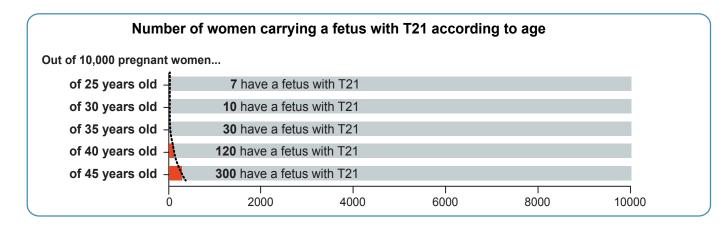




Should I take the serum integrated test to screen for fetal Trisomy 21 (Down syndrome) ?

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?

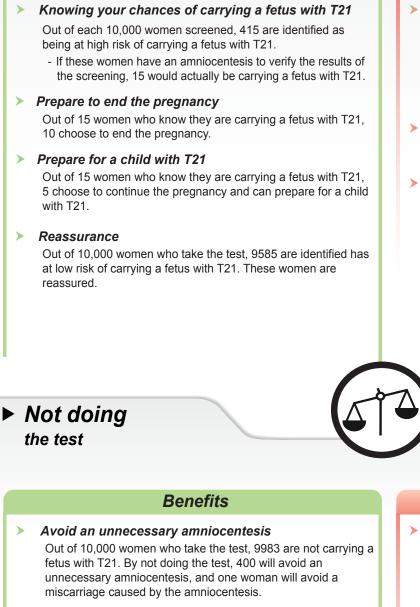
- This test estimates the risk of carrying a fetus with T21.
- If the risk is high, the doctor offers an amniocentesis* to see if the fetus does have T21.
- This information helps you decide whether to prepare for a child with special needs or consider ending the pregnancy.

* 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 the test

Benefits



> 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

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.

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.

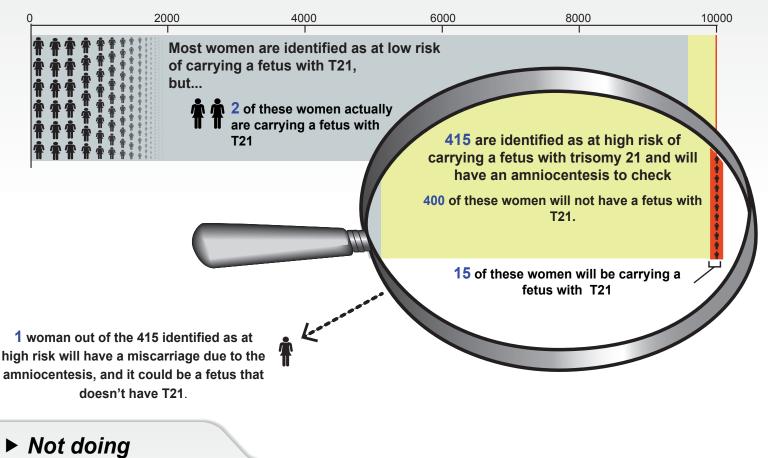
Anxiety due to the outcome of the pregnancy Women who don't take the test may be anxious because

they don't know if their child will have T21 or not.

Doing

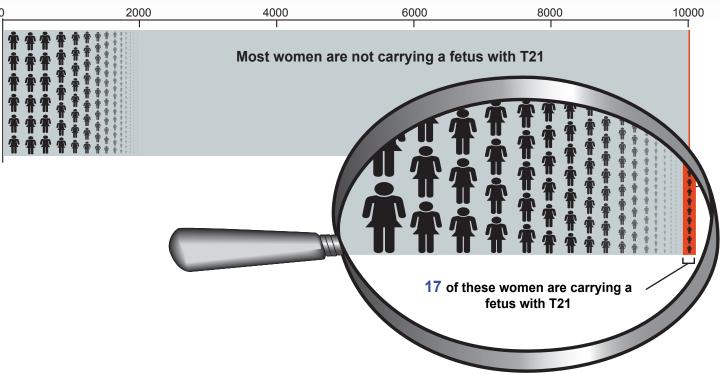
the test

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



the test

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



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	l don't know

Are you comfortable with this decision?

Sure of myself	1) Do you feel sure about the best choice for you?	
Understand information	2) Do you know the benefits and harms of doing or not doing the test?	
R isks/benefits ratio	3) Are you clear about which benefits and harms of doing or not doing the test matter most to you?	
Encouragement	4) Do you have enough support and advice to make a choice?	

C SURE test; O'Connor & Légaré 2008

References

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www.decisionbox.ulaval.ca

Yes

No