

## Decision Box

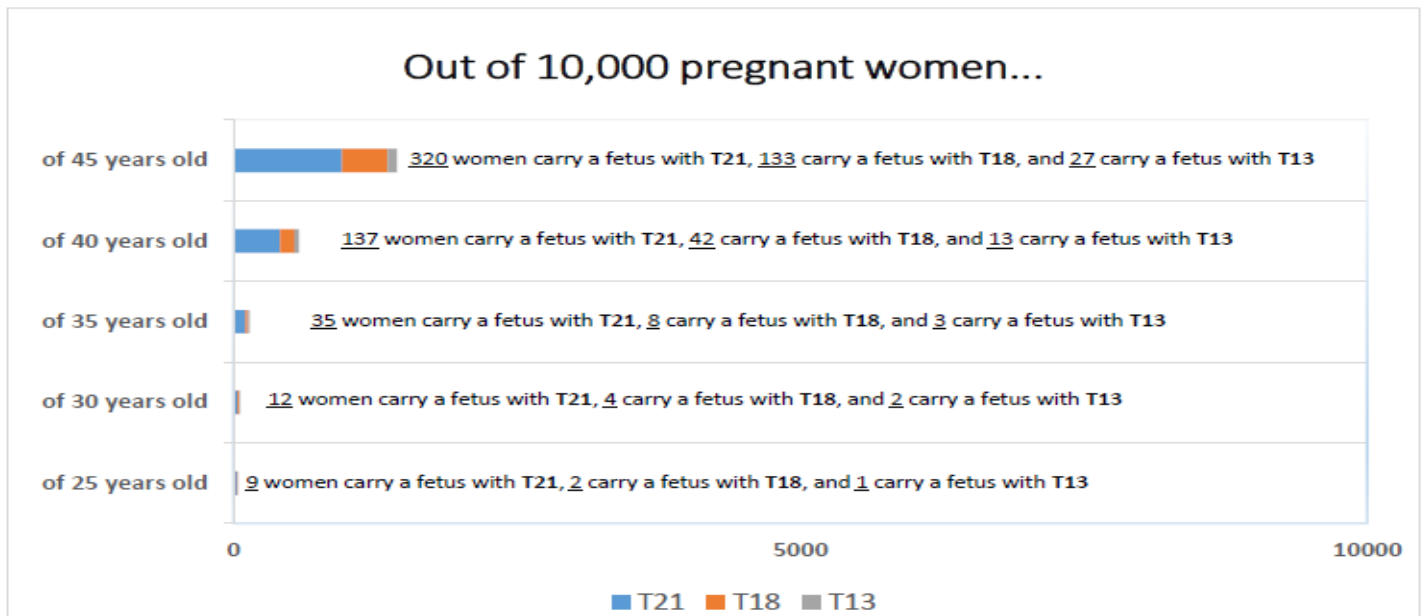
PATIENT

...to help you make a decision

### What are my options regarding prenatal screening tests?

#### ► Who might consider being screened?

All pregnant women can choose to have screening. The risk of Trisomy 21 (T21), Trisomy 18 (T18) and Trisomy 13 (T13) increases with the woman's age.



What is Trisomy 21 (or Down syndrome)?

- It is caused by having an extra copy of chromosome 21.
- People with T21 have intellectual disabilities that vary from slight to moderate, but are sometimes serious, with poor muscle tone, very supple joints, greater risk of vision, hearing defects, cardiac and/or gastro-intestinal defects.
- 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 fulfilling lives for themselves, their families and friends.

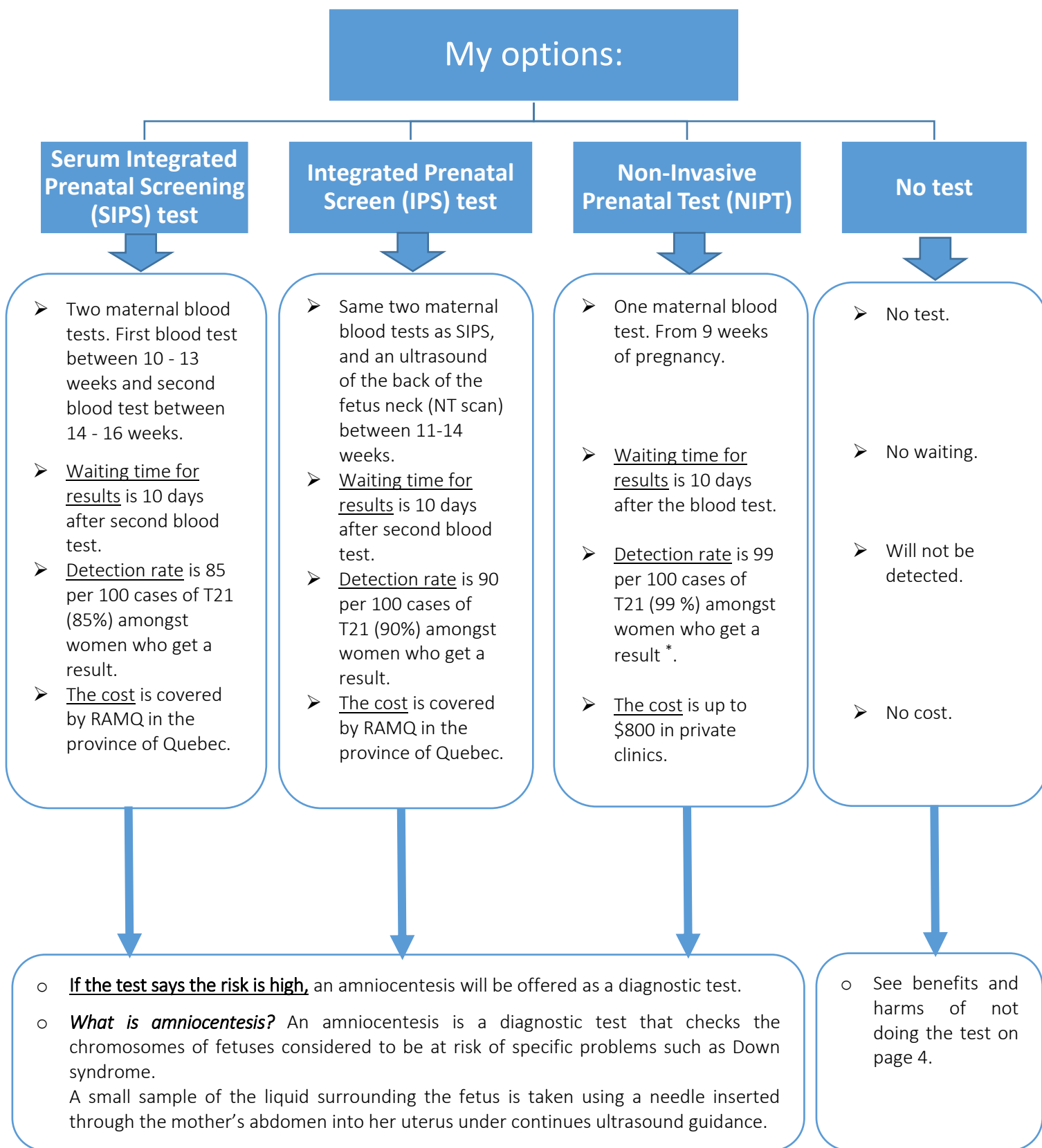
What are Trisomy 18 and Trisomy 13?

- T18 and T13 are caused by having an extra copy of chromosome 18 or 13.
- Many pregnancies with T18 and T13 will be miscarried or result in the fetus dying in utero.
- Babies born with T18 and T13 rarely live more than a few months because of serious heart and brain defects, and poor growth before and after birth.

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 and on your values and preferences.
  - Share the decision with your health professional, and partner.

➤ *What are my options for prenatal screening tests?*



\*About 5% of women who take the NIPT will not have results on the first try, and will have to redo the test or take a different screening test.

➤ What can happen after the prenatal screening test?

## SIPS test

Out of 10,000 women doing the SIPS test...

**521** women identified at **high risk** of carrying a fetus with T21

**9,479** women identified at **low risk** of carrying a fetus with T21

Among women identified at low risk, **4** of these women are in fact carrying a fetus with T21

**After amniocentesis**

**22** of these **521** women will be carrying a fetus with T21

**499** of these **521** women will not carry a fetus with T21

## IPS test

Out of 10,000 women doing the IPS test...

**522** women identified at **high risk** of carrying a fetus with T21

**9,478** women identified at **low risk** of carrying a fetus with T21

Among women identified at low risk, **3** of these women are in fact carrying a fetus with T21

**After amniocentesis**

**23** of these **522** women will be carrying a fetus with T21

**499** of these **522** women will not carry a fetus with T21

## NIPT test\*

Out of 10,000 women doing the NIPT test...

**44** women identified at **high risk** of carrying a fetus with T21

**9,456** women identified at **low risk** of carrying a fetus with T21

**500** women will not have results and should redo the screening test

Among women identified at low risk, **less than one** of these women are in fact carrying a fetus with T21

**After amniocentesis**

**25** of these **44** women will be carrying a fetus with T21

**19** of these **44** women will not carry a fetus with T21

**1 in 909 women will have a miscarriage due to amniocentesis.**

\* As there are not many studies on this use of the NIPT test, these numbers are approximate.

➤ **What concerns me about the benefits and harms of doing the test and not doing the test?**

1. Review the possible benefits and harms of each test. Add any other benefits and harms that are important to you.
2. Show how important each benefit and harm is to you by circling the stars (5=very important, 1=not important).

**Benefits and harms of doing the prenatal screening test:**

Benefits:	How important is it to you?	Harms:	How important is it to you?
➤ <b>Reassurance</b> For example, out of <u>10,000</u> women who take the NIPT test, <u>9,456</u> are identified at low risk of carrying a fetus with T21. These women are reassured.	*****	➤ <b>False reassurance</b> For example, <u>3</u> of the <u>9,478</u> women identified by IPS test as at low risk of carrying a fetus with T21 will actually be carrying a T21 fetus. These women will have been falsely reassured.	*****
➤ <b>Prepare to end the pregnancy or to have a child with T21</b> Among the women who know they are carrying a fetus with T21, those who choose to continue the pregnancy can prepare for a child with T21.	*****	➤ <b>False alarm</b> For example, out of the <u>522</u> women identified by IPS test as being at high risk of carrying a fetus with T21, <u>499</u> are not actually carrying a fetus with T21. Many of these women experience anxiety. 1 in 909 will have a miscarriage as a result of the amniocentesis to verify screening test results.	*****
➤ <b>Knowing your chances of carrying a fetus with T21</b> For example, out of each <u>10,000</u> women screened, <u>44</u> are identified by NIPT test as being at high risk of carrying a fetus with T21. If these women have an amniocentesis to verify the results of the screening, <u>25</u> would actually be carrying a fetus with T21.	*****	➤ <b>Anxiety while waiting for results</b> Based on previous studies, child-related anxiety levels were higher in women who chose to be screened compared to women who declined screening.	*****
➤ <b>Other benefits:</b> .....	*****	➤ <b>Other harms:</b> .....	*****

**Benefits and harms of not doing the prenatal screening test:**

Benefits:	How important is it to you?	Harms:	How important is it to you?
➤ <b>Avoid an unnecessary test</b> Out of <u>10,000</u> women doing IPS test, <u>9,478</u> are not carrying a fetus with T21. By not doing the test, <u>499</u> of the <u>522</u> pregnant women (identified by IPS test as being at high risk of carrying a fetus with T21) will avoid an unnecessary amniocentesis, and <u>1 in 909</u> women will avoid a miscarriage caused by the amniocentesis.	*****	➤ <b>Not knowing your risk of carrying a fetus with T21</b> For example, out of <u>10,000</u> women who do not take the IPS screening test, <u>23</u> are carrying a fetus with T21. These women cannot prepare for living with a child with special needs. They may regret not having done the prenatal screening test.	*****
➤ <b>Stay true to your personal convictions</b> For some women, not doing the test is in keeping with their personal convictions.	*****	➤ <b>Anxiety about the outcome of the pregnancy</b> Women who don't take the prenatal screening test may be anxious because they don't know if their child will have T21 or not.	*****
➤ <b>Avoid anxiety and avoid difficult decisions such as whether to end the pregnancy</b> 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 if the test shows a high risk of T21. - making a decision about ending the pregnancy.	*****	➤ <b>Other harms:</b> .....	*****
➤ <b>Other benefits:</b> .....	*****		

➤ **What is your decision?**

Do the test ☐

Not doing the test ☐

If you chose "Do the test" go to the **page 5** and choose the test. If you chose "Not doing the test", go to the **page 6**.

## ➤ Which prenatal screening test should I choose?

The blue boxes on the left show the concerns about the tests that may be important to you. You can add other concerns in the last box depending on your values or opinions.

**1)** Show how important each concern is to you by circling the stars (5 = very important, 1 = not important).

**2)** Considering the importance of each of your concerns, select the best test in the righthand column.

**3)** Choose the test which is best for you.

		1) Importance of this concern		2) Considering this concern, which test(s) do you prefer?	
		1	2	3	4
Different concerns about prenatal screening tests	Week of pregnancy that test will be taken	SIPS: 1 <sup>st</sup> blood test in 10 - 13 weeks and 2 <sup>nd</sup> blood test in 14 - 16 weeks of pregnancy.			SIPS <input type="checkbox"/>
		IPS : 1 <sup>st</sup> blood test in 10 - 13 weeks , 2 <sup>nd</sup> blood test in 14 - 16 weeks, and NT scan in 11-14 weeks of pregnancy.	★★★★★		IPS <input type="checkbox"/>
		NIPT: From 9 weeks of pregnancy.			NIPT <input type="checkbox"/>
	Waiting time for the results	SIPS: 10 days after <u>second blood test</u> .			SIPS <input type="checkbox"/>
		IPS : 10 days after <u>second blood test</u> .	★★★★★		IPS <input type="checkbox"/>
		NIPT: 10 days after blood test.			NIPT <input type="checkbox"/>
	Detection rate of each test	SIPS: 85 per 100 cases of T21 (85%) among women who do the test.			SIPS <input type="checkbox"/>
		IPS: 90 per 100 cases of T21 (90%) among women who do the test.	★★★★★		IPS <input type="checkbox"/>
		NIPT: 99 per 100 cases of T21 (99%) among women <u>who get results</u> .			NIPT <input type="checkbox"/>
	Worried for nothing (risk of a false positives)	SIPS: About 500 per 10,000 pregnancies.			SIPS <input type="checkbox"/>
		IPS: About 500 per 10,000 pregnancies.	★★★★★		IPS <input type="checkbox"/>
		NIPT: About 19 per 10,000 pregnancies.			NIPT <input type="checkbox"/>
	Cost of each test	SIPS: Covered by RAMQ in province of Quebec.			SIPS <input type="checkbox"/>
		IPS: Covered by RAMQ in province of Quebec.	★★★★★		IPS <input type="checkbox"/>
		NIPT: Up to \$800 in private clinics.			NIPT <input type="checkbox"/>
	Your other concerns ...	SIPS: .....			SIPS <input type="checkbox"/>
		IPS: .....	★★★★★		IPS <input type="checkbox"/>
		NIPT: .....			NIPT <input type="checkbox"/>

➤ **3)** Considering my concerns and their importance, I choose ...

SIPS ☐

IPS ☐

NIPT ☐

➤ ***Are you comfortable with your decision?***

<b>S</b>	1) Do you feel sure about the best choice for you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>U</b>	2) Do you feel you have all the information you need to make a decision about prenatal screening test?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>R</b>	3) Are you clear about which benefits and harms matter most to you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>E</b>	4) Do you have enough support and advice to make a choice?	Yes <input type="checkbox"/>	No <input type="checkbox"/>

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**References:**

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**Next Update:**

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