatal testing. (R)

7. I am [was] clear about how important the personal benefits are [were] to me in this decision. (R)

8. It is [was] clear what choice is [was] best for me. (R)

9. I am [was] clear about how important the personal risks are [were] to me in this decision. (R)

10. I am [was] clear which is [was] more important to me (the benefits or risks). (R)

11. I am making [made] this decision without any pressure from others. (R)

12. I have [had] the right amount of support from others in making this decision. (R)

13. I have [had] enough advice about the options. (R)

14. I made an informed choice. (R)

15. My decision shows what is important to me. (R)

16. I stuck with my original decision. (R)

17. I am satisfied with my decision. (R)

Response options: Strongly disagree; Disagree; Slightly disagree; Neutral; Slightly agree; Agree; Strongly agree

(R): reversed item

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Scoring: Responses were recoded as 6, 5, 4, 3, 2, 1, 0 for reversed item (R), and 0, 1, 2, 3, 4, 5, 6 for the non-reversed item; the mean was score for the items was multiplied by 100 and divided 6 to generate 0-to-100 scales (with higher scores indicating more conflict) for the following subscales as well as the overall decisional conflict scale:

Decision uncertainty; 4 items (1, 2, 4, 8)
Factors contributing to uncertainty; 9 items (3, 5, 6, 7, 9, 10, 11, 12, 13)
Ineffective decision; 4 items (14, 15, 16, 17)
Overall decisional conflict; all 17 items

G. Decision regret

1. I wish that I had followed someone else’s advice about prenatal testing.
2. If I could do it all over again, I would make different testing decisions for this pregnancy.
3. I feel that I would be better off had I made a different decision.

Response options: Definitely true; Mostly true; Neither true nor false; Mostly false; Definitely false

Scoring: Anyone who replied definitely or mostly true to any of the items was categorized as having decision regret.

References


5. Hecht CA, Hook EB. Rates of Down syndrome at livebirth by one-year maternal age intervals in studies with apparent close to complete ascertainment in populations of European origin: a proposed revised rate schedule for use

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