Non-invasive prenatal testing: future possibilities
What is your current age?
  o  Under 18 - you are unfortunately not eligible to complete this survey
  o  18-25
  o  26-30
  o  31-35
  o  36-40
  o  41+
YOUR EXPERIENCE WITH NIPT

What were your reasons for seeking NIPT (the percept™ test)? Please tick all that apply.

☐ I wanted to know if a chromosomal abnormality is present in my baby
☐ I/baby’s father/other family member have a genetic or medical condition
☐ I wanted reassurance
☐ I wanted to know the sex of the baby
☐ I have a risk factor for a chromosomal abnormality such as increased age
☐ The medical professional managing my pregnancy advised me to have the test
☐ I wanted to avoid a CVS or amniocentesis procedure
☐ Other ___________________________ ___________________________

What year(s) did you undergo NIPT?
☐ 2013
☐ 2014
☐ 2015
☐ 2016
☐ 2017

Before undergoing NIPT, did you or your partner have (please tick any that apply):

☐ Genetic screening (e.g. for cystic fibrosis carrier status)
☐ Ultrasound
☐ Combined first-trimester screening (blood test and ultrasound to estimate the risk of a baby having a chromosomal abnormality)
☐ I don’t recall
Where did you get information about NIPT? Please tick all that apply.

- My doctor
- My midwife
- Medical websites
- Social media and forums
- Family & friends
- Other ______________________________

Who were the primary professionals treating you during your pregnancy?

- GP alone
- Midwife alone
- GP shared care with public hospital obstetric unit
- Public hospital obstetric unit
- Private obstetrician
- Other ______________________________

Do you feel you were provided with adequate information on the nature of the percept™ test and possible results?

Definitely not    Mostly not    Neutral    Mostly    Definitely

Do you feel you were sufficiently informed of what the consequences of a positive result (e.g. for trisomy 21 (Down syndrome)) would be?

Definitely    Mostly    Neutral    Mostly not    Definitely not
After undergoing NIPT, did you undergo other forms of prenatal screening or testing? Please tick all that apply.

- None
- Ultrasound
- Combined first-trimester screening
- Amniocentesis
- Chorionic villus sampling (CVS)

Do you feel you were provided with adequate information and counselling after you received the results of the percept™ test?

- Definitely not
- Mostly not
- Neutral
- Mostly
- Definitely

What was the result of your test?

- No increased risk of any chromosomal abnormality (go to page 8)
- Increased risk of trisomy 21 (Down syndrome), 13 or 18 (go to page 7)
- Increased risk of too many or too few sex chromosomes (X or Y) (go to page 7)
- Other (go to page 7)
Did you have any of the following procedures? Please tick any that apply.

☐ Chorionic villus sampling (CVS)
☐ Amniocentesis
☐ Neither (go to page 8)

If either amniocentesis or CVS, what was the result?

  o Typical chromosome result
  o Trisomy 21, 13, or 18
  o Increased (XXX, XXY, XYY) or decreased (X) sex chromosome number
  o Other

If a chromosomal abnormality was identified, did you:

  o Continue the pregnancy
  o Have a pregnancy termination
If you had another pregnancy, how likely would you be to undergo NIPT again?

- Definitely not
- Unlikely
- Unsure
- Likely
- Definitely

Do you think termination of a pregnancy (abortion) should be legal and accessible?
- Yes
- No
- It depends ________________________________

Would you personally consider a termination of a pregnancy for any reason?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely
CURRENT & FUTURE USES OF NIPT

Many of the following are not possible now but may be in the future. We are interested to know what you think about these uses of NIPT and whether you think these should be offered in the future.

We understand that some of the following questions might be confronting or of a sensitive nature. Once again, all of your answers to this survey are anonymous, and we appreciate your responses greatly.
Non-invasive prenatal tests such as percept™ already test for the sex of the baby. You can choose whether or not you would like to know this.

Do you think NIPT should be available to find out the sex in a pregnancy?

Definitely  Probably  Unsure  Probably not  Definitely not

Would you want to use NIPT to find out the sex in your pregnancy?

Definitely not  Probably not  Unsure  Probably  Definitely

How likely would you be to terminate based on the sex of your baby?

Definitely not  Unlikely  Unsure  Likely  Definitely
Trisomy 21, or Down syndrome, is a non-lethal genetic condition caused by an extra copy of chromosome 21. People with Down syndrome have physical growth delays, intellectual disability, and are more prone to heart defects. With the right support, many people with Down syndrome live fulfilling lives.

Do you think NIPT should be available to find out if a baby had a non-lethal genetic condition, such as trisomy 21 (Down Syndrome)?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

Would you want to use NIPT to find out if your baby had a non-lethal genetic condition, such as trisomy 21 (Down Syndrome)?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

How likely would you be to terminate based on a non-lethal genetic condition, such as trisomy 21 (Down Syndrome)?

- Definitely not
- Unlikely
- Unsure
- Likely
- Definitely
Trisomy 13 (Patau syndrome) and trisomy 18 (Edwards syndrome) are genetic conditions caused by extra copies of chromosomes 13 and 18, respectively. They are associated with severe physical and intellectual disabilities. Most babies with these conditions are either stillborn or die soon after birth.

Do you think NIPT should be available to find out if a baby had a condition that was generally fatal in the early weeks of life, such as trisomy 13 or 18?

Definitely  Probably  Unsure  Probably not  Definitely not

Would you want to use NIPT to find out if your baby had a condition that was generally fatal in the early weeks of life, such as trisomy 13 or 18?

Definitely not  Probably not  Unsure  Probably  Definitely

How likely would you be to terminate based on a condition that was generally fatal in the early weeks of your baby’s life, such as trisomy 13 or 18?

Definitely  Likely  Unsure  Unlikely  Definitely not
Mental illness can sometimes run in families. In these cases, there can be strong genetic risk factors for certain mental illnesses. These can include conditions such as depression, bipolar disorder, and schizophrenia.

Do you think NIPT should be available to find out if a baby had an increased risk of mental illness?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

Would you want to use NIPT to find out if your baby had an increased risk of mental illness?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

How likely would you be to terminate based on an increased risk of mental illness?

- Definitely not
- Unlikely
- Unsure
- Likely
- Definitely
There is not a specific gene for non-medical traits such as increased intelligence, but rather many genes contribute to these traits. Studies may be able to identify genetic patterns associated with these traits in the future.

Do you think NIPT should be available to find out about non-medical traits, such as increased or decreased intelligence?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

Would you want to use NIPT to find out about non-medical traits, such as increased or decreased intelligence?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

How likely would you be to terminate based on non-medical traits, such as increased or decreased intelligence?

- Definitely
- Likely
- Unsure
- Unlikely
- Definitely not
There is no single cause of autism spectrum disorders, but there is a strong genetic basis for them. Autism spectrum disorders are characterised by difficulties with social interaction, difficulties with communication, and repetitive behaviours.

Autism spectrum disorders are classified from mild impact (sometimes called Asperger syndrome) through to severe autism, which is associated with a severe impact on intellect. There are no genetic tests that can currently diagnose most autism spectrum disorders, but this may change in the future.

Do you think NIPT should be available to find out about conditions such as low-functioning/severe autism?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

Would you want to use NIPT to find out about conditions such as low-functioning/severe autism?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

How likely would you be to terminate based on conditions such as low-functioning/severe autism?

- Definitely
- Likely
- Unsure
- Unlikely
- Definitely not
Do you think NIPT should be available to find out about conditions such as *high-functioning/mild autism* (Asperger Syndrome)?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

Would you want to use NIPT to find out about conditions such as *high-functioning/mild autism* (Asperger Syndrome)?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

How likely would you be to terminate based on conditions such as *high-functioning/mild autism* (Asperger Syndrome)?

- Definitely not
- Unlikely
- Unsure
- Likely
- Definitely
Impulse control disorders are characterised by difficulty in controlling behaviour or resisting an urge. Attention Deficit Hyperactivity Disorder (ADHD) is one such condition. People with ADHD may also have problems paying attention to tasks and this affects their education and employment prospects if left untreated.

Do you think NIPT should be available to find out about *impulse control disorders*, such as ADHD?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

Would you want to use NIPT to find out about *impulse control disorders*, such as ADHD?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

How likely would you be to terminate based on *impulse control disorders*, such as ADHD?

- Definitely not
- Unlikely
- Unsure
- Likely
- Definitely
Sociopathy is an informal term for Antisocial Personality Disorder (ASPD). People with this disorder generally show a disregard for others, lack of conscience and remorse, and impulsive and aggressive behaviour. This disorder is very difficult to treat.

Do you think NIPT should be available to find out about antisocial traits and disorders such as sociopathy?

Definitely    Probably    Unsure    Probably not    Definitely not

Would you want to use NIPT to find out about antisocial traits and disorders such as sociopathy?

Definitely not    Probably not    Unsure    Probably    Definitely

How likely would you be to terminate based on antisocial traits and disorders such as sociopathy?

Definitely not    Unlikely    Unsure    Likely    Definitely
Some sex chromosome disorders result in decreased general intelligence (as commonly measured by IQ) but they have no effect on fertility. That is, someone with such a disorder can still have their own children.

Do you think NIPT should be available to find out about sex chromosome disorders which *reduce IQ by 20%* but have *no effect on fertility*?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

Would you want to use NIPT to find out about sex chromosome disorders which *reduce IQ by 20%* but have *no effect on fertility*?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

How likely would you be to terminate based on sex chromosome disorders which *reduce IQ by 20%* but have *no effect on fertility*?

- Definitely
- Likely
- Unsure
- Unlikely
- Definitely not
Some sex chromosome disorders generally result in infertility - people with these conditions will be unable to have children. They may also result in slightly decreased general intelligence (as commonly measured by IQ).

Do you think NIPT should be available to find out about sex chromosome disorders which reduce IQ by 10% but cause infertility?

Definitely not  Probably not  Unsure  Probably  Definitely

Would you want to use NIPT to find out about sex chromosome disorders which reduce IQ by 10% but cause infertility?

Definitely  Probably  Unsure  Probably not  Definitely not

How likely would you be to terminate based on sex chromosome disorders which reduce IQ by 10% but cause infertility?

Definitely not  Unlikely  Unsure  Likely  Definitely
Deafness is sometimes genetic.

Do you think NIPT should be available to find out about traits such as *deafness*?

- Definitely
- Probably
- Unsure
- Probably not
- Definitely not

Would you want to use NIPT to find out about traits such as *deafness*?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

How likely would you be to terminate based on traits such as *deafness*?

- Definitely
- Likely
- Unsure
- Unlikely
- Definitely not
Many diseases that appear later in life have a genetic basis. These include heart disease and cancer. However, preventive and screening measures can help avert or reduce these diseases (for example, a healthy diet, or a regular colonoscopy to check for signs of bowel cancer in a person with an increased risk of this condition).

Do you think NIPT should be available to identify a baby’s risk for adult onset diseases for which preventive and/or screening measures exist, such as heart disease or cancer?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

Would you want to use NIPT to identify your baby’s risk for adult onset diseases for which preventive and/or screening measures exist, such as heart disease or cancer?

- Definitely not
- Probably not
- Unsure
- Probably
- Definitely

How likely would you be to terminate based on your baby’s risk for adult onset diseases for which preventive and/or screening measures exist, such as heart disease or cancer?

- Definitely not
- Unlikely
- Unsure
- Likely
- Definitely
Alzheimer disease can sometimes be due to an identifiable gene fault and this often manifests earlier in life than typical Alzheimer disease, often before the age of 65. People with Alzheimer disease experience dementia and generally die three to ten years from onset. No definitive preventive measures currently exist.

Do you think NIPT should be available to identify a baby’s risk for adult onset diseases for which no preventive measures currently exist, such as early-onset Alzheimer disease?

Definitely    Probably    Unsure    Probably not    Definitely not

Would you want to use NIPT to identify your baby’s risk for adult onset diseases for which no preventive measures currently exist, such as early-onset Alzheimer disease?

Definitely    Probably    Unsure    Probably not    Definitely not

How likely would you be to terminate based on your baby’s risk for adult onset diseases for which no preventive measures currently exist, such as early-onset Alzheimer disease?

Definitely    Likely    Unsure    Unlikely    Definitely not
Are there any other conditions you think NIPT *should* be available to test for?

Are there any other conditions you think NIPT *should not* be available to test for?
Do you think NIPT should be (please select one):
  o  Only available on a user pays basis, as is currently the case
  o  Government funded (e.g. by Medicare)
  o  Government funded for significant medical conditions, but user pays for non-medical traits such as intelligence within the standard range

Do you think it is fair that women/couples currently must pay to access NIPT?

  Definitely not  Probably not  Unsure  Probably  Definitely
PERSONAL BELIEFS

These questions are unrelated to your experience of NIPT but may help us understand how your answers to questions relate to your beliefs.

Please select the most applicable to you:

How often do you think about religious issues?

Never          Rarely         Occasionally          Often          Very often

To what extent do you believe that God or something divine exists?

Not at all     Not very much   Moderately       Quite a bit   Very much so

How often do you take part in religious services?

Never          Rarely         Occasionally          Often          Very often

How often do you pray?

Never          Rarely         Occasionally          Often          Very often

How often do you experience situations in which you have the feeling that God or something divine intervenes in your life?

Never          Rarely         Occasionally          Often          Very often
People often think about issues such as the use of NIPT in different ways. We would like to look at associations between people’s responses to this survey and their general beliefs. This is a new scale that has been developed to ascertain people's approach to these sorts of issues. There are no right or wrong answers!

Please note these are purely imaginary and should reflect what you believe is right, not what is legal or illegal.

Please indicate how much you agree or disagree with each of the following statements

(1 = strongly disagree, 4 = neither agree nor disagree, 7 = strongly agree)

If the only way to save another person’s life during an emergency is to sacrifice one’s own leg, then one is morally required to make this sacrifice.

1 2 3 4 5 6 7

From a moral point of view, we should feel obliged to give one of our kidneys to a person with kidney failure since we don’t need two kidneys to survive, but really only one to be healthy.

1 2 3 4 5 6 7

From a moral perspective, people should care about the well-being of all human beings on the planet equally; they should not favor the well-being of people who are especially close to them either physically or emotionally.

1 2 3 4 5 6 7
It is just as wrong to fail to help someone as it is to actively harm them yourself.

It is morally wrong to keep money that one doesn’t really need if one can donate it to causes that provide effective help to those who will benefit a great deal.

It is morally right to harm an innocent person if harming them is a necessary means to helping several other innocent people.

If the only way to ensure the overall well-being and happiness of the people is through the use of political oppression for a short, limited period, then political oppression should be used.

It is permissible to torture an innocent person if this would be necessary to provide information to prevent a bomb going off that would kill hundreds of people.

Sometimes it is morally necessary for innocent people to die as collateral damage if more people are saved overall.
YOUR INFORMATION

What is your highest completed level of education?
  o Primary school
  o Secondary school (VCE or equivalent)
  o Technical or trade certificate
  o Bachelor’s degree
  o Postgraduate qualification (e.g. Masters, PhD)

Do you live in Victoria?
  o Yes
  o No

  If yes, what is your postcode? ______________

How many children do you currently have?
  o 0
  o 1
  o 2
  o 3
  o 4
  o 5+

Do you plan to have more children?
  o Yes
  o No
  o Currently pregnant
  o Unsure
What is your marital status?
 o Single
 o Partnered
 o Married
 o Divorced
 o Other ________________________________

What is your combined household income?
 o Less than $25,000
 o $25,000 – $49,999
 o $50,000 - $69,999
 o $70,000 - $99,999
 o $100,000 - $129,999
 o $130,000 - $149,999
 o More than $150,000

In general, how liberal/left-wing or conservative/right-wing do you consider yourself to be?
 (1 = Very liberal/left; 4 = Moderate/Centrist; 7 = Very Conservative/right)

1       2       3       4       5       6       7

Do you identify as having a disability?
 o Yes
 o No
Do any of your close family members (e.g. sibling, child) identify as having a condition or trait mentioned in this survey?
   o Yes
   o No

If yes, which one(s)?

Do any of your close family members (e.g. sibling, child) identify as having any other disability?
   o Yes
   o No
Are there any other points you would like to make in relation to this survey?

Thank you for completing this survey!
Your participation is greatly valued and we appreciate you taking the time to respond.