

Understanding women’s experiences of non-invasive prenatal testing (NIPT) for Down’s syndrome

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Introduction

- Down’s syndrome** (DS) is the most common chromosomal condition diagnosed during pregnancy, and screening is offered routinely through the National Health Service (NHS).¹
- There have been many changes to the screening pathway for DS, most recently with the introduction of **non-invasive prenatal testing (NIPT)** as a secondary screening test to Wales (2018), Scotland (2020) and England (2021).
- NIPT is offered to pregnant women who are identified by initial screening as having a higher chance of having a baby with DS, Edwards’ or Patau’s syndrome.
- The roll-out of NIPT in Scotland is under ongoing quantitative evaluation.²
- There is a paucity of **qualitative** research to understand the **experiences** of those being offered NIPT, and the potential impact it may have on their wellbeing and decision making during their pregnancy.

Objective

To understand the discourse and lived experience of those accessing NIPT screening for Down’s syndrome through the National Health Service (NHS) in the UK.

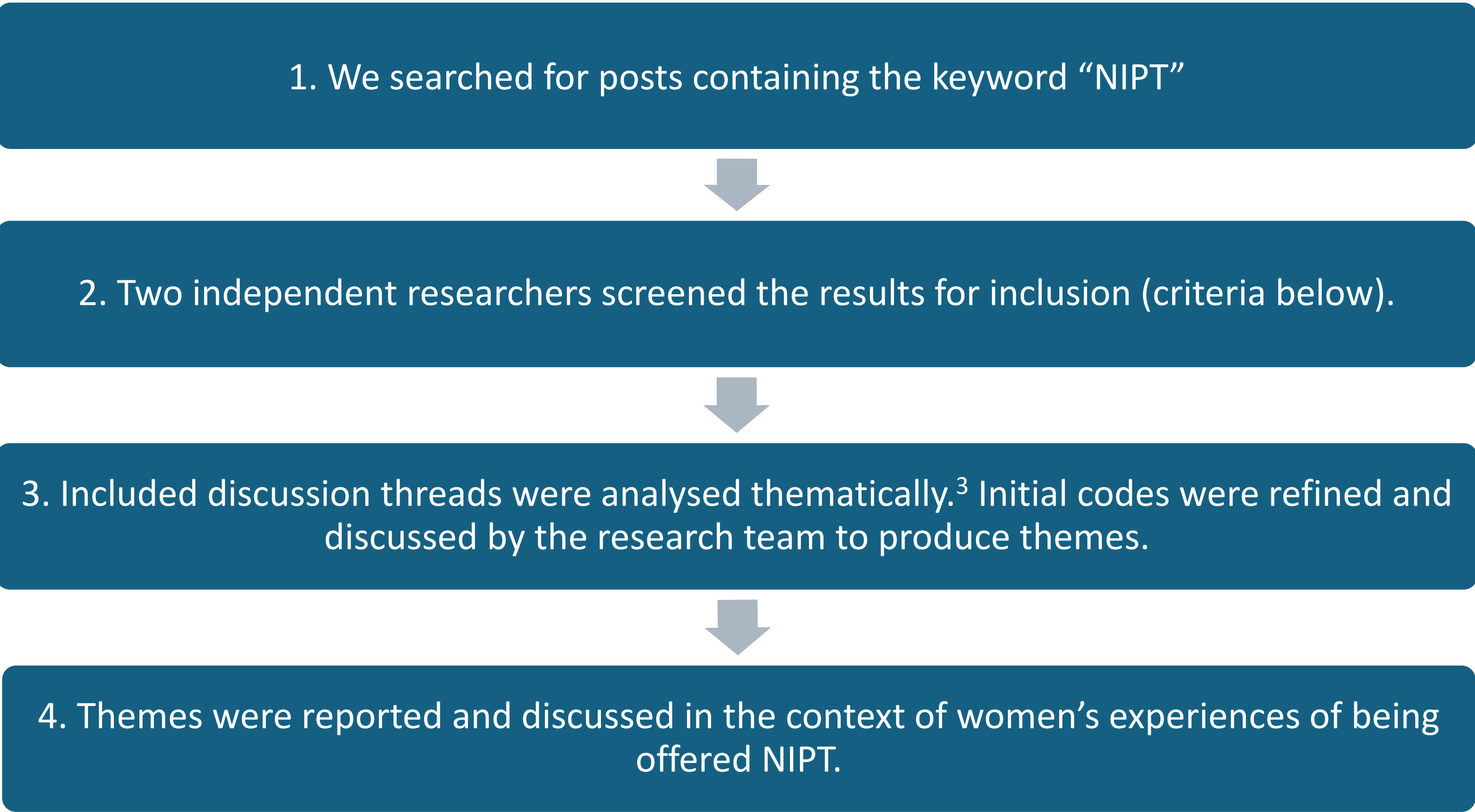
Methods

Discussion thread = An initial post and series of replies.

A **qualitative thematic analysis** of online discussion threads (2020-2024) held within the site Mumsnet (mumsnet.com). A content analysis of key phrases was also conducted.

Inclusion criteria: UK-based user and offered NIPT through the NHS after a higher-chance combined screening result for DS.

Exclusion criteria: NIPT used for sex determination or other non-trisomy conditions, or NIPT was accessed privately.



Ethics: Users of Mumsnet have anonymous usernames. Discussion threads are publicly available without creating an account. All identifiable information was removed from quotes. No ethical approval was required for this work, as discussed with Institution Research Governance representatives.

Results

63 discussion threads were included for analysis following extraction and screening.

Four key themes were identified:

1. Anxiety

Many women felt anxious during NIPT screening. They struggled with the waiting time for NIPT results and with trusting the result of the NIPT, especially if they had a very high chance combined screening result.

“waiting on the NIPT results were torture and I was an anxious/crying mess- it felt like a lifetime of waiting!”

“I didn’t have the combined test with my last...but the combined test results this time around have made me nervous.”

“Has anyone gone through similar and what did you do?!”

“Has anyone mentioned ARC to you? They can offer support and they are brilliant: www.arc-uk.org/”

2. Information seeking and sharing

Posters wanted to hear from those who had a similar experience, particularly if it had a positive outcome. Those who had already had NIPT screening offered advice, online resources and organisations to contact. Individuals wanted help understanding and interpreting their screening results, sharing detailed personal medical information.

“This group has been really helpful and there have been times in the last 2 weeks whereby I’ve read your messages of support and advice repeatedly.”

“fingers crossed for today. But whatever happens, things will be alright.”

3. Positive support and community building

A sense of community was fostered between women with similar experiences – sharing anxieties, validating concerns and offering reassurance. Often the same users would check in on each other, asking for updates.

“...midwife really talked us out of having the amnio, stating the nipt is just as effective”

“me wanting to know what's going on really outweighed the risk for me of having the cvs”

4. Influences on decision making

Those posting often discussed being faced with a difficult decision about screening, diagnostic testing, or pregnancy outcome. They spoke of the factors influencing these decisions. This included family members with additional needs, advice from healthcare professionals, trust in the screening test, and their personal acceptable level of risk.

Conclusion

This study highlighted the experiences of women undergoing NIPT, along with the psychological and informational challenges associated with this process. Our findings demonstrate the need for enhanced support and resources to help women understand their results and navigate the emotional impact of screening, especially whilst waiting for test results.

Acknowledgments

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