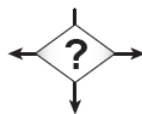


Appendix 3



Decision Box

PATIENT

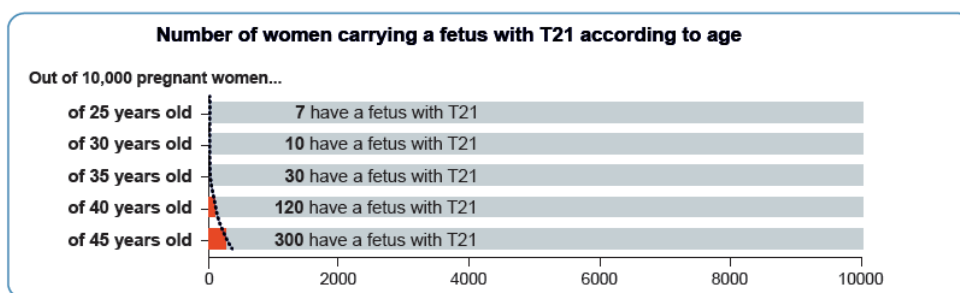
... to help you make a decision



Should I take the serum integrated test to screen for fetal Trisomy 21 (Down syndrome) ?

► Who might consider being tested?

All pregnant woman. The risk of Trisomy 21 (T21) increases with the woman's age.



► A decision to make

Doing and not doing the test are both acceptable choices. We suggest that you:

- ♦ base your decision on the best scientific evidence
- ♦ base your decision on your values and preferences
- ♦ share the decision with your health professional

► Information to help you make the decision

► What is the serum integrated test?

Two blood samples must be taken: **1st** : between 10 and 13 weeks of pregnancy
2nd : between 14 and 16 weeks of pregnancy

► What is Trisomy 21 (or Down syndrome)?

- ♦ It is caused by having an extra copy of chromosome 21.
- ♦ People with T21 have slanted eyes, a thickened nuchal fold, a round face, poor muscle tone, very supple joints, greater risk of vision and hearing defects and cardiac and gastro-intestinal defects, and intellectual disabilities that vary from slight to moderate, but are sometimes serious.
- ♦ 60% of children with T21 require specialized home care.
- ♦ Some adults with T21 have jobs and are almost completely independent.
- ♦ People with T21 can develop meaningful emotional relationships and lead lives that are fulfilling for themselves and their families and friends.

► What is the integrated serum test for?

- ♦ This test estimates the risk of carrying a fetus with T21.
- ♦ If the risk is high, the doctor offers an amniocentesis* to see if the fetus does have T21.
- ♦ This information helps you decide whether to prepare for a child with special needs or consider ending the pregnancy.

*What is an amniocentesis?

An amniocentesis is a diagnostic test that checks the chromosomes of fetuses considered to be at risk of specific problems such as Down syndrome. A small sample of the liquid surrounding the fetus is taken using a needle inserted through the mother's abdomen into her uterus..

Doing or not doing the test


► **Doing the test**

Benefits

- **Knowing your chances of carrying a fetus with T21**
Out of each 10,000 women screened, 415 are identified as being at high risk of carrying a fetus with T21.
 - If these women have an amniocentesis to verify the results of the screening, 15 would actually be carrying a fetus with T21.
- **Prepare to end the pregnancy**
Out of 15 women who know they are carrying a fetus with T21, 10 choose to end the pregnancy.
- **Prepare for a child with T21**
Out of 15 women who know they are carrying a fetus with T21, 5 choose to continue the pregnancy and can prepare for a child with T21.
- **Reassurance**
Out of 10,000 women who take the test, 9585 are identified as at low risk of carrying a fetus with T21. These women are reassured.

Harms

- **False alarm**
Of the 415 women identified as being at high risk of carrying a fetus with T21, 400 are not actually carrying a fetus with T21.
 - many of these women experience anxiety.
 - of these 415 women, 1 will have a miscarriage following an amniocentesis to verify test results.
- **Anxiety while waiting for results**
Women waiting for test results (3 to 7 days) have anxiety levels 10 times higher than normal.
- **False reassurance**
Two of the 9585 women identified as at low risk of carrying a fetus with T21 will actually be carrying a T21 fetus. These women will have been falsely reassured.



► **Not doing the test**

Benefits

- **Avoid an unnecessary amniocentesis**
Out of 10,000 women who take the test, 9983 are not carrying a fetus with T21. By not doing the test, 400 will avoid an unnecessary amniocentesis, and one woman will avoid a miscarriage caused by the amniocentesis.
- **Stay true to your personal convictions**
For some women, not doing the test is in keeping with their personal convictions.
- **Avoid anxiety**
Women who do not take the test avoid the anxiety of:
 - waiting for the test results.
 - making a decision about whether to do the amniocentesis or not if the test shows a high risk of T21.

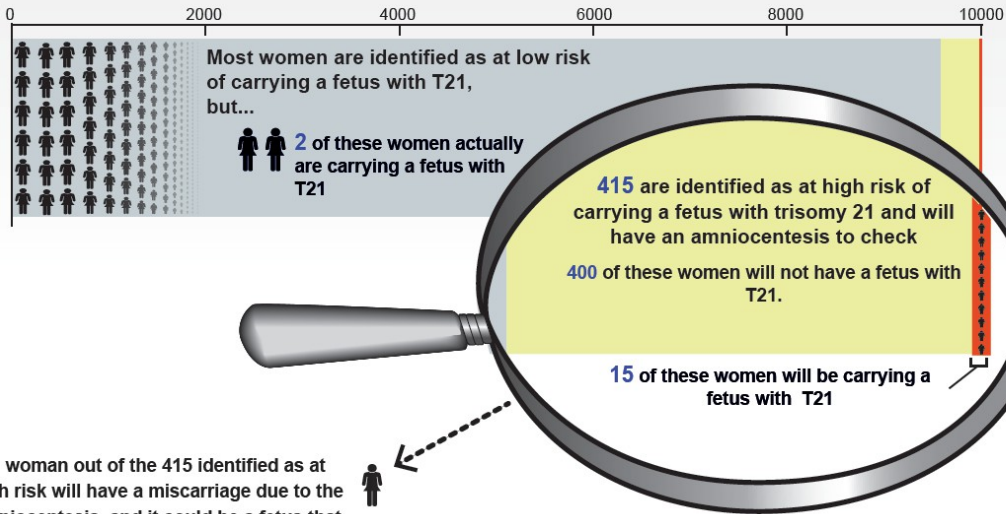
Harms

- **Not knowing your risk of carrying a fetus with T21**
Out of 10,000 women who do not take the test, 17 are carrying a fetus with T21. These women cannot prepare for:
 - an increased chance of miscarriage: two of them will miscarry due to T21.
 - living with a child with T21: 15 out of the 17 will carry the pregnancy to full term.
- **Anxiety due to the outcome of the pregnancy**
Women who don't take the test may be anxious because they don't know if their child will have T21 or not.

Discussion with your health professional

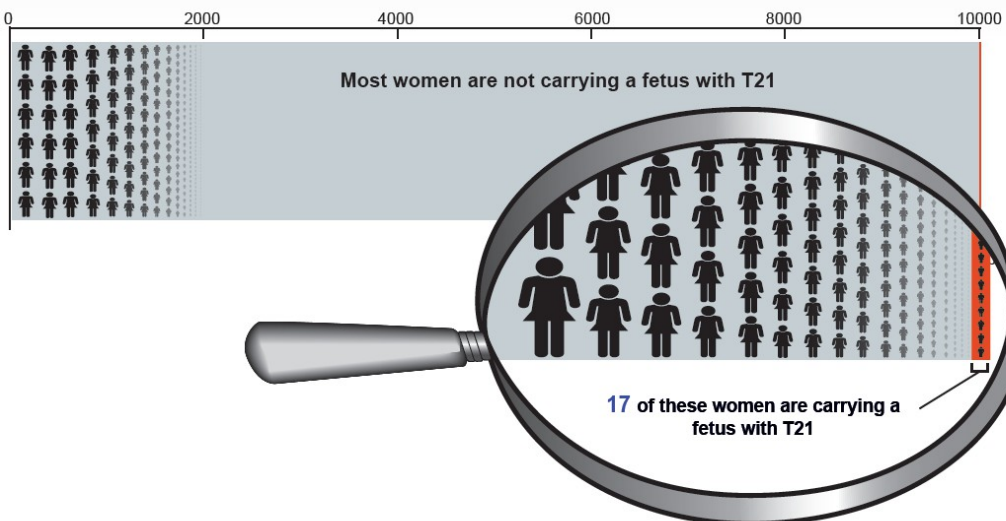
► **Doing the test**

► Out of **10,000** pregnant women who do the test ...



► **Not doing the test**

► Out of **10,000** pregnant women who do the test...



Multimedia Appendix 3

Psychosocial Factors of Health Professionals' Intention to Use a Decision Aid for Down Syndrome Screening: Cross-Sectional Quantitative Study, A.Rahimi et al.

► What are the benefits and harms that matter most to you?

Doing the test	Not doing the test
Benefits _____ _____	Benefits _____ _____
Harms _____ _____	Harms _____ _____
Other considerations: _____	Other considerations: _____

► What is your decision?

Do the test	Don't do the test	I don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

► Are you comfortable with this decision?

		Yes	No
Sure of myself	1) Do you feel sure about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>
Understand information	2) Do you know the benefits and harms of doing or not doing the test?	<input type="checkbox"/>	<input type="checkbox"/>
Risks/benefits ratio	3) Are you clear about which benefits and harms of doing or not doing the test matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>
Encouragement	4) Do you have enough support and advice to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>

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