

# **An annotated cost questionnaire for completion by patients**

by

Sally Thompson<sup>1</sup>

Sarah Wordsworth<sup>2</sup>

On behalf of the UK Working Party on Patient Costs

HERU Discussion Paper No. [03/01]

1. Centre for Health Economics, University of York
2. Health Economics Research Unit, University of Aberdeen

## **Acknowledgements:**

**The authors would like to thank John Cairns for helpful comments on an earlier draft of this paper. Funding from GlaxoSmithKline is acknowledged. HERU is supported by the Chief Scientist Office of the Scottish Executive Health Department (SEHD). The views in this paper are that of the authors and not attributable to either funding body.**

## **Working Party membership**

Ken Buckingham	Cornwall Health Authority (Chair)
Nicola Cooper	Health Policy and Practice, University of East Anglia
Wendy Coucill	Health Economics Facility, University of Birmingham
Joe Eastman	Centre for Health Planning and Management, University of Keele
Marilyn James	Centre for Health Planning and Management, University of Keele
Elaine McColl	Centre for Health Services Research, University of Newcastle
Panos Papanikolaou	University of Wales, College of Medicine
Adam Parnaby	Health Economics Research Group, Brunel University
Sally Thompson	Centre for Health Economics, University of York
Sarah Wordsworth	Health Economics Research Unit, University of Aberdeen

Correspondence to:

Sarah Wordsworth

Health Economics Research Unit

Department of Public Health

University of Aberdeen

Aberdeen AB25 9ZD

E-mail: [s.wordsworth@abdn.ac.uk](mailto:s.wordsworth@abdn.ac.uk) or [costquestionnaire@yahoo.com](mailto:costquestionnaire@yahoo.com)

# CONTENTS

<b>CHAPTER 1: INTRODUCTION</b> .....	<b>3</b>
1.1 INTRODUCTION AND PROJECT AIMS.....	3
1.2. GUIDANCE NOTES FOR USERS.....	5
<b>CHAPTER 2: INTRODUCING A QUESTIONNAIRE</b> .....	<b>9</b>
<b>CHAPTER 3: SINGLE VISITS TO HEALTH CARE FACILITIES</b> .....	<b>13</b>
3.1 PATIENT TRAVEL COSTS.....	13
3.2 PATIENT TIME COSTS .....	18
3.3 COMPANION COSTS.....	21
3.4 CHILDCARE AND OTHER DEPENDENT COSTS .....	25
<b>CHAPTER 4: MULTIPLE VISITS TO HEALTH CARE FACILITIES</b> .....	<b>29</b>
4.1 PATIENT TRAVEL COSTS.....	29
4.2 PATIENT TIME COSTS .....	33
4.3 COMPANION COSTS.....	36
4.4 CHILDCARE AND OTHER DEPENDENT COSTS .....	40
<b>CHAPTER 5: DOMICILIARY CARE COSTS</b> .....	<b>43</b>
5.1 HEALTH AND SOCIAL CARE PROFESSIONAL COSTS .....	43
5.2 CARE ASSISTANT COSTS .....	46
5.3 HOME HELP COSTS.....	48
5.4 MEALS-ON-WHEELS .....	50
5.5 INFORMAL CARE COSTS .....	51
5.6 CHILDCARE AND OTHER DEPENDENT COSTS.....	58
5.7 RESIDENTIAL CARE COSTS.....	66
<b>CHAPTER 6: PRODUCTIVITY LOSSES DUE TO ILLNESS</b> .....	<b>68</b>
6.1 PRODUCTIVITY LOSSES DUE TO ACUTE ILLNESS.....	68
6.2 PRODUCTIVITY LOSSES DUE TO CHRONIC ILLNESS .....	73
<b>CHAPTER 7: MEDICATION AND MEDICAL SUPPLIES</b> .....	<b>74</b>
7.1 PRESCRIBED MEDICATION .....	74
7.2 MEDICATION PURCHASED WITHOUT A PRESCRIPTION .....	78
7.3 DEVICES AND APPLIANCES .....	79
<b>CHAPTER 8: PRIVATE CONSULTATIONS</b> .....	<b>81</b>
<b>CHAPTER 9: ADDITIONAL INFORMATION</b> .....	<b>83</b>
9.1 OTHER COSTS.....	83
9.2. SOCIODEMOGRAPHICS .....	85
<b>CHAPTER 10: BIBLIOGRAPHY</b> .....	<b>88</b>

## **CHAPTER 1: INTRODUCTION**

### **1.1 INTRODUCTION AND PROJECT AIMS**

This questionnaire and its associated documentation was produced in response to the interest showed to an e-mail request to the UK Health Economists' Study Group members for advice on whether a standard patient cost questionnaire was available for use in prospective health economic evaluations. Although some respondents to the request were aware of some questionnaires, it was also evident that many others would value further information. It seemed sensible, therefore, to try to produce a standard set of questions that would avoid unnecessary duplication, would be reliable and would facilitate comparisons between the results of different investigators. GlaxoWellcome offered to fund the travel and associated costs of a working party, which was established with representatives from most of the major Health Economics centres in the United Kingdom.

The aim of the project was to produce a resource for investigators throughout the United Kingdom to develop questionnaires for administration to patients for the collection of health care costs. While the greater part of the questionnaire concerns costs to patients and their families, we recognise that, for convenience, the patient is occasionally used as the source of information for costs that fall on other parties. Strictly speaking therefore we are providing a 'Cost questionnaire for completion by patients' rather than a 'Patient cost questionnaire'. We are seeking to measure and value inputs into the health production function that relate directly to patients and informal caregivers for which

patients may be used as a source of information.

We decided to include only basic questions relating to productivity losses associated with absenteeism from work for reasons of complexity and also the fact that there is an existing instrument that has been designed specifically for this purpose. Where more detailed questions measuring productivity losses are required we refer investigators to the Health and Labour Questionnaire developed by van Roijen et al (1996). In addition, we chose to avoid questions on productivity losses without absenteeism, for similar reasons plus the fact that such questions are likely to be relevant only in select circumstances. We refer investigators interested in this topic to the instrument recently developed by Brower et al (1999).

Investigators should be aware that although much attention has been paid to the wording and layout of questions most have not, at this point in time, been formally pilot tested. Our purpose in making the questionnaire available to the research community at this stage is that we believe others can already benefit from our work and we want to encourage widespread use of the questions as early as possible. We welcome any feedback that others who choose to use our questions are willing to share. We plan to revise the questionnaire once our own formal pilot testing has been completed.

We are grateful to the investigators outside of the working party who gave us copies of their own cost questionnaires, particularly Jenny Beecham (PSSRU), Adrian Griffin (GlaxoWellcome), Loretto Lacey (GlaxoWellcome), Tricia Meldrum (Stobhill Research), Martin Price (GlaxoWellcome) and

Andy Street (Centre for Health Economics). These questionnaires were extremely helpful in providing a checklist of topics and in generating ideas for further development. We are grateful to GlaxoWellcome for their financial support.

## **1.2. GUIDANCE NOTES FOR USERS**

This is a resource for investigators throughout the United Kingdom to develop questionnaires for administration to patients for the collection of health care costs, where patients may be used as a source of that information. In developing this resource we have tried to follow general principles of good questionnaire design. In particular, we decided to adopt the following positions:

- To avoid using categories to record numerical data and so keep variables continuous wherever possible. Apart from making the results less mathematically tractable, grouping data into categories results in a loss of information. However, we are aware of the trade-off to be made between gathering interval data and tick the box type questions that may be easier for patients to complete and therefore result in less missing data.
- To ease use simple yes/no options for questions that prompt either of these two answers.
- To use ‘sign-posting’ to guide the respondent through various elements of the questionnaire.

The questions included in this document are suitable for self-completion by patients, although it is recognised that in some circumstances respondents may require assistance from others to complete the details requested.

We have indicated in *italics* places where you should substitute a word or phrase appropriate your own research. Italics are also used to offer guidance throughout the questionnaire. It may still be necessary for you to conduct your own pilot work to identify cost categories that are relevant to your study (e.g. whether their patients receive support from social services, chiropody, or whatever).

The investigator should also give detailed thought to the context in which the questionnaire is to be used and consider, for example, where the questionnaire is to be completed by patients the appropriate print size. We recognise that questionnaires are frequently bundled together, and recommend that questions be numbered sequentially throughout a composite questionnaire. Questions in this document are numbered for reference purposes only. Also, if the patient cost questionnaire is to be administered separately from other instruments and/or detached from other instruments during the analysis phase of the study then it is recommended that several key patient variables be included for identification purposes. Suggestions are the patient identification number as well as the respondent's gender and/or date of birth.

Investigators need to consider the relevance of each question to their own particular study. Appropriate questions will obviously depend on the profile of the disease, the perspective of the economic evaluation and the context in which the questionnaire is to be used (e.g. if it is gathering data on single or multiple visits to a health care facility).

We have left the decision of selecting an appropriate recall period to each investigator. However, for maximum reliability we recommend a period of not more than 2 weeks if this is a feasible option. Patient recall depends on numerous factors, including the degree of detail asked about in the questionnaire, the personal significance of the information being requested to the respondent and the time period involved. For events considered significant a longer recall period may be acceptable.

In terms of the questions relating to multiple visits to a health care facility, we carefully considered the issue of whether it was best to ask the patient about the “the last time” the relevant event occurred or what the patient “normally” did when the event occurred. We decided to opt for the “normally” option but recognise that in some circumstances investigators may prefer to use “the last time”. Asking patients about “the last time” may present fewer problems in terms of recall bias. Also, some respondents may find it difficult to decide on what “normally” actually means. On the other hand, if there were any systematic reason as to why the “last time” might be different from normal behaviour then the results obtained through asking patients about their most recent experience would be biased. For fluctuating conditions we recommend asking patients to complete a diary.

Finally, we decided not to make recommendations about specific methods of valuation, in particular with regard to the valuation of productivity losses, but rather to direct investigators to selected and more recent literature that has been published on this topic.



## CHAPTER 2: INTRODUCING A QUESTIONNAIRE

*Although we believe that the costing section of a questionnaire to patients requires its own 'preamble', we have not recommended a specific form of words since this will differ widely between the contexts in which the questionnaire is used. Instead we have chosen simply to list the issues we believe should be addressed and provide some examples of explanations authors can use as a basis for developing their own introductory comments. We suggest that the following issues be addressed:*

- *The purpose of the questionnaire*
- *Encouragement to complete the survey*
- *Assurance of confidentiality*
- *Contact details of investigator*

*Examples of explanations are included below.*

*In addition, if the costing project is not attached to a clinical trial then respondents will need to be informed in a covering letter how their name came to be included in the study.*

*Investigators might also wish to suggest in the introduction section of the questionnaire that respondents should feel free to note any additional comments they have beside the relevant questions.*

### **Statement 2.1**

*(Include something such as is written below for a self-administered questionnaire that is to be returned directly to the investigator and is asking about the costs incurred in attending a single health care facility)*

*'We would like to find out what extra money and time you and your family had to spend to visit the (specify location). Your answers are important because they will give those who make decisions about patient treatment within the National Health Service an idea of how much it costs you to use health services.'*

*(Alternatively, for retrospective data collection via a mail questionnaire asking about the costs of attending a single health care facility include something such as below)*

‘We would like to find out what extra money and time you and your family had to spend when you last visited (*specify location*). Your answers are important because they will give persons who make decisions about patient treatment within the National Health Service idea of how much it costs you to use health services.’

*(Alternatively, for either a mail questionnaire or a self-administered questionnaire to be administered at a clinic and asking about the costs of a specific condition include something such as below)*

‘In this questionnaire we are trying to find out about the costs to you, the patient and also the costs to your family of the treatment you have been receiving for (*specify condition*). Your answers are important because they will give persons who make decisions about patient treatment within the National Health Service an idea of how much the treatment costs you.’

### **Statement 2.2**

*(Include for a questionnaire that is to be returned directly to the investigator)*

‘Please answer every question. If you are not sure or cannot remember the exact details, please give the best answer you can. If you have a problem in answering any question, please write that problem beside the question.’

*(Alternatively, for a mail questionnaire include something such as below)*

‘We hope you will be able to find the time to complete this questionnaire. It would be very helpful if you could reply within the next (*specify number of days*) and return the questionnaire in the enclosed pre-paid envelope. If you have difficulty with answering any of the questions please give the best answer you can.’

### **Statement 2.3**

*(Include for all questionnaires)*

‘The information that you provide will be completely confidential. Your answers will be combined with the answers of other patients involved in the study and reported in such a way that it will not identify you or influence your pattern of treatment.’

*Note that we recommend the use of the term “confidentiality” rather than “anonymity”, since in most cases the investigator would wish to keep track of the identity of the respondent, to link data from various parts of a study, to send postal reminders etc.*

**Statement 2.4**

*(Include for all questionnaires)*

'If you would like any further information about this study please contact *(name)* at *(location)* on *(telephone number)*.'

## CHAPTER 3: SINGLE VISITS TO HEALTH CARE FACILITIES

*This section of the questionnaire asks about the costs associated with attending health care facilities on a one-off basis only. The wording of the questions is slightly different depending on whether the questionnaire is to be completed at the health care facility or retrospectively.*

### 3.1 PATIENT TRAVEL COSTS

This part of the questionnaire asks about the costs of your travelling **to** the (*specify location e.g. general practitioner surgery or hospital clinic*).

#### **Question 3.1.1**

*(Include if the questionnaire is to be completed at the health care facility)*

How did you travel to the (*specify location e.g. general practitioner surgery or hospital clinic*)?

Please circle the number that best describes how you travelled from your home to the (*specify location e.g. general practitioner surgery or hospital clinic*). If you used more than one form of transport please indicate the way you travelled for the **main** (longest in terms of distance) part of your journey.

Walked .....	1
Cycled.....	2
Bus.....	3
Train/metro.....	4
Taxi.....	5
Private car .....	6
Motorbike .....	7
Hospital car .....	8
Ambulance.....	9
Other ( <b>please specify</b> ).....	10

14 An annotated cost questionnaire for completion by patients

---

Please indicate any other forms of transport you used to travel from your home to the (*specify location e.g. general practitioner surgery or hospital clinic*). You may circle more than one answer (*use 'response' if preferred*) if appropriate. Please circle 'No other forms of transport' if you used only one form of transport as indicated above.

- No other forms of transport..... 1
- Walked ..... 2
- Cycled..... 3
- Bus..... 4
- Train/metro..... 5
- Taxi..... 6
- Private car ..... 7
- Motorbike ..... 8
- Hospital car ..... 9
- Ambulance.....10
- Other (**please specify**).....11

*(Alternatively, if the questionnaire is to be completed retrospectively then ask the following question)*

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), how did you travel?

Please circle the number that best describes how you travelled from your home to the (*specify location e.g. general practitioner surgery or hospital clinic*). If you used more than one form of transport please indicate the way you travelled for the **main** (longest in terms of distance) part of your journey.

- Walked ..... 1
- Cycled..... 2
- Bus..... 3
- Train/metro..... 4
- Taxi..... 5
- Private car ..... 6
- Motorbike ..... 7
- Hospital car ..... 8
- Ambulance..... 9
- Other (**please specify**)..... 10

Please indicate any other forms of transport you used to travel from your home to the (*specify location e.g. general practitioner surgery or hospital clinic*). You may circle more than one answer (*use 'response' if preferred*) if appropriate. Please circle 'No other forms of transport' if you used only one form of transport as indicated above.

- No other forms of transport..... 1  
 Walked ..... 2  
 Cycled..... 3  
 Bus..... 4  
 Train/metro..... 5  
 Taxi..... 6  
 Private car ..... 7  
 Motorbike ..... 8  
 Hospital car ..... 9  
 Ambulance..... 10  
 Other (**please specify**)..... 11

### **Question 3.1.2**

*(Include if the investigator wishes to value the cost of patient travel using actual expenditures)*

If you travelled by public transport (e.g. bus or train) for part or the entire journey, what was the cost of the one-way fare? Please write the cost in the box below. Put zero if you did not travel by public transport at all or if you did not pay a fare.

Cost of one-way fare (£)   -   Pence

If you travelled by taxi for part or the entire journey, what was the cost of the one-way fare? Please write the cost in the box below. Put zero if you did not travel by taxi at all or if you did not pay a fare.

Total cost of one-way fare (£)   -   Pence

If you travelled by private car or motorbike for part or the entire journey how many (*specify as appropriate e.g. miles or kilometres*) did you travel one-way? Please write the number of (*specify as appropriate e.g. miles or kilometres*) in the box below. Put zero if you did not travel by private car or motorbike at all.

Number of (*specify*) one-way 

--	--	--

If you travelled by private car or motorbike for part or all of the journey and had to pay tolls or parking fees how much did these amount to? Please write the cost in the box below. Put zero if you did not travel by private car or motorbike at all or did not pay tolls or parking fees.

Expenditure on tolls or parking fees (£) 

--	--

 - 

--	--

 pence

***(Alternatively, if the investigator wishes to value patient travel costs using their own unit prices then ask the following question)***

How far away from the (*specify location e.g. general practitioner surgery or hospital clinic*) do you live? Please write the number of (*specify as appropriate e.g. miles or kilometres*) in the box below.

Number of (*specify*) 

--	--	--

*Note that people are generally poor at estimating distances. Therefore, we recommend use of the more detailed questions outlined above if possible.*

**Question 3.1.3**

*(Include if the questionnaire is to be completed at the health care facility)*

How long did it take to travel from your home to the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please write the number of hours and minutes in the box below.

Number of hours   -   minutes

*(Alternatively, if the questionnaire is to be completed retrospectively then ask the following question)*

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), how long did it take to travel there from your home? Please write the number of hours and minutes in the box below.

Number of hours   -   minutes

**Question 3.1.4****Return journey**

*If there is the possibility that the patient could return home using a different form of transport, it will be necessary to ask whether the patient will return home using the same form of transport. If the patients states that they will be returning in a different manner, then it will be necessary to repeat the options for mode of transport and the cost, as shown in the journey to the specified location.*

*(Include if the questionnaire is to be completed at the health care facility)*

Will you return home using the same form of transport?

*(Alternatively, if the questionnaire is to be completed retrospectively then ask the following question)*

Did you return home using the same form of transport?

### 3.2 PATIENT TIME COSTS

The next section of the questionnaire asks about the effect of your visit to the (*specify location e.g. general practitioner surgery or hospital clinic*) on your paid work (or business activity if self-employed), unpaid work or leisure activity. By unpaid work we mean activities such as household chores shopping, caring for children and voluntary work, non-leisure activities that involve your time but for which you do not get paid. Leisure activity includes any activity in which you engage that is not related either to paid or unpaid work, for example, hobbies, pastimes and social activities.

#### **Question 3.2.1**

*(Include if the questionnaire is to be completed at the health care facility)*

How long did you spend at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please write the number of hours and minutes in the box below. Please include in your answer the time spent waiting and also the time spent with the (*specify health professional e.g. doctor or nurse*).

Number of hours 

--	--

 - 

--	--

 minutes

*(Alternatively, if the questionnaire is to be completed retrospectively then ask the following question)*

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), how long did you spend there? Please write the number of hours and minutes in the box below. Please include in your answer the time spent waiting and also the time spent with the (*specify health professional e.g. doctor or nurse*).

Number of hours 

--	--

 - 

--	--

 minutes

**Question 3.2.2**

*(Include if the investigator wishes to value patient time according to the activity displaced)*

What would you otherwise have been doing as your **main** activity if you had not come to the (specify location e.g. general practitioner surgery or hospital clinic)? Please circle the number that best describes what you otherwise would have been doing as your main activity if you had not come to the (specify location e.g. general practitioner surgery or hospital clinic).

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave..... 7
- Seeking work ..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If you took time off from paid work (or business activity if self-employed) please continue with question 3.2.3. Otherwise, go to (specify next section of the questionnaire).

**Question 3.2.3**

*(Include if the investigator wishes to value lost patient paid work time as distinct from other patient time)*

If you took time off from paid work (or business activity if self-employed) to come to the (specify location e.g. general practitioner surgery or hospital clinic) approximately how much time did you take off work (or business activity if self-employed)? Please write the number of hours and minutes in the box below.

Number of hours   -   minutes

**Question 3.2.4**

*(Include if the investigator wishes to value lost patient earnings as distinct from other lost patient work time)*

Did you lose earnings as a result? Please circle the appropriate answer (*use 'response' if preferred*).

Yes ..... 1

No ..... 2

**Question 3.2.5**

*(Include if the investigator wishes to value lost patient work time using the human capital approach and not asked elsewhere in the questionnaire)*

What is your **main** occupation (*use 'job' if preferred*)?

.....

*Note that patients are not asked to estimate lost earnings, as the results are unlikely to be reliable.*

### 3.3 COMPANION COSTS

The next section of the questionnaire asks about the time and travel costs to persons who accompanied you to the (*specify location e.g. general practitioner surgery or hospital clinic*).

#### **Question 3.3.1**

*(Include if the questionnaire is to be completed at the health care facility)*

Did anyone come with (*use 'accompany' if preferred*) you to the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 3.3.2) .....1

No (go to (*specify next section of the questionnaire*)) .....2

*(Alternatively, if the questionnaire is to be completed retrospectively then ask the following question)*

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), did anyone go with (*use 'accompany' if preferred*) you? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 3.3.2) .....1

No (go to (*specify next section of the questionnaire*)) .....2

**Question 3.3.2**

Who accompanied you to the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please circle the number(s) that best describe the person(s) who accompanied you to the (*specify location e.g. general practitioner surgery or hospital clinic*). You may circle more than one answer (*use 'response' if preferred*) if appropriate.

- Partner/spouse..... 1
- Child/children under 16 years ..... 2
- Other relative..... 3
- Paid caregiver..... 4
- Other (**please specify**)..... 5

If any one or more of the persons considered above **needed** to go with (*use 'accompany' if preferred*) you to the appointment because of your own poor state of health please continue with question 3.3.3. Otherwise, go to (*specify next section of the questionnaire*).

**Question 3.3.3**

Please think about your **main** companion, that is the person who most needed to go with (*use 'accompany' if preferred*) you to the (*specify location e.g. general practitioner surgery or hospital clinic*).

If your main companion travelled with you by public transport for part or the entire journey how much did they pay one-way in fares (if anything)? Please write the cost in the box below. Put zero if your main companion did not travel by public transport at all or did not pay a fare.

Cost of one-way fare (£)   -   pence

**Question 3.3.4**

How long did that person spend with you both in terms of travel time and whilst you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please write the number of hours and minutes in the box below.

Number of hours   -   minutes

**Question 3.3.5**

*(Include if the investigator wishes to value companion time according to the activity displaced)*

What would your companion otherwise have been doing as their **main** activity if they had not accompanied you to the (*specify location e.g. general practitioner surgery or hospital clinic*)?

Please circle the number that best describes what your main companion would otherwise have been doing as their main activity if they had not accompanied you to the (*specify location e.g. general practitioner surgery or hospital clinic*).

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave ..... 7
- Seeking work ..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If your main companion took time off from paid work (or business activity if self-employed) please continue with question 3.3.5. Otherwise, go to (*specify next section of the questionnaire*).

**Question 3.3.6**

*(Include if the investigator wishes to value lost companion paid work time as distinct from other companion time)*

If your companion took time off from paid work (or business activity if self-employed) to go with (use 'accompany' if preferred) you to the appointment approximately how much time did they take off work? Please write the number of hours and minutes in the box below. Put zero if your main companion did not take time off from paid work (or business activity if self-employed) to go with (use 'accompany' if preferred) you to the appointment.

Number of hours 

--	--

 - 

--	--

 minutes

**Question 3.3.6**

*(Include if the investigator wishes to value lost companion paid work time using the human capital approach)*

What is your companion's **main** occupation (use 'job' if preferred)?

.....

*Note that for companion travel we assume the same mode of transport as for the patient. We ask about public transport fares as these may have been different.*

### 3.4 CHILDCARE AND OTHER DEPENDENT COSTS

This next section of the questionnaire asks about any assistance that you needed to look after your child/children or other dependants when you were at the (*specify location e.g. general practitioner surgery or hospital clinic*). Here we are interested only in assistance that you needed because of your (*specify condition*) and not for any other reason.

#### **Question 3.4.1**

*(Include if the questionnaire is to be completed at the health care facility)*

Did you get someone to look after your child/children or other dependants (if you have any) when you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please circle the appropriate answer (*use 'response' if preferred*).

- Yes (please continue with question 3.4.2) .....1
- No (go to (*specify next section of the questionnaire*)) .....2
- Not applicable (no children or other dependants) (go to (*specify next section of the questionnaire*)) .....8

*(Alternatively, if the questionnaire is to be completed retrospectively then ask the following question)*

When you were at the (*specify location e.g. general practitioner surgery or hospital clinic*), did you get someone to look after your child/children or other dependants (if you have any)? Please circle the appropriate answer (*use 'response' if preferred*).

- Yes (please continue with question 3.4.2) .....1
- No (go to (*specify next section of the questionnaire*)) .....2
- Not applicable (no children or other dependants) (go to (*specify next section of the questionnaire*)) .....8

**Question 3.4.2**

How many hours and minutes did they spend looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please write the number of hours and minutes in the box below.

Number of hours 

--	--

 - 

--	--

 minutes

**Question 3.4.3**

Please think about the **main** caregiver, that is the person who was mostly responsible for looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*).

Did you pay that person to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes .....1

No (please continue with question 3.4.5) .....2

**Question 3.4.4**

How much did you pay that person to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please specify the amount in the box below.

Amount paid for care (£) 

--	--

 - 

--	--

 pence

If you paid that person to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*) please go to (*specify next section of questionnaire*).

**Question 3.4.5**

*(Include if the investigator wishes to value caregiver time according to the activity displaced)*

If they were not paid, what would that person have been doing as their **main** activity if they had not been looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)?

Please circle the number that **best** describes what that person would have been doing as their main activity if they had not been looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)?

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave..... 7
- Seeking work..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If the main caregiver took time off from paid work (or business activity if self-employed) please continue with question 3.4.6. Otherwise, go to (*specify next section of the questionnaire*).

**Question 3.4.6**

*(Include if the investigator wishes to value lost caregiver paid work time as distinct from other caregiver time)*

If the main caregiver took time off from paid work (or business activity if self-employed) to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*) approximately how much time did they take off paid work? Please write the number of hours and minutes in the box below.

Number of hours   -   minutes

**Question 3.4.7**

*(Include if the investigator wishes to value lost caregiver paid work time using the human capital approach)*

What is the caregiver's **main** occupation (*use 'job' if preferred*)?

.....

## CHAPTER 4: MULTIPLE VISITS TO HEALTH CARE FACILITIES

This section of the questionnaire asks about costs associated with attending health care facilities.

*Note that the following questions will need to be copied for each location the respondent might have visited for their condition throughout the survey period. The questions assume the same mode of transport and associated costs for the return journey.*

### 4.1 PATIENT TRAVEL COSTS

This first part of the questionnaire asks about the costs of your travelling to the (*specify location e.g. general practitioner surgery or hospital clinic*).

#### **Question 4.1.1**

Over the **last (*specify number of weeks*)** how many times have you visited the (*specify location e.g. general practitioner surgery or hospital clinic*) for your (*specify condition*)? Please write the number of times in the box below. Put zero if you have not visited the (*specify location e.g. general practitioner surgery or hospital clinic*) over the last (*specify number of weeks*) for your (*specify condition*).

Number of times

If you answered 1 or more to the question above please continue with question 4.1.2. Otherwise, go to (*specify next section of the questionnaire*).

**Question 4.1.2**

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), how did you **normally** travel?

Please circle the number that best describes how you **normally** travelled from your home to the (*specify location e.g. general practitioner surgery or hospital clinic*). If you normally used more than one form of transport please indicate the way you travelled for the **main** (longest in terms of distance) part of your journey.

- Walked ..... 1
- Cycled..... 2
- Bus..... 3
- Train/metro..... 4
- Taxi..... 5
- Private car ..... 6
- Motorbike ..... 7
- Hospital car ..... 8
- Ambulance..... 9
- Other (**please specify**)..... 10

Please indicate any other forms of transport you **normally** used to travel from your home to the (*specify location e.g. general practitioner surgery or hospital clinic*). You may circle more than one answer (*use 'response' if preferred*) if appropriate. Please circle 'No other forms of transport' if you used only one form of transport as indicated above.

- No other forms of transport..... 1
- Walked ..... 2
- Cycled..... 3
- Bus..... 4
- Train/metro..... 5
- Taxi..... 6
- Private car ..... 7
- Motorbike ..... 8
- Hospital car ..... 9
- Ambulance..... 10
- Other (**please specify**)..... 11



**Question 4.1.3**

*(Include if the investigator wishes to value the cost of patient travel using actual expenditures)*

If you **normally** travelled by public transport (e.g. bus or train) for part or the entire journey, what was the cost of the one-way fare? Please write the cost in the box below. Put zero if you did not normally travel by public transport at all or if you did not normally pay a fare.

Cost of one-way fare (£)   -   pence

If you **normally** travelled by taxi for part or the entire journey, what was the cost of the one-way fare? Please write the cost in the box below. Put zero if you did not normally travel by taxi at all or if you did not normally pay a fare.

Total cost of one-way fare (£)   -   pence

If you **normally** travelled by private car or motorbike for part or the entire journey how many (*specify as appropriate e.g. miles or kilometres*) did you travel one-way? Please write the number of (*specify as appropriate e.g. miles or kilometres*) in the box below. Put zero if you did not normally travel by private car or motorbike at all.

Number of (*specify*) one-way

If you **normally** travelled by private car or motorbike for part or the entire journey and had to pay tolls or parking fees how much did these amount to? Please write the cost in the box below. Put zero if you did not normally travel by private car or motorbike at all or did not normally pay tolls or parking fees.

Expenditure on tolls or parking fees (£)   -   pence

*(Alternatively, if the investigator wishes to value patient travel costs using their own unit prices then ask the following question)*

How far away from the (*specify location e.g. general practitioner surgery or hospital clinic*) do you live? Please write the number of (*specify as appropriate e.g. miles or kilometres*) in the box below.

Number of (*specify*)

*Note that people are generally poor at estimating distances. Therefore, we recommend the use of the more detailed questions outlined above if possible.*

**Question 4.1.4**

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), how long did it normally take to travel there from your home? Please write the number of hours and minutes in the box below.

Number of hours 

--	--

 - 

--	--

 minutes

**Return journey**

*If there is the possibility that the patient could return home using a different form of transport, it will be necessary to ask whether the patient will return home using the same form of transport. If the patients states that they will be returning in a different manner, then it will be necessary to repeat the options for mode of transport and the cost, as shown in the journey to the specified location.*

## 4.2 PATIENT TIME COSTS

The next section of the questionnaire asks about the effect of your visits to the (*specify location e.g. general practitioner surgery or hospital clinic*) on your paid work (or business activity if self-employed), unpaid work (e.g. household chores or voluntary work) or leisure activity. By unpaid work we mean activities such as household chores shopping, caring for children and voluntary work, non-leisure activities that involve your time but for which you do not get paid. Leisure activity includes any activity in which you engage that it not related either to paid or unpaid work, for example, hobbies, pastimes and social activities.

### **Question 4.2.1**

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), how long did you **normally** spend there? Please write the number of hours and minutes in the box below. Include in your answer the time you **normally** spent waiting and also the time you **normally** spent with the (*specify health professional e.g. doctor or nurse*).

Number of hours   -   minutes

### **Question 4.2.2**

*(Include if the investigator wishes to value patient time according to the activity displaced)*

What would you **normally** have been doing as your **main** activity if you had not gone to the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please circle the number that best describes what you **normally** would have been doing as your main activity if you had not gone to the (*specify location e.g. general practitioner surgery or hospital clinic*).

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave..... 7
- Seeking work ..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If you **normally** took time off from paid work (or business activity if self-employed) please continue with question 4.2.3. Otherwise, go to *(specify next section of the questionnaire)*.

**Question 4.2.3**

*(Include if the investigator wishes to value lost patient paid work time as distinct from other patient time)*

If you took time off from paid work (or business activity if self-employed) to go to the *(specify location e.g. general practitioner surgery or hospital clinic)* approximately how much time did you **normally** take off work (or business activity if self-employed)? Please write the number of hours and minutes in the box below.

Number of hours 

--	--

 - 

--	--

 minutes

**Question 4.2.4**

*(Include if the investigator wishes to value lost patient earnings as distinct from other lost patient work time)*

Did you **normally** lose earnings as a result? Please circle the appropriate answer *(use 'response' if preferred)*.

Yes ..... 1

No ..... 2

**Question 4.2.5**

*(Include if the investigator wishes to value lost patient work time using the human capital approach and not asked elsewhere in the questionnaire)*

What is your **main** occupation *(use 'job' if preferred)*?

.....

### 4.3 COMPANION COSTS

The next section of the questionnaire asks about the time and travel costs to persons who **normally** accompanied you to the (*specify location e.g. general practitioner surgery or hospital clinic*).

#### **Question 4.3.1**

When you visited the (*specify location e.g. general practitioner surgery or hospital clinic*), did anyone **normally** go with (*use 'accompany' if preferred*) you? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 4.3.2) .....1

No (go to (*specify next section of the questionnaire*)) .....2

#### **Question 4.3.2**

Who **normally** went with (*use 'accompanied' if preferred*) you to the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please circle the number(s) that best describe the person(s) who **normally** went with (*use 'accompanied' if preferred*) you to the (*specify location e.g. general practitioner surgery or hospital clinic*). You may circle more than one answer (*use 'response' if preferred*) if appropriate.

Partner/spouse..... 1

Child/children under 16 years..... 2

Other relative..... 3

Paid caregiver..... 4

Other (**please specify**)..... 5

If any one or more of the persons considered above **needed** to go with (*use 'accompany' if preferred*) you to the appointments because of your poor state of health please continue with question 4.3.3. Otherwise, go to (*specify next section of the questionnaire*).

**Question 4.3.3**

Please think about your **main** companion, that is the person who went with (*use 'accompanied' if preferred*) you on the most number of occasions to the (*specify location e.g. general practitioner surgery or hospital clinic*).

If your main companion **normally** travelled with you by public transport for part or the entire journey how much did they normally pay one-way in fares (if anything)? Please write the cost in the box below. Put zero if your main companion normally did not travel by public transport at all or did not normally pay a fare.

Cost of one-way fare (£)   -   pence

**Question 4.3.4**

How long did that person **normally** stay with you at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please write the number of hours and minutes in the box below.

Number of hours   -   minutes

**Question 4.3.5**

*(Include if the investigator wishes to value companion time according to the activity displaced)*

What would your companion **normally** have been doing as their **main** activity if they had not gone with *(use ‘accompanied’ if preferred)* you to the *(specify location e.g. general practitioner surgery or hospital clinic)*?

Please circle the number that best describes what your main companion **normally** would have been doing as their main activity if they had not gone with *(use ‘accompanied’ if preferred)* you to the *(specify location e.g. general practitioner surgery or hospital clinic)*.

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave..... 7
- Seeking work..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If your main companion **normally** took time off from paid work (or business activity if self-employed) please continue with question 4.3.6. Otherwise, go to *(specify next section of the questionnaire)*.

**Question 4.3.6**

*(Include if the investigator wishes to value lost companion paid work time as distinct from other companion time)*

If your companion **normally** took time off from paid work (or business activity if self-employed) to go with (use 'accompany' if preferred) you to the appointment approximately how much time did they **normally** take off work? Please write the number of hours and minutes in the box below. Put zero if your main companion did not **normally** take time off from paid work (or business activity if self-employed) to go with (use 'accompany' if preferred) you to the appointment.

Number of hours 

--	--

 - 

--	--

 minutes

**Question 4.3.7**

*(Include if the investigator wishes to value lost companion paid work time using the human capital approach)*

What is your companion's **main** occupation (use 'job' if preferred)?

.....

*Note that for companion travel we assume the same mode of transport as for the patient. We ask about public transport fares, as these may have been different.*

#### 4.4 CHILDCARE AND OTHER DEPENDENT COSTS

This next section of the questionnaire asks about any assistance that you needed to look after your child/children or other dependants when you were at the (*specify location e.g. general practitioner surgery or hospital clinic*). Here we are interested only in assistance that you needed because of your (*specify condition*) and not for any other reason.

##### **Question 4.4.1**

When you were at the (*specify location e.g. general practitioner surgery or hospital clinic*), did you **normally** get someone to look after your child/children or other dependants (if you have any)? Please circle the appropriate answer (*use 'response' if preferred*).

- Yes (please continue with question 4.4.2) .....1
- No (go to (*specify next section of the questionnaire*)) .....2
- Not applicable (no children or other dependants) (go to (*specify next section of the questionnaire*)) .....8

##### **Question 4.4.2**

How many hours did they **normally** spend looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please write the number of hours and minutes in the box below.

Number of hours 

--	--

 - 

--	--

 minutes

##### **Question 4.4.3**

Please think about the **main** caregiver, that is the person who was mostly responsible for looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*).

Did you **normally** pay that person to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please circle the appropriate answer (*use 'response' if preferred*).

- Yes .....1
- No (please continue with question 4.4.5) .....2

*If you paid that person to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*) please go to (*specify next section of questionnaire*)?*



**Question 4.4.4**

How much did you **normally** pay that person to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)? Please specify the amount in the box below.

Amount paid for care (£)  -  pence

**Question 4.4.5**

*(Include if the investigator wishes to value caregiver time according to the activity displaced)*

If they were not paid, what would that person **normally** have been doing as their **main** activity if they had not been looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)?

Please circle the number that **best** describes what that person **normally** would have been doing as their main activity if they had not been looking after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*)?

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave..... 7
- Seeking work..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If the main caregiver **normally** took time off from paid work (or business activity if self-employed) please continue with question 4.4.6. Otherwise, go to (*specify next section of the questionnaire*).

**Question 4.4.6**

*(Include if the investigator wishes to value lost caregiver paid work time as distinct from other caregiver time)*

If the main caregiver **normally** took time off from paid work (or business activity if self-employed) to look after your child/children or other dependants while you were at the (*specify location e.g. general practitioner surgery or hospital clinic*) approximately how much time did they **normally** take off work? Please write the number of hours and minutes in the box below.

Number of hours 

--	--

 - 

--	--

 minutes

**Question 4.4.7**

*(Include if the investigator wishes to value lost caregiver paid work time using the human capital approach)*

What is the caregiver's **main** occupation (*use 'job' if preferred*)?

.....

## **CHAPTER 5: DOMICILIARY CARE COSTS**

This next section of questions asks about domiciliary care, that is care you have received in your home, either from health and/or social care professionals or from family and friends, because of your (*specify condition*).

### **5.1 HEALTH AND SOCIAL CARE PROFESSIONAL COSTS**

This next set of questions asks about any care you have received **in your home** from health and/or social care professionals because of your (*specify condition*). Health and social care professionals include (*specify as appropriate e.g. social workers, district nurses, physiotherapists, speech therapists, occupational therapists, counsellors, psychologists and dieticians*). Here we are interested only in assistance that you needed because of your (*specify condition*) and not for any other reason.

#### **Question 5.1.1**

Over the last (*specify number of weeks*) have you received care **in your home** from a health and/or social care professional such as a (*specify as appropriate e.g. a social worker, district nurse, physiotherapist, speech therapist, occupational therapist, counsellor, psychologist and dietician*) because of your (*specify condition*).

Yes (please continue with question 5.1.2).....1

No (go to (*specify next section of the questionnaire*)) .....2

**Question 5.1.2**

Which health and/or social care professionals have helped and/or cared for you **in your home** because of your (*specify condition*)? You may circle more than one answer (*use 'response' if preferred*) if appropriate.

- Social worker ..... 1  
 District nurse..... 2  
 Physiotherapist..... 3  
 Speech therapist ..... 4  
 Occupational therapist..... 5  
 Counsellor ..... 6  
 Psychologist..... 7  
 Dietician ..... 8  
 Other (**please specify**)..... 9

*Investigators are advised to carefully consider the types of health and/or social care professionals relevant to their own study and to amend the above list accordingly.*

*Note that the questions in the following section should be copied for each health and/or social care professional listed above.*

**Question 5.1.3**

If you received care **in your home** from a (*specify as appropriate e.g. social worker*) because of your (*specify condition*) please write the number of visits or care episodes in the box below. Put zero if you did not receive any visits or care episodes from a (*specify as appropriate e.g. social worker*) in your home over the last (*specify number of weeks*).

Number of visits 

--	--

What was the **average** length of the visits or care episodes? Please write the average length in the box below. Put zero if you did not receive any visits or care episodes in your home from a (*specify as appropriate e.g. social worker*) over the last (*specify number of weeks*) because of your (*specify condition*).

Number of hours 

--	--

 - 

--	--

 minutes

**Question 5.1.4**

For how many visits or care episodes did you pay? Please write the number of visits or care episodes for which you paid in the box below. Put zero if you did not receive any visits or care episodes in your home from a (*specify as appropriate e.g. social worker*) over the last (*specify number of weeks*) because of your (*specify condition*) or you did not pay for any of the visits or care episodes you received.

Number of visits 

--	--

**Question 5.1.5**

What was the **average** cost of a visit or care episode? Please write the average cost of a visit or care episode in the box below. Put zero if you did not receive any visits or care episodes in your home from a (*specify as appropriate e.g. social worker*) over the last (*specify number of weeks*) because of your (*specify condition*) or you did not pay for any of the visits or care episodes you received.

Average cost of a visit (£) 

--	--

 - 

--	--

 pence

## 5.2 CARE ASSISTANT COSTS

This next set of questions asks about any care you have received from a **care assistant** because of your (*specify condition*). By care assistant we mean any person who is employed to carry out tasks for you such as bathing and the preparation of meals, tasks that family members or friends might otherwise have been able to perform for you. Here we are interested only in assistance that you needed because of your (*specify condition*) and not for any other reason.

### **Question 5.2.1**

Over the last (*specify number of weeks*) have you been helped and/or cared for by a **care assistant** in your home because of your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 5.2.2) .....1

No (go to (*specify next section of the questionnaire*)) .....2

### **Question 5.2.2**

*(Include where care is not likely to have been given on a daily basis)*

Over the last (*specify number of weeks*) how often has a **care assistant** helped and/or cared for you in your home because of your (*specify condition*)? Please write the number of visits or care episodes in the box below.

Number of visits 

--	--

What was the **average** length of the visits or care episodes? Please write the average length in the box below.

Number of hours 

--	--

 - 

--	--

 minutes

*(Alternatively, if care is likely to have been given on a daily basis)*

In the table below please write how many days over the last week and how many hours on each of those days that person spent helping and/or caring for you in your home because of your (*specify condition*). Write zero if you had no help on a particular day.

Day	Number of hours
Yesterday	
The day before yesterday	
3 days ago	
4 days ago	
5 days ago	
6 days ago	
7 days ago	

### **Question 5.2.3**

For how many visits or care episodes did you pay? Please write the number of visits or care episodes for which you paid in the box below. Put zero if you did not receive any visits or care episodes from a care assistant or home help in your home because of your (*specify condition*) over the last (*specify number of weeks*) or you did not pay for any of the visits or care episodes you received.

Number of visits

### **Question 5.2.4**

What was the **average** cost of a visit or care episode? Please write the average cost of a visit or care episode in the box below. Put zero if you did not receive any visits or care episodes from a care assistant or a home help over the last (*specify number of weeks*) in your home because of your (*specify condition*) or you did not pay for any of the visits or care episodes you received.

Average cost of a visit (£)  -  pence

### 5.3 HOME HELP COSTS

This next set of questions asks about any care you have received from a **home help** because of your (*specify condition*). By home help we mean any person who is employed to carry out tasks for you such as cleaning the house or doing your ironing or gardening. Here we are interested only in assistance that you needed because of your (*specify condition*) and not for any other reason.

#### **Question 5.3.1**

Over the last (*specify number of weeks*) have you been assisted and/or cared for by a **home help** in your home because of your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 5.3.2) .....1

No (go to (*specify next section of the questionnaire*)) .....2

#### **Question 5.3.2**

*(Include where care is not likely to have been given on a daily basis)*

Over the last (*specify number of weeks*) how often has a home help assisted and/or cared for you in your home because of your (*specify condition*)? Please write the number of visits or care episodes in the box below.

Number of visits 

--	--

What was the **average** length of the visits or care episodes? Please write the average length in the box below.

Number of hours 

--	--

 - 

--	--

 minutes

*(Alternatively, if care is likely to have been given on a daily basis)*

In the table below please write how many days over the last week and how many hours on each of those days that person spent assisting and/or caring for you in your home because of your (*specify condition*). Write zero if you had no help on a particular day.

Day	Number of hours
Yesterday	
The day before yesterday	
3 days ago	
4 days ago	
5 days ago	
6 days ago	
7 days ago	

### **Question 5.3.3**

For how many visits or care episodes did you pay? Please write the number of visits or care episodes for which you paid in the box below. Put zero if you did not receive any visits or care episodes from a home help in your home because of your (*specify condition*) over the last (*specify number of weeks*) or you did not pay for any of the visits or care episodes you received.

Number of visits

### **Question 5.3.4**

What was the **average** cost of a visit or care episode? Please write the average cost of a visit or care episode in the box below. Put zero if you did not receive any visits or care episodes from a home help over the last (*specify number of weeks*) in your home because of your (*specify condition*) or you did not pay for any of the visits or care episodes you received.

Average cost of a visit (£)  -  pence

## 5.4 MEALS-ON-WHEELS

This next set of questions asks about any **additional** services you have received from meals-on-wheels organisations because of your (*specify condition*). By additional services we mean any services you have received other than services that would have been provided had you not been ill with (*specify condition*).

### **Question 5.4.1**

Over the last (*specify number of weeks*) have you received additional services from **meals-on-wheels** organisations because of your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 5.4.4) .....1

No (go to (*specify next section of the questionnaire*)) .....2

### **Question 5.4.2**

If you received additional services from meals-on-wheels organisations because of your (*specify condition*) please write the number of meals you received over the last (*specify number of weeks*) in the box below.

Number of meals

### **Question 5.4.3**

For how many meals did you pay? Please write the number of meals for which you paid in the box below. Put zero if you did not receive any additional services from meals-on-wheels organisations because of your (*specify condition*) or you did not pay for any of these additional meals.

Number of meals paid

### **Question 5.4.4**

What was the cost of each meal? Please write the cost of each meal in the box below. Put zero if you did not receive any additional services from meals-on-wheels organisations over the last (*specify number of weeks*) or you did not pay for any of these additional meals.

Cost per meal (£)   -   pence

### 5.5 INFORMAL CARE COSTS

This next set of questions asks about any care you have received from **informal caregivers** such as relatives and/or friends because of your (*specify condition*). Here we are interested only in assistance that you needed because of your (*specify condition*) and not for any other reason.

#### **Question 5.5.1**

Over the last (*specify number of weeks*) have you been helped and/or cared for by a relative or friend because of your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 5.5.2) .....1

No (go to (*specify next section of the questionnaire*)) .....2

#### **Question 5.5.2**

Over the last (*specify number of weeks*) how many relatives or friends have helped and/or cared for you because of your (*specify condition*)? Please write the number of relatives or friends in the box below.

Number of relatives or friends 

--	--

**Question 5.5.3**

*(Include where care is not likely to have been given on a daily basis)*

Please think about the relative or friend who you consider has provided you with the **most** help and/or care over the last (*specify number of weeks*) because of your (*specify condition*).

Over the last (*specify number of weeks*) how many hours has that person helped and/or cared for you because of your (*specify condition*)? Please write the number of hours in the box below. Include only hours in addition to any usual care arrangements.

Number of hours

*(Alternatively, if care is likely to have been given on a daily basis)*

Please think about the relative or friend who you consider has provided you with the **most** help and/or care over the last week because of your (*specify condition*).

In the table below please write how many days over the last week and how many hours on each of those days that person spent helping and/or caring for you. Please include only hours in addition to any usual caring activities. Write zero if you received no help on a particular day.

<b>Day</b>	<b>Number of hours</b>
Yesterday	
The day before yesterday	
3 days ago	
4 days ago	
5 days ago	
6 days ago	
7 days ago	

**Question 5.5.4**

*(Include if the investigator wishes to value caregiver time according to the activity displaced)*

What would that person **normally** have been doing as the **main** activity if they had not been helping and/or caring for you? Please circle the number that best describes what that person would normally have been doing as their main activity if they had not been helping and/or caring for you.

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave ..... 7
- Seeking work ..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If your relative or friend **normally** took time off from paid work (or business activity if self-employed) please continue with question 5.5.5. Otherwise, go to *(specify next section of the questionnaire)*.

**Question 5.5.5**

*(Include if the investigator wishes to value lost caregiver paid work time as distinct from other caregiver time)*

If your relative or friend **normally** took time off from paid work as their **main** activity (or business activity if self-employed), approximately how much time in the last (*specify number of weeks*) did they take off work to help and/or care for you? Please write the **total** number of hours in the box below.

Total number of hours 

--	--

**Question 5.5.6**

*(Include if the investigator wishes to value lost caregiver paid work time using the human capital approach)*

What is your relative or friend's **main** occupation (*use 'job' if preferred*)?

.....

If more than one relative or friend provided you with help and/or care over the last (*specify number of weeks*) please continue with question 5.5.9. Otherwise, go to (*specify next section of the questionnaire*).

*Note that the following questions should be copied for each additional relative or friend that provided care throughout the survey period.*

**Question 5.5.7**

*(Include where care is not likely to have been given on a daily basis)*

Please think about any other relative or friend who has provided you with help and/or care over the last (*specify number of weeks*) because of your (*specify condition*).

Over the last (*specify number of weeks*) how many hours has that person helped and/or cared for you because of your (*specify condition*)? Please write the number of hours in the box below. Include only hours in addition to any usual care arrangements.

Number of hours 

--	--

*(Alternatively, if care is likely to have been given on a daily basis)*

Please think about any other relative or friend who has provided you with additional help and/or care over the last week because of your (*specify condition*).

In the table below please write how many days over the last week and how many hours on each of those days that person spent helping and/or caring for you. Please include only hours in addition to any usual care activities. Write zero if you received no help on a particular day.

Day	Number of hours
Yesterday	
The day before yesterday	
3 days ago	
4 days ago	
5 days ago	
6 days ago	
7 days ago	

**Question 5.5.8**

*(Include if the investigator wishes to value caregiver time according to the activity displaced)*

What would that person **normally** have been doing as the **main** activity if they had not been helping and/or caring for you? Please circle the number that best describes what that person would normally have been doing as their main activity if they had not been helping and/or caring for you.

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave ..... 7
- Seeking work ..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If your relative or friend **normally** took time off from paid work (or business activity if self-employed) please continue with question 5.5.10. Otherwise, go to *(specify next section of the questionnaire)*.

**Question 5.5.9**

*(Include if the investigator wishes to value lost caregiver paid work time as distinct from other caregiver time)*

If your relative or friend **normally** took time off from paid work as their **main** activity (or business activity if self-employed), approximately how much time in the last (*specify number of weeks*) did they take off work to help and/or care for you? Please write the **total** number of hours in the box below.

Total number of hours 

--	--

**Question 5.5.10**

*(Include if the investigator wishes to value lost caregiver paid work time using the human capital approach)*

What is your relative or friend's **main** occupation (*use 'job' if preferred*)?

.....

## 5.6 Childcare and other dependent costs

This section of the questionnaire asks about any assistance that you might have needed to look after your child/children or other dependants because of your (*specify condition*). Here we are interested only in assistance that you needed because of your (*specify condition*) and not for any other reason.

### **Question 5.6.1**

Over the last (*specify number of weeks*), was it necessary for someone to look after your child/children or other dependants because of your (*specify condition*) (if you have any), in addition to any usual childcare arrangements? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 5.6.2) .....1

No (go to (*specify next section of the questionnaire*)) .....2

Not applicable (no children or other dependants) (go to (*specify next section of the questionnaire*)) .....8

### **Question 5.6.2**

Over the last (*specify number of weeks*) how many different people (excluding yourself) have looked after your child/children or other dependants because of your (*specify condition*)? Please write the number of people in the box below. Indicate only people who have provided you with care in addition to any usual childcare arrangements.

Number of people 

--	--

**Question 5.6.3**

*(Include where care is not likely to have been given on a daily basis)*

Please think about the person who spent the **most** amount of time caring for your child/children or other dependants because of your (*specify condition*) over the last (*specify number of weeks*). Over the last (*specify number of weeks*) how many hours has that person cared for your child/children or other dependants? Please write the number of hours in the box below. Please include only hours in addition to any usual childcare arrangements.

Number of hours 

--	--

*(Alternatively, if care is likely to have been given on a daily basis)*

Please think about the person who spent the **most** amount of time caring for your child/children or other dependants because of your (*specify condition*) over the last week.

In the table below please write how many days over the last week and how many hours on each of those days that person spent helping and/or caring for your child/children or other dependants. Please include only hours in addition to any usual childcare arrangements. Write zero if there was no care provided on a particular day.

Day	Number of hours
Yesterday	
The day before yesterday	
3 days ago	
4 days ago	
5 days ago	
6 days ago	
7 days ago	

**Question 5.6.4**

Did you pay that person to look after your child/children or other dependants while you were ill with (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes .....1

No (please continue with question 5.6.6) .....2

**Question 5.6.5**

How much did you pay that person, in total, to look after your child/children or other dependants while you were ill with (*specify condition*) over the last (*specify number of weeks*)? Please specify the amount in the box below.

Total amount paid for care (£)  -  pence

**Question 5.6.6**

*(Include if the investigator wishes to value caregiver time according to the activity displaced)*

If they were not paid, what would that person normally have been doing as their **main** activity if they had not been looking after your child/children or other dependants because of your (*specify condition*)?

Please circle the number that best describes what that person normally would have been doing as their main activity if they had not been looking after your child/children or other dependants while you were ill with (*specify condition*).

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave..... 7
- Seeking work..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If the caregiver normally took time off from paid work (or business activity if self-employed) please continue with question 5.6.7. Otherwise, go to (*specify next section of the questionnaire*).

**Question 5.6.7**

*(Include if the investigator wishes to value lost caregiver paid work time as distinct from other caregiver time)*

If your caregiver normally took time off from paid work (or business activity if self-employed) as their **main** activity, approximately how much time over the last (*specify number of weeks*) did they take off work to look after your child/children or other dependants because of your (*specify condition*)? Please write the total number of hours in the box below.

Total number of hours 

--	--

**Question 5.6.8**

*(Include if the investigator wishes to value lost caregiver paid work time using the human capital approach)*

What is the caregiver's **main** occupation (*use 'job' if preferred*)?

.....

If more than one person looked after your child/children or other dependants because of your (*specify condition*) over the last (*specify number of weeks*) please continue with question 5.6.9. Otherwise, go to (*specify next section of the questionnaire*).

*Note that the following questions should be repeated for each additional caregiver that looked after the child/children or other dependants of the ill person throughout the survey period.*

**Question 5.6.9**

*(Include where care is not likely to have been given on a daily basis)*

Please think about another person who cared for your child/children or other dependants because of your (*specify condition*) over the last (*specify number of weeks*).

Over the last (*specify number of weeks*) how many hours has that person cared for your child/children or other dependants? Please write the total number of hours in the box below. Include only hours in addition to any usual childcare arrangements.

Total number of hours

--	--

***(Alternatively, if care is likely to have been given on a daily basis)***

Please think about another person who cared for your child/children or other dependants because of your *(specify condition)* over the last week.

In the table below please write how many days over the last week and how many hours on each of those days that person spent helping and/or caring for your child/children or other dependants. Please include only hours in addition to any usual childcare arrangements. Write zero if there was no care provided on a particular day.

Day	Number of hours
Yesterday	
The day before yesterday	
3 days ago	
4 days ago	
5 days ago	
6 days ago	
7 days ago	

**Question 5.6.10**

Did you pay that person to look after your child/children or other dependants because of your *(specify condition)*? Please circle the appropriate answer *(use 'response' if preferred)*.

Yes (go to *(specify next section of the questionnaire)*) .....1

No (please continue with question 5.6.10) .....2

**Question 5.6.11**

Over the last *(specify number of weeks)* how much did you pay that person, in total, to look after your child/children or other dependants because of your *(specify condition)* over the last *(specify number of weeks)*? Please specify the amount in the box below.

Total amount paid for care (£) 

--	--

 - 

--	--

 pence

**Question 5.6.12**

*(Include if the investigator wishes to value caregiver time according to the activity displaced)*

If they were not paid, what would that person normally have been doing as their **main** activity if they had not been looking after your child/children or other dependants because of your (*specify condition*)?

Please circle the number that best describes what that person normally would have been doing as their main activity if they had not been looking after your child/children or other dependants because of your (*specify condition*).

- Housework..... 1
- Childcare..... 2
- Caring for a relative or friend..... 3
- Voluntary work..... 4
- Leisure activities..... 5
- Attending school or university..... 6
- On sick leave..... 7
- Seeking work..... 8
- Paid work..... 9
- Other (**please specify**)..... 10

If the caregiver normally took time off from paid work (or business activity if self-employed) please continue with question 5.6.13. Otherwise, go to (*specify next section of the questionnaire*).

**Question 5.6.13**

*(Include if the investigator wishes to value lost caregiver paid work time as distinct from other caregiver time)*

If your caregiver took time off from paid work (or business activity if self-employed) as their **main** activity, approximately how much time over the last (*specify number of weeks*) did they take off work to look after your child/children or other dependants because of your (*specify condition*)? Please write the total number of hours in the box below.

Total number of hours 

--	--

**Question 5.6.14**

*(Include if the investigator wishes to value lost caregiver paid work time using the human capital approach)*

What is the caregiver's **main** occupation (*use 'job' if preferred*)?

.....

## 5.7 RESIDENTIAL CARE COSTS

This next set of questions asks about any residential care (i.e. care outside of the home, either daytime or overnight) you have received because of your (*specify condition*). Here we are interested only in care that you received because of your (*specify condition*) and not for any other reason.

### **Question 5.7.1**

Over the last (*specify number of weeks*) have you received any additional **daytime** residential care because of your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 5.7.2).....1

No (go to question 5.7.3).....2

### **Question 5.7.2**

If you received additional **daytime** residential care because of your (*specify condition*) please write the number of sessions or care episodes received over the last (*specify number of weeks*) in the box below. Put zero if you did not receive any additional daytime residential care over the last (*specify number of weeks*) because of your (*specify condition*).

Number of episodes 

--	--

What was the average length of each care episode? Put zero if you did not receive any additional daytime residential care over the last (*specify number of weeks*) because of your (*specify condition*).

Average length of episodes 

--	--

### **Question 5.7.3**

Over the last (*specify number of weeks*) have you received any additional **overnight** residential care because of your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 5.7.4).....1

No (go to (*specify next section of the questionnaire*)) .....2

### **Question 5.7.4**

If you received additional **overnight** residential care because of your (*specify condition*) please write the number of nights on which you received care over the last (*specify number of weeks*) in the box below. Put zero if you did not receive any overnight residential care over the last (*specify*

*number of weeks*) because of your (*specify condition*).

Number of nights 

--	--

## CHAPTER 6: PRODUCTIVITY LOSSES DUE TO ILLNESS

### 6.1 PRODUCTIVITY LOSSES DUE TO ACUTE ILLNESS

The next section of the questionnaire asks about how your (*specify as appropriate e.g. illness, condition or treatment*) has affected both your paid work (if you are currently in employment or business activity if self-employed) and your unpaid work. By unpaid work we mean activities such as household chores, shopping, caring for children and voluntary work, non-leisure activities that involve your time but for which you do not get paid.

#### **Question 6.1.1**

Please indicate the date (*specify as appropriate e.g. 'of your diagnosis,' 'on which you commenced treatment' or 'of onset of your illness'*).

Day ..... Month.....Year.....

Please indicate today's date.

Day ..... Month.....Year.....

#### **Question 6.1.2**

Before your (*specify as appropriate e.g. diagnosis, treatment, illness or condition*), were you in **paid** work (or business activity if self-employed)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 6.1.3).....1

No (go to question 6.1.10).....2

#### **Question 6.1.3**

How many hours a week, on average, did you work? Please write the number of hours in the box below.

Number of hours worked, on average, per week 

--	--

**Question 6.1.4**

Since your (*specify as appropriate e.g. diagnosis, treatment, illness or condition*) have you returned to **paid** work (or business activity if self-employed)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 6.1.5).....1

No (go to question 6.1.9).....2

**Question 6.1.5**

How long after your (*specify as appropriate e.g. diagnosis or treatment*) did you return to **paid** work (or business activity if self-employed)? Please write the number of weeks and days in the box below. Put zero if you returned to paid work immediately.

Number of weeks 

--	--

 - 

--	--

 days

**Question 6.1.6.1**

When you first returned to paid work (or business activity if self-employed) was the number of hours you actually worked a week less compared with before your (*specify as appropriate e.g. diagnosis or treatment*)? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 6.1.7)..... 1

No (go to question 6.1.9)..... 2

Cannot remember (go to question 6.1.9) ..... 9

**Question 6.1.7**

Please indicate in Table 2 below when you first returned to paid work (or business activity if self-employed) how many hours a week, on average, you worked. Please indicate any increases in hours since that time and the number of weeks for which you worked those hours. For example (as shown in Table 1 below), you may have worked 20 hours for the first four weeks after returning to work, then 30 hours for the next two weeks before resuming your usual schedule of 40 hours for the past 3 weeks.

Table 1. Example:

Number of hours worked per week since first returned to <b>paid</b> work	Number of weeks worked those hours
20 hours	4 weeks
30 hours	2 weeks
40 hours	Usual schedule for the past 3 weeks

Table 2. Please enter your number of work hours, on average, per week since returning to paid work in the table below:

Number of hours worked per week since first returned to <b>paid</b> work	Number of weeks worked those hours

*Please note that the above question is complex and if a gradual return to work is likely then the use of a patient diary or regular surveying of patients may be more appropriate.*

**Question 6.1.8**

Over the last (*specify number of weeks*), how many hours a week, on average, did you spend in paid work? Please write the number of hours in the box below.

Number of hours worked, on average, per week

**Question 6.1.9**

*(Include if the investigator wishes to value patient time using the human capital approach and if not asked previously in the questionnaire)*

What is your **main** occupation (*use 'job' if preferred*)?

.....

**Question 6.1.10**

Before your (*specify as appropriate e.g. diagnosis or treatment*), how many hours a week, on average, did you spend on **unpaid** work (e.g. household chores, shopping, caring for children or voluntary work)? Please write the number of hours in the box below.

Number of hours worked, on average, per week

**Question 6.1.11**

Since your (*specify as appropriate e.g. diagnosis or treatment*) have you returned to **unpaid** work at all? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 6.1.12) .....1

No (go to (*specify next section of the questionnaire*)) .....2

**Question 6.1.12**

How long after your (*specify as appropriate e.g. diagnosis or treatment*) did you return to **unpaid** work? Please write the number of weeks and days in the box below. Put zero if you returned to unpaid work immediately.

Number of weeks  -  days

**Question 6.1.13**

Please indicate in Table 2 below when you first returned to **unpaid** work how many hours a week, on average, you worked. Please indicate any increases in hours since that time and the number of weeks for which you worked those hours. For example (as shown in the example Table 1 below), you may have worked 5 hours for the first four weeks after returning to work, then 10 hours for the next two weeks before resuming your usual schedule of 20 hours for the past 3 weeks.

Table 1. Example:

Number of hours worked per week since first returned to <b>unpaid</b> work	Number of weeks worked those hours
5 hours	2 weeks
10 hours	3 weeks
20 hours	Usual schedule for the past 3 weeks

Table 2. Please enter your number of work hours, on average, per week since resuming unpaid work in the table below:

Number of hours worked per week since first returned to <b>unpaid</b> work	Number of weeks worked those hours

**Question 6.1.14**

Over the last (*specify number of weeks*), how many hours a week, on average, did you spend on your **unpaid** work? Please write the number of hours in the box below.

Number of hours worked, on average, per week



**6.2 PRODUCTIVITY LOSSES DUE TO CHRONIC ILLNESS**

The next section of the questionnaire asks about how your (*specify as appropriate e.g. illness, condition or treatment*) has affected both your paid work (if you are currently in employment or business activity if self-employed) and your unpaid work. By unpaid work we mean activities such as household, chores shopping, caring for children and voluntary work, non-leisure activities that involve your time but for which you do not get paid.

**Question 6.2.1**

Are you in **paid** work? Please circle the appropriate answer (*use 'response' if preferred*).

- Yes (please continue with question 6.2.2) .....1
- No (go to question 6.2.4).....2

**Question 6.2.2**

Over the last (*specify number of weeks*), how many hours a week, on average, did you work? Please write the number of hours in the box below.

Number of hours worked, on average, per week 

--	--

**Question 6.2.3**

*(Include if the investigator wishes to value patient time using the human capital approach and if not asked previously in the questionnaire)*

What is your **main** occupation (*use 'job' if preferred*)?

.....

**Question 6.2.4**

Over the last (*specify number of weeks*), how many hours a week, on average, did you spend on **unpaid** work? Please write the number of hours in the box below.

Number of hours worked, on average, per week 

--	--

## CHAPTER 7: MEDICATION AND MEDICAL SUPPLIES

The next section of the questionnaire asks about how your (*specify as appropriate e.g. illness, condition or treatment*) has affected both your paid work (if you are currently in employment or business activity if self-employed) and your unpaid work. By unpaid work we mean activities such as household chores, shopping, caring for children and voluntary work, non-leisure activities that involve your time but for which you do not get paid.

### 7.1 PRESCRIBED MEDICATION

The following section asks about any **prescribed** medications that you have used on a regular daily basis or on an occasional when needed basis during the last (*specify number of weeks*) for your (*specify condition*).

#### **Question 7.1.1**

In the last (*specify number of weeks*), what medications **prescribed** by your doctor (including tablets, capsules, inhalers, injections, creams, lotions and mixtures) have you used on a **regular daily** basis to (*specify as appropriate e.g. control, treat or manage*) your (*specify condition*)? Do not include medications that you only use (*include some phrase such as 'if your condition deteriorates' that is appropriate to the condition under consideration and conveys the meaning of medications taken on an occasional when needed basis*).

Please write the information in the table below. Becotide<sup>R</sup> is given as an example of how we would like you to complete the table. You may find it helpful to look on the packaging of your medication for some of the details.

<b>Name</b>	<b>Strength</b>	<b>Dosage form (e.g. tablets, inhaler, creams ointments etc.</b>	<b>Dose (e.g. number of tablets or puffs of inhaler)</b>	<b>Number of times daily you normally use this dose</b>	<b>How long ago did you start using the medication (if within the last <u>(specify number of weeks)</u>)? Else write <u>“more than (specify number of weeks)”</u></b>	<b>When did you stop using the medication (if within the last <u>(specify number of weeks)</u>)? Else write <u>“continuing”</u></b>
Becotide <sup>R</sup>	100 mcg	Inhaler	Two puffs	Twice daily	More than (specify number of weeks)	Continuing

**Question 7.1.2**

In the last (*specify number of weeks*), what medications **prescribed** by your doctor (including tablets, capsules, inhalers, injections, creams, lotions and mixtures) have you used on an occasional **when needed** basis (*alternatively, use a phrase which implies occasionally when needed and is relevant to the illness being investigated e.g. during an asthma attack*) to (*specify as appropriate e.g. control, treat or manage*) your (*specify condition*)?

In the table below, please write the name, strength and dosage form (for example tablets, capsules, inhaler, cream or mixture) of each medication and how often you have used each medication over the last (*specify number of weeks*).

Ventolin<sup>R</sup> is given as an example of how we would like you to complete the table. Again, you may find it helpful to look on the packaging of your medication for some of the details.

Name	Strength	Dosage form	Dose	How often have you used the medication over the last ( <i>specify number of weeks</i> )
Ventolin <sup>R</sup>	100 mcg	Inhaler	Two puffs	On eight occasions.

*Note that the medications listed as examples above serve as a guide for investigators on how the tables should be completed. Investigators are encouraged to substitute in the above table examples of medications relevant to their particular disease area or illness under study.*

*Note also that the above tables are obviously complex and where the equivalent information can be obtained from patient records or where the use of a diary is feasible these approaches are recommended.*

The following questions ask about payment for your prescriptions.

**Question 7.1.3**

Over the last (*specify number of weeks*) have you paid for any of your prescriptions? Please circle the appropriate answer (*use 'response' if preferred*).

Yes (please continue with question 7.1.4) .....1

No (go to (*specify next section of the questionnaire*)) .....2

**Question 7.1.4**

Over the last (*specify number of weeks*) how much, in total, have you paid for your prescriptions? Please specify the amount in the box below.

Total amount spent on prescriptions (£) 

--	--

 - 

--	--

 Pence

## 7.2 MEDICATION PURCHASED WITHOUT A PRESCRIPTION

The next question asks about medications you purchased **without** a prescription (e.g. over-the-counter from chemists or from a supermarket) for your (*specify condition*).

### **Question 7.2.1**

In the last (*specify number of weeks*), have you used any of the following medications to (*specify as appropriate e.g. control, treat or manage*) your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*) for each medication listed.

Laxatives	YES/NO
Cough medicines	YES/NO
Pain-relievers such as aspirin or paracetamol	YES/NO
Other ( <b>please specify</b> ).....	
.....	

In the table below, please indicate the name, strength and dosage form (for example tablets, capsules, inhaler, cream or mixture) and dose of each medication and how often you have used each medication in the last (*specify number of weeks*). Please also indicate how much money you spent on each medication.

Panadol<sup>R</sup> is given as an example of how we would like you to complete the table. Again, you may find it helpful to look on the packaging for some of the details.

Name	Strength	Dosage form	Dose	How often you have used this medication over the last ( <i>specify number of weeks</i> )	Amount spent on medication
Panadol <sup>R</sup>	700 mg	Tablets	Two tablets	On 6 occasions	£.....-.....p
					£.....-.....p
					£.....-.....p
					£.....-.....p

*Note that the non-prescription medication listed above serves as a guide for individual investigators on drugs that are likely to be of interest to include in any cost questionnaire. However, there may be others relevant to specific diseases. Investigators are encouraged add these to the table above.*

**7.3 DEVICES AND APPLIANCES**

The next section of the questionnaire asks about any **equipment** you have purchased for your (*specify condition*).

**Question 7.3.1**

Since (*specify as appropriate e.g. being diagnosed with this condition*) have you bought any of the following types of equipment to help (*specify as appropriate e.g. control, treat or manage*) your (*specify condition*)? Please circle the appropriate answer (*use 'response' if preferred*) for each item of equipment listed.

Special mattresses	YES/NO
Special bedding	YES/NO
Nebulisers	YES/NO
Spacers	YES/NO
Dehumidifier	YES/NO
Other ( <b>please specify</b> )..... .....	

*Note that the equipment listed above serves as a guide for individual investigators on items that may be of interest to include in a patient cost questionnaire in one specific disease area, namely asthma. There will be different equipment of relevance to other disease areas. Investigators are advised to consider all possibilities relevant to the disease under study and to amend the above table accordingly.*

**Question 7.3.2**

*(Include if the investigator wishes to value equipment at actual purchase price rather than the wholesale price)*

Over the last (*specify number of weeks*) how much have you paid **out of pocket** for the special equipment listed above? Please specify the amount in the box below. Put zero if you have not paid any money out of pocket over the last (*specify number of weeks*) for special equipment for your condition.

Amount spent on special equipment (£) 

--	--

 - 

--	--

 pence

*Note that some of the above items may be provided free of charge to patients through social services, hospitals and so forth.*

## CHAPTER 8: PRIVATE CONSULTATIONS

*Note that NHS referrals are not included in this section as details of such encounters should be available from patient records.*

The following questions ask about any contacts you have had with **health care professionals outside the (specify payer or service provider e.g. NHS or hospital clinic)** in order to help (specify as appropriate e.g. control, treat or manage) your (specify condition) and for which you have made some payment

### **Question 8.1.1**

Over the last (specify number of weeks) were you visited by or did you visit a health care professional other than for your normal (specify e.g. hospital appointments) in order to help (specify as appropriate e.g. control, treat or manage) your (specify condition) and for which you made some payment? Please circle the appropriate answer (use 'response' if preferred).

Yes (please continue with question 8.1.2) .....1

No (go to (specify next section of the questionnaire)) .....2

**Question 8.1.2**

In the table below please write the number of visits to each type of professional listed and the amount of any payments made. Please write zero if there were no visits to each of the professionals listed.

Care professional	Number of visits	If you had to pay for any of these services please indicate how much for each visit
Hospital doctor or consultant		£.....-....p
Nurse		£.....-....p
Physiotherapist		£.....-....p
Homeopath/Naturopath		£.....-....p
Acupuncturist		£.....-....p
Other ( <b>please specify</b> ).....		£.....-....p

*Note that the professionals listed above serve as a guide for individual investigators. There may be others of interest and these should be included in specific questionnaires. Investigators are advised to consider all possibilities relevant to the disease under study and amend the above table accordingly. The purpose behind this set of questions is to gauge patient initiated consultations for the conditions under study in particular those with professionals working outside of public insurance programmes such as the National Health Service in Britain. The question would be most relevant to include where a treatment is co-ordinated through a single centre and medical records cannot be used to provide this information.*

**CHAPTER 9: ADDITIONAL INFORMATION**

**9.1 OTHER COSTS**

The next section of the questionnaire asks whether there are any other costs not covered previously in this questionnaire.

**Question 9.1.1**

*(Include if the questionnaire refers to single visit to a health care facility and is to be completed at that health care facility)*

Have you incurred any other costs because of coming to *(specify location e.g. general practitioner surgery or hospital clinic)*?

Yes .....1

No .....2

If yes, what were they for and how much did you spend? In the table below please write the purpose of other costs and the amount of money spent.

Purpose	Amount spent
	£.....-.....p

Do you have any further comments or any information you would like to add about the cost to you of coming to *(specify location e.g. general practitioner surgery or hospital clinic)* for *(specify as appropriate e.g. treatment)*?

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

**Question 9.1.2**

*(Include if the questionnaire relates to an acute or chronic illness)*

Please write down any other costs you have had to pay for related to your (*specify condition*) in addition to the things we have already asked about in this questionnaire. For example, telephone calls, extra laundry, clothing or heating, or additional travel expenses such as having to use taxis rather than private car or public transport.

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

Is there anything else that you would like to tell us about your (*specify condition*) or this questionnaire?

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

## 9.2. SOCIODEMOGRAPHICS

Finally, could you please provide a few details about yourself. The aim of these questions is just to know how answers vary across respondents depending on these circumstances. All answers will be treated as confidential. Please circle the correct answer (*use 'response' if preferred*) or indicate the correct number or description as necessary.

### **Question 9.2.1**

Are you?

- Male .....1  
 Female.....2

### **Question 9.2.2**

What is your date of birth? Please indicate below.

Day ..... Month.....Year.....

### **Question 9.2.3**

What is your marital status? Please circle the appropriate answer (*use 'response' if preferred*).

- Single.....1  
 Married or living as married.....2  
 Separated .....3  
 Divorced.....4  
 Widowed.....5  
 Other (SPECIFY).....6

**Question 9.2.4**

What is your employment status? Please circle the appropriate answer (*use 'response' if preferred*).

- In full-time work.....1
- In part-time work.....2
- Currently seeking work.....3
- Homemaker.....4
- Retired.....5
- Other (SPECIFY).....6

**Question 9.2.5**

What is the highest level of education you completed? Please circle the appropriate answer (*use 'response' if preferred*).

- Primary.....1
- Some secondary.....2
- All secondary.....3
- College.....4
- University.....5
- Post-graduate university (SPECIFY).....6

**Question 9.2.6**

Could you please provide an estimate of your annual household income from all sources (before tax and other deductions and including your partner/spouse)? Please tick the appropriate box.

Less than £5,000		£15,000-£19,999		£30,000-£34,999	
£5,000-£9,999		£20,000-£24,999		£35,000-£39,999	
£10,000-£14,999		£25,000-£29,999		Over £40,000	

**Question 9.2.7**

How many adults are there in your household? Please indicate the number of adults in the box below.

Number of adults

**Question 9.2.8**

How many children are there in your household? Please indicate the number of children in the box below.

Number of children

## **CHAPTER 10: USEFUL REFERENCES**

1. Brouwer WBF, Koopmanschap MA, Rutten FFH. Productivity costs measurement through quality of life? A response to the recommendation of the Washington Panel. *Health Economics* 1997;6(3):253-259.
2. Brouwer WBF, Koopmanschap MA, Rutten FFH. Patient and informal caregiver time in cost-effectiveness analysis - A response to the recommendations of the Washington panel. *International Journal of Technology Assessment in Health Care* 1998;14(3):505-513.
3. Brouwer WB, Koopmanschap MA, Rutten FF. Productivity losses without absence: measurement validation and empirical evidence. *Health Policy* 1999 Jul;48(1):13-27.
4. Brouwer WB, van Exel NJ, Koopmanschap MA, Rutten FF. The valuation of informal care in economic appraisal. A consideration of individual choice and societal costs of time. *Int J Technol Assess Health Care* 1999 Winter;15(1):147-60.
5. Caro JJ, Getsios D, Raggio G, Caro G, Black L. Treatment of migraine in Canada with naratriptan: a cost-effectiveness analysis. *Headache* 2001 May;41(5):456-64.
6. Goossens ME, Rutten-van Molken MP, Vlaeyen JW, van der Linden SM. The cost diary: a method to measure direct and indirect costs in cost-effectiveness research. *J Clin Epidemiol* 2000 Jul;53(7):688-95.
7. Grant DM, Mauskopf JA, Bell L, Austin R. Comparison of valaciclovir and acyclovir for the treatment of herpes zoster in immunocompetent patients over 50 years of age: a cost-consequence model. *Pharmacotherapy* 1997 Mar-Apr;17(2):333-41.
8. Johannesson M, Meltzer D. Some reflections on cost-effectiveness analysis. *Health Economics* 1998;7(1):1-7.
9. Leigh JP, Seavey W, Leistikow B. Estimating the costs of job related arthritis. *J Rheumatol* 2001:Jul;28(7):1647-54.
10. Liljas B. How to calculate indirect costs in economic evaluations. *Pharmacoeconomics* 1998;13(1):1-7.

11. Liljas B. How to calculate indirect costs in economic evaluations - The author's reply. *Pharmacoeconomics* 1998;13(5 Pt1):566-569.
12. Lucas DO, Zimmer LO, Paul JE, Jones D, Slatko G, Liao W, Lashley J. Two-year results from the asthma self-management program: long-term impact on health care services, costs, functional status, and productivity. *J Asthma* 2001 Jun;38(4):321-30.
13. Norlund A, Apelqvist J, Bitzen PO, Nyberg P, Schersten B. Cost of illness of adult diabetes mellitus underestimated if comorbidity is not considered. *J Intern Med* 2001 Jul;250(1):57-65.
14. Schulman EA, Cady RK, Henry D, Batenhorst AS, Putnam DG, Watson CB, O'Quinn SO. Effectiveness of sumatriptan in reducing productivity loss due to migraine: results of a randomized, double-blind, placebo-controlled clinical trial. *Mayo Clin Proc* 2000 Aug;75(8):782-9.
15. The UK Working Party on Patient Costs. An annotated cost questionnaire for completion by patients. Health Economists' Study Group meeting, Aberdeen 1999.
16. Ungar WJ, Coyte PC. Prospective study of the patient-level cost of asthma care in children. *Pediatr Pulmonol* 2001 Aug;32(2):101-8.
17. van Roijen L, Essink-Bot ML, Koopmanschap MA, Bonsel G, Rutten FFH. Labor and health status in economic evaluation of health care - The health and labor questionnaire. *International Journal of Technology Assessment in Health Care* 1996;12(3):405-415.
18. van Roijen L, Essink-Bot ML, Koopmanschap MA, Bonsel G, Rutten FF. Labor and health status in economic evaluation of health care. The Health and Labor Questionnaire. *Int J Technol Assess Health Care* 1996 Summer;12(3):405-15.
19. Weinstein MC, Siegel JE, Garber AM, Lipscomb J, Luce BR, Manning WG, et al. Productivity costs, time costs and health-related quality of life: A response to the Erasmus group. *Health Economics* 1997;6(5):505-510.