



The psychological impact of receiving findings other than trisomy 21, 18 and 13 with Non-Invasive Prenatal Testing (NIPT)

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Introduction

In the Netherlands, **NIPT** is offered to all pregnant women as a **first trimester prenatal screening test** within the **TRIDENT-2 study** (nationwide uptake n = 73,239; 42%).*

Findings other than trisomy 21, 18 or 13 (**incidental findings (IF)**) are reported on **request** of the pregnant woman.

→ **78%** of women chose to have these reported.*

We **examined** women's **experiences** using a cross-sectional **questionnaire** study.

* [Van der Meij et al. AJHG, 2019](#)



Aim: to examine women's **experiences** with, and the **psychological impact** of, receiving a finding **other than** trisomy 21, 18 or 13 from **NIPT**.

Methods

The first year, **207** incidental findings were detected.

113 women (54.6%) completed the questionnaire.

The questionnaire was developed by a **multidisciplinary** team.

The questionnaire included measures on psychological **well-being**, intolerance of **uncertainty**, health literacy, demographics and specific questions aimed to assess **experiences** and **satisfaction** with testing and follow-up.

Results – part I

For **22 women** the IF NIPT result impacted the **health of their unborn child**. In 51 cases, the finding was **confined** to the **placenta**. For 19 women the result regarded their **own health**.
→ Most **children** were **born without congenital anomalies**.

Most women (59.3%) chose to learn about **IF** because they wanted to **know as much as possible** about the health of their unborn child.

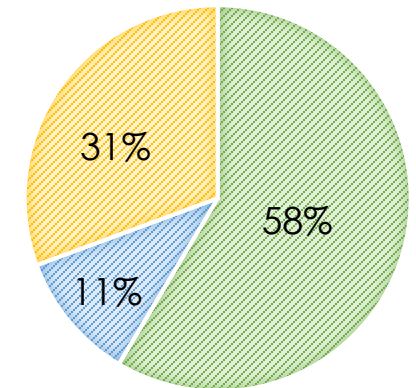
For **most women** (85.9%) their IF NIPT result caused them a great amount of **worry**, and 58.4% said the IF NIPT result had a **negative impact** on their **feelings** about their **pregnancy**.



Most women did **not know** what kind of findings to **expect** beforehand. Most of them were very **shocked** and **worried** upon receiving their IF NIPT result.

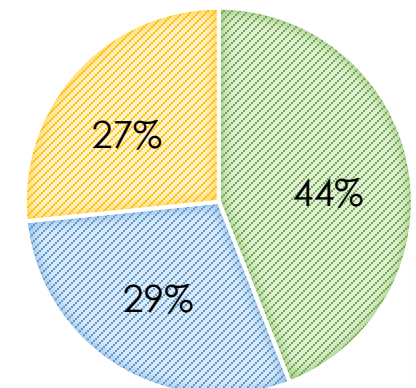
I FOUND DECIDING FOR INCIDENTAL FINDINGS DIFFICULT

■ No ■ Neutral ■ Yes



I HAD AN IDEA OF WHAT INCIDENTAL FINDINGS COULD BE BEFORE HAVING NIPT

■ No ■ Neutral ■ Yes



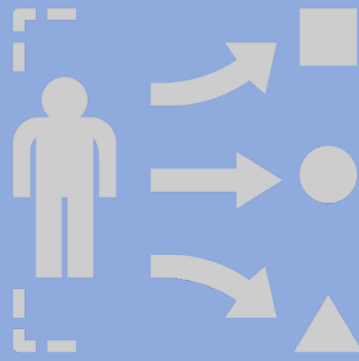
Results – part II

Almost all women (98.2%) received genetic **counselling** by a **clinical geneticist**. For 82.3% of them this **helped** them in **understanding** the meaning of their IF NIPT result.

16% of the women received **support** from a **psychologist /medical social worker** regarding their **IF NIPT result**.
→ Of those who did not, **20%** indicated they **would have wanted** psychological support.

Twenty women (18%) **regret choosing** for **incidental findings** from NIPT.

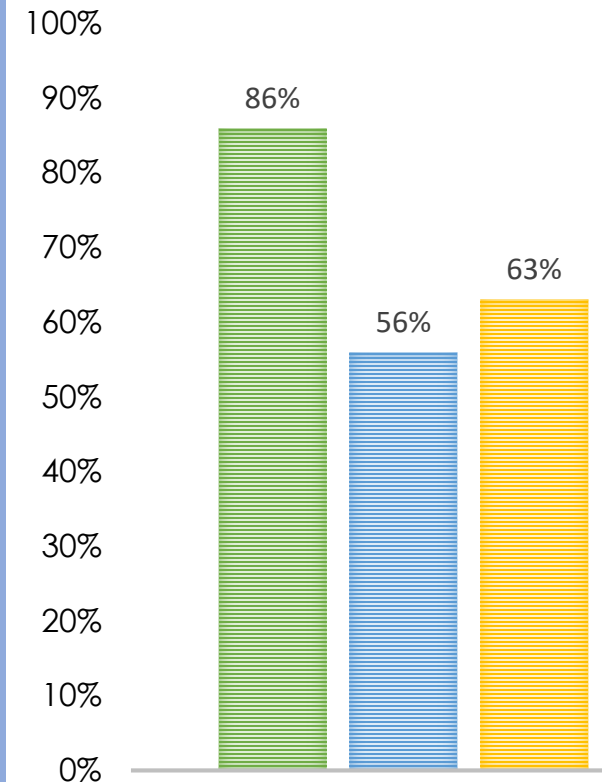
Most women (63%) believe that **all IF NIPT results** should be disclosed.



Most women would **opt for NIPT with incidental findings again** in a future pregnancy. This is, however, **dependent on the origin of their IF NIPT result**.

WOULD OPT FOR NIPT WITH INCIDENTAL FINDINGS (IF) AGAIN

- Origin of IF in child
- Origin of IF in placenta
- Origin of IF in mother



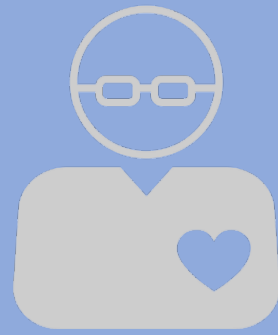
Discussion

NIPT is being offered in a **scientific study** in the Netherlands until **2023**, after that the **government** has to decide how NIPT will be **offered**.

→ Knowing **how** pregnant women **deal** with receiving (incidental) findings is **important**.

Inclusion of the **second year** of the study has been **completed**.

A **limitation** of this study is that we have not **compared** the impact of receiving a **trisomy 21, 18 or 13 finding** with receiving other findings. Therefore, it is **unknown** whether the psychological impact **differs**.



Receiving **adequate** and **timely care** is of utmost importance in this **stressful** and **uncertain** period for women during their **pregnancy**.

Summary

This study is a **first insight** in how women **deal** with receiving **other findings** than trisomy 21, 18 or 13 from **NIPT**.

Most women chose for other findings because they wanted to **know as much as possible** about the health of their unborn child.

Receiving other findings caused a great amount of **worry** for women.

Most women would **opt** for NIPT with other findings **again**, this is however **dependent** on the **origin** of their IF NIPT **result**.