**Report Supplementary Materials 13**

**Public preferences for travelling for treatment and follow-up**

## Introduction

One consequence for patients of a move to a more centralised provision of vascular services is the need for significant numbers of them to travel for treatment and follow-up appointments to a hospital that is not their local hospital. For many patients, having to travel to a specialist hospital is likely to be regarded as an inconvenience, and as such represents a source of disutility.

In considering the relative efficiency of alternative options for vascular services reorganisation, the disutility of travel should ideally be included, along with improvements in health, on the benefits side of an economic evaluation. However, for it to be explicitly incorporated into the cost-effectiveness models presented in this report, in which outcome is expressed in terms of quality adjusted life years (QALYs), the disutility of travelling would also need to be expressed in terms of QALYs. The aim of this research, therefore, was to develop a method for eliciting preferences for travelling such that the preferences could be valued in terms of QALYs and thus included in the models.

## Methods

The method involved surveying members of the UK population, through individual telephone interviews, to elicit their preferences for having to travel for treatment and follow-up for three types of vascular disease, namely abdominal aortic aneurysm (AAA) repair, carotid artery disease (CAD), and peripheral arterial disease (PAD).

The theoretical basis for the method is that which underlies cost-benefit analysis (CBA), in which changes in utility resulting from a proposed change in the state of the world from S0 (e.g. the current provision of a vascular service) to S1, (e.g. a proposed change to the provision of a vascular service) are measured. Any policy change will almost always result in some people gaining (i.e. their utility increases) and some people losing (i.e. their utility decreases). For example, consider an individual faced with the prospect of a policy which will move them from state of the world S0 where their utility is U0 to state of the world S1 where their utility is U1. If they are a gainer U1 > U0, whereas if they are a loser U1 < U0. The magnitude of any gain or loss is simply U1 – U0.

In a CBA, these changes in utility are measured by asking potential gainers to state their maximum willingness to pay (WTP) for the change and/or potential losers to state their minimum willingness to accept (WTA) compensation for the change. For convenience, the numeraire in CBA is money, but in principle an alternative numeraire could be used.

The potential policy change we are considering here is a move from the current provision of vascular services (S0) to a more centralised provision (S1). From our qualitative work with patients across the range of vascular conditions being considered in the programme, having to travel for treatment and/or follow-up was identified as being the factor that most concerned people about a move to S1. Having to travel is perceived to have a negative impact on utility so that, ceteris paribus, we expect U0 > U1.

In order to measure the magnitude of the utility loss, we need to elicit from potential losers the minimum amount of compensation they would require to restore their utility to U0 from U1. Instead of eliciting this in terms of a monetary equivalent (as would happen in a standard CBA), the method adopted here asks individuals to express their compensation demands in terms of the extra chance of treatment success at the specialist hospital (compared to their local hospital) they would require to compensate them for having to travel (i.e. to return their utility to U0 from U1).

The method by which probabilities of treatment success can be transformed into a QALY equivalent will be presented after we have described how the telephone interviews were organised and conducted.

### Participants

Participants were 18 years of age or over, citizens of the United Kingdom and had no previous diagnosis of a vascular condition (self-assessed). The justification for sampling members of the public rather than patients lies in the context of how the values are likely to be used, namely to inform national health care priority setting. In this context, NICE states a preference for QALYs to be based upon general population values.1 The total target sample size was 200, which is based on previous applications of similar techniques among members of the general public2-4.

### Recruitment and consent

Participants were recruited via 10 NHS trusts across the UK. Research nurses approached potential participants who were waiting in hospital clinics to ask if they would agree to volunteer for a 30-minute telephone interview. When recruiters were approaching potential participants’ efforts were made to ensure the sample was representative of the general population with regard to age and gender. Contact details of these potential participants, were securely transferred to the research team. Next, the research team contacted these participants (between September 2017 and January 2018) to arrange a date and time for telephone interviews. Following this, each participant was sent an interview booklet approximately one week before interviews took place. Participants were advised to read the interview booklet prior to the interviews to familiarise themselves with information enclosed. Verbal consent was obtained over the phone prior to commencing the interview and recorded. The use of verbal consent was accepted and approved by the South East Coast - Brighton & Sussex Research Ethics Committee.

**Interview process**

The interview schedules for AAA, CAD and PAD followed the same structure, with any differences being due to the characteristics of the particular condition being considered. For AAA, we elicited separate values for EVAR and open treatment.

For ease of exposition, we will describe the process for CAD (the process is essentially the same for all other options). Following some introductory information giving the background to the study, the respondent was taken through a simple diagram explaining the concepts of chance and probability (see Figure 1). An interview booklet which had been sent to respondents beforehand was used to illustrate the concepts using pictures. Once the respondent indicated they understood and were happy to proceed, the main interview began.

Respondents were first taken through a description of a typical CAD health state (A) and asked to imagine they were experiencing the symptoms. A treatment for CAD was then presented and respondents were asked to consider two further health states – a ‘good’ health state (B) into which they would move following successful treatment (in this case, full health) and a ‘bad’ health state (C) into which they would move if the treatment was unsuccessful (in this case, having experienced a non-fatal stroke). Descriptions of all the health states and treatments presented to respondents were in the interview booklet and are reproduced for all three disease areas in Appendix 21 to 23.

Next, respondents were told that treatment is available at their local hospital where the chance of a successful outcome was 95 in 100. They were then were asked to consider a situation where treatment for CAD would no longer be available at the local hospital and that they would have to travel to a specialist hospital which is X miles further away than their local hospital. X could take the value of 5, 15, 30 or 60 miles, with these distances allocated evenly across the sample. We then elicited from them what the minimum chance of success would need to be at the specialist hospital to just compensate them for the inconvenience of travelling. This was done by presenting respondents with different probabilities of success in a ‘ping pong’ fashion until the lowest chance of success was arrived at. At the end of the interview, respondents were asked a number of socio-demographic questions.

### Valuing outcomes in terms of QALYs

There were three possible responses to the question asking respondents to state how much compensation they required to travel to a specialist hospital:

1. The individual does not require compensation to travel, i.e. the respondent is willing to travel to the specialist hospital even if the probability of a successful outcome is that same as that at the local hospital. We interpret this as there being no disutility from travelling for the respondent. They might prefer not to travel, but their strength of preference for travelling is not sufficiently strong for them to demand compensation for having to do so. Therefore, for these people the value of the disutility from travelling is zero.
2. The individual requires compensation to travel. The amount of compensation is determined by the extra chance of a successful outcome at the specialist hospital they demand to compensate them for travelling. How this is converted to a QALY equivalent is described below.
3. The individual is not willing to travel no matter high the compensation that is offered to them, i.e. even if the chance of a successful outcome at the specialist hospital is 100%, this is not sufficient to compensate them for having to travel. Even though we do not know their true preference, in order to include these respondents in the analysis we have assumed they would be willing to travel if the procedure was guaranteed to be successful. This represents a minimum value of the disutility of them from having to travel. Responses such as these represent a limitation of the study design and will be discussed in more depth in the discussion section below.

In order to quantify the process disutility of travelling for those demanding compensation we need estimates of the typical QALY profiles following successful and unsuccessful treatment. Specifically, we need estimates of the expected discounted lifetime QALYs following successful and unsuccessful treatment.

Continuing with the CAD example from above, suppose the expected discounted lifetime QALYS following successful and unsuccessful treatment are 10.5 and 6.1 QALYs, respectively. Suppose further that an individual requires the probability of a successful outcome at the specialist hospital to be 97 in 100 (compared to 95 in 100 at the local hospital) to compensate them for the inconvenience of travelling X miles. We can then calculate the expected lifetime QALYs at both the local and specialists hospitals as follows:

Expected lifetime QALYs at local hospital = EQL = (0.95 x 10.5) + (0.05 x 6.1) = 10.28 QALYs

Expected lifetime QALYs at specialist hospital = EQS = (0.97 x 10.5) + (0.03 x 6.1) = 10.368 QALYs

The compensation demanded for travelling is simply the difference between the two amounts.

Extra expected lifetime QALYs demanded = EQS – EQL = 10.368 – 10.28 = 0.088 QALYs

Thus, for this individual, if vascular services are reorganised so that they must travel X miles for treatment and follow up, they suffer a disutility equivalent to 0.088 expected lifetime QALYs which must be netted off from any gain in expected QALYs which are expected to arise from treating CAD at a specialist rather than a local hospital.

### Analysis

Descriptive statistics for public preferences and sociodemographic characteristics were calculated using frequencies and percentages for categorical variables and means, medians, interquartile ranges for continuous variables. Group differences were explored using hypotheses tests including the t test, Mann-Whitney U test, and Chi-Square test where appropriate. Reasons for preferring EVAR or Open surgery were coded into themes using NViVO version 12 software. All quantitative analyses were undertaken using SPSS version 24.

### Public Involvement

In designing study materials, the research team were cognisant of participants’ likely unfamiliarity with vascular conditions and treatment options. They were also aware that participants needed to fully understand what was being asked of them and that risk (chance of success) in particular needed to be presented in a way that was understandable. The interview booklet, containing health states and treatment descriptions, was developed by the research team with extensive input from patients and clinicians familiar with the conditions and treatments concerned. Study materials were extensively tested with five members of the Sheffield Teaching hospitals NHS Foundation Trust Online Public Advisory Panel. Ten pilot telephone interviews along with several peer review exercises were also carried out. The overall aim was to test the language, structure and comprehension of the study materials in order to gather feedback and refine the survey. The feedback obtained included suggestions on the wording, design of study materials, and the need to present risk (percentages) in an understandable way. All of the feedback was incorporated into the final version of the study materials. In particular, while presenting risk a simple diagram to explain what was meant by chance of success was designed, this was included in the interview booklet and used as a guide to decision making during the telephone interview (See Figure 1).

## Results

A total of 608 participants completed three telephone questionnaires, giving a response rate of 64.4%. Two additional participants were interviewed but they were classified as “protesters” and were subsequently excluded from the study because they chose not to engage in the preference elicitation questions. Among the 608 participants missing, data were low and did not exceed 5%. To ensure quality, the interviewers checked whether the participants understood the concept of risk involved in undergoing surgery for vascular treatment. A simple diagram explaining risk was presented to the participants, and when asked to interpret it, the vast majority of participants stated that they fully understood the concept of chance of treatment success or failure. Only two participants asked for further clarification. Interviews took between five and 45 minutes to complete.

### Characteristics of study population

Of the 608 participants who completed the three different questionnaires on AAA, CAD and PAD, approximately two thirds were female (Table 1). The average age of the three samples was between 56 - 58 years, with an age range between 20 to 91 years. Just over half of the participants were in paid employment or self-employed. Approximately 33% were retired, with the remaining interviewees being categorised as unemployed, students or doing housework. The majority of participant were married or living with their partners (~70%), with the remaining participants being widowed, divorced or single. The average household size of the three samples was similar (~ 2.5), with a range from one to seven. Approximately two thirds of the sample had either a college or a university level qualification.

The average distance that the participants travelled to their local hospital was approximately seven miles. The shortest and longest distances travelled were 0.2 miles and 35 miles, respectively. The mode of transport for the majority of those interviewed was their own private car (>70 %). The next most popular mode of travel was walking, followed by bus. The range of journey time from respondents’ homes to hospital was between 2 and 75 minutes.

**Willingness to travel**

The proportions of people willing to travel for AAA (open), AAA (EVAR), CAD and PAD were 89%, 86.5%, 79.7% and 96.1%, respectively. Of these, 56.2%, 55.5%, 64.0% and 66.2% stated they required compensation to travel for AAA (open), AAA (EVAR), CAD and PAD, respectively (Table 2).

The most oft cited reasons for not requiring compensation for travelling was a belief that patients would get better quality treatment at the specialist hospital and a greater confidence that the treatment at a specialist centre would be successful. Other reasons included a general perception that the specialist centre would have better equipment and facilities, the surgeons would be of a higher calibre, the staff would generally be better trained and better qualified in the vascular speciality. Some of the respondents thought that they would get their treatment more quickly if they were willing to travel to a specialist centre rather than waiting for the local hospital to treat them.

A number of respondents felt they travelled quite a distance to their “local” hospital and therefore they did not perceive travelling extra mileage as a major problem and were quite happy to receive treatment further afield. Many of those presented with the 5 mile option, and to some extent the 15 mile option, said that the regarded the distance as being insignificant and so would be willing to travel.

A small number of participants did not have any strong feelings about where their treatment was performed. They were just as happy to travel for treatment as to have their treatment in a local hospital, and would be happy to go to wherever the treatment was available.

Among the respondents who were not willing to travel, the main reason cited for not being willing to do sol was a preference for local services and/or a belief that all services should be available locally. Other reasons stated were transport difficulties with making the journey, not wanting to burden family and friends, and a concern among participants that they would feel isolated without having family and friends around them if there was no local provision.

A number of respondents expressed concerns that they would not be able to manage the journey using public transport, while others cited the expense of travelling further as the main reason they would not be able to do so.

A small number of people said that they had caring responsibilities, which would make it difficult for them to be treated a long way from home, while others simply did not want to travel for their treatment under any circumstances.

**The disutility of travelling**

Table 3 shows the mean and median probabilities of success at the specialist hospital which were demanded as compensation for having to travel. These results pertain to the whole sample, with those who were not willing to travel being assigned the maximum value they could have stated, namely 100%. While the amount of compensation required to travel by this group is unknown, in order to include them in the analysis, they have been assigned the maximum value. This means that the value of the disutility of travelling reported below for the sample as a whole should be regarded as a minimum value (this issue is discussed further in the Discussion below).

Table 4 shows the mean disutilities of travelling in terms of extra expected lifetime QALYs demanded. As above, these results pertain to the whole sample. Looking at some general comparisons, it can be seen that there is little difference disutility across the groups with respect to travelling 5 miles. Travelling 15 miles sees a proportionately large increase in disutility for AAA and PAD, but not for CAD where there is effectively no change. For AAA (open), the addition to disutility of travelling 30 and 60 miles is relatively modest compared to travelling 15 miles. The disutility of travelling 30 and 60 miles for AAA (EVAR) is bigger than that for AAA (open) which may reflect the extra burden of having to travel for annual follow-up appointments with EVAR compared to one appointment with open. There is a relatively large increase in disutility between travelling 5 miles and 15 miles for PAD (from 0.0928 to 0.6462) PAD. With the exception of the 5 mile category, the disutility of PAD is highest across the clinical areas. In contrast, CAD is associated with the lowest disutility.

As outlined in the Methods section above, the figures presented in Table 4 were derived from applying estimated expected lifetime QALYs associated with the good and bad outcomes from treatment to the probabilities of success demanded by respondents. For AAA and PAD, the QALY profiles were derived from Hospital Episode Statistics (HES) data. For CAD, we were unable to identify a severe disabling stroke reliably within the HES data, and as such the QALY profiles were based on those reported in a previously published study.5

**Discussion**

**Principal findings**

This study conducted telephone interviews with 608 members of the general public to elicit their preferences for the disutility of having to travel for treatment and follow-up for three types of vascular disease, namely abdominal aortic aneurysm (AAA) repair (with separate values being elicited for EVAR and open repair), carotid artery disease (CAD), and peripheral arterial disease (PAD). The disutilities were valued in terms of extra expected lifetime QALYs demanded as compensation for travelling. The amount of compensation demanded ranged from 0.0795 QALYs for travelling 5 miles for treatment and follow-up with EVAR to 0.7916 QALYs for travelling 60 miles for treatment and follow up for CAD.

### Strengths and limitations of the study

The main strength of this study is that the disutility of travelling for treatment and follow-up has not only been quantified, but it has been valued in terms of expected lifetime QALYs. This means that the value attached to the disutility can be readily and explicitly incorporated into the cost-effectiveness models described elsewhere in this report.

Arguably, the biggest limitation to this study is the sample. The team deliberately chose to interview members of the public rather than patients in order to adhere to NICE’s preference for values upon which QALYs are based to be those of the general population.1 However, surveying members of the public presents a number of challenges and potential limitations. Chief among these is that the approach relies upon participants being able to digest and understand the information presented to them and to go on and imagine themselves in a scenario where they are experiencing ill health and are faced with a choice between treatments. This is no easy task, and every effort was made to help the participants with their understanding and engagement with the exercise. Despite this, several participants remarked that they found it very difficult to imagine how they would react if they were faced with the kind of choices presented to them in a real-life situation. Furthermore, the sample was not representative of the UK population, and as such the generalisability of these results may be limited. For example, AAAs are a condition which predominantly affect men, yet around two thirds of this sample were female. Despite attempts to address this by asking the trusts to recruit more males, the gender imbalance persisted as more women than men agreed to be interviewed. Nevertheless, several studies have reported an increase in ruptured AAA in women6-8, and as such, the findings may be applicable to this subgroup.

Another limitation is the use of changes in risk to value people’s strength of preference. Risk is a difficult concept for people to understand, yet the validity of these results rely upon people being able to comprehend risk and probability. To mitigate this, a carefully constructed exercise was designed in which people were introduced to the concept of risk and how it would be used in the interview. The team explicitly asked if people felt comfortable with the concept before proceeding with the interview, but nevertheless it may have been the case that some members of the sample did not fully understand this concept, thus calling into question the validity of their responses.

Another limitation is the decision to only vary the probability of a successful outcome at the specialist hospital. This was done to for two reasons. Firstly, to minimise the cognitive burden on respondents from only having to consider variation in one risk, and secondly, to reflect the real-world situation where larger specialist hospitals are likely to have better success rates than smaller local hospitals. However, this introduced a limitation when eliciting values from respondents in that the amount of compensation they could demand was constrained to the range of success rates between the local and specialist hospital. For AAA and CAD, respondents were limited to expressing a value for success between 95% and 100%, while for PAD this range was between 55% and 100%. This constraint may be responsible for a proportion of respondents stating they were not willing to travel insofar as they may have been willing to travel had the compensation available to them been larger. One way in which we could have offered larger compensation would have been to ask those who were not willing to travel to consider reductions in the probability of success at the local hospital. The finding that the proportion of people who were not willing to travel was lowest in the PAD group, where the range of potential values was larger, suggests the constraint on responses was a problem.

## Conclusion

Our results valuing the burden of travelling for treatment and follow-up clearly indicate it is a potentially important component of disutility in our sample for each of the three clinical areas considered. As such, we would suggest there is a need take this disutility into account when considering the implications of any decision to reorganise vascular services to a more centralised provision. To that end, the impact on cost-effectiveness of including the values placed on the disutility of travelling has been investigated in the economic modelling (Chapter 6).

**Table 1**: Characteristics of the study population

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristic** | **AAA sample (N=200)** **No. (%)**  | **CAD sample (N=202)****No. (%)** | **PAD sample (N=206)****No. (%)** |
| *Sex* |  |
| Male  | 63 (31.5) | 75 (37.1) | 69 (33.5) |
| Female | 137 (68.5) | 127 (62.9) | 137 (66.5) |
| *Employment status* |  |
| In paid-employment | 116 (58) | 112 (55.4) | 109 (52.9) |
| Self-employed | 5 (2.5) | 15 (7.4) | 2 (1) |
| Unemployed | 4 (2) | 3 (1.5) | 6 (2.9) |
| Housework | 4 (2) | 3 (1.5) | 3 (1.5) |
| Retired | 66 (33) | 68 (33.7) | 83 (40.3) |
| Voluntary work | 3 (1.5) | - | - |
| Student | 2 (1) | 1 (0.5) | 1 (0.5) |
| Semi-retired | - | - | 2 (1) |
| *Marital status* |  |
| Married | 133 (66.5) | 137 (67.8) | 127 (61.7) |
| Living with partner | 21 (10.5) | 19 (9.4) | 19 (9.2) |
| Widowed | 8 (4) | 9 (4.5) | 16 (7.8) |
| Divorced | 14 (7) | 10 (5) | 14 (6.8) |
| Single/live alone | 24 (12) | 27 (13.4) | 29 (14.1) |
| *Education Level* |  |
| Primary | 2 (1) | 11 (5.4) | 4 (1.9) |
| O/level/GCSE | 53 (26.5) | 33 (16.3) | 53 (25.7) |
| A/level | 17 (8.5) | 18 (8.9) | 15 (7.3) |
| College/University | 128 (64) | 139 (68.8) | 133 (64.6) |
| *Travel mode- hospital* |  |
| In my own private car | 141 (70.5) | 152 (75.2) | 163 (79.1) |
| relative/friend’s car | 7 (3.5) | 9 (4.5)  | 9 (4.4) |
| Bus | 18 (9) | 15 (7.4) | 13 (6.3) |
| Taxi | 1 (.5) | 4 (2) | 3 (1.5) |
| Walk | 29 (14.5) | 21 (10.4) | 13 (6.3) |
| Ambulance | 2 (1) | - | - |
| Tube | 1 (.5) | 1 (0.5) | - |
| Cycle | 1 (.5) | - | 2 (1) |
| Voluntary service | - | - | 1 (0.5) |
| Motorbike | - | - | 2 (1) |
|   | **Mean (SD) [range]** | **Mean (SD) [range]** | **Mean (SD) [range]** |
| Age, y | 55.57 (16.17) [23-89] | 56.46 (15.78) [20-88] | 58.48 (16.46) [20-91] |
| Household size | 2.45 (1.13) [1-6] | 2.52 (1.12) [1-7] | 2.48 (1.18) [1-7] |
| Miles to hospital  | 6.46 (5.09) [0.5-20] | 7.48 (5.97) [0.25-35] | 7.95 (6.03) [0.2 - 25] |
| Travelling time hospital  | 20.45 (11.59) [ 5 -70] | 21.98 (12.1) [2 -60] | 22.13 (12.27) [3-75] |

**Table 2:** Willingness to travel to a specialist hospital for vascular treatment and follow-up

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Travel Preference** | **AAA (Open)**N=200 | **AAA (EVAR)**N=200 | **CAD** N=202 | **PAD** N=206 |
| Willing to travel without compensation | 78 (39%) | 77 (38.5%) | 58 (28.7%) | 67 (32.5%) |
| Willing to travel with compensation | 100 (50%) | 96 (48%) | 103 (51%) | 131(63.6%) |
| Not willing to travel | 22 (11%) | 27 (13.5%) | 41 (20.3%) | 8 (3.9%) |

**Table 3:** Compensation for travelling to specialist hospital for the whole sample, this includes those who were not willing to travel, we assigned them the maximum process utility they could have (5% for CAD, AAA and 45% for PAD) - Reference case is 95% chance of treatment success at local hospital for AAA & CAD and 55% for PAD .

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Miles | AAA - Open (n=200)Mean (SD); Median  | AAA - EVAR (n=200)Mean (SD); Median | CAD(n=202)Mean (SD); Median | PAD(n=206)Mean (SD); Median |
| 5 | 95.63 (1.1); 95 | 95.51 (0.9); 95 | 96.28 (1.7); 96 | 56.33 (3.6); 55 |
| 15 | 96.87 (1.9); 96.8 | 96.99 (2); 96.5 | 96.37 (1.6); 96 | 64.24 (12.9); 60 |
| 30 | 97.06 (1.8); 97 | 97.48 (2); 97.3 | 97.56 (1.8); 97 | 64.02 (9.1); 60 |
| 60 | 97.09 (2); 96.3 | 97.37 (2.1); 97.5 | 97.90 (2.1); 98 | 66.31 (12.5); 60 |

**Table 4: Disutilities of travelling for the age group <65 / Extra expected lifetime QALYs demanded**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Miles | AAA - Open (n=200) | AAA - EVAR (n=200) | CAD (n=202) | PAD (n=206) |
| 5 | 0.1084 | 0.0795 | 0.1019 | 0.0928 |
| 15 | 0.3217 | 0.3102 | 0.1094 | 0.6462 |
| 30 | 0.3541 | 0.3869 | 0.2041 | 0.6310 |
| 60 | 0.3587 | 0.3695 | 0.2314 | 0.7916 |

**Figure 1**: Diagram used to explain chance of treatment success and failure



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