



## ► **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**

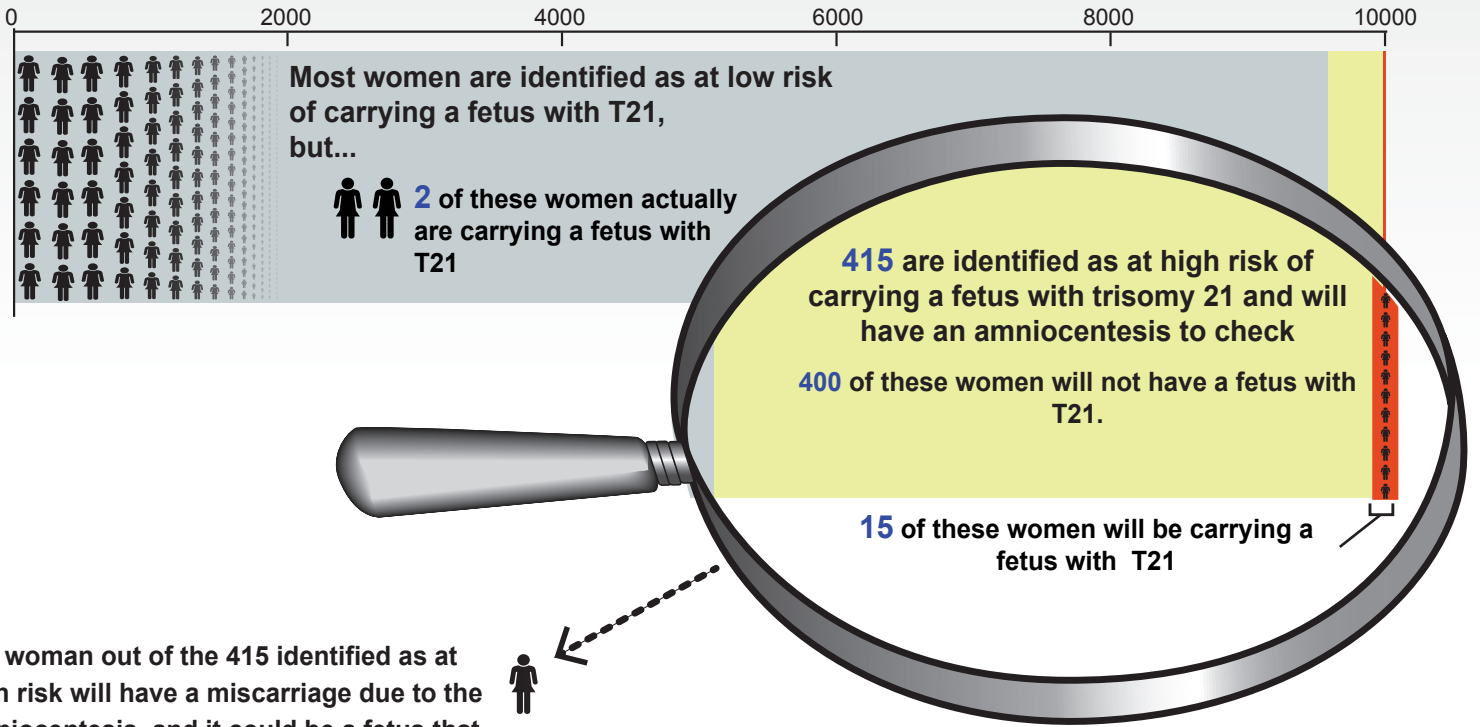
- **Avoid an unnecessary amniocentesis**  
Out of 10,000 women who take the test, 9983 are not carrying a fetus with T21. By not doing the test, 400 will avoid an unnecessary amniocentesis, and one woman will avoid a miscarriage caused by the amniocentesis.
- **Stay true to your personal convictions**  
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.

► **Doing the test**

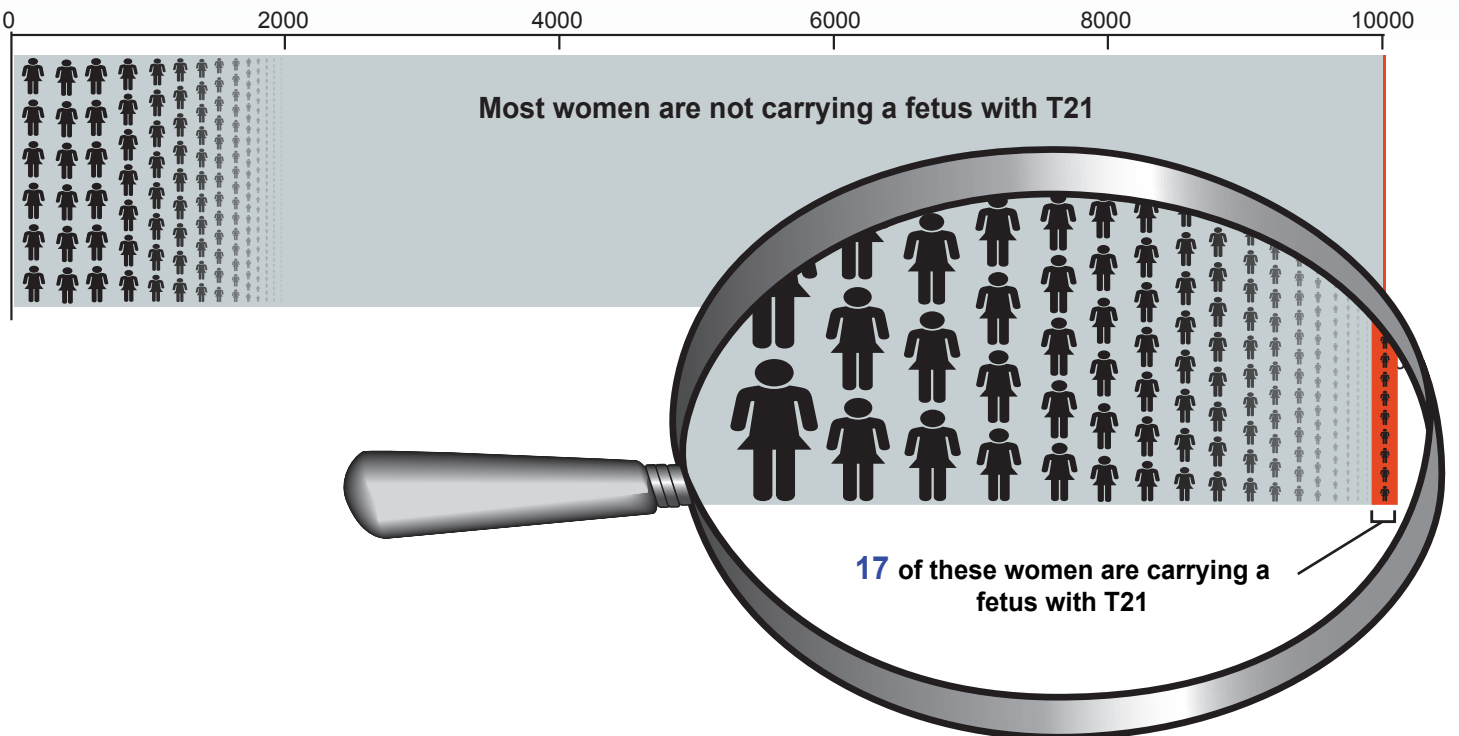
► Out of **10,000** pregnant women who do the test ...



1 woman out of the 415 identified as at high risk will have a miscarriage due to the amniocentesis, and it could be a fetus that doesn't have T21.

► **Not doing 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
<b>Benefits</b>	<b>Benefits</b>
_____	_____
_____	_____
<b>Harms</b>	<b>Harms</b>
_____	_____
_____	_____
<b>Other considerations:</b> _____	<b>Other considerations:</b> _____

► **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
<b>Sure of myself</b>	1) <i>Do you feel sure about the best choice for you?</i>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Understand information</b>	2) <i>Do you know the benefits and harms of doing or not doing the test?</i>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Risks/benefits ratio</b>	3) <i>Are you clear about which benefits and harms of doing or not doing the test matter most to you?</i>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Encouragement</b>	4) <i>Do you have enough support and advice to make a choice?</i>	<input type="checkbox"/>	<input type="checkbox"/>

© SURE test; O'Connor & Légaré 2008

**References**

Schieve et al. Disabil Health J. 2011; (4): 68–77. ACOG Practice Bulletin No. 77. Obstet Gynecol. Jan 2007;109(1): 217-227. Morris et al. J Med Screen. 2002; 9(1): 2-6. Malone et al. N Engl J Med. 2005; 353(19): 2001-2011. Wald et al. Health Technol Assess. 2003; 7(11): 1-77. Green et al. Health Technol Assess. 2004; 8(33): iii, ix-x, 1-109. Won et al. Prenatal diagnosis. 2005; 25(7): 608-611.

**Authors:** Anik Giguère (PhD), Maria-Esther Leiva-Portocarrero (BSc), Maria-Margarita Becerra-Perez (BSc), Hubert Robitaille (PhD) and France Légaré (MD, PhD), CHU de Québec Research Centre, Université Laval, Québec, Canada.

**No conflict of interest:** This tool was developed with funding by a research grant from Genome Canada and Genome Quebec. Neither the granting agency, the authors, nor their affiliated organizations have interests at stake in the decisions made by patients after using this Decision Box.

**Next update:** March 2015.