

Down syndrome in maternity care: Mothers' experiences of mental health support



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Introduction

- Receiving unexpected news about an unborn or newborn child is an emotional, impactful life event¹
- It is essential that parents receiving a higher chance screening result or Down syndrome diagnosis receive appropriate information and support
- Lack of support and information can exacerbate risks of poor maternal mental health in the perinatal period

Objectives

To investigate **how mothers of children with Down syndrome experienced their NHS maternity care, and its impact on their mental wellbeing**. To highlight the importance of positive practice as well as areas where greater mental health support is needed.

Methods



Anonymous online survey
Open and closed questions about maternity care experiences from screening to postnatal period



Mothers of children with Down syndrome born from 2019 – 2022 in England, Scotland or Wales (**N = 317**)
Recruited online via DSUK parent networks



Participants received: prenatal diagnosis (19.1%), higher chance prenatal screening result(s) (30.0%) or postnatal diagnosis (50.9%) of Down syndrome

References

- 1 - Clark, L., et al. (2020). Qual. Health Res., 30(12).
2 - Kratovil, A. L., & Julion, W. A. (2017). J. Perinat., 37(1).
3 - Care Quality Commission (2023) 2022 Maternity Survey: Statistical Release.

Results

“Our hospital was amazing once the diagnosis was confirmed and we stated we wanted to continue with the pregnancy. Termination was never mentioned again and everyone professional we met was fully supportive”

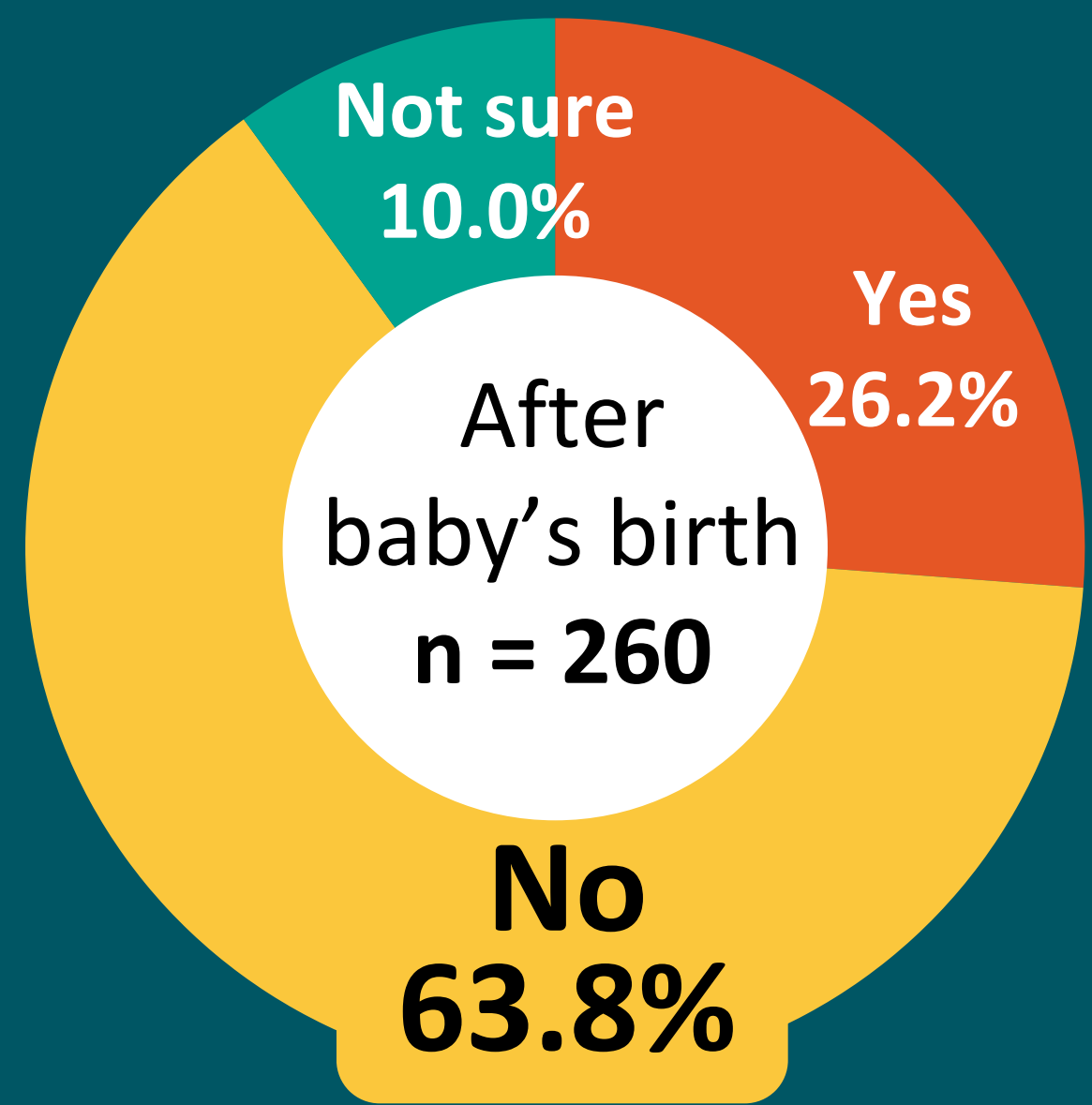
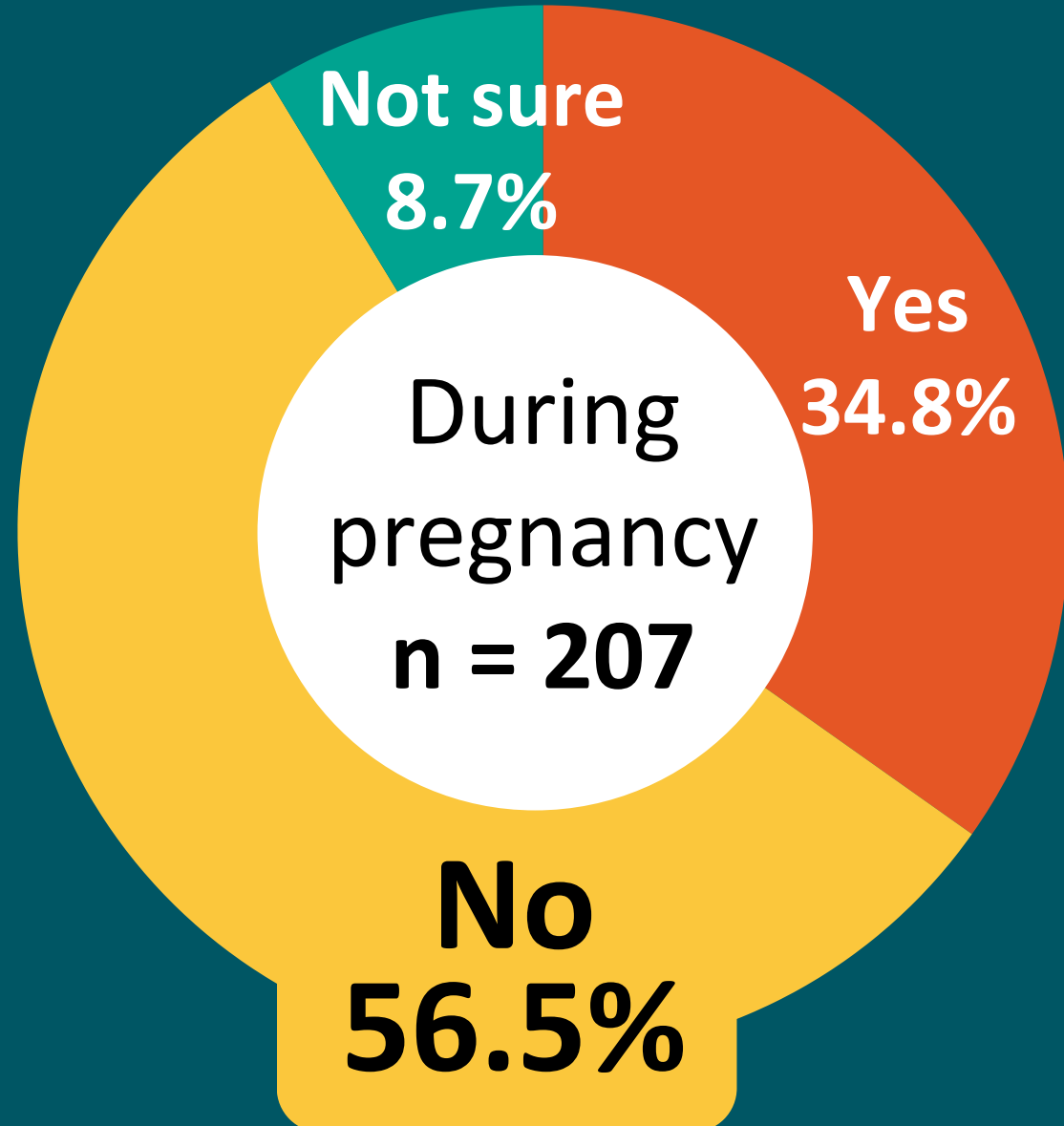
Support and validation for decisions

Kindness, understanding, personalised support

Hopeful, realistic and reassuring messages

Contact with other families and support organisations

Was there enough support available for your own mental wellbeing...



Were you given enough **reassurance about the future** for you, your baby and your family? (n = 258)

Yes
31.4%

No
58.1%

Not sure
10.5%

Did the attitude shown by HCPs towards your baby having DS have a **negative impact on your mental wellbeing**? (n = 258)

Yes
37.6%

No
51.2%

Not sure
11.2%

“We were given NO emotional support and were left feeling shell shocked, overwhelmed and terrified for our future”

“I was very upset but because I then declined further testing, I had no follow up counselling... Felt like they didn't care after I had turned down the amniocentesis”

Limited opportunity to discuss results / diagnosis

Insensitive or stigmatising language

Lack of emotional support or follow-up

Sense of isolation exacerbated by lack of information & support

Conclusions & Implications

- Most mothers of children with Down syndrome felt there was **insufficient support for their mental wellbeing** both during and after pregnancy
- **Discrepancy with general population:** 85% of women surveyed nationally felt there was enough mental health support available during pregnancy,³ vs 38% of our participants*
- There are important opportunities to positively impact mothers' wellbeing during this critical period by: recognising and **responding to their individual emotional needs; supporting their decisions; providing reassurance; and facilitating connections**
- Up to date **resources and information**, and **Down syndrome training**, must be available to healthcare professionals to ensure they can meet parents' essential support needs

*Comparative figure excluding 'not sure' responses

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Down Syndrome UK



Research report