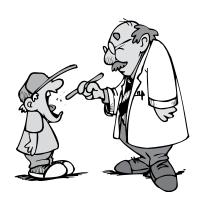# NESSTAC

North of **E**ngland and **S**cotland **S**tudy of **T**onsillectomy and **A**deno-tonsillectomy in **C**hildren

The Tonsil Study

Parent/Guardian's Interview Handbook

INTRODUCE SELF

Thank you for agreeing to be interviewed

INTRODUCTION

- This research is a project to find out more about tonsils and sore throat in children

- We want to find out people's opinions of the quality of life associated with tonsillitis and sore throat

- In this interview I will ask for your opinions about children's quality of life associated with tonsillitis and sore throat. There are no right or wrong answers. We are interested in your opinion

- Your answers will be treated in the strictest confidence. They will not be made available to anyone not involved in the project. Your name and address do not appear on the forms used during the interview

- Throughout the interview we will be talking about serious problems associated with illness and treatment including death. Sometimes, people are upset reading and talking about illness. However I would like to take this opportunity to reassure you that this is only being done to find out your attitudes to risk. Death is NOT an expected outcome of your child's treatment. We have to include it in this exercise as it helps us to understand how much you value the health descriptions we are going to give you that's all. If you find that you feel uncomfortable answering any of our questions, please don't feel that you have to go on with the interview. We can talk about it, and stop, if you want to

- Throughout the interview I will use a set form of wording, although it may seem repetitive and impersonal it will make the interview easier for both of us. Please give comments as we go along and there will be time at the end of the interview if you have any final comments on the whole exercise.

RANKING PROCEDURE - PART I

- Before we go on I would like you to read these two cards, each of which describe the possible effects tonsils and sore throat can have on a child's life

- Each of these two imaginary descriptions show different kinds of experiences that a child with tonsils and sore throat may have

➡ *Show person cards*

- Please read these two descriptions, taking your time, and tell me when you've finished. You don't need to memorise the details

➡ *Give person time to consider descriptions*

- Is there anything about the descriptions that is not clear?

➡ *If 'yes', give brief explanation making sure information is understood*

- I would also like you to read the description of Good Health

➡ *Give person time to consider description*

I want you to imagine how a child like yours would feel in the two descriptions as described on the green cards. Imagine how their relationships with family and friends, how their home, school and social life could be affected and how they would feel having the different symptoms. The symptoms described on these cards would last until your child reaches 18. After this time try to imagine that the child would return to full health. I would like you to choose which description you think is best – what you would choose for your child if you were faced with these 2 options.

- In a moment I am going to ask you to make some choices between 2 treatment options where the outcomes of the treatments will be the same as the symptoms on the cards you have just looked at.

- One choice will involve a risk and the other choice will be definite. The amount of risk will be changed until we find out how much risk you will take to avoid the definite choice. This may seem complicated but once we have gone through it, it will make a lot more sense

- As before there are no right or wrong answers, only what you think

- To make this easier to understand we are going to use a chance board

- It's called a chance board because it indicates the chance or how likely it is that a certain event will happen. As you can see the top part of the board is labelled Choice A

- and the lower part of the board is labelled Choice B

- You will be asked to pick Choice A or Choice B.

- Now the best way to explain how a chance board works is to work through an example together. Let's imagine you were in an accident and hurt your leg. When you see the doctor, she explains that you have two choices. Here are the descriptions for this example

➔ *Place example cards in chance board pockets*

- Choice A is an operation and Choice B is to let your leg heal by itself. If you were to let your leg heal by itself, choice B, you would definitely have a limp. You would be able to walk, but you would **not** be able to run. Everyone who lets their leg heal by itself will have these health outcomes. If something is definite it is a 100%. On the other hand, you can choose the operation. The operation, choice A, is risky. It doesn't always work. If the operation **did** work, your leg would be fixed and you would walk and run normally. If the operation **didn't** work, you'd have to use crutches

➔ *Point to the pink section of circle*

- The chance of walking and running normally after the operation is shown by the pink amount of circle you can see. 90% of the circle is pink so the chances are that the treatment would work, and you would be able to walk and run after the operation

➔ *Point to the blue section of circle*

- The chance of having to use crutches after the operation is shown by the amount of blue colour you can see. 10% of the circle is blue so it is not very likely that you would have to use crutches, but there is still a chance

- Here, the chances of walking and running normally are 90% with a 10% chance of having to use crutches. Another way to think of it is that, on average, for

every 100 people who choose A, the operation, 90 will walk and run normally afterwards but 10 will have to use crutches to get around after the operation

➜ *Change spinner and board to 50/50*

- Now I've changed the chances.

- The chance that the operation will go well is the same as the chance that the operation won't go well. There is an **equal** amount of pink and blue showing on the circle. So now if I were to ask you if you would choose A or B, your answer might be different because there is a bigger chance that the operation would leave you having to use crutches. Do you think you understand how the chance board works?

➜ *If 'yes', continue below. If 'no', return to beginning of chance section and repeat the exercise.*

Before we continue I just want to remind you of the two cards that you ranked before.

➜ *hand green cards to respondent and give them time to re-read.*

We'll work through the first question together. Imagine that there are two types of treatment; treatment A and treatment B. With treatment A the outcome of the treatment is uncertain, you could either return to good health if it works or you could have the symptoms which are shown on the blue card if it doesn't. On the other hand you could opt for treatment B where you are certain of what will happen and you will definitely have the symptoms which are displayed on the green card – in this first question this is the health state that you said was best.

- ➜ *Hand respondent "ranked 1" card*

- Please can you read over the description and when you are finished I'll put it next to the board

➜ *Place "…" card next to board when respondent is finished*
➜ *Be sure wheel is set to 100/0*

STEP 1

- Now we are ready to begin. As you can see choice A is now a 100% chance of good health and a zero chance of the worst health state (HEALTH STATE XXXX). Choice B is 100% chance of the health described on the card you have just finished reading. If I was to ask you to choose between Choice A and Choice B, Which would you choose? This is a pretty unrealistic situation to start with as its unlikely that there would be 2 treatments both of which would offer you a 100% chance of the outcomes presented here but it helps us to get into the exercise.

➜ *A - Go to step 2*

➜ *B - Circle response (?), Ask "why…" and record response verbatim*

STEP 2

Move wheel to 10/90

- Now I've changed Choice A to show there is a 10% chance of good health and a 90% chance of HEALTH STATE XXXX. Choice B is still a 100% chance of the health described on the card. Would you pick treatment A or B now?

➜ *B – Go to step 3*

➜ *A?? - Prompt "Do you mean that you would prefer your child to have a 90% chance of being in the health state you ranked worst and a 10% chance of good health rather than living in the state of health described on the cards in choice B"*

➜ *No - Repeat choices shown on board*

➜ *Yes - ask "If choice A was certain death with no chance of good health, do you think this would be better than living as choice B or worse than living as choice B?"*

➜ *Better - Mark response (negative)*

➜ *Equal - mark response (0.00)*

➜ *Worse - Mark response (0.05)*

➜ *State "Thank you that ends this question"*

STEP 3

Move wheel to 90/10

- The board now shows choice A to be a 90% chance of good health with a 10% chance of HEALTH STATE XXXX and Choice B remains the same as before Which treatment would you prefer now, A or B?

➜ *A – Go to step 4*

➜ *B -Ask what if the odds were changed to 95% good health with a 5% chance of health state XXX. (if accept, mark response 0.975) If still prefer choice B ask what they would choose if the odds were 99% good health and 1% health state XXX (if accept mark response 0.99. if still prefer choice B, mark response as 1. Finish by saying "Thank you that ends this question*

Move wheel to 20/80,

- Now I've changed choice A to a 20% chance of good health with an 80% chance of HEALTH STATE XXXX Choice B is still a 100% chance of the health state described. Which treatment would you prefer, A or B?

➔ *B -Go to step 5*

➔ *A - Mark response (0.15) and state "Thank you that ends this question"*

Move wheel to 80/20

- Choice A is now an 80% chance of good health with a 20% chance of the worse health state HEALTH STATE XXXX. Choice B is still the same as before. Would you prefer treatment A or B?

➔ *A - Go to step 6*

➔ *B - Mark response (0.85) and state "Thank you that ends this question"*

Move wheel to 30/70

- The choices have now been changed so that Choice A has a 30% chance of good health but a 70% chance of the worse health state HEALTH STATE XXXX. Choice B is still the same. Which treatment would you prefer now?

➔ *B – Go to step 7*

➔ *A - Mark response (0.25) and state "Thank you that ends this question"*

STEP 7

Move wheel to 70/30

- Now I've changed Choice A to a 70% chance of good health and a 30% chance of HEALTH STATE XXXX. As before Choice B remains the same. Which treatment would you prefer now?

➔ *A – Go to step 8*

➔ *B - Mark response (0.75) and state "Thank you that ends this question"*

STEP 8

Move wheel to 40/60

- Choice A has now been adjusted to indicate a 40% chance of perfect health and a 60% chance of the worse health state HEALTH STATE XXXX. Would you prefer treatment A or B?

➔ *B – Go to step 9*

➔ *A- Mark response (0.35) and state "Thank you that ends this question".*

STEP 9

Move wheel to 60/40

- If Choice A had a 60% chance of good health and a 40% chance of HEALTH STATE XXXX as shown on the board would you pick A or B?

➔ *A – Go to step 10*

➔ *B - Mark response (0.65) and state "Thank you that ends this question"*

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STEP 10

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Move wheel to 50/50

- Now I have changed Choice A to a 50% chance of good health and a 50% chance of HEALTH STATE XXXX. Choice B remains the same. Which choice would you prefer now?

➔ *A-Mark response (0.45)*

➔ *B- Mark response (0.55)*

- Thank you, that ends this question

We are now going to run through this exercise again but this time we are going to change the health states that you will have to make choices between. One of the health states that will be included this time is death. I would just like to say again that death is not an expected outcome of your child's treatment. We have to use it in this exercise as it helps us to understand how much you value the different health states that you see.

➔ *Go back to step 1 and repeat exercise using good health and death in choice A and the worst ranked health state in choice B.*

➔ *At the end of the SG exercise for all respondents who ranked health state Z above health state X complete WTP question in response booklet.*