

We are carrying out a study to investigate the awareness and opinions of pregnant women about tests that screen for Down Syndrome and other fetal anomalies.

We greatly appreciate if you could take a few minutes to complete this short anonymous questionnaire. Thank you.

The first section is about you.

Please complete the following questions. Tick one.

What is your age? _____

What is your ethnicity?

- | | |
|-------------------|---|
| 1 Irish | 5 African |
| 2 Irish Traveller | 6 Any other Black background |
| 3 Other White | 7 Asian |
| 4 Mixed Ethnicity | 8 Other _____ additional comments _____ |

How many children do you have?

- | | | |
|---------------------|--------------------------|---------------------------------|
| 0 First pregnancy | 2 Two children already | 4 Four or more children already |
| 1 One child already | 3 Three children already | |

Have you had a previous miscarriage or pregnancy loss?

- | | |
|-------|------|
| 1 Yes | 0 No |
|-------|------|

What is your highest education level?

- | | |
|--------------------|--|
| 1 Primary school | 3 Third level education (University/College) |
| 2 Secondary school | 4 Postgraduate education (Masters/PhD) |

Which type of clinic are you attending?

- | | |
|----------|-----------|
| 1 Public | 2 Private |
|----------|-----------|

Which type of clinician is taking care of your pregnancy?

- | | | |
|-----------|-----------------------------------|----------------------------------|
| 1 Midwife | 2 Consultant/Registrar (Hospital) | 3 Consultant/Registrar (Private) |
|-----------|-----------------------------------|----------------------------------|

The next section is about screening tests for Down Syndrome.

Please complete the following questions. Tick all that you think apply.

What do you understand by 'screening for fetal anomalies'? **0 = no, 1 = yes**

- 0 1 Blood tests to look at the baby's DNA for risk of Down syndrome
- 0 1 Blood tests to look at levels in the mother's blood.
- 0 1 Ultrasound scan to look for signs of Down syndrome
- 0 1 Measuring fluid on back of baby's neck
- 0 1 Anatomy scan (also called "20-week scan" or "detailed scan" or "the big scan")
- 0 1 Unsure

Where do you go to find information about screening tests for fetal anomalies? **0 = no, 1 = yes**

- | | |
|--------------|--|
| 0 1 GP | 0 1 Obstetrician |
| 0 1 Friends | 0 1 Midwife at antenatal clinic |
| 0 1 Family | 0 1 I have never researched Prenatal Screening |
| 0 1 Internet | 0 1 Other _____ additional comments _____ |

This next section is about the availability the screening tests.

Please complete the following questions. Tick one.

I believe all women should be routinely offered a prenatal screening test, regardless of age.

- | | | |
|---------|------------|----------|
| 1 Agree | 2 Disagree | 3 Unsure |
|---------|------------|----------|

I believe only women over the age of 35 should be routinely offered a prenatal screening test.

- | | | |
|---------|------------|----------|
| 1 Agree | 2 Disagree | 3 Unsure |
|---------|------------|----------|

The next section is about your perception of risk.

Please complete the following questions. Tick one.

Screening tests report the risk of Down syndrome in your baby (1 in 200 for example). At a certain level, the woman is said to be “high risk,” and may be offered a follow up diagnostic test. What level do you think is “high risk”?

- | | | | | | | | |
|---|---------|---|------------|---|--------------|---|--------------|
| 1 | 1 in 2 | 3 | 1 in 100 | 5 | 1 in 10,000 | 7 | 1 in 200,000 |
| 2 | 1 in 10 | 4 | 1 in 1,000 | 6 | 1 in 100,000 | 8 | Unsure |

What does a low risk screening test result for Down Syndrome mean?

- 1 My baby definitely does not have Down Syndrome
- 2 My baby is less likely to have Down Syndrome
- 3 My baby is more likely to have Down Syndrome
- 4 My baby definitely does have Down Syndrome
- 5 Unsure

What does a high risk screening test result for Down Syndrome mean?

- 1 My baby definitely does not have Down Syndrome
- 2 My baby is less likely to have Down Syndrome
- 3 My baby is more likely to have Down Syndrome
- 4 My baby definitely does have Down Syndrome
- 5 Unsure

Women who receive an ‘*increased risk*’ result from a screening test may choose to undergo further tests that give a definite “yes or no” answer about conditions like Down syndrome. For example, women may choose to undergo an amniocentesis, where a very fine needle is directed through the mother’s abdomen into the womb, and a sample of amniotic fluid is taken. However, this carries a 1 in 200 risk of miscarriage.

- 1 I would never undergo an amniocentesis test no matter what the screening test indicated about my personal risk result.
- 2 I would always undergo an amniocentesis test no matter what the screening test indicated about my personal risk result.
- 3 I would prefer a diagnostic test like an amniocentesis test rather than a screening test.
- 4 I am not sure if I would undergo amniocentesis

The next section is about pregnancy termination.

Please complete the following questions. Tick all that apply.

My views on termination for my own pregnancies are: **0 = no, 1 = yes**

- 0 1 I would never terminate a pregnancy.
- 0 1 I would only terminate a pregnancy if my health was at risk.
- 0 1 I am unsure about terminating a pregnancy.
- 0 1 I would terminate a pregnancy only because of a fatal fetal anomaly.
- 0 1 I am not opposed to terminating a pregnancy.

In Ireland, women can choose to terminate their pregnancy before 12 weeks. Termination after 12 weeks is only allowed if a fatal fetal anomaly is diagnosed. Which of the following do you think are classified as fatal fetal anomalies? **0 = no, 1 = yes**

- 0 1 Anencephaly (a neural tube defect that causes abnormal development of the brain)
- 0 1 Edwards Syndrome (Trisomy 18)
- 0 1 Down Syndrome (Trisomy 21)
- 0 1 Spina Bifida (a neural tube defect which causes incomplete development of the spinal cord)

Prenatal screening tests only report on the *risk* of the baby having Down Syndrome or another condition. If the screening result shows a 'high risk' of Down Syndrome, this is not a diagnosis, only a risk of Down Syndrome. Would you terminate before getting a definitive diagnosis from a test like amniocentesis? **0 = no, 1 = yes**

- 0 1 Yes
- 0 1 No, I would not terminate a pregnancy
- 0 1 No, I would want a definitive diagnosis through a test like amniocentesis
- 0 1 No, not for Down Syndrome but I would for other fetal anomalies. Please list them below.

Additional comments

I would only terminate a pregnancy after a definitive diagnostic test like amniocentesis came back positive indicating that my baby was affected with which of the following?

- 0 1 Anencephaly (a neural tube defect that causes abnormal development of the brain)
- 0 1 Edwards Syndrome (Trisomy 18)
- 0 1 Down Syndrome (Trisomy 21)
- 0 1 Spina Bifida (a neural tube defect which causes incomplete development of the spinal cord)
- 0 1 I would not terminate a pregnancy

The next section is about the Non-Invasive Prenatal Tests (NIPT).

Please complete the following questions. Tick one.

Have you ever heard of non-invasive prenatal tests?

- 1 Yes
- 0 No
- 2 Unsure

Can you name any non-invasive prenatal tests? **0 = no, 1 = yes**

Additional comments

What do you think non-invasive prenatal tests cost?

- 1 €0- €100
- 2 €101- €200
- 3 €201- €300
- 4 €301- €400
- 5 €401- €500
- 6 Over €500

The next section is about the financial aspects of screening tests for fetal anomalies.

Please complete the following questions. Tick one.

How much would you be willing to pay for screening tests for fetal anomalies?

- 1 €50
- 2 €100
- 3 €150
- 4 €200
- 5 €250
- 6 €500
- 7 Any amount
- 8 Nothing, it should be free

Who do you think should be responsible for paying for screening tests for fetal anomalies?

- 1 HSE
- 2 Hospital
- 3 Woman being tested

When/where do you want to receive information about screening tests for fetal anomalies?

- 1 First clinic visit
- 2 From your GP
- 3 Hospital Website

Do you have any other comments or suggestions regarding screening tests for fetal anomalies?

Additional comments