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Are there socio-economic inequalities in the uptake of Down Syndrome screening in the UK?

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1 **Conflicts of interest**

2 None

3 **What's already known about this topic?**

- 4 • There are socio-economic inequalities in the uptake of a number of screening
- 5 programmes in the UK
- 6 • Previous research, using maternal self-report , found little evidence of socio-economic
- 7 inequalities in the uptake of Down Syndrome screening in the UK

8 **What this study adds**

- 9 • Using prospectively collected data we found no evidence of socio-economic inequalities
- 10 in uptake of Down Syndrome screening in the UK

11

In the UK, national guidelines state that Down syndrome screening involving nuchal translucency and/or serum tests should be offered to all pregnant women before 20 weeks gestation. Recent data suggest that whilst around 90% of pregnant women are offered such screening, uptake may be much lower (Rowe et al., 2008). The reasons for ~~refusal of~~ declining this screening ~~of screening~~ include negative attitudes towards the test, negative attitudes towards termination of pregnancy, and willingness to keep the fetus whether or not Down syndrome is diagnosed (Kuppermann et al., 2006, Li et al., 2008).

Previous research has found strong socio-economic gradients in the uptake of other screening tests, including those for cervical and breast cancer (White et al., 2009). Whilst markers of low socio-economic position (SEP) have been associated with lower uptake of Down syndrome screening in France and the USA (Kuppermann et al., 2006, Khoshnood et al., 2003), such inequalities are not consistently reported in the UK, especially when key confounders, including maternal age, are controlled for (Alderdice et al., 2008, Rowe et al., 2008, Rowe and Garcia, 2003). However, most previous research has relied on maternal self-report of screening uptake, which may be subject to systematic socio-economic bias (Khoshnood et al., 2004).

We used routine data from Northern England to explore the association between an area-based marker of SEP and objectively measured uptake of Down Syndrome screening.

The Northern Congenital Abnormality Survey (NorCAS) is a high quality, population-based register of congenital anomalies (Richmond and Atkins, 2005). Since 1985, NorCAS has collected information on all cases of Down syndrome occurring to women resident in the

North East and North Cumbria . From 2004, NorCAS has collected enhanced information on Down syndrome cases.

Information on all Down syndrome affected pregnancies between 01 April 2004 and 31 December 2009 was abstracted from the NorCAS database. All diagnoses were confirmed by cytogenetics. Pregnancies were excluded from the analysis if: structural fetal anomalies were diagnosed at the dating scan (8-12 weeks of gestation), an early miscarriage occurred before the first hospital antenatal visit had taken place, if the first hospital antenatal visit occurred outside of the study region or if the women was not eligible for screening (i.e. booked too late).

Uptake of screening was defined as accepting any screening test in either the first or second trimester of pregnancy as recorded in maternal health records. Socio-economic position was measured using the rank of the Index of Multiple Deprivation 2007 (IMD) score of the lower super output area of residence, identified from the postcode of maternal residence at the first hospital antenatal visit. Index of Multiple Deprivation is an area-based marker of deprivation compiled from data across seven domains: income, employment, health deprivation and disability, education skills and training, barriers to housing and services, crime, and living environment (Noble et al., 2008). Index of Multiple Deprivation ranks were collapsed into quintiles, based on scores across England and Wales as a whole, for analysis. Maternal age, defined as the age at termination or delivery, was modelled as a continuous variable.

Differences in the distribution of maternal age between those who did and did not accept screening were investigated using the Mann-Whitney test. Cuzick's non-parametric test was

used to identify a potential trend in screening uptake across IMD quintiles. Multivariate logistic regression was used to estimate odds ratios (ORs) and 95% confidence intervals (CIs) corresponding to ~~the in~~ uptake of screening across IMD quintiles, before and after adjusting for maternal age. All statistical analyses were performed using SPSS 17.0 and Stata 11.

NorCAS is exempt from requiring consent for inclusion on the register under section 251 of the NHS Act 2006 and has ethics approval (09/H0405/08) to undertake studies involving the data.

A total of 510 Down syndrome affected pregnancies were notified to NorCAS during the study period. Following exclusions, 351 (68.8%) pregnancies remained. All women with included pregnancies had been offered Down syndrome screening and 207 (59.0%) of these took up the offer.

The median age of women who took up screening was 36 years (IQR: 30-39), compared with 35 years (IQR: 28-39) in those who did not. The distribution of age did not vary between women who accepted and declined screening ($p=0.42$).

Table 1 shows the odds of uptake of Down syndrome screening by deprivation quintile.

There was no significant ~~trend~~ differences in the uptake of screening across deprivation quintiles ($p=0.23$). The odds of uptake in quintiles two to five did not vary significantly from the odds of uptake in quintile one (the most deprived group). There was no evidence that screening uptake was associated with maternal age (Table 1). Adjusting for age did not change the lack of association between deprivation and screening uptake.

[Insert Table 1 here]

Amongst a group of women who had pregnancies that resulted in a diagnosis of Down syndrome in Northern England, we found no differences in uptake of NHS Down syndrome screening by SEP either before or after adjustment for maternal age. Our use of prospectively recorded, objective measures of screening uptake represents a significant improvement on previous work that has relied on maternal self-report of screening uptake. These results confirm other UK data suggesting no evidence of socio-economic differences in uptake of Down syndrome screening (Alderdice et al., 2008, Rowe et al., 2008, Rowe and Garcia, 2003). However, they contrast with findings from the USA and France which show strong socio-economic differences in Down syndrome screening uptake (Kuppermann et al., 2006, Khoshnood et al., 2003).

This study used data from a high quality regional congenital anomaly register which is known to have a high degree of completeness and accuracy (Richmond and Atkins, 2005). In particular, we used objectively and prospectively recorded information on uptake of Down syndrome screening. Unlike previous work (Alderdice et al., 2008, Khoshnood et al., 2003, Kuppermann et al., 2006, Rowe et al., 2008) we did not, therefore, have to rely on women's retrospective self-report of whether or not they took up screening.

We used IMD as a measure of SEP. Whilst this is the UK government's preferred measure of deprivation, and is therefore highly policy relevant, IMD scores are based on area level data. They, therefore, represent the average conditions of all individuals living in a small area, but do not necessarily represent the actual conditions of any one particular individual living in that area. As individual-level markers of SEP (e.g. educational attainment, income, or occupation) are not held in the NorCAS database, IMD was the only marker of SEP available

to us. Future work should explore differences in screening uptake according to other markers of SEP.

Our data are restricted to Northern England and only pregnancies that resulted in a diagnosis of Down syndrome. This may limit generalisability. However, it is difficult to think of any reason why there might be systematic regional differences in socio-economic trends in uptake of screening across the UK or between pregnancies that did and did not result in a diagnosis of Down syndrome.

Our data are restricted to information on Down syndrome screening within the NHS. Thus information on screening that was obtained privately is not included in our dataset. As private screening can entail substantial financial costs (around £100-200), more affluent women are likely to use private screening more often. However, only 1% of pregnant women make use of private antenatal care/screening in the UK. It is therefore unlikely that our exclusion of private screening significantly altered our results.

Our results confirm previous findings suggesting no evidence of socio-economic differences in uptake of Down syndrome screening in the UK (Alderdice et al., 2008, Rowe et al., 2008, Rowe and Garcia, 2003). Uptake of screening is related to, amongst other things, attitudes towards the screening test (Kuppermann et al., 2006, Li et al., 2008). In the UK, attitudes towards the screening test are not related to SEP (Dormandy et al., 2005) and this may explain why there are no socio-economic differences in uptake. Why attitudes to the test might be socio-economically patterned in some countries but not others is unclear.

1 Additionally, logistical difficulties with accessing the test in countries, such as the USA,
2 where screening is not necessarily provided free at the point of delivery, may play a role in
3 socio-economic differences in uptake in some countries, but not others.

4 It is striking that socio-economic differences in uptake in some, but not all, screening tests
5 have been reported in the UK. This could be related to the procedures used to invite people
6 for screening. For example, Down syndrome screening is offered to all women in the UK
7 during existing antenatal visits and no additional visit should be required. This is quite
8 different from the procedures used to invite women to, for example, cervical or breast
9 cancer screening, where invitation letters offering an appointment or requesting that one is
10 made are sent to women's homes. Further research should explore this more fully in order
11 to ensure that health promotion programmes do not, inadvertently, lead to socio-economic
12 inequalities in uptake and thus outcome.

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Table 1: Uptake of the NHS Down Syndrome screening programme by deprivation quintile, North of England, 2004-09

Deprivation quintile	Uptake of screening (n=351)		Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI)*	p-value
	Accepted (n=207); n (%)	Declined (n=144); n (%)				
1 (most deprived)	72 (57.6)	53 (42.4)	1	--	1	--
2	40 (54.1)	34 (45.9)	0.87 (0.49 to 1.54)	0.63	0.85 (0.47 to 1.52)	0.58
3	40 (60.6)	26 (39.4)	1.13 (0.62 to 2.08)	0.69	1.10 (0.59 to 2.03)	0.77
4	23 (59.0)	16 (41.0)	1.06 (0.51 to 2.20)	0.88	1.01 (0.48 to 2.13)	0.98
5 (least deprived)	32 (68.1)	15 (31.9)	1.57 (0.77 to 3.19)	0.21	1.51 (0.74 to 3.11)	0.26
Age (yrs), median (IQR)	36 (30-39)	35 (28-39)	--	--	1.01 (0.98 to 1.04)	0.57

* Adjusted for maternal age