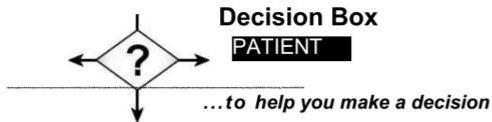


## Appendix 1



### 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.

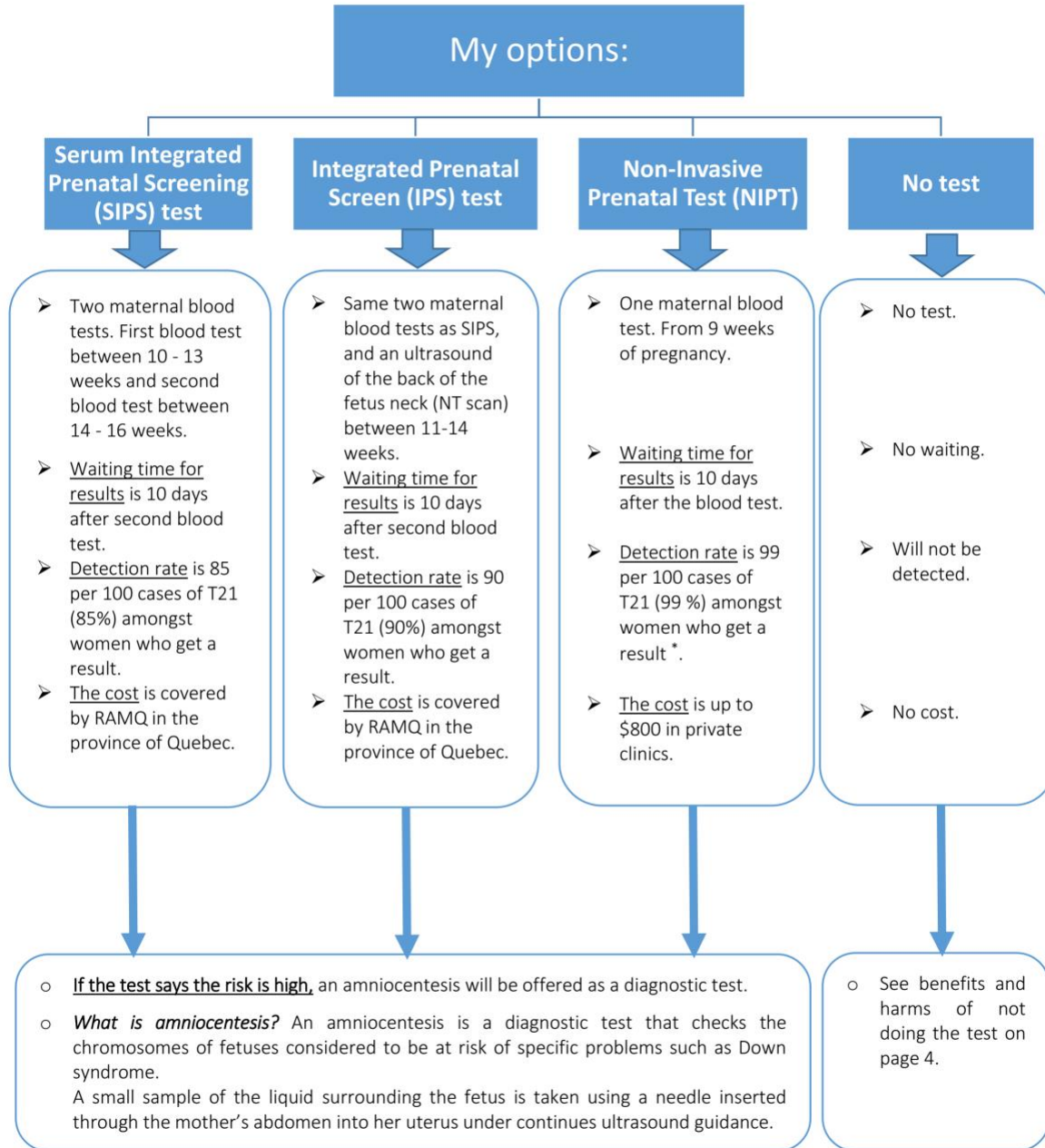
What are Trisomy 18 and Trisomy 13?

- 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?

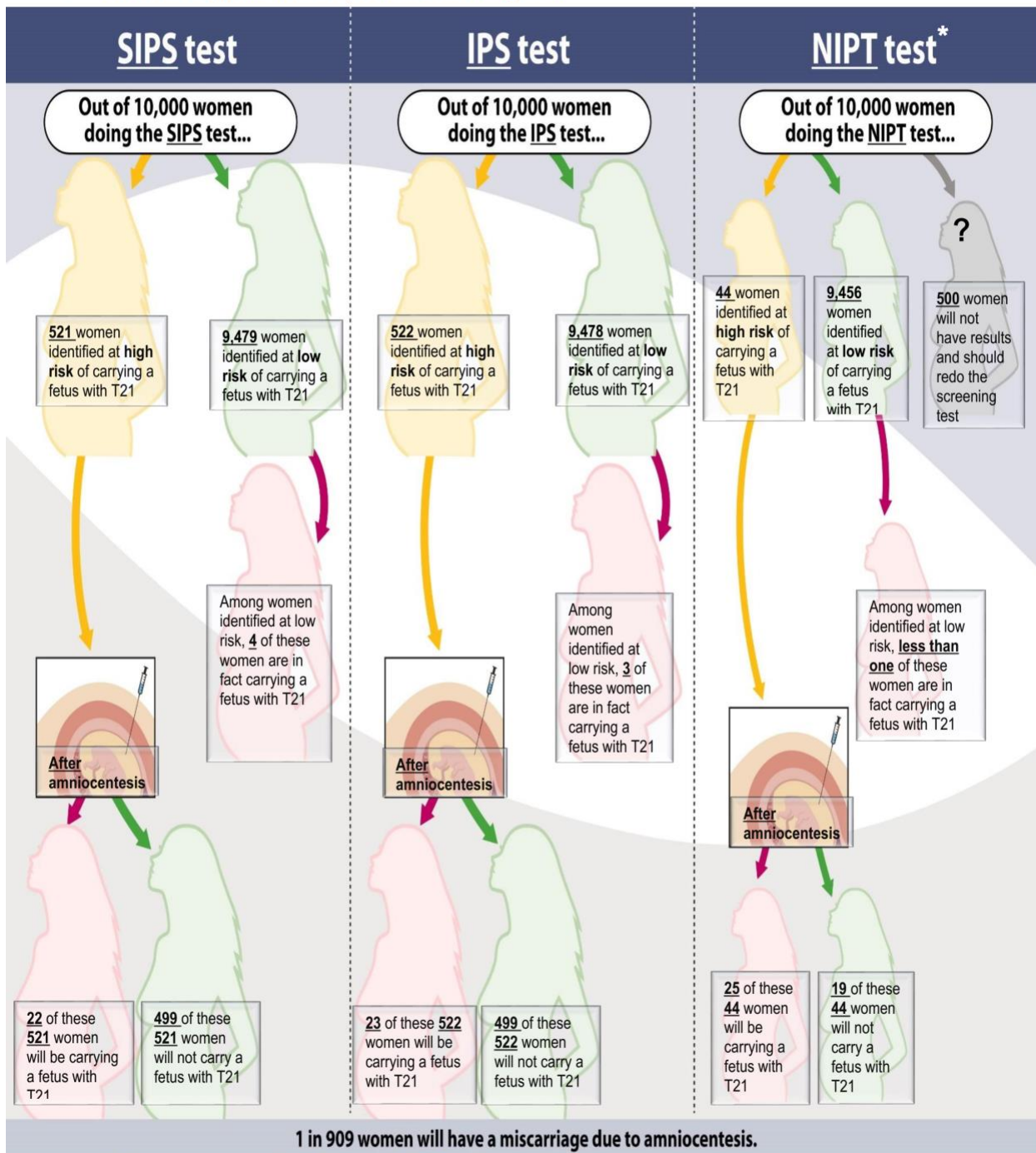


\*About 5% of women who take the NIPT will not have results on the first try, and will have to redo the test or take a different screening test.

Multimedia Appendix 1

An Analytical Mobile App for Shared Decision Making About Prenatal Screening: Protocol for a Mixed Methods Study

➤ What can happen after the prenatal screening test?



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



# Multimedia Appendix 1

## An Analytical Mobile App for Shared Decision Making About Prenatal Screening: Protocol for a Mixed Methods Study

### ➤ 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?		
		Stars	Test Selection	SIPS	IPS	NIPT
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.		<input type="checkbox"/>	<input type="checkbox"/>	<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.	★★★★★	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		NIPT: From 9 weeks of pregnancy.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Waiting time for the results	SIPS: 10 days after <u>second</u> blood test.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		IPS : 10 days after <u>second</u> blood test.	★★★★★	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		NIPT: 10 days after blood test.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Detection rate of each test	SIPS: 85 per 100 cases of T21 (85%) among women who do the test.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	IPS: 90 per 100 cases of T21 (90%) among women who do the test.	★★★★★	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	NIPT: 99 per 100 cases of T21 (99%) among women <u>who get results</u> .		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Worried for nothing (risk of a false positives)	SIPS: About 500 per 10,000 pregnancies.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	IPS: About 500 per 10,000 pregnancies.	★★★★★	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	NIPT: About 19 per 10,000 pregnancies.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Cost of each test	SIPS: Covered by RAMQ in province of Quebec.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	IPS: Covered by RAMQ in province of Quebec.	★★★★★	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	NIPT: Up to \$800 in private clinics.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Your other concerns ...	SIPS: .....		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	IPS: .....	★★★★★	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	NIPT: .....		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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

SIPS

IPS

NIPT

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### *An Analytical Mobile App for Shared Decision Making About Prenatal Screening: Protocol for a Mixed Methods Study*

<b>&gt; Are you comfortable with your decision?</b>			
<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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#### **No conflict of interest to declare:**

The development of the tool was financed by a research grant from Genome Canada and Génomique Québec. Neither the funding agency, the authors nor their affiliated institutions have any interest at stake in the decisions made by patients after using this decision aid.

#### **Next Update:**

May 2018.