Childhood tonsillectomy: who is referred and what treatment choices are made? Baseline findings from the North of England and Scotland Study of Tonsillectomy and Adenotonsillectomy in Children (NESSTAC)

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Abstract

Background
Tonsillectomies are frequently performed yet variations exist in tonsillectomy rates. Clinicians use guidelines, but complex psychosocial influences on childhood tonsillectomy include anecdotal evidence of parental enthusiasm. Studies indicate that undergoing preferred treatment improves outcome. Despite the enthusiasm with which tonsillectomy is offered and sought, there is little evidence of efficacy. This resulted in a randomised controlled trial to evaluate the cost-effectiveness of (adeno)tonsillectomy in children with recurrent sore throats.

Objective
To compare characteristics of children entering the randomised trial with those recruited to a parallel, non-randomised study, to establish trends in referral and patient preferences for treatment.

Design
Baseline data from a randomised controlled trial with parallel non-randomised preference study, comparing surgical intervention with medical treatment in children aged 4 to 15 years with recurrent sore throat referred to five secondary care otolaryngology departments located in the north of England or west central Scotland.

Results
Centres assessed 1546 children; 21% were not eligible for tonsillectomy. Among older children (8–15 years), girls were significantly more likely to be referred to secondary care. Of 1015 eligible children, 268 (28.2%) agreed to be randomised while 461 (45.4%) agreed to the parallel, non-randomised preference study, with a strong preference for tonsillectomy. Participants reporting that progress at school had been impeded or with more experience of persistent sore throat were more likely to seek tonsillectomy. Referred boys were more likely than girls to opt for medical treatment. Socioeconomic data showed no effect.

Conclusion
Preference for tonsillectomy reflects educational impact and recent experience, rather than age or socioeconomic status.
Background

Tonsillectomy is frequently performed in the United Kingdom (UK) with over 51,000 operations in England in the National Health Service (NHS) in 2005/06. Around 58% were in children (aged 0-14 years [www.hesonline.nhs.uk](http://www.hesonline.nhs.uk)). The majority of tonsillectomies are for recurrent sore throats however there are wide geographical variations in the rate of tonsillectomy¹.

Guidelines for tonsillectomy from the Scottish Intercollegiate Guidelines Network recommend that patients should meet all of the following criteria:

- sore throats due to tonsillitis
- 5+ episodes of sore throat/year
- symptoms for at least a year
- episodes of sore throat are disabling/prevent normal functioning²

However most clinicians operate selection criteria based on published research from two decades ago³. Guidelines may not be uniformly implemented, even when locally derived, and surgeons tend to break guidelines more often in favour of performing than withholding surgery⁴.

Complex psychosocial influences on tonsillectomy rates include anecdotal evidence of parental enthusiasm for intervention⁵, lack of information⁶ and maternal use of psychotropic drugs which increases two-fold the rate of consultation for childhood sore throat⁷ ⁸. Private medical insurance is also associated with higher selective surgical rates for (adeno)tonsillectomy in children under the age of seven years⁹, an important consideration as 13% of all Ear Nose and Throat (ENT) surgical activity in the UK is in the independent sector¹⁰.

Research into patient preferred treatment options for recurrent sore throat is limited⁵ although studies for other conditions have found that patients receiving their preferred treatment did better than those who were indifferent or not allocated their preference¹¹.

Despite the popularity of tonsillectomy and the enthusiasm with which it is offered and sought, high quality evidence of efficacy remains sparse¹²-¹⁴. This resulted in the UK NHS Health Technology Assessment Research and Development Programme funding a pragmatic randomised controlled trial to evaluate the cost-effectiveness of (adeno)tonsillectomy in children with recurrent sore throats (NESSTAC)¹⁵. Surgical intervention was compared with medical treatment in children with recurrent sore throat (trial group). Eligible subjects who declined randomisation received their preferred treatment and were offered enrolment in a parallel non-randomised preference study (preference group). Trial and preference subjects completed identical outcome measures at each data collection point. This paper compares baseline characteristics of children and parents entering the trial, with those entering the preference study, for trends in referral and patient preferences for treatment.
Methods

Subjects
Subjects were children aged 4-15 years with recurrent sore throats referred from primary care to five secondary care otolaryngology departments located in the north of England or west central Scotland. The study inclusion/exclusion criteria are shown in Box 1. These criteria are a simplified version of the original criteria used. This amendment was made mid-way through the study, on advice of the steering committee, in an attempt to simplify the recruitment process. Thus two slightly different sets of criteria were used.

Box 1
Inclusion criteria
- 4+ episodes of sore throat within each of the preceding 2 years or
- 6+ episodes of sore throat within the last year.

Exclusion criteria
- Previous tonsillectomy.
- Hospitalisation due to tonsillitis.
- Quinsy.
- Marked obstructive airway during attack.
- Co-morbidity affecting ability to undergo surgery within 6 months.
- Bleeding disorder.
- Otitis media with effusion.
- Sleep apnoea syndrome.
- Rare medical condition (e.g. glomerulonephritis or Henoch Schonlein purpura).
- Suspected velopharyngeal insufficiency.
- Congenital/valvular heart disease.

Recruitment
Recruitment took place in secondary care between May 2002 and July 2006. All primary care referrals of children with recurrent sore throat to the five study centres were considered by participating surgeons. Trained research nurses introduced the study to children and parents who were shown a video describing the main aspects of the study, from the perspective of a putative parent and child interrogating a recruiting otolaryngologist. Information included current evidence regarding effectiveness of treatment options and natural history of the disease (see supplement). Printed information sheets were also provided. In light of this information, the research nurses discussed the study with children and parents who then went on to have a further, informed, discussion with the participating surgeon. For children and parents willing to participate in either the trial or the preference study, the research nurses obtained written consent and collected baseline data. Children recruited to both the trial and preference studies were stratified by age into three groups (4-7, 8-11, 12-15 years).

Data
Anonymous eligibility forms were completed by the surgeon for each child approached about the study, recording basic demographics (gender, age) and reported history of sore throat. Baseline questionnaires were completed by participants upon recruitment to the study (see supplement). Questionnaire data included detailed history of sore throat, associated problems with school, social class based on occupation, quality of life and economic data (not presented here).
Ethics
This study was approved by the Northern and Yorkshire Multi-centre Research Ethics Committee, Local Research Ethics Committees, and the NHS Research and Development department and Caldicott Guardian from each participating secondary care site. The study received a Clinical Trial Authorisation from the Medicines and Healthcare products Regulatory Agency.

Analysis
Comparisons between groups were made using $\chi^2$ tests for categorical data and one way ANOVA for comparisons of means. Factors influencing the choice of group to which the child was entered were investigated using multinomial regression. The analysis was undertaken using SPSS version 15. Further details of the study can be found in the published protocol (ISRCTN47891548).
Results
In line with the sampling stratification strategy, results are reported by the three age strata adopted where appropriate.

Recruitment
Figure 1 shows the flow of children into the study up to baseline assessment. For those opting for surgery the main reason given was that the child was unable to participate in school/nursery. Those children who did not meet the inclusion/exclusion criteria are show in Table 1.

Figure 1: Flowchart of children in the study.
Table 1: Reasons for ineligibility

<table>
<thead>
<tr>
<th>Reason for ineligible</th>
<th>Total (n=531)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not meet inclusion criteria</td>
<td>328</td>
<td>57</td>
</tr>
<tr>
<td>Previous tonsillectomy</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Hospitalisation due to tonsillitis</td>
<td>26</td>
<td>4</td>
</tr>
<tr>
<td>Quinsy</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Marked obstructive airway during attack</td>
<td>52</td>
<td>9</td>
</tr>
<tr>
<td>Co-morbidity (unable to undergo surgery within 6/12)</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Bleeding disorder</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Otitis media with effusion</td>
<td>29</td>
<td>5</td>
</tr>
<tr>
<td>Sleep apnoea syndrome</td>
<td>54</td>
<td>9</td>
</tr>
<tr>
<td>Rare medical conditions</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Suspected velopharyngeal insufficiency</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Congenital/valvular heart disease</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Other reasons</td>
<td>64</td>
<td>11</td>
</tr>
<tr>
<td>Total *</td>
<td>578</td>
<td>100</td>
</tr>
</tbody>
</table>

* Multiple reasons for ineligible were given for 41 (8%) of the 531 ineligible children.

Scrutiny of all assessed children by age and gender revealed an overall significant gender bias with increasing age. In the youngest age group (4-7 years) there were equal numbers of males and females presenting however the proportion of females per group increased in line with increasing age (Table 2).

Table 2: Age group by gender for all assessed children (n=1546)

| Gender, n (%) | Age 4-7 yrs (n=660) | Age 8-11 yrs (n=468) | Age 12-15 yrs (n=418) | Total (n=1546) | Test of difference between groups
|---------------|----------------------|----------------------|-----------------------|-----------------|---------------------------|
| Males | 332 (50%) | 146 (31%) | 121 (29%) | 599 (39%) | $\chi^2 = 65.29; p < 0.001$
| Females | 328 (50%) | 322 (69%) | 297 (71%) | 947 (61%) |

Note: $\chi^2$ = chi-squared statistic

Characteristics of all eligible children

There were no significant differences in gender or age between trial, preference and declined groups (Table 3).

Table 3: Characteristics of all eligible children

| Gender, n (%) | Trial (n=268) | Preference (n=461) | Declined (n=286) | Total (n=1015) | Test of difference between groups
|---------------|--------------|-------------------|-----------------|----------------|---------------------------|
| Males | 93 (25%) | 179 (48%) | 99 (27%) | 371 | $\chi^2 = 1.89; p = 0.389$
| Females | 175 (27%) | 282 (44%) | 187 (29%) | 644 |
| Age Group, n (%) | | | | | $\chi^2 = 5.74; p = 0.220$
| 4-7 years | 100 (27%) | 170 (46%) | 97 (26%) | 367 |
| 8-11 years | 95 (29%) | 149 (45%) | 85 (26%) | 329 |
| 12-15 years | 73 (23%) | 142 (45%) | 104 (33%) | 319 |

Note: $\chi^2$ = chi-squared statistic
Characteristics of trial and preference children

The trial population was compared to the patient preference group who opted for surgery as well as the preference group who opted for medical management. A baseline questionnaire response rate of 88% [642/729] was achieved. Questionnaire responders were compared to non-responders. While there were no significant differences according to gender ($\chi^2 = 0.81; p = 0.367$) and age group ($\chi^2 = 1.57; p = 0.456$) there was a significant difference according to study group with more non-responders in the randomised trial ($\chi^2 = 6.31; p = 0.043$).

Responses to questions relating to the child’s health over three months prior to the baseline survey are summarised in Table 4. Most of the children (97%) reported at least one sore throat. Although the difference between groups was not significant at the 5% level the trend across the groups was replicated in the other variables relating to sore throats (where the difference between groups was significant). Children (and parents) who opted to retain their tonsils had fewer and shorter sore throats than other children, and a smaller number of very prolonged attacks, or complicating episodes of reported ear infection, while children who opted to have their tonsils removed tended to report the most frequent and most severe sore throats. Randomised children were somewhere in the middle. The same response pattern was observed in the questions relating to interruption of schooling and quality of life: children opting for surgery reported the greatest perceived disruption and poorest quality of life; children opting for medical management reported the least perceived disruption and best quality of life. There was some evidence that the proportion of boys was higher in the group opting for medical management than in the other two groups. There was no evidence that age influenced choice of group. There were no significant differences between trial and preference participants in terms of social class based on parental occupation across all age groups (Age 4-7, $\chi^2 = 8.7; p = 0.85$) (Age 8-11, $\chi^2 = 9.8; p = 0.78$) (Age 11-15, $\chi^2 = 12.2; p = 0.43$).

Factors influencing the choice of group to which the child entered were investigated using multinomial regression. The dependent variable was the choice of study group: 1=preference medical, 2=trial, 3=preference surgical. All the variables listed in Table 4 were investigated as potential explanatory variables. Significance tests were based on changes in log likelihood. The greatest change in log likelihood was obtained by fitting the variables described in Table 5.
Table 4: Sore throat symptoms, school activity and quality of life over the last three months and age and sex by study group

<table>
<thead>
<tr>
<th>Variable</th>
<th>Preference medical (n=67)</th>
<th>Trial (n=225)</th>
<th>Preference surgery (n=349)</th>
<th>Test of differences between groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any sore throats? t/n (%)</td>
<td>63/67 (94%)</td>
<td>212/219 (97%)</td>
<td>341/346 (99%)</td>
<td>$\chi^2 = 5.26; p = 0.067$</td>
</tr>
<tr>
<td>Mean number of sore throats lasting less than 2 weeks, (SD)</td>
<td>2.7 (1.6) [n = 67]</td>
<td>3.2 (2.4) [n = 220]</td>
<td>3.6 (2.5) [n = 346]</td>
<td>$F_{2,630} = 4.92; p = 0.008$</td>
</tr>
<tr>
<td>Mean length (days) last sore throat, (SD)</td>
<td>5.3 (3.2) [n = 67]</td>
<td>7.2 (5.5) [n = 220]</td>
<td>7.8 (4.6) [n = 346]</td>
<td>$F_{2,630} = 8.14; p &lt; 0.001$</td>
</tr>
<tr>
<td>Any persistent (&gt;2wks) sore throat? t/n (%)</td>
<td>13/67 (19%)</td>
<td>65/216 (30%)</td>
<td>155/341 (46%)</td>
<td>$\chi^2 = 22.23; p &lt; 0.001$</td>
</tr>
<tr>
<td>Sore throat resulted in ear infection? t/n (%)</td>
<td>20/66 (30%)</td>
<td>76/215 (35%)</td>
<td>153/341 (45%)</td>
<td>$\chi^2 = 7.79; p = 0.021$</td>
</tr>
<tr>
<td>Any days off school? t/n (%)</td>
<td>52/66 (79%)</td>
<td>187/215 (87%)</td>
<td>320/345 (93%)</td>
<td>$\chi^2 = 13.15; p = 0.002$</td>
</tr>
<tr>
<td>Mean number of days off school, (SD)</td>
<td>6.6 (6.4) [n = 67]</td>
<td>8.3 (7.9) [n = 222]</td>
<td>11.2 (9.0) [n = 347]</td>
<td>$F_{2,632} = 13.17; p &lt; 0.001$</td>
</tr>
<tr>
<td>Progress at school affected, t/n (%)</td>
<td>19/66 (29%)</td>
<td>84/216 (39%)</td>
<td>215/347 (62%)</td>
<td>$\chi^2 = 42.33; p &lt; 0.001$</td>
</tr>
<tr>
<td>Males, t/n (%)</td>
<td>36/67 (54%)</td>
<td>76/219 (35%)</td>
<td>129/346 (37%)</td>
<td>$\chi^2 = 8.26; p = 0.016$</td>
</tr>
<tr>
<td>Age:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-7 years, t/n (%)</td>
<td>28/67 (42%)</td>
<td>80/225 (36%)</td>
<td>126/349 (36%)</td>
<td>$\chi^2 = 4.24; p = 0.375$</td>
</tr>
<tr>
<td>8-11 years, t/n (%)</td>
<td>24/67 (36%)</td>
<td>81/225 (36%)</td>
<td>108/349 (31%)</td>
<td></td>
</tr>
<tr>
<td>12-15 years, t/n (%)</td>
<td>15/67 (22%)</td>
<td>64/225 (28%)</td>
<td>115/349 (33%)</td>
<td></td>
</tr>
<tr>
<td>PedsQL: Mean Physical Health Summary Score (SD)</td>
<td>77.2 (18.5) [n = 65]</td>
<td>77.5 (18.8) [n = 219]</td>
<td>71.1 (22.3) [n = 338]</td>
<td>$F_{2,621} = 7.21; p = 0.001$</td>
</tr>
<tr>
<td>PedsQL: Mean Mental Health Summary Score (SD)</td>
<td>76.6 (13.2) [n = 66]</td>
<td>72.4 (14.5) [n = 221]</td>
<td>68.9 (15.4) [n = 334]</td>
<td>$F_{2,620} = 9.03; p &lt; 0.001$</td>
</tr>
</tbody>
</table>

Note: r = number of children giving indicated response; n = total number of children responding to that question; $\chi^2$ = chi-squared statistic; F = F statistic from variance ratio test
The most important predictor of choice of group was whether it was perceived that the child’s progress at school was affected by their condition in the three months prior to baseline. The second most important predictor was whether the child had had any persistent sore throats in the three months prior to baseline. The final explanatory variable was gender. Once these variables were included in the model none of the other variables (age, number of episodes and duration of sore throats, ear infection or time off school) produced a significant reduction in -2 log likelihood. Similarly none of the two way interactions between any of the variables produced a significant improvement in the fit of the model.

Examining the parameter estimates (Table 6) revealed that children were more likely to be entered into the preference surgical group than the randomised trial if it was perceived that their progress at school was affected by their symptoms. Children were more likely to be entered into the preference surgical group than the randomised trial if they had experienced a persistent sore throat in the three months prior to baseline. Boys were more likely than girls to be entered into the preference medical group rather than the randomised trial.
Discussion

Randomised controlled trials are the gold standard for research, including evaluation of health care interventions in an evidence-based health care system. Assessment of clinical and cost-effectiveness of health technologies that are well established and widely used in clinical practice is particularly challenging in health technology assessment where patients (or clinicians) express preferences for particular treatments. Standard randomised controlled trials used where there are strong preferences experience high non-participation (refusal) rates and consequently decreased generalisability. Patient preference trials that combine the randomised controlled trial with a non-randomised experimental design are increasingly used where there may be strong preferences17 18.

(Adeno)tonsillectomy for the treatment of children with recurrent sore throat has been routine clinical practice for over 50 years. In developing the study, we anticipated patient preferences to increase the non-participation rate in a standard randomised controlled trial and therefore combined a pragmatic randomised controlled trial19 with a parallel non-randomised preference group in the study design15.

Patient-preference trials of interventions for childhood conditions also raise the question of “whose preference?” particularly where teenagers are participating. In this study we did not differentiate between the preferences of parents and children. We are therefore unable to specify “who wants childhood tonsillectomy?” but are able to highlight the characteristics of children for whom a preference for surgical or medical intervention is known.

The proportion of parents and children participating in the study who stated a preference was 63% [461/729]. In sensitivity analysis we assumed that for all eligible children for whom participation in the study was declined (286) there was a preference. This suggests that the proportion of parents and children with a treatment preference is 74% [461+286/1015].

For the additional 328 patients (21% of those screened for eligibility) who were found not, for the most part, to have sufficiently severe sore throats to be eligible (Table 1), either there is a lack of understanding of current referral guidance by referring doctors, or doctors themselves have a preference, or they in turn have bowed to patient preference for a surgical opinion. The design of the study does not capture the process of self-referral to primary care and the decision-making processes taken by the doctor in partnership with parents and children. Therefore it is not possible to estimate the number of children, who would have been eligible for the study but not referred. Nor is it possible to understand how patient preferences played a role in this process, especially as we have shown that preference is, in part at least, linked to disease severity and that we have no knowledge comparing the natural history of sore throat in the two genders. However the data revealed a potential gender difference in the demand and referral for secondary care opinion with girls in the older age group presenting to the study centres more frequently than boys. This is consistent with data from Denmark20.

Of the 461 preference participants i.e. those who were not in ‘equipoise’16% [74/461] opted for medical management and 84% [387/461] for (aden)tonsillectomy. This preference for surgical removal was anticipated given that the procedure is well established and ‘expected’ by many patients referred to ENT. Perhaps somewhat more interesting, therefore is the not insignificant number of participants who opted for medical management following referral to ENT.
A number of factors may have influenced the 387 preference participants who had elected for surgery. Earlier studies suggested that in addition to demographic and clinical variables, school attendance and school performance were important. Here, 62% of preference participants opting for surgical management reported that their progress at school was impeded by recurrent sore throats compared with 29% of the preference medical group and 39% of trial participants. The multinomial regression model confirms the importance of perceptions of school performance, along with the experience of persistent sore throat and female gender. However in this study it was perceived disruption to schooling rather than experience of sore throat that was most highly associated with treatment choice. It is also worth noting the almost two fold magnitude in measured differences in outcomes such as number of days off school and number of persistent sore throats between participants opting for medical management and participants opting for surgical management.

Thus in answer to the questions posed in this paper, the study suggests that older girls (8–15 year olds) are more likely to be referred for secondary care opinion than older boys. Participants reporting that progress at school had been impeded are more likely to seek surgical treatment of sore throat. In addition participants with more experience of persistent sore throat will seek surgery. Referred boys are more likely than girls to opt for routine medical treatment. A recent analysis of intervention rates over the last century observed higher rates in less well off areas, and concluded that “it is the affluent, better equipped with information and empowered to influence the decisions that concern them, who have been able to alter their pattern of healthcare more effectively”. Our results showed no link between social class based on parental occupation and patient preference. Factors other than parental empowerment may underlie any such differences.

These results suggest that children recruited into the trial cannot be regarded as a representative sample of children who meet the eligibility criteria for the study. The implication of this is that any estimate of the effects of tonsillectomy based purely on children in the trial is likely to be biased. Any statements about the effectiveness of tonsillectomy in the whole study population will have to take into account the baseline factors that have influenced the choice of study group as well as limitations imposed by poor response rates.
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Contributors
All authors contributed ideas to the manuscript, assisted data analysis and interpretation, were responsible for critical review and final approval of the version submitted for publication and have full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

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Competing interest
All authors declare that the answer to the questions on your competing interest form are all NO and therefore have nothing to declare.

What is already known on this topic?
- Tonsillectomy is one of the most frequently performed childhood operations although there are wide variations in tonsillectomy rates.
- Most clinicians use guidelines for surgical intervention however there is anecdotal evidence of parental enthusiasm for the procedure. Research into patient preferred treatment options for persistent sore throat is limited.

What this study adds
- There is a gender difference in the demand and referral for secondary care opinion with girls in the older age groups (8–15 year olds) presenting to the study Ear Nose and Throat centres more frequently than boys.
- Children and parents exhibited strong preferences for the surgical management of recurrent sore throats particularly when progress at school has been impeded or for those with more experience of persistent sore throat. Referred boys are more likely than girls to opt for routine medical treatment.
References


Supplement 1

NESSTAC patient recruitment video – DIALOGUE 04/11/04


- Explain addition of sites here ie 2nd text screen NESSTAC with addition of Bradford and Glasgow to x, y and z.

Dialog Parent, Child and Doctor –

Doctor: Good morning. As you know, your GP has asked you to come up to clinic today so we can discuss the treatment options for John. In children who have recurrent sore throats and tonsillitis there really are two options. The first option, particularly in children who are getting better, is to keep an eye on the episodes of tonsillitis, we need to watch and see what happens. The second option in children who have more severe attacks of tonsillitis or sore throats is to take the tonsils out and this is done with an operation called a tonsillectomy. In some children it’s easy to decide what is best to do but in children who are having infrequent episodes of sore throat or tonsillitis or perhaps who are getting less frequent episodes than they had been previously, we can keep an eye on them and watch and wait and see what happens. In children who have more severe episodes of tonsillitis, perhaps those who’ve been admitted to hospital in the past because of it, then we would think about taking their tonsils out. However, there is a large group of children who are not having those two extremes of sore throats and tonsillitis, in whom we’re not so sure what is the best line of management.

Parent: That sounds like John.

Doctor: Yes it’s probably the commonest group.

Parent: So what’s the best form of treatment for these in-between children?

Doctor: Well, in the UK certainly in the past lots of tonsils have been taken out because it was felt it was the best thing to do. However in Europe the tonsillectomy procedure is actually very uncommon. Tonsillectomy is a safe operation but it’s never really been tested to see if it produces long term benefits for a child’s health. On the one hand taking the tonsils out means the child won’t get tonsillitis again. But tonsillectomy requires a general anaesthetic and an overnight stay in hospital. In most children who keep the tonsils, the number of episodes of tonsillitis diminishes as time goes on, so we don’t really know what the best form of treatment is and that’s why the National Health Service have asked us to perform the NESSTAC Trial.

Parent: What sort of trial?

Simple animation showing people going through 2 doors

- Different – little coloured people walking into two groups!
Doctor: Children will be divided into equal groups. Each group will be given one of two different treatments. Both treatments are safe and in common usage and have been used many times in the past, we just don’t know which treatment form is best.

Parent: What are the two treatments?

Doctor: The first group is the keep tonsils group. Those children will not have a tonsillectomy and will see their general practitioner as and when required if they have a sore throat. In addition they will also have a hospital follow-up appointment at nine months to see how they’re getting on.

Parent: What's the other treatment?

Doctor: The second group will be placed on a waiting list to have their tonsils out and when they get to the top of the waiting list then they'll be admitted for a tonsillectomy. It may be at that time they also have their adenoids removed as well if the surgeon believes that’s the most appropriate treatment.

Parent: So who chooses which children go into which group?

Doctor: No-one will choose which group each of the children go into. The decision will be made by random by a computer. That means that each child has a 50/50 chance of either going into the tonsils out group or keeping tonsils group.

Parent: So why has John been chosen to take part in this study?

Doctor: All children who are referred with recurrent tonsillitis or sore throats in the three (five) centres – that’s Newcastle, Manchester and Liverpool (and Bradford and Glasgow – are being invited to take part in the trial. We need approximately 400 children in total.

Parent: Can you tell me a bit more about the keep tonsils group?

Doctor: In the keep tonsils group children who suffer with recurrent episodes of tonsillitis or sore throat will seek the advice of their General Practitioner as before. It’s quite likely that this group of children will suffer at least one further episode of tonsillitis or sore throat.

Parent: Presumably that would be similar to the usual attacks that John’s been getting?

Doctor: Yes. Tonsillitis is unpleasant but it generally clears up within a few days. We know that children who suffer with recurrent sore throats and tonsillitis usually begin to get better after a couple of years or so and we know that hopefully within the next two years that John’s symptoms will be less severe than they have been previously.

Parent: Are there any risks with this treatment?
Doctor: There are theoretical risks with recurrent tonsillitis but complications are very uncommon indeed. And John has been suffering with recurrent tonsillitis for a long time now and has never had a complication and indeed if he’d had a complication in the past then he wouldn’t be considered for the trial.

Parent: So what's involved if the tonsils are taken out?

Doctor: The operation involves coming into hospital usually for an overnight stay. The risks of the procedure are very small indeed and the risks are usually bleeding and infection. Approximately 2 children in every 100 are likely to suffer with an episode of bleeding that would possibly necessitate them having to return to theatre for a further operation. The usual side effects are nausea and vomiting and of course it’s normal for children to experience some pain after a tonsillectomy. But that’s rather like having another episode of tonsillitis.

Parent: Does having the tonsils out affect the immune system?

Doctor: No, there’s no evidence at all that having a tonsillectomy leads to further infections.

Parent: How do I know that John's going to get the best treatment for him?

Doctor: If we knew exactly what the best treatment for John was then we’d offer him that treatment. However John falls into that group of children in whom we’re not sure whether a tonsillectomy or whether waiting and seeing is the best form of treatment and that’s what we hope to do with the NESTAC trial. Are there any questions you want to ask John?

John: Do I have to take any special medicine to take part in the trial?

Doctor: No, there are no special medicines you need to take during this trial. If you have another episode of sore throat or tonsillitis then you may need to go to your General Practitioner to get some medicine from him in the normal way. The only other thing we will ask you to do is to complete a diary and some questionnaires. These are to give us an idea of how well you’re getting on during the trial period.

Line appear on screen reading “only children aged 8 and over will be asked to help with the questionnaires and diaries” – *move to end and for translation*

John: What sort of diary?

Doctor: These diaries aren’t like a normal sort of diary you keep on holiday where you write whole sentences in the diary. These diaries ask you questions and you ring your response to them. I’ve got a copy here to show you.

Diary appears full screen with animation showing number being circled as doctor talks.
For example this page asks which symptoms you have had today. If you’ve had a sore throat and difficulty swallowing you would ring 1 and 3. If you have no symptoms at all then you would ring 10. Do you see what I mean John?

John: Yeah.

Parent: So how long does each child stay in the study?

Doctor: Each child stays in the study for 2 years and during that time we will also ask you to complete 4 questionnaires.

Parent: What happens if John's condition gets much better or much worse during that time?

Doctor: Well if that happens during the trial it may mean we need to reconsider and take a fresh decision and of course at any stage during the trial you’re free to decide to leave the trial if that’s what you want to do. If you do agree to let John take part in the trial then you’ll be helping us to answer some questions about the treatment of children with recurrent sore throats and tonsillitis in the future. We will ask you to sign a consent form before you take part in the study and we’ll also provide an information sheet which you can take home with you. If you have any other questions then you could contact us using the number on the information sheet.

*The NESSTAC study team would like to thank you for watching this video.*

Screen at end

- 5 sites, not 3 ("In addition to 3 sites mentioned, the study is now…
- children over 8 ‘text’ diaries and questionnaires, + Parents will be required…
- keep tonsils group – very few children randomised to the gp have then crossed over and chosen to have their tonsils out “In the study so far, very few children …
Supplement 2

CONFIDENTIAL

UNIVERSITY OF NEWCASTLE

NESSTAC
North of England and Scotland Study of Tonsillectomy and Adeno-tonsillectomy in Children

The Tonsil Study

Parent's Questionnaire
How to answer these questions

Throughout this questionnaire we talk about your child’s “condition”. By “condition” we mean any sore throats your child has had, together with any complications as a result of the sore throats and any treatment side-effects. We are interested in finding out whether your child's condition has affected everyday life, both for him or her and for you and your family. We would also like to know about any use of health services for your child's condition. It is important to hear from you even if your child has not suffered any sore throats for a while.

Some questions ask you to think back over the last month and some over the last three months. This is because we realise that some things are easier to recall than others. Please read the instructions carefully throughout the questionnaire.

Almost all the questions can be answered simply by ringing a number next to the answer which applies to your child. Occasionally you are asked to write in the answer.

Usually, after answering a question, you should go on to the next one. Sometimes there will be an instruction in a shaded box next to the number you ring, telling you which question to answer next.

Example:  
Yes .................. 1  
No ................... 2

In this example if you circle 1 for ‘Yes’ you should go on to answer part a). If you circle 2 for ‘No’ you should go to question 7.

If you are unsure about how to reply to a particular question, please give the best answer you can and write in any other comments you have. Please contact us if you have any questions – a contact number is given at the end of the questionnaire.

The information you provide will be strictly confidential. Your child’s name will not appear on the questionnaire and any information you give us will not be used in any way that could identify you or your child personally.
Your child’s condition

1. **Over the last three months**, has your child had any sore throats at all?
   - Yes .............. 1
   - No .............. 2

   **Answer Q2**
   **Go to Q8**

2. **Over the last three months**, how many sore throats, each lasting less than two weeks, has your child had?
   - [ ] sore throats

3. How long did your child’s most recent sore throat last?
   - [ ] days

4. **Over the last 3 months**, has your child had any constant or chronic sore throats that lasted more than 2 weeks?
   - Yes .............. 1
   - No .............. 2

   **Answer a)**
   **Go to Q5**

   If yes, a) How many weeks were they affected in total?
   - [ ] weeks

5. Sometimes sore throats can lead on to other problems or complications. Did any of the episodes of sore throat your child had result in any complications?
   - Yes, ear infection .............. 1
   - Yes, other complications *(please say what these were below)* .............. 2

   Please ring all that apply

   - No, no complications .............. 3

6. **Over the last 3 months**, has your child taken any antibiotics to treat his/her sore throats and/or related complications?
   - Yes .............. 1
   - No .............. 2

   **Answer Q7**
   **Go to Q8**
7. Sometimes children get side-effects from the antibiotics they take. **Over the last three months**, has your child suffered any of these symptoms either while they were taking or during the week after taking antibiotics?

   - Feeling sick (nausea) and or being sick (vomiting) .......... 1
   - Diarrhoea .......... 2
   - Skin rash .......... 3
   - Thrush (yeast infection) .......... 4
   - Other side-effects *(please say what these were)* .......... 5

   ........................................................................................................
   
   No, no side effects .......... 6

Please ring all that apply
The next set of questions asks you to say how much you agree or disagree with each of the statements. Please show how much you agree or disagree by circling one number on each line.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Over the last 3 months, my child has not grown or not put on as much weight as I think he/she should</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Over the last 3 months, my child has put on too much weight</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Over the last 3 months, my child has missed out on their usual day to day activities (eg playing with friends, regular clubs and hobbies) because of their condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Over the last 3 months, my child has missed out on activities that are important to him/her (eg birthday parties, playing sport in a school team, being in the school play, school trips out) because of their condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Over the last 3 months, the whole family has had to reschedule or miss out on activities because of my child's condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Taking everything together, which of the faces below shows best how you feel about your child's life as a whole?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Please tell us how much of a problem each one has been for your child during the past ONE month by circling:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.

### Physical functioning (problems with…)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Walking down the road a little bit</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Running</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. Participating in sports or running games</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. Lifting heavy things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. Having a bath or shower by him or herself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. Doing chores, like picking up his or her toys</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. Having hurts or aches</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. Feeling very tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Emotional functioning (problems with…)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. Feeling afraid or scared</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. Feeling sad or unhappy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. Feeling angry or cross</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. Trouble sleeping at night</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. Worrying about what will happen to him or her</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Social functioning (problems with…)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
</table>

There are no right or wrong answers.
<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never</th>
<th>times</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>27. Getting on with other children</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>28. Other children not wanting to be his or her friend</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>29. Getting bullied by other children</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>30. Not able to do things that other children his or her age can do</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>31. Keeping up when playing with other children</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**School functioning (problems with...)**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Neve r</th>
<th>Almos t Never</th>
<th>Some - times</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. Paying attention in class</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33. Forgetting things</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. Keeping up with schoolwork</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. Having days off school because of not feeling well</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36. Having days off school to go to the doctor or hospital</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Use of NHS health services

The next set of questions asks you about your child’s use of NHS health services over the last three months. We are interested both in overall use of NHS health services and in use of NHS health services for the condition. Remember – by condition we mean any sore throats, complications of sore throats, and any side-effects of treatment.

37. Over the past three months, have you done any of the following because of your child’s condition or other health reasons?
If yes, please tell us the number of times. (Please be sure to answer either ‘yes’ or ‘no’ to every item.)

a) Has your child been seen by the family doctor or another GP at a doctor’s surgery?
Yes, because of their condition ............ 1  Please write in no. times 9-11
Yes, because of other health reasons... 2  Please write in no. times 12-14
No ......................................................... 3

b) Has your child been seen by a nurse at a surgery?
Yes, because of their condition ............ 1  Please write in no. times 16-18
Yes, because of other health reasons... 2  Please write in no. times 19-21
No ......................................................... 3

c) Did you speak to a nurse from a doctor’s surgery about your child on the telephone?
Yes, because of their condition ............ 1  Please write in no. times 23-25
Yes, because of other health reasons... 2  Please write in no. times 26-28
No ......................................................... 3

d) Did you speak to a doctor about your child on the telephone?
Yes, because of their condition ............ 1  Please write in no. times 30-32
Yes, because of other health reasons... 2  Please write in no. times 33-35
No ......................................................... 3

e) Did you phone NHS Direct about your child?
Yes, because of their condition ............ 1  Please write in no. times 37-39
Yes, because of other health reasons... 2  Please write in no. times 40-42
No ......................................................... 3

f) Has your child been seen by a nurse at home?
Yes, because of their condition ............ 1  Please write in no. times 44-46
Yes, because of other health reasons... 2  Please write in no. times 47-49
g) **Has your child been seen by a doctor at home?**

Yes, because of their condition........... 1  Please write in no. times

Yes, because of other health reasons... 2  Please write in no. times

No ......................................................... 3

h) **Has your child visited an emergency doctor at an "out of hours" clinic?**

Yes, because of their condition........... 1  Please write in no. times

Yes, because of other health reasons... 2  Please write in no. times

No ......................................................... 3

i) **Has your child been to a hospital casualty (A&E) department?**

Yes, because of their condition........... 1  Please write in no. times

Yes, because of other health reasons... 2  Please write in no. times

No ......................................................... 3

j) **Has your child been seen by a doctor at a hospital clinic, hospital ward or outpatient department?**

Yes, because of their condition........... 1  Please write in no. times

Yes, because of other health reasons... 2  Please write in no. times

No ......................................................... 3

k) **Has your child been admitted to hospital as an in-patient or a day patient?**

Yes, because of their condition........... 1  Please write in no. times

Yes, because of other health reasons... 2  Please write in no. times

No .............................................................. 3

l) **Did your child make use of the emergency ambulance service at all?**

Yes, because of their condition........... 1  Please write in no. times

Yes, because of other health reasons... 2  Please write in no. times

No ......................................................... 3

m) **Has your child had some other contact with the NHS?**

Yes, because of their condition........... 1  Please write in no. times

Yes, because of other health reasons... 2  Please write in no. times

No ......................................................... 3
### Costs of your child’s condition

The next set of questions are about the costs of your child’s condition and of any treatment for their condition. Remember – by condition we mean any sore throats, complications of sore throats, and any side-effects of treatment.

38. **Over the last three months**, have you bought any medicines (for example Calpol, throat sweets, herbal remedies) for your child from a pharmacy or other shop? **Do not include prescription medicines like antibiotics as we are getting this information from your doctor.**

<table>
<thead>
<tr>
<th>Yes ............. 1</th>
<th>No ............. 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Go to Q39</strong></td>
</tr>
</tbody>
</table>

**If yes, a)** Please write down the name of each medication you bought for your child over the last three months, and how much you spent on it.

<table>
<thead>
<tr>
<th>Please give the name(s) of the medication <em>(Brand name if possible)</em></th>
<th>How much did you pay for it overall?</th>
<th>Did they take this medication for their condition? <em>(please tick if yes)</em></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>p</td>
</tr>
<tr>
<td>10-16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17-23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24-30</td>
<td></td>
<td></td>
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<tr>
<td>31-37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38-44</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
39. Over the last three months, has your child missed any days at school because of his/her condition?

<table>
<thead>
<tr>
<th>Option</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes........................................1</td>
<td></td>
</tr>
<tr>
<td>No...........................................2</td>
<td></td>
</tr>
<tr>
<td>Does not apply – my child is not yet at school.................3</td>
<td>45</td>
</tr>
</tbody>
</table>

If yes, a) How many days of school has your child missed in the last three months because of their condition?

<table>
<thead>
<tr>
<th>Number of days missed (please write in)</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>46-47</td>
</tr>
</tbody>
</table>

40. Over the last three months, do you think your child’s condition has affected his/her progress at school?

<table>
<thead>
<tr>
<th>Option</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, progress has been affected...............1</td>
<td></td>
</tr>
<tr>
<td>No, progress has not been affected...............2</td>
<td></td>
</tr>
<tr>
<td>Not sure.....................................3</td>
<td></td>
</tr>
</tbody>
</table>

41. Over the last three months, has your child had any private tuition/coaching because his/her progress at school has been affected due to their condition?

<table>
<thead>
<tr>
<th>Option</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes........................................1</td>
<td></td>
</tr>
<tr>
<td>No...........................................2</td>
<td></td>
</tr>
</tbody>
</table>

If yes, a) How much did you pay for this?

<table>
<thead>
<tr>
<th>£</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>p</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50-55</td>
</tr>
</tbody>
</table>
42. **Over the last three months**, did you have any other extra expenses **because of your child’s condition**?

Yes .............. 1

No .............. 2

**Answer a)**

**Go to Q43**

If yes, a) Please tell us the reason and how much you have spent on each item:

**Item 1:**
- Reason for expense
- Amount spent overall £ --- • --- p

**Item 2:**
- Reason for expense
- Amount spent overall £ --- • --- p

**Item 3:**
- Reason for expense
- Amount spent overall £ --- • --- p

**Item 4:**
- Reason for expense
- Amount spent overall £ --- • --- p
Your child and your work

The next set of questions are about the impact of your child's **condition and treatment** on your employment. **Remember** – by condition we mean any sore throats, complications of sore throats, and any side-effects of treatment.

43. Which of the following **best** describes your current position about paid work?

*Please ring one number only.*

- Full or part time .............. 1
- Retired .............. 2
- At home and not looking for paid employment .............. 3
  (eg looking after your home, family or other dependants)
- Unable to work due to illness or disability .............. 4
- Unemployed and looking for work .............. 5
- In full time education .............. 6
- Other (*please write in*) .............. 7

........................................................................

........................................................................
The next set of questions asks about you and your work. **If you are not working at present for any reason then please tell us about your last main job.**

44. **IF YOU ARE WORKING**, please answer a) to f) below about your present job.

**IF YOU ARE RETIRED OR ARE NOT WORKING AT PRESENT**, please answer a) to f) below about your last main job.

**IF YOU HAVE NEVER WORKED**, please tick this box and go to Q52.

a) How many hours do you/did you work? ____ hours per week

b) Please write in your job title:

c) What do/did you actually do?

d) What does the firm or organisation you work(ed) for make or do?

e) Are/were you?

   An employee .......... 1

   or self-employed .......... 2

f) Are/were you a manager, foreman or supervisor of any kind?

   Yes, manager .......... 1

   Yes, supervisor .......... 2

   No, neither .......... 3

45. **Over the last three months**, have you been in paid employment/self employment at all?

   Yes .......... 1

   No .......... 2

   Answer Q46

   Go to Q49

46. **Over the last three months**, have you taken any time off work because of your child’s condition (eg to look after your child when they were ill or to go with them to the doctor or hospital)? **Do not include times when you took work home or made**
up the time later.

Yes ............. 1
No ............. 2

47. How many days or hours did you take altogether in that time?


 hours

48. Did you lose any earnings while off work to look after your child in that time?

Yes ............. 1
No ............. 2

If yes, a) Please write in the amount of earnings you lost: £  

23

24-27

28

29-34
49. **Over the last three months**, has your work **situation** been affected in any way by your child's condition (including changes due to an **improvement** in your child's condition)? *(please ring all that apply)*

   No, no effect on my work at all ............ 1
   I took some time off work to look after my child but **no other effect** ....... 2
   
   Yes, I have not been able to work at all .......... 3
   Yes, I stopped working and haven't started again .......... 4
   Yes, I was not working but I am now .......... 5
   Yes, I changed the type of job or tasks I do .......... 6
   Yes, I changed my place of work .......... 7
   Yes, I changed the number of hours I work .......... 8
   Yes, I retired early from work .......... 9
   Other *(please write in what)* .......... 0
   ..........................................................
50. **Over the last three months**, has there been any change in your earnings from paid or self employment because of your child’s condition?

- Yes, earnings have changed............ 1
- No, no change............ 2

If your earnings have changed,

  a) What were your earnings before the change? *(please give the amount before tax)*

  ![Currency and period] Was that per … *(please circle the one that applies)*

  - week
  - month
  - year

  and

  b) What are your earnings now? *(please give the amount before tax)*

  ![Currency and period] Is that per … *(please circle the one that applies)*

  and

  c) Was the change in your earnings due to:

  - A change in the number of hours you work............ 1
  - An increase in your wage............ 2
  - A decrease in your wage............ 3
  - Loss of a job............ 4

If hours changed,

  a) How many hours per week were you working **before the change**?  

  ![Hours] hours

  How many hours per week do you work **now**?  

  ![Hours] hours

51. **Over the last three months**, have you been unemployed at any time because of your child’s condition? *Please include all times when you were not working even if you were not eligible for unemployment benefits.*

- Yes............ 1
- No............ 2

If yes, a) Altogether, how many days were you unemployed in that time?  

![Days] days

and  

b) What were your earnings before you lost or gave up work?

*Parent’s Under 8_v3 (1 Nov 2004)*
£[ ] [ ] [ ] ● [ ]

Was that per … (please circle the one that applies)

week 1
month 2
year 3

70-77
52. Are you:

- Married or living with a partner .......... 1
- Divorced or separated .......... 2
- Widowed .......... 3
- Single .......... 4

The next set of questions are about the impact of your child's condition and treatment on your spouse or partner and their employment. (Remember – by condition we mean any sore throats, complications of sore throats, and any side-effects of treatment).

53. Which of the following best describes your spouse or partner's current position about paid work? Please ring one number only.

- Full or part time .......... 1
- Retired .......... 2
- At home and not looking for paid employment .......... 3
  (eg looking after your home, family or other dependants)
- Unable to work due to illness or disability .......... 4
- Unemployed and looking for work .......... 5
- In full time education .......... 6
- Other (please write in) .......... 7
- ........................................................

Answer Q53

Go to Q62
The next set of questions asks about your spouse or partner and their work. If they are not working at present for any reason then please tell us about their last main job.

54. **IF YOUR SPOUSE OR PARTNER IS WORKING**, please answer a) to f) below about their present job.

**IF YOUR SPOUSE OR PARTNER IS RETIRED OR NOT WORKING AT PRESENT**, please answer a) to f) below about their last main job.

**IF YOUR SPOUSE OR PARTNER HAS NEVER WORKED**, please tick this box and go to Q62.

a) How many hours does/did your partner work? __________ hours per week

b) Please write in your spouse or partner’s job title:

c) What do/did they actually do?

d) What does the firm or organisation they work(ed) for make or do?

e) Are/were they?

   - An employee .............. 1
   - self-employed .............. 2

f) Are/were they a manager, foreman or supervisor of any kind?

   - Yes, manager .............. 1
   - Yes, supervisor .............. 2
   - No, neither .............. 3

55. **Over the last three months**, has your spouse or partner been in paid employment/self employment at all?

   - Yes .............. 1
   - No .............. 2

   Answer Q56
   Go to Q59

56. **Over the last three months**, has your spouse or partner taken any time off work because of your child’s condition (eg to look after your child when they were ill or...
to go with your child to the doctor or hospital? Do not include times when they took work home or made up the time later.

Yes ............. 1
No ............. 2

| Answer Q57 | Go to Q59 |

57. How many days or hours did your spouse or partner take altogether in that time?

☐ days or ☐ hours

25-28

58. Did your spouse or partner lose any earnings while off work to look after your child in that time?

Yes ............. 1
No ............. 2

| Answer a) | Go to Q59 |

If yes, a) Please write in the amount of earnings they lost: £

☐ ☐ ☐ ☐ • p

30-35
59. **Over the last three months**, has your **spouse or partner’s work situation** been affected in any way **by your child’s condition** (including changes due to an **improvement** in your child’s condition)? *(please ring all that apply)*

<table>
<thead>
<tr>
<th>No, no effect on their work at all</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>They took some time off work but no other effect</td>
<td>2</td>
</tr>
</tbody>
</table>

Yes, they have not been able to work at all over the last 3 months

| Yes, they stopped working and haven't started again | 4 |
|Yes, they were not working but they are now | 5 |
|Yes, they changed the type of job or tasks they do | 6 |
|Yes, they changed their place of work | 7 |
|Yes, they changed the number of hours they work | 8 |
|Yes, they retired early from work | 9 |
|Other *(please write in what)* | 0 |

..........................................................................................................................

Go to Q62

Go to Q60
60. **Over the last three months**, has there been any change in your spouse or partner's earnings from paid or self employment because of your child's condition?

Yes, earnings have changed ........... 1
No, no change ........... 2

**If your spouse or partner's earnings have changed,**

a) What were their earnings before the change? *(please give the amount before tax)*

| £ | p |  |

Was that per ... *(please circle the one that applies)*

1 week 2 month 3 year

and b) What are their earnings now? *(please give the amount before tax)*

| £ | p |  |

Is that per ... *(please circle the one that applies)*

1 week 2 month 3 year

and c) Was the change in your spouse or partner's earnings due to:

A change in the number of hours they work ........... 1
An increase in their wage ........... 2
A decrease in their wage ........... 3
Loss of a job ........... 4

If hours changed,

a) How many hours per week were they working **before the change**?  

B

How many hours per week do they work now?  

B

---

*Parent's Under 8_v3 (1 Nov 2004)*
61. **Over the last three months,** has your spouse or partner been unemployed at any time **because of your child’s condition?** Please include all times when they were not working **even if they were not eligible for unemployment benefits.**

    Yes ............. 1
    No ............. 2

**Answer a) and b)**

If yes, a) Altogether, how many days were they unemployed in that time?

    [ ] days

and b) What were their earnings before they lost or gave up work?

    [ ] £

Was that per … *(please circle the one that applies)*

    week 1
    month 2
    year 3

62. **Over the last three months,** has anybody else other than you and your spouse or partner looked after your child **because of his/her condition?**

    Yes ............. 1
    No ............. 2

**Answer Q63**

**Go to Q64**
63. Can you please tell us about the people who looked after your child? *Please provide as much information as you can in the box below.*

If you paid anything for that help, please tell us how much you paid **altogether** over the last three months.

<table>
<thead>
<tr>
<th>Who looked after your child?</th>
<th>Please tick all that apply.</th>
<th>How long did they look after your child <strong>altogether</strong> over the last three months? (Days or Hours)</th>
<th>If you paid anything for that help, please tell us how much you paid <strong>altogether</strong> over the last three months.</th>
</tr>
</thead>
<tbody>
<tr>
<td>A grandparent</td>
<td></td>
<td></td>
<td>9-17</td>
</tr>
<tr>
<td>Another relative</td>
<td></td>
<td></td>
<td>18-26</td>
</tr>
<tr>
<td>A friend</td>
<td></td>
<td></td>
<td>27-35</td>
</tr>
<tr>
<td>A child minder</td>
<td></td>
<td></td>
<td>36-44</td>
</tr>
<tr>
<td>A nanny</td>
<td></td>
<td></td>
<td>45-53</td>
</tr>
<tr>
<td>Other (please write in who)</td>
<td></td>
<td></td>
<td>54-62</td>
</tr>
</tbody>
</table>
About you and your child

64. What is your relationship to your child? Are you:
   - His/her mother .............. 1
   - His/her father .............. 2
   - His/her step-mother .......... 3
   - His/her step-father .......... 4
   - Other: (please write in relationship) .............. 5

65. What is his/her date of birth? (please write the date in the boxes provided)

66. What is your date of birth?

67. When did you answer these questions? (please write the date in the boxes provided)
68. If there is anything else you would like to tell us about your child’s condition and any related costs you have had to meet, or this questionnaire, please write it in the space below.

Thank you for taking the time to fill in the questionnaire. We are very grateful for your help.

Please return the questionnaire in the envelope provided. No stamps are needed.

If you have any questions about the questionnaire, or about the NESSTAC study in general, please contact Mary Dickinson at:

Centre for Health Services Research
21 Claremont Place
Newcastle upon Tyne
NE2 4AA

℡ 0191 222 8709
Childhood tonsillectomy: who is referred and what treatment choices are made? Baseline findings from the North of England and Scotland Study of Tonsillectomy and Adenotonsillectomy in Children (NESSTAC)

Catherine A Lock, Janet Wilson, Nick Steen, Martin Eccles, Katie Brittain, Sean Carrie, Ray Clarke, Haytham Kubba, Chris Raine, Andrew Zarod and John Bond

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