

Time and travel costs incurred by women attending antenatal tests: a costing study

Abstract

Objective To estimate the costs to women, their friends and family for different antenatal tests in the Down's syndrome (DS) screening pathway.

Design Questionnaire-based costing study.

Setting Eight maternity clinics across the UK.

Participants Pregnant women (n=574) attending an appointment for DS screening, NIPT or invasive testing between December 2013 and September 2014.

Measurements Using data collected from the questionnaires we calculated the total costs to women by multiplying the time spent at the hospital and travelling to and from it by the opportunity costs of the women and accompanying person and adding travel and childcare costs. Assumptions about the value of opportunity costs were tested in one-way sensitivity analyses. The main outcome measure was the mean cost to the women and friends/family for each test (DS screening, NIPT, and invasive testing).

Findings Mean costs to women and their family/friend were £33.96 per visit, of which £22.47 were time costs, £9.15 were travel costs and £2.34 were childcare costs. Costs were lowest for NIPT (£22), £32 for DS screening (£44 if combined with NIPT), and highest for invasive testing (£60). Sensitivity analysis revealed that variations around the value of leisure time opportunity costs had the largest influence on the results.

Key conclusions There are considerable costs to women, their friends and family when attending different tests in the DS screening pathway.

Implications for practice When assessing the cost-effectiveness of changes to this pathway, costs to women should be considered.

Keywords: Patient costs, Down's syndrome screening, non-invasive prenatal testing, cell free DNA, health economics

Introduction

In the UK, all pregnant women are offered screening for Down's syndrome (DS) and other aneuploidies. Women with a high risk of DS ($\geq 1:150$) after screening are offered diagnostic testing, which is currently invasive testing by amniocentesis or chorionic villus sampling (CVS), both of which are associated with a small risk of miscarriage. Non-invasive prenatal testing (NIPT) involves the analysis of cell free DNA in maternal plasma and allows detection of DS (and other genetic problems) in the fetus (Gil et al., 2015). NIPT is available in many parts of the world, but mostly through private sector healthcare providers (Minear et al., 2015). It is expected that if NIPT was offered to women with a high screening risk for DS, the number of invasive tests (and procedure-related miscarriages) could decrease dramatically (Warsof et al., 2015). Implementation of NIPT in the current screening programme could therefore lead to significant changes to the screening programme. Recently, the costs to the UK National Health Service (NHS) of implementing NIPT in the national screening programme were investigated (Morris et al., 2014). However, implementing NIPT may have cost implications beyond those incurred by health service providers, for example for the women taking part in the screening programme. These may include direct costs, such as travel and childcare expenses or lost pay, and indirect costs of unpaid time (Posnett and Jan, 1996). Some women might be accompanied by a friend or family member or need someone to look after their children. This will also have cost implications, and so an analysis fully considering costs incurred by women attending antenatal tests ought to include these costs too. Little is known about the costs to women, their friends and family for attending DS screening, NIPT or invasive testing. One study assessed women's costs of antenatal ultrasound screening in 2002 and did not include costs to women for invasive testing or for NIPT (Henderson et al., 2002). The aim of this study was to estimate the costs to women, their friends and family of different antenatal appointments in the Down's syndrome screening pathway.

Methods

Participants

Women attending one of eight hospitals for Down's syndrome screening, NIPT or invasive testing during the period December 2013 to September 2014 were asked to complete a questionnaire detailing the time and money costs they incurred when attending the hospital. In these hospitals NIPT was offered as a contingent test to women with a traditional DS screening risk of $\geq 1/1000$ as part of a study evaluating introduction of NIPT into the pathway (Hill et al., 2014). In two hospitals a one-stop DS screening service was in place and NIPT was usually offered on the same day as DS screening and women could therefore have a combined screening and NIPT appointment. In the other clinics, women with a screening result $\geq 1/1000$ were contacted by phone and offered a further appointment for NIPT.

Questionnaire

The questionnaire (see Supplement) consisted of nine questions asking for information about the costs incurred by pregnant women, their friends and family when attending the hospital for antenatal tests. A similar questionnaire (including the same 9 questions) was used in a previous study examining the costs of antenatal ultrasound screening (Henderson et al., 2002), so a pilot was not performed for the current study. The first two questions were used to determine what the woman would have been doing if she was not attending the clinic, and, if she was working, what arrangements were made to take time off work (paid or unpaid leave, etc). The questionnaire also asked about mode and costs of travel and the amount of time spent travelling, whether the woman was accompanied by someone during the appointment, how much time was spent at the hospital, whether it was advised to take extra time off work, and what amount of money income was lost. A question was also included about the need for childcare and associated costs.

Time costs

The opportunity costs of time lost from work (for the visit to the clinic, including travel time) was estimated using the median full-time gross weekly earnings for women in the UK (£458.80), as described in the Annual Survey of Hours and Earnings 2013 (ONS, 2013). We estimated tax, pension and national insurance contribution at 35% and assumed a 37.5-hour working week; net hourly earnings for women were therefore assumed to be £7.95. This wage rate was used for women who had unpaid absence from work or had to work additional hours in lieu of the appointment. When women attended the clinic outside work time or took annual leave, i.e., during leisure time, their time was valued at 40% of the female wage rate (£3.18). This valuation of leisure time was used in a previous study (Henderson et al., 2002). When the woman took paid leave from work, we assumed no opportunity costs to the woman as these costs were borne by the employer. For women not in paid employment we assumed the opportunity costs were equal to the wage rate of women in the lowest paid occupations (£4.93) (Henderson et al., 2002).

When women were accompanied during their visit, the companion could either be male or female. Therefore, we used the median adult wage rate to value their time (£8.97 (ONS, 2013)) if this person took time off work (assuming they took unpaid leave), and the median adult wage rate for the lowest paid occupations (£5.84 (ONS, 2013)) if they would not have been working otherwise.

Travel costs

When women travelled to the clinic by foot or bicycle, we assumed zero travel costs. For women who travelled to the clinic by car, we assumed a mean distance to the clinic of 16.1 km at a cost of £0.28/km (AA Motoring costs, 2013; Propper et al., 2006). Parking fees and costs of public transport/taxi were taken from the questionnaire directly.

Childcare costs

When someone was paid to look after children or other dependents, these costs were taken from the questionnaire. When someone took time off work to look after children or other dependents, we valued their opportunity costs using the median adult wage rate (£8.97).

All costs are expressed in 2013-14 UK£.

Statistical analysis

Total costs for each woman were calculated by multiplying the time spent at the hospital and travelling by the opportunity costs of the women and accompanying person and adding travel and childcare costs. The different tests in the DS screening pathway were grouped into the following categories: DS screening; NIPT; DS screening and NIPT; invasive testing; and, other. For each test we calculated the average total costs and used regression analysis to adjust for variations by centre in which the woman had her appointment.

Sensitivity analysis

We performed several sensitivity analyses. For the main analysis, we valued leisure time at 40% of the female wage rate. A value of zero to 150% of the wage rate has been used to value leisure time, based on the argument that for overtime work employers often pay a higher wage rate (Drummond et al., 2005). We therefore performed two alternative analyses; one in which the opportunity cost of leisure time was zero and another one in which these costs were 150% of the female wage rate. In another sensitivity analysis we costed the time of women not in paid employment at zero (in the main analysis we used the wage rate of women in the lowest paid occupations). Wages have a skewed distribution, the mean and median wage rates are not similar. We therefore performed an analysis based on the mean net hourly female rate (£9.26) instead of the median (£7.95). Lastly, we calculated the costs to employers for women who took paid leave from work by valuing their time spent at the hospital and travelling using the female wage rate.

Findings

In total, 574 women completed the questionnaire, each for a single visit. The majority attended an appointment for DS screening (364 women). Of the remaining women, 87 attended an appointment for NIPT, 46 for both DS screening and NIPT, 53 for invasive testing, and 24 for other tests (Table 1). Responses to the questionnaire are summarized in Table 2.

Time costs

If not attending the clinic, 335 women (58%) would have been in paid employment. For 164 (49%) of these women, the costs were borne by the employer, while 119 (36%) lost pay because they took unpaid absence or would make the time up and 52 (16%) came to the clinic outside work or took annual leave. Of the women not in paid employment, 165 (29% of all women) were looking after a child or relative, 11 (2%) were studying at school or college and 63 (11%) had leisure time. A large proportion of the women (n=420, 73%) were accompanied by someone and almost 300 (71%) of these accompanying persons took time off work to come to the hospital with the woman. The mean time spent at the clinic was 71 minutes, but this varied by the type of test (Table 3). Mean time costs for the woman and accompanying person were £22.47 per visit. Twenty-nine women (5%) were advised to take some time off work after their visit to the clinic for mean 1.6 days. Fifty-five women (10%) said they were losing income through attending the clinic, ranging from £3 to £250.

Travel costs

More than half of the women (58%) came to the clinic by private car. Mean parking fees were £3.61 per attendance. Another 33% of the women came by public transport, with a mean cost of £3.32 (one way) and 2% took a taxi (mean £8.78 one way). On average, women spent 31.5 minutes travelling (each way) and mean travel costs per visit were £9.15.

Childcare costs

Forty-two women (7%) paid someone to look after their children or dependents, with a mean cost of £25. In 15 cases (3%) someone had taken time off work to look after them. Mean childcare costs per visit were £2.34.

Total costs per test

Table 3 shows the mean time spent in the hospital per test and the total costs including travel costs, time costs of the women themselves and the persons accompanying them and childcare costs. On average, women spent 71 minutes at the clinic to have their test and mean costs to the woman and her family/friends were £33.96. The shortest test was NIPT (38 minutes), DS screening took a mean time of 68 minutes, invasive testing 115 minutes and DS screening combined with NIPT 116 minutes. The costs to women and their family/friends were lowest for NIPT (£22), £32 for DS screening (£44 if combined with NIPT), and highest for invasive testing (£60). The results were adjusted by centre, though this did not affect the results appreciably.

Sensitivity analysis

If leisure time was valued at 0% of the female wage rate, the mean costs per visit would have been almost £5 lower than in our main analysis (£29 vs £34) (Table 4). If leisure time was valued at 150% however, mean costs for would have been around £8 higher (£42). The impact of valuing time of women not in paid employment at £0 and using the mean female wage rate was smaller. Costs to the employer were on average £5, but varied between £3 and £12 depending on the test performed (highest for DS screening combined with NIPT).

Discussion

Main findings

There are considerable costs to women and their family and friends associated with the DS screening pathway, with a mean cost of £34 per visit. Costs for NIPT were £22, for DS screening were £32 (£44 if combined with NIPT), and for invasive testing were £60. Many assumptions were made to estimate the value of the opportunity costs to women. Of these assumptions, the value of leisure time had the largest impact on the results. If leisure time was valued at 150% of the wage rate, the tests would have been more costly to women (£8-£15 extra). Other assumptions did not have such a large impact on the results.

Strengths and Limitations

The main strength of this study is that it was based on data from a large sample of women were recruited from eight different clinics across the UK. This reduces the chance of bias caused by the type of clinic or location. In view of this and the large sample size, we believe the results should be representative for most women undergoing tests in the DS screening pathway. There are several limitations. Some women may have been eligible to have their travel costs reimbursed by the Healthcare Travel Costs Scheme and women in the UK are entitled to paid leave to attend antenatal appointments (<https://www.gov.uk/working-when-pregnant-your-rights>). Neither of these were taken into account and thus costs may be overestimated. However, as relatively few women would be eligible for these benefits, the impact will be small. Some women or accompanying persons might have taken a day or half a day off work, instead of the duration the appointment and travel only. In this case, the costs calculated in this study would have been underestimated. This would also apply for people taking time off work to take care of the children or dependents of the women. However, the extra time taken off work could have been used in another useful way and therefore this time may not really be lost. A final limitation is that the data for this study were collected in 2013/14, and

wage rates from this period were also applied; we acknowledge that the timings and wage rates may change over time.

Interpretation (in light of other evidence)

To our knowledge this is the first study to calculate the costs to women of different tests in the DS screening pathway. Henderson *et al.* reported that the costs to women of antenatal ultrasound screening in 2002 were £12.42 (Henderson et al., 2002). When we inflate these costs to 2013/14 (approximately £20), they are similar to the costs we found for NIPT, but lower than the costs for DS screening (which may include an ultrasound scan and also phlebotomy).

A visit to the clinic for NIPT takes less time than for invasive testing and is therefore less costly to women. This means that introduction of NIPT could decrease the costs to women if fewer invasive tests are needed in the DS screening pathway. This could be relevant when assessing the cost-effectiveness of implementing NIPT in the DS screening pathway. NIPT could be a more attractive option for women compared to invasive testing, not only because the test is less invasive and lowers the risk of procedure related miscarriages, but also because the costs incurred to attend the test are lower. Further research should be undertaken to assess the cost-effectiveness of NIPT using a societal perspective.

The main implication of our study for practice is that costs to women and their families ought to be borne in mind in the DS screening pathway.

Conclusion

Our two conclusions are that, first, there are considerable costs to women, their friends and family when attending clinics for different tests in the DS screening pathway. Second, when assessing the cost and cost-effectiveness of changes to this pathway these costs should be considered.

Details of Ethics Approval

This was a prospective cohort study with National Research Ethics Approval (13/LO/0082) performed between 1.11.2013 and 28.2.2015.

Disclosure of interests

None of the authors have any conflicts of interest.

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Tables

Table 1. Test and centre attended

	n	%
Test		
DS screening	364	63%
NIPT	87	15%
DS screening & NIPT	46	8%
Invasive testing	53	9%
Other	24	4%
Centre		
1	125	22%
2	75	13%
3	132	23%
4	79	14%
5	99	17%
6	39	7%
7	24	4%
8	1	0%
Total	574	100%

Table 2. Responses to the questionnaire regarding employment, travel type and child-care

	n	%	Valuation
What would you have been doing today if you were not attending the clinic?			
Paid Employment	335	58%	See below
Looking after Child/Relative	165	29%	Non-working opportunity costs
Studying at school/college	11	2%	Non-working opportunity costs
Leisure Time	63	11%	Lost leisure
What arrangements did you make to take time off work?			
Paid Absence from work	164	29%	None
Unpaid absence from work	54	9%	Lost pay
Will make the time up	65	11%	Lost pay
Came to clinic outside work	25	4%	Lost leisure
Took Holiday	27	5%	Lost leisure
Did you travel here today by			
Walking	38	7%	None
Bicycle	7	1%	None
Private Car	333	58%	16.1 km, 28p/km
parking fees	236	41%	From questionnaire (mean: £3.61, range £0.60-£20.00)
Public Transport	187	33%	From questionnaire (mean: £3.32, range £0.00-£30.0)
Taxi	9	2%	From questionnaire (mean: £8.78, range £2.00-£13.0)
How long did the whole journey take?	31.48	minutes	
Did anyone come with you to hospital, <u>and wait</u> for you while you received your care?			
Yes	420	73%	
If yes, did they take time off work?			
Yes	298	52%	Lost pay
No	117	20%	Non-working opportunity costs
If you have children or other dependants, have you paid someone to look after them?			
Yes	42	7%	From questionnaire (mean: £24.79, range £0.00-£75.00)
Someone has taken time off work to look after them	15	3%	Lost pay
Total	574	100%	

Table 3. Costs to women or their family and friends of attending the clinic

Test attended for	n	%	Time at hospital (minutes)	Total costs \pm SD (unadjusted)	Total costs; 95% CI (adjusted for centre)
Total/average	574	100%	70.88	£33.96 \pm £20.52	£33.96
DSS	364	63%	68.12	£31.91 \pm £16.60	£31.71; £29.83-£33.60
NIPT	87	15%	38.07	£22.77 \pm £16.44	£21.75; £17.73-£25.75
DSS&NIPT	46	8%	115.67	£42.44 \pm £24.12	£44.17; £38.67-£49.66
IPD	53	9%	115.23	£58.03 \pm £25.86	£59.56; £54.47-£64.66
Other	24	4%	59.75	£36.20 \pm £21.81	£36.19; £28.56-£43.82

DSS=Down's Syndrome Screening, NIPT=Non-Invasive Prenatal Testing, IPD=Invasive Prenatal Testing

Table 4. Results of the sensitivity analyses

	Mean	DSS	NIPT	DSS&NIPT	IPD	Other
Main analysis	£33.96	£31.71	£21.75	£44.17	£59.56	£36.19
Leisure time valued at 0% of female wage rate	£29.29	£27.22	£18.03	£40.39	£51.50	£31.17
Leisure time valued at 150% of female wage rate	£42.43	£39.78	£28.47	£51.22	£74.76	£45.00
Time of women not in paid employment valued at £0	£30.67	£28.48	£19.10	£41.66	£54.31	£32.43
Mean female wage rate used (instead of median)	£34.80	£32.55	£22.46	£44.96	£60.66	£37.25
Costs to employers only	£5.31	£4.10	£4.95	£11.71	£9.76	£2.61

DSS=Down's Syndrome Screening, NIPT=Non-Invasive Prenatal Testing, IPD=Invasive Prenatal Testing