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 2 Irish Traveller 3 Other White 4 Mixed Ethnicity	 5 African 6 Any other Black background 7 Asian 8 Other <u>additional comments</u> 			
1 One child already 3	Two children already Three children already 4 Four or more children already already			
Have you had a previous miscarriage or predated Yes	egnancy loss? 0 No			
What is your highest education level? 1 Primary school 2 Secondary school	3 Third level education (University/College)4 Postgraduate education (Masters/PhD)			
Which type of clinic are you attending? 1 Public	2 Private			
Which type of clinician is taking care of yo 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				
0 1 GP0 1 Friends0 1 Family0 1 Internet	of the screening tests for fetal anomalies? $0 = no$, $1 = yes$ Of the local			
This next section is about the availability the screening tests.				
Please complete the following questions. Tick one.				
I believe all women should be routinely off 1 Agree 2	Fered a prenatal screening test, regardless of age. Disagree 3 Unsure			
I believe only women over the age of 35 sh 1 Agree 2	ould be routinely offered a prenatal screening test. Disagree 3 Unsure			

Prenatal Screening can detect all babies with a disease of 1 Agree 2 Disagree	or disability. 3 Unsure			
The next section is about Down syndrome.				
Please complete the following questions. Tick one.				
How many babies are born with Down syndrome in Ire 1 1 in 70,000 2 1 in 7,000 3 1 in 700	land per year? 4 1 in 70 5 1 in 7 6 Unsure			
Prenatal Screening can detect all babies with Down syn 1 True 2 False	ndrome. 3 Unsure			
Most Down syndrome babies are born to women over 3 1 True 2 False	35 years of age. 3 Unsure			
Which of the following factors increase a woman's like all that apply. $0 = no$, $1 = yes$ 0 1 Increased age of mother 0 1 Increased age of father 0 1 Previous child with Down syndrome 0 1 Previous miscarriage	 0 1 Other family members with Down syndrome 0 1 Other family members with autism 0 1 No folic acid supplementation during pregnancy 0 1 Unsure 			
What do you think is your own personal risk of having 1 Non-existent 2 Low 3 Moderate	a Down syndrome baby?4 High5 Quite high6 Unsure			
This next section is about your views on screening in early pregnancy to detect Down Syndrome.				
Please complete the following questions. Tick all that If you were offered screening to test for Down Syndrom 0.1 Yes 0.1 Yes, and I had this test in this pregnancy 0.1 Undecided				
 If you would choose screening, why? 0 1 To help make the decision to have a diagnostic test like amniocentesis 0 1 I believe that I am at a higher risk for having a baby with Down Syndrome 0 1 In order to check if my baby is healthy 0 1 To allow my obstetrician to care for me with all the information 0 1 I want to consider termination of pregnancy 0 1 To allow everyone to better prepare before the baby is born if affected by Down syndrome 0 1 To allow everyone to better prepare for another fetal anomaly 0 1 Other additional comments 	 If you would not choose screening, why not? 0 1 Not necessary – my personal risk is too low 0 1 I am not sure how to get the test 0 1 I think the screening test is inaccurate 0 1 I am worried about what to do if the baby is affected 0 1 I do not want to consider termination of pregnancy 0 1 Potential cost of screening test 0 1 Media reports about inaccuracy of screening 0 1 Amniocentesis test needed for diagnosis after screening has too high a risk of miscarriage 0 1 Other additional comments 			

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 = ves

- 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 = ves

- 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)

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-I Please complete the following quest						
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			Unsure			
Additional comments	itai tests: V – I	10, 1 – yes				
What do you think non-invasive pren-	atal tests cost?					
1 €0-€100 2 6101 6200	3 €201-€3		€401- €500			
2 €101-€200	4 €301-€		Over €500			
The next section is about the finance Please complete the following quest			iomalies.			
How much would you be willing to p						
1 €50	4 €200	7	Any amount			
2 €100 3 €150	5 €250 6 €500	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 i 1 First clinic visit	nformation abo 2 From yo	-	anomalies? Hospital Website			
Do you have any other comments or suggestions regarding screening tests for fetal anomalies?						
Additional comments						