

# EUROFAMCARE

## Questionnaire User Guide

### Welcome the Eurofamcare Project

Welcome to the EUROFAMCARE Project. You have joined a team of people across six countries in Europe Germany, Greece, Italy, Poland, Sweden and the UK, all of whom are undertaking interviews for the project at the same time; here the University of Sheffield is coordinating the project and we intend to speak to 1,000 carers from all over the UK. More and more people are living to an older age and often face longer periods in need of care. Present British and European policies aim to help older people to continue to live at home for as long as they can and this is only possible with the support of family carers. The aim of our project is to answer these questions

The main aim of the project is to answer these questions.

- Which services are available to support family carers?
- What are family carers' experiences of using these services?
- Do these services really reach the people most in need of support?
- What do family carers think of those services?
- What are the barriers that keep family carers from using support services?
- Do the services meet the needs and demands of caregivers?
- What makes an effective support service for carers?
- Do support services improve the quality of life for the older person?

This user guide is designed to help you complete the questionnaire, if however you have any questions about the project please feel free to contact us, Jayne or Louise on 0114 2715915 or 0114 2229870 both numbers have answer phones so if we are not around please leave us your details and we promise to get back to you. We are really pleased to welcome you to the team and hope you enjoy meeting new people and talking to carers of older people.

All the best

Jayne Brown

UK coordinator for the Eurofamcare project

## What is my part in the project?

This is a large and complex project that has a number of stages outlined below:

- A) Questionnaire to a 1,000 carers, this is the part of the project that you are helping us with now.
- B) A twelve month follow up telephone interview to a selection of the participants in stage A to see if things have changed for them over the year. You will not be expected to undertake this interview but we do need your help to ask carers you interview if they would mind one of the research team phoning them in a years time to undertake a brief follow up interview.
- C) We are going to conduct interviews with the people who provide services. Again another member of the research team will do this but we do need your help to ask participants you interview that use services if we can contact their service providers. **It is important that you stress we will not mention them or the person they care for by name nor discuss the service provided to any individual.**

So to summarise you will undertake the interview with carers now, completing the questionnaire, and that the same time you ask the participants permission for us to undertake a follow up interview by phone in a years time and permission for us to contact service providers. (See consent below)

## Who do we want to speak to?

**WE ARE INTERESTED IN TALKING TO PEOPLE WHO CARE FOR OR SUPPORT PEOPLE WHO ARE 65 YEARS OLD, OR MORE, FOR FOUR HOURS A WEEK OR MORE.**

## Who is a carer?

Many of these people will be related to the older people (son or wife for example) but we are not restricting contributions to the project to **family members**. Therefore other people such as **neighbours or friends** can also take part. Be warned many people do not see themselves as 'carers', if you have to give increasing amounts of help to your husband or wife for example you may not describe yourself as their carer, so it may be better to use the term support when recruiting participants. For example: *Do you give support to someone who is over 65 years old.* Remember take a broad view of who is a carer, its makes your life easier too!

## What do you mean by care or support?

Care or support can be anything other than just giving the older person money. So for example if someone helps with domestic chores, social outings, organising everyday life or spends time talking with an older person to prevent anxiety or depression for four or more hours a week, they can take part in the study. As you can see, once again, we have a very broad definition of care and support.

## What exactly do you mean by four or more hours a week?

The four hours care or support can be given at any time during the week in a block of time or spread over time. For example someone who spends 2 hours with an older person twice a week, an hour four times a week, or one morning a week would all be eligible to take part, again we are trying to be as flexible as possible here.

### Tell me about the consent form

Having established that your participant carer qualifies for the study we then need to gain their signature of consent. To make life easy for you this form is printed on the inside page of the questionnaire.

### This project is about services to support carers. Do they or the older people they care for have to use services in order to take part in the study?

No, the views of people who do not use services are just as important as those who do and we are also interested in understanding what factors encourage or discourage people from using services. Please include people whether or not they use services.

### Completing the questionnaire

#### 'Elder'

Throughout the questionnaire you will see the word 'Elder' we use this to represent the cared for older person. However we do not intend for you to use this term in the interview, we would like you to substitute the more personal term preferred by the carer, e.g. your mother, Jenny, your Grandfather.

#### Some general points

As you can see the questionnaire is quite detailed and although we have provided you with 'show' cards to help people chose the correct answer for them you may find, as we did when we did some interviews, that it sometimes helps to give the carer a copy of the questionnaire to follow as you complete it.

You will see that many of the response options are numbered for you but in some cases you will need to write the code number in. As a general rule [although there are exceptions] you will find that:

- |   |       |         |                  |
|---|-------|---------|------------------|
| ① | = No  | ⑧ or ⑧⑧ | = Not applicable |
| ① | = Yes | ⑨ or ⑨⑨ | = Missing data   |

Many of the responses options require you to circle the appropriate response. For example:

<b>What is your relationship to ELDER?</b>	Spouse / Partner ①	Child ②
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You circle the appropriate response

<b>What is your relationship to ELDER?</b>	Spouse / Partner ①	Child ②
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Sometimes you may need to ✓ boxes instead of circling but this will be clear in the questionnaire

Occasionally you will find a X in a response box, this means that you are not allowed to use that box for that particular item, as in the example below the N/A, not applicable, is not an available option for the first item

122 C122COPE	Do you feel you cope well as a caregiver?	①	②	③	④	N/A
124 C124COPE	Does caregiving cause difficulties in your relationships with friends?	①	②	③	④	⑧

**The questionnaire page by page**

**Front page**

Questionnaire Number (from 1 to 1000) **XXXX**

This will already be completed for you

# EUROFAMCARE

## Questionnaire

This is already completed for you

This is already completed for you

001 G001INT	<b>NAME / NUMBER OF INTERVIEWER</b>	<input type="text"/>
002 G002CTRY	<b>COUNTRY</b> (see User Guide to insert appropriate code)	<input type="text"/>
003 G003REG	<b>REGION</b> (see User Guide to insert appropriate code)	<input type="text"/>
004 G004LOCA	<b>LOCALITY:</b> ① metropolitan ② urban ③ rural	<input type="text"/>
005 G005SITE	<b>SITE</b> (write the name of the site)	<input type="text"/>
006 G006ID	<b>CASE NUMBER</b> (for individual interviewer)	<input type="text"/>

See list provided in your pack, this code will be next indicated on the same list as question 5 site

'Site' means the name of the small local area in which you are working, please write in the name and the code number of the site on the list provided

This refers to the number of interview for you as an individual interviewer. So if you were going to do 10 interviews in total and this was your second you would write 2/10

**DATE OF INTERVIEW: (Day / Month / Year)**  
**OLDER present at the interview?** ① Yes ② No

**MODE OF RECRUITMENT**

Health or social care professional (e.g. Doctor or social worker)	①
Priest/parish/religious organisations	②
Door to door	④
Voluntary organisation e.g. carer support group	⑤
Advertisement (e.g. Newspaper, handbill/flyer/posters)	⑥
Lists (e.g. of older residents, or electoral role)	⑦
Other:	⑧
Specify, _____	
Snowball	⑨
Snowball channel if known	

If you contact a carer through more than one source, e.g. doctor and priest please only record the first source

See note on pages below

### Completing 'Mode of recruitment'

On the first page you will see a section marked 'Mode of Recruitment' you should circle **one** appropriate box. For example

Health or social care professional (e.g. Doctor or social worker)	<input checked="" type="radio"/>
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You will see that one of the categories is called 'snowball'. This term indicates that from interviewing one person you gain an interview with another. For example interviewing a respondent you recruited by calling 'door to door' in an area they tell you about a carers group they attend. You contact this group and gain another interview this is a snowball and you will circle ⑨. You then need to indicate the channel from which the snowball started, in this example 'door to door' recruitment ①.

Snowball	<input checked="" type="radio"/>
Snowball channel if known	1.

### Page One - Consent

As I am sure you know we have to gain written consent from all participants in academic research. To make life easier for you the consent form below is printed on page one of the questionnaire.

		Yes	No
1	I confirm that I have read and understood the information sheet and have had the opportunity to ask questions		
2	I agree to being contacted again in 12 months time for a second short follow up interview. <b>NB. If the respondent answers no to this question it is still possible for them to take part in the study by completing this current interview</b>		
3	I understand that my name address and telephone number will be kept on a database for the duration of the study; that only one of the researchers, will have access to those details and that the database will be destroyed at the end of the study <b>NB. If the respondent answers no to this question it is still possible for them to take part in the study by completing this current interview</b>		
4	Where I use services, I give permission for the researcher to contact the service provider. I understand that they will not mention my name or the name of the person I care for, nor discuss specifically any service we receive <b>NB. If the respondent answers no to this question it is still possible for them to take part in the study by completing this current interview</b>		

5	I understand that I am free to withdraw from the study without giving any explanation or my rights to receive services being affected		
6	I agree to take part in this study		
Name of participant		Date	Signature
Name of person taking the consent		Date	Signature

*When you are recruiting participants it is important to give them the information sheet that tells them all about the project and **question 1** just confirms that you have done that. In **question 2** participants are giving their permission for us to contact them again in 12 months time, however, should carers agree to be interviewed by you but do not want to be followed up they can still complete this questionnaire and we will ensure that we do not contact them again. In **question 3** we are ensuring that we have carers permission to keep enough details so that we can ring them again in a years time, it would be little use people agreeing to speak to us again if they refuse to let us keep their details but once again if people refuse they can still take part in the study by completing the questionnaire with you. We would like to contact the providers of services that respondents use and we are asking their permission to do that in **question 4** . However, if carers would prefer that we did not contact their service providers then they can still fill in this questionnaire and we will ensure that we do not contact any of their service providers. **Question 5** is important, it is highly unlikely that having agreed to take part carers would wish to withdraw from the study however it is equally important that they understand that they can withdraw without suffering any ill effects. **Question 6** just confirms their willingness to take part in the study*

THANK YOU FOR HELPING WITH OUR WORK. WE WOULD LIKE TO BEGIN WITH SOME QUESTIONS ABOUT YOUR CARING SITUATION AND THE PERSON YOU CARE FOR.

011 C011NUM	<b>How many family members do you give support / care to for more than four hours a week who are over 65 years old?</b>		<input type="text"/>
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**INTERVIEWER:**

*If the carer gives support to more than one elder, please ask them to think of the person to which they give most help and answer with him / her in mind. If they give the same amount of care to each person ask them to think of only one person when answering.*

*Find out what name the respondent wishes to use for the older person (e.g. mum, harry) and use that name wherever you see the word 'elder' in the questionnaire.*

*Of course all the people you are interviewing are caring for someone [over the age of 65] for more than four hours a week, however, some will be caring for more than one person, their mother and father for example. We only want to interview them about caring for one person and in order to chose which one we ask them to think about the person to whom they give the most care during the interview. If, however, they give equal amounts of care to both then we need to ask them to think of only one of the two, and it is they that become 'Elder' for the purposes of this questionnaire*

012 C012HRSA C012HRSB C012HRSC C012HRSD	<b>On average, how many hours a week do you give care and support to Elder</b>		
013	How many people who are not elderly [e.g. children etc] do you give care and support?		
014	In total how many hours a week do you give care and support to all the people <u>other than Elder</u> , you care for?		
015 E013RELA E013RELO	<b>What is your relationship to ELDER?</b>	Spouse / Partner ① Sibling ③ Uncle/ Aunt ⑤ Cousin ⑦	Daughter ② Son ④ Other specify: ⑤
016 E014SEX	<b>What is ELDER's Gender?</b>	Male ①	Female ②
017 E015AGE	<b>How old is ELDER?</b>		<input type="text"/>
018 E016NAT1 E016NAT2 E016NAT2	<b>What is ELDER's nationality?</b>		List: xx xx xx
019 E017CTR1 E017CTR2 E017CTR3	<b>What is Elder's ethnic origin?</b>		List: xx xx xx
020 E018MARI	<b>What is ELDER's marital status?</b>	Married / Cohabiting ① Divorced / Separated ③	Widowed ② Single ④
021 C021HOME	<b>Where do you and ELDER live?</b>		In the same household ① In different households but the same building ② Within walking distance ③ Within 10 minutes drive / bus or train journey ④ Within 30 minutes drive / bus or train journey ⑤ Within 1 hours drive / bus or train journey ⑥ Over 1 hours drive / bus or train journey ⑦

This means all other people and could include, other older people, children, or grandchildren for example. Write 0 if help is given to no other person

You need to add up the hours of care the carer gives to all the individuals, except Elder, referred to in the previous question. If non write 0

Missing information = 999 for this question

See the separate sheet of codes provided for this question and write in the appropriate code

022 E022_1	<b>Where does Elder usually live?</b>	In their own home	①
You need to ensure that you record a response for each of the options in this question		In a care home	'In their own home' includes older people who live with members of their families
		Sheltered housing	
		Other	
		Please specify	
023	<b>Who does Elder live with? (circle all that apply)</b>	Alone	Yes ① No ①
E22CHILD	With their Children	Yes ① No ①	N/A ⑧
E22PARTN	With their partner	Yes ① No ①	N/A ⑧
E22PAID	With paid carers (in their own home)	Y	This question will help us to work out the economic costs of caring but should <u>only</u> be completed for those Elder's who <u>do not live</u> either in a care home or with the carer. You must <u>ensure that you write 0</u> if there are no people under 14 in Elders household
E22OTHER	With others, please	Y	
specify: _____			
E22OTHSP			
024	<b>For those who do not live in a care home or with the carer</b>		
What is the total number of people in Elder's household, including Elder themselves?			
And how many of them are aged 14 years or less?			

*We would now like to look at elder's needs for support and care in a little more detail.*

025 E025REA1 E025REA2 E025REA3 E025REA4	<b>In your opinion what is the main reason that Elder needs care and support?</b>	
(For example, problems with walking, problems with safety if left alone, has to stay in bed, other age related issues / disorders / diseases)		
Write only one main reason here		
026	<b>Are there any other reasons?</b>	
Write up to four more reasons here		

C) Would you like more help for ELDER to meet these needs? (Circle as many as apply)											
B) Who, if anyone, helps ELDER to meet their needs? ↓ (Circle as many as apply) ↓											
A) Does ELDER have a need for help with any of these areas (below)? If so, do they rely partially or completely on others to meet that need? (Circle as appropriate) ↓											
		Completely	Partially	Does not have this need	No one	The interviewed Carer	Other informal carers	Service / support organisations (voluntary private or public)	Yes	No	Not Applicable
027 E031NEDA- E031NEDF	<b>Health needs:</b> (e.g. assistance with medication, medical treatment, rehabilitation, therapy etc)	②	①	①	○	○	○	○	①	①	⑧
028 E032NEDA- E032NEDF	<b>Physical / Personal:</b> (e.g. washing, dressing, eating or going to the toilet)	②	①	①	○	○	○	○	①	①	⑧
029 XXXXXXDA- XXXXXXDF	<b>Mobility e.g. inside or outside the house, transport</b>	②	①	①	○	○	○	○	○	①	⑧
030 E033NEDA- E033NEDF	<b>Emotional / Psychological / Social:</b> (e.g. companionship, reassurance)	②	①	①	○	○	○	○	○	①	⑧
031 E034NEDA- E034NEDF	<b>Domestic:</b> (e.g. housework)										
032 E035NEDA- E035NEDF	<b>Financial management:</b> (e.g. paying bills for the cared for from ELDER's own money)										
033 E036NEDA- E036NEDF	<b>Financial support:</b> (e.g. Supporting ELDER by providing them with money)										
034 E037NEDA- E037NEDF	<b>Organising and managing care &amp; support: (e.g. contacting services)</b>	②	①	①	○	○	○	○	①	①	⑧

In this table we want to know if Elder has any of the needs in column A, such health, physical or emotional for example. Then we want to know if they need any help in that area, who, if anyone gives that help and would the carer like more help for Elder with those needs

The answer given to the question in column 'A' determines how Columns 'B' and 'C' are completed.

If you tick ① in column 'A' then you need not complete column 'B' and 'C' for that item, otherwise you need to complete each column

*Some of the most stressful situations for carers are related to problems which affect the memory and behaviour of the cared for person. The next questions relate to these issues.*

035 E041MEM	<b>Has ELDER any memory problems?</b> (Such as having difficulty in remembering what day it is, or recognising friends or neighbours)	Yes ①	No ①
036 E042MEM	<b>IF YES</b> , has the doctor given you any cause of ELDER's memory problems?	Yes ①	No ①
037 E043MEM	<b>IF YES</b> , please specify:		
		Dementia ①	Other ②
		<b>Specify</b>	

038 E044BEH	<b>Does ELDER suffer from any behavioural problems?</b> (Such as wandering, constantly repeating what is said, shouting inappropriately)	Yes ①	No ②
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		Most of the time	Sometimes	Rarely	Never
039 E051BEH	Wander in or outside the home environment or behaves in a way that endangers their safety	①	②	③	④
040 E052BEH	Have difficulty holding normal conversation or has no insight into their problems, become uncooperative with your requests				
041 E058BEH	Do they behave in ways that you find upsetting. For example constantly ask questions, follow you around, repeat what has been said shout and scream for no particular reason or inappropriately dress/ undress		①	②	③

It may be necessary to let respondents read these options

*Elder's problems you have identified mean that they need your support and care. The next questions are intended to help us to understand how dependent elder is and what that means for you in terms of time and commitment.*

042 E070DEP	<b>How dependent is the person you care for?</b>	
	<b>Severely Dependent</b> - Unable to carry out most activities of daily living, without help (e.g. feeding themselves, or going to the toilet)	①
	<b>Moderately Dependent</b> - Able to carry out <u>some</u> basic activities of daily living (for example, bathing, feeding, dressing) but unable without help to carry out <u>most</u> instrumental activities of daily living (e.g. shopping, cooking, housework)	②
	<b>Slightly Dependent</b> - Able to carry out <u>most</u> activities of daily living, but requires help with <u>some</u> instrumental activities (e.g., shopping, cooking, housework, etc)	③
	<b>Independent</b> - Able to carry out most activities of daily living, but may need some help occasionally	④

It may be necessary to let the respondent read these options for themselves so that they have the opportunity to consider their answer

**The next questions are about activities that we all need to do as part of our daily lives.  
If Elder was alone would they be able to carry out the following activities? If not, do they rely partially or completely on others to perform them?**

Circle as appropriate ↘		Unable	With some help	Without help	
43	E43IADL1	Housework (clean floors etc.)	①	②	
44	E44IADL2	Prepare their own meals	①	②	
45	E45IADL3	Go shopping		②	
46	E46IADL4	Handle their own money		②	
47	E47IADL5	Use the telephone	①	②	
48	E48IADL6	Take their own medicines	①	②	
49	E49MOB	Walk outside	①	②	
50	E50BAR1	Get around indoors	①	②	③
		Unable	In a wheelchair without help or walking with major physical help	Walking with some help guided or supervised	May use any aid, e.g. stick, zimmer
51	E51BAR2	Manage stairs	①	②	
52	E52BAR3	M n	①	②	③
		Unable, no sitting balance	Major help (1 or 2 people, physical)	Minor help (verbal or physical)	Without help
53	E53BAR4	Use the toilet (or commode)	①	②	
54	E54BAR5	Use the bath or shower	①	②	
55	E55BAR6	Keep up their personal appearance (brush hair, shave, make up etc.)	①	②	
56	E56BAR7	Dress themselves	①	②	
57	E57BAR8	Feed themselves	①	②	
58	E58BAR9	Does Elder have accidents with their bladder (incontinence of urine)?	①	②	
		Once a day or more or needs catheter	Less than once a day	No accidents (continent)	
59	E57BAR10	Does Elder have accidents with their bowels (incontinence of faeces)?	①	②	
		Once a week or more or needs of enema	Less than once a week	Continent	

We want to know if left alone Elder can perform the tasks in this column with or without help

Some tasks have different answer options

60-66	<b>Let's think about the last typical caring week for you: When in that week did you provide care or support for ELDER?</b> <b>INTERVIEWER -Place a ✓ tick all the boxes that apply</b>						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Early morning (approximately 5am to 9am)	C60MO1	C61TU1	C62WE1	C63TH1	C64FR1	C65SA1	C66SU1
Morning (approximately 9am to 12noon)	C60MO2	C61TU2	C62WE2				C66SU2
Afternoon (approximately 12 noon to 5pm)	C60MO3	C61TU3	C62WE3				C66SU3
Evening (approximately 5pm to 10pm)	C60MO4	C61TU4	C62WE4	C63TH4	C64FR4	C65SA4	C66SU4
Night (approximately 10pm to 5am)	C60MO5	C61TU5	C62WE5	C63TH5	C64FR5	C65SA5	C66SU5

Tick all the times that apply. So if for example someone says they are 24 hours a day seven days a week tick all the boxes

067 C071DURA	<b>How long have you been caring for ELDER?</b>	Months: <input type="text"/>
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68 C68BILL	<b>If you were ill is there anybody who would step in to help with ELDER?</b>	Yes, I could find someone quite easily ①
		Yes, I could find someone but with some difficulty ②
		No, there is no one ③
69 C69BREAK	<b>If you needed a break from your caring role is there someone who would look after ELDER for you?</b>	Yes, I could find someone quite easily ①
		Yes, I could find someone but with some difficulty ②
		No, there is no one ③

*We would now like to explore how care giving or supporting ELDER affects your life.*

<b>What factors influenced your decision to care for ELDER?</b> (Ensure that there is an answer 'yes', or 'no' for each item)		Yes	No
070 C103MOTI	A sense of duty	<input type="radio"/>	<input type="radio"/>
071 C105MOTI	There was no alternative	<input type="radio"/>	<input type="radio"/>
072 C111MOTI	The cost of professional care would be too high	<input type="radio"/>	<input type="radio"/>
073 C112MOTI	Emotional bonds (love, affection)	<input type="radio"/>	<input type="radio"/>
074 C114MOTI	Caring for Elder makes me feel good	<input type="radio"/>	<input type="radio"/>
075 C115MOTI	ELDER would not wish for anyone else to care for them	<input type="radio"/>	<input type="radio"/>
076 C116MOTI	Because of my	<input type="radio"/>	<input type="radio"/>
077 C117MOTI	I found myself in these circumstances almost by chance without ma	<input type="radio"/>	<input type="radio"/>
078	There were economic benefits for me [Carer] and / or Elder	<input type="radio"/>	<input type="radio"/>
079	A personal sense of obligation toward Elder as a family member.	<input type="radio"/>	<input type="radio"/>
080	Other please state		

circle 'yes' or 'no' for each item in the list

081 What is the principle reason for caring among those you have indicated above? Put appropriate number in the box



Don't forget to complete this last question

Here we look at the support that is available to you as a carer.		Always	Often	Sometimes	Never	N / A
082 C122COPE	Do you feel you cope well as a caregiver?	①	②	③	④	<input type="checkbox"/>
083 C123COPE	Do you find caregiving too demanding?	①	②	③	④	<input type="checkbox"/>
084 C124COPE	Does caregiving cause difficulties in your relationships with friends?	①	②	③	④	⑧
085 C125COPE	Does caregiving have a negative effect on your physical health?	①	②	③	④	<input type="checkbox"/>
086 C126COPE	Does caregiving cause difficulties in your relationship with your family?	①	②	③	④	⑧
087 C127COPE	Does caregiving cause you financial difficulties?	①	②	③	④	<input type="checkbox"/>
088 C128COPE	Do you feel trapped in your role as a caregiver?	①	②	③	④	<input type="checkbox"/>
089 C129COPE	Do you feel well supported by your friends and / or neighbours?	①	②	③	④	⑧
090 C130COPE	Do you find caregiving worthwhile?	①	②	③	④	<input type="checkbox"/>
091 C131COPE	Do you feel well supported by your family?	①	②	③	④	⑧
092 C132COPE	Do you have a good relationship with the person you care for?	①	②	③	④	<input type="checkbox"/>
093 C133COPE	Do you feel well supported by health and social services? (for example, public, private, voluntary)	①	②	③	④	⑧
094 C134COPE	Do you feel that anyone appreciates you as a caregiver?	①	②	③	④	⑧
095 C135COPE	Does caregiving have a negative effect on your emotional well-being?	①	②	③	④	<input type="checkbox"/>
096 C121COPE	Overall, do you feel well supported in your role of caregiver?	①	②	③	④	<input type="checkbox"/>

The 'not applicable' option is not available for all items in this instrument

*We are interested in how you view your health and your quality of life.*

097 C140QOL	In general, would you say your health is:								
	Excellent ①	Very good ②	Good ③	Fair ④	Poor ⑤				
	Over the last two weeks...			All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
	cheerful and in good			⑤					①
	calm and relaxed			⑤					①
	active and vigorous			⑤					①
C1440	wake up feeling fresh and rested			⑤	④	③	②	①	①
102 C145Q	My daily life has been filled with things that interest me			⑤	④	③	②	①	①
103 C146QOL	Overall, how would you rate your quality of life in the last two weeks?								
	Very poor	Poor	Neither good nor poor	Good	Very good				

These questions look similar but please note the different response scales

As there are a number of similar responses possible give the respondent chance to see these options as they answer

The next two pages form one table and they are seen in the questionnaire side by side. This table is very important, as it is the crux of our study.

Begin completing the instrument by listing the services that the Elder and the Carer have used in the last six months, show the respondent the list of services that you have been provided with and note the code number of the service in column A. If respondents identify services that are not on the list then write the name and a brief description of the service in column A.

As you can see the top section is for services used by Elder and the bottom by the carer – please take care to use the appropriate part of the form for Elder and Carer [see left hand column]

**If you find that the Elder or Carer uses more services than you have space for on the form then continue on a separate sheet, ensure it is clear if this is a carer or Elder service, contains the serial number and fix firmly to the questionnaire**

Then taking each of the services identified by the carers in turn answer the questions in column B and C. If the answer is 'Yes' in column C you then need to complete the question in column D, if the answer in column C is 'No' then go onto complete columns E, F and G.

When you one have done this for all the services that Elder uses go to the lower section of the table and do the same in relation to services that the respondent / carer uses.

**NB** Only itemise services that the carer utilise as a direct consequence of their caring roles and responsibilities.

**A 'UNIT' of a service is the measurement by which the carer or ELDER uses the service e.g. by the visit, by the hour or week.**

*As you know we are interested in the use of services and support organisations. We would like to know which services and support organisations ELDER and you have used and if they have met your needs. Let's begin with ELDER. Can you tell me what health services they have used in the last 12 months?*

	A. 1. What services have ELDER and YOU used in the last 6 months?  SERVICES [Show card]		B. Has the service met ELDER's / YOUR needs?		C. Do you or Elder pay for this service when you utilise it?	
			Mostly Yes	Mostly No	Yes	No
	A		B		D	
104 SC171A- SC171H	<b>E L D E R</b>	<input type="checkbox"/>	①	①	①	①
105- SC172H		<input type="checkbox"/>	①	①	①	①
106 SC173A- SC173H		<input type="checkbox"/>	①	①	①	①
107 SC174A- SC174H		<input type="checkbox"/>	①	①	①	①
108 SC175A- SC175H		<input type="checkbox"/>	①	①	①	①
109 SC176A- SC176H		<input type="checkbox"/>	①	①	①	①
110 SC177A- SC177H		<input type="checkbox"/>	①	①	①	①
111 SC178A- SC178H		<input type="checkbox"/>	①	①	①	①
112 SC179A- SC179H		<input type="checkbox"/>	①	①	①	①
113 SC178A- SC178H	<b>C A R E R</b>	<input type="checkbox"/>	①	①	①	①
114 SC178A- SC178H		<input type="checkbox"/>	①	①	①	①
115 SC178A- SC178H		<input type="checkbox"/>	①	①	①	①
116 SC178A- SC178H		<input type="checkbox"/>	①	①	①	①
117 SC180A- SC180H		<input type="checkbox"/>	①	①	①	①
118 SC181A- SC181H		<input type="checkbox"/>	①	①	①	①



119	<b>Are there any services that you or ELDER still need that you have <u>stopped</u> using?</b>		
S119STOP	Yes ①		No ②
<i>Ask questions in grey section</i>			
<b>If yes, which ones?</b>			
<i>INTERVIEWER: list the 3 most important to be chosen from the 'show' card of services</i>			
S119SER1 S119SER2 S119SER3	<input type="text"/>	<input type="text"/>	<input type="text"/>
<b>Service 1      Service 2      Service 3</b>			
<b>What was your decision?</b>			
	<b>Service 1</b>	<b>Service 2</b>	<b>Service 3</b>
S119EXP1- S119EXP3	<b>Too expensive</b>	<input type="radio"/>	<input type="radio"/>
	S119EXP1	S119EXP2	S119EXP3
S119DIS1- S119DIS3	<b>Too distant</b>	<input type="radio"/>	<input type="radio"/>
	S119DIS1	S119DIS2	S119DIS3
S119QUA1 - S119QUA3	<b>Low quality of service</b>	<input type="radio"/>	<input type="radio"/>
	S119QUA1	S119QUA2	S119QUA3
S119AV1- S119AV3	<b>Not available any more</b>	<input type="radio"/>	<input type="radio"/>
	S119AV1	S119AV2	S119AV3
S119ENT1- S119ENT3	<b>No longer entitled to use them</b>	<input type="radio"/>	<input type="radio"/>
	S119ENT1	S119ENT2	S119ENT3
S119OTH	<b>Other (specify)</b>	<input type="text"/>	
120	<b>Are there any services that you or ELDER <u>need</u> but have not used so far?</b>		
S120NOUS	Yes ①		No ②
<i>Ask questions in grey section</i>			
<b>If yes, which ones?</b>			
<i>INTERVIEWER: list the 3 most important, to be chosen from the 'show' card of services</i>			
S120SER1 S120SER2 S120SER3	<input type="text"/>	<input type="text"/>	<input type="text"/>
	<b>Service 1</b>	<b>Service 2</b>	<b>Service 3</b>
<b>If yes, what were the reasons for your decision?</b>			
<i>Please circle all boxes that apply</i>			
	<b>Service 1</b>	<b>Service 2</b>	<b>Service 3</b>
S120EXP1- S120EXP3	<b>Too expensive</b>	<input type="radio"/>	<input type="radio"/>
	S120EXP1	S120EXP2	S120EXP3
S120DIS1- S120DIS3	<b>Too distant</b>	<input type="radio"/>	<input type="radio"/>
	S120DIS1	S120DIS2	S120DIS3
S120QUA1 - S120QUA3	<b>Low quality of service</b>	<input type="radio"/>	<input type="radio"/>
	S120QUA1	S120QUA2	S120QUA3
S120KNO1- S120KNO3	<b>Didn't know about it</b>	<input type="radio"/>	<input type="radio"/>
	S120KNO1	S120KNO2	S120KNO3
S120ENT1- S120ENT3	<b>Are not entitled to use them</b>	<input type="radio"/>	<input type="radio"/>
	S120ENT1	S120ENT2	S120ENT3
S120OTH	<b>Other (specify)</b>	<input type="text"/>	

If the respondent answers yes complete all grey sections. If no move on to question 120

Put the number from the 'show' card of services in here

Then circle those that apply for each service. If the answer option you need is not available then choose 'other' and specify

121	<b><u>FOR RESPONDENTS WHO USE NO SERVICES ONLY</u></b>	
	<b>What are the reasons that you and Elder do not access services? (List three most important)</b>	
	Please Specify	
	1.	
	2.	
	3.	

122 S261HELP	<b><u>ASK ALL RESPONDENTS THE FOLLOWING QUESTION</u></b>	
	<b>In your experiences as a caregiver who or what do you consider to have been the greatest help to you in accessing services / support? (List three most important)</b>	
	1.	
	2.	Do not forget to ask all respondents the questions from here, whether they use services or not
3.		

123 S262DIFF	<b><u>ASK ALL RESPONDENTS THE FOLLOWING QUESTION</u></b>	
	<b>In your experiences as a caregiver who or what do you consider to have caused the greatest difficulties to you in accessing services / support? (List three most important)</b>	
	1.	
	2.	Tick either yes or no to all these options use the 'other' if needed
3.		

124 F335COST	<b>Has caring resulted in any additional financial costs?</b>				
	Adaptation of the Home environment and or furniture	Yes	①	No	①
	Travel costs	Yes	①	No	①
	Special food	Yes	①	No	①
	Medicines	Yes	①	No	①
	Other, specify: <input type="text"/>	Yes	①	No	①

Regardless of the support you may or may not currently receive. We are interested in the types of support that you would like for yourself and ELDER, and whether such support is currently being met					B. Is this currently being met for you? ↓		
A. How important is support that gives you.....?		Very important	Quite important	Not important	N / A	Mostly No	Mostly Yes
		A				B	
125 S221IMPA S221IMPB S221IMPC	Information and advice about the type of help and support that is available and how to access it	②	①	①	X	①	①
126 S222IMPA S222IMPB S222IMPC	Information about the disease that ELDER has	②	①	①	X	①	①
127 S223IMPA S223IMPB S223IMPC	Help to develop the skills I need	②	①	①		①	①
128 S224IMPA S224IMPB S224IMPC	Help to do activities outside of home	②	①	①		①	①
129 S225IMPA S225IMPB S225IMPC	Help to take a holiday or take a break from caring	②	①	①	X	①	①
130 S226IMPA S226IMPB S226IMPC	Opportunities for ELDER to undertake activities they enjoy	②	①	①	X	①	①
131 S227IMPA S227IMPB S227IMPC	Help with planning for the future care	②	①	①	X	①	①
132 S228IMPA S228IMPB S228IMPC	The possibility to combine care giving with paid employment	②	①	①	⑧	①	①
133 S229IMPA S229IMPB S229IMPC	The opportunity to talk over my problems as a carer	②	①	①	X	①	①
134 S230IMPA S230IMPB S230IMPC	Opportunities to attend a carer support group	②	①	①	X	①	①
135 S231IMPA S231IMPB S231IMPC	More money to help provide things I need to give good care	②	①	①	X	①	①
136 S232IMPA S232IMPB S232IMPC	Opportunities to spend more time with my family	②	①	①	⑧	①	①
137 S233IMPA S233IMPB S233IMPC	Help to deal with family disagreements	②	①	①	⑧	①	①
138 S234IMPA S234IMPB S234IMPC	Help to make ELDER's environment more suitable for caring	②	①	①	⑧	①	①

Column A is a list of the types of support and we would like to know how important they are to respondents

Column B seeks to find out if each of the forms of support are being provided for the respondent

'Not applicable' is not available where you see these X's

139	Of those types of support you have stated are very important which would you rate as the most important to you?	Item-number: <input type="text"/>
140	The second most important?	Item-number: <input type="text"/>
141	The third most important?	Item-number: <input type="text"/>

Write down the number of the 3 forms of support that the respondent finds most important e.g. if 'help to deal with family disagreements' is most important write 137 in the first box

Regardless of the support you may or may not currently receive we are interested in finding out which service characteristics you value				B. Is this currently being met for you? ↓		
A. How important are the following characteristics of a service for you?		Very important	Quite important	Not important	Mostly No	Mostly Yes
		A			B	
142 S241CHAA S241CHAB S241CHAC	Help is available at the time				⓪	①
143 S242CHAA S242CHAB S242CHAC	The help provided fits in with routines				⓪	①
144 S243CHAA S243CHAB S243CHAC	Help arrives at the time it is				⓪	①
145 S244CHAA S244CHAB S244CHAC	Care workers have the skills and training they require	②	①	⓪	⓪	①
146 S245CHAA S245CHAB S245CHAC	Care workers treat ELDER with dignity and respect	②	①	⓪	⓪	①
147 S246CHAA S246CHAB S246CHAC	Care workers treat you with dignity and respect	②	①	⓪	⓪	①
148 S247CHAA S247CHAB S247CHAC	Your views and opinions are listened to	②	①	⓪	⓪	①
149 S248CHAA S248CHAB S248CHAC	The help provided improves the quality of life of ELDER	②	①	⓪	⓪	①
150 S249CHAA S249CHAB S249CHAC	The help provided improves your quality of life	②	①	⓪	⓪	①
151 S250CHAA S250CHAB S250CHAC	The help provided is not too expensive	②	①	⓪	⓪	①
152 S251CHAA S251CHAB S251CHAC	Help is provided by the same care worker each day	②	①	⓪	⓪	①
153 S252CHAA S252CHAB S252CHAC	Help focuses on your needs as well as those of ELDER	②	①	⓪	⓪	①

This table is similar to the one above, and it completed in the same way, but here we are exploring the characteristics of services that respondents most value. Even if people use no services at all they will still know if a characteristic is important to them and whether it is being met for them in any way

154 S253CHAR	<b>Of those characteristics you have stated are very important which would you rate as the most important to you?</b>	Item-number: <input type="text"/>
155 S254CHAR	<b>The second most important?</b>	Item-number: <input type="text"/>
156	<b>The third?</b>	Item-number: <input type="text"/>

Once again write down the number of the 3 characteristics that the respondent finds most important

***We would like to ask you about caring for ELDER in the future***

157 C271FUT	<b>In the next year, are you willingly to continue to provide of care to ELDER?</b>	
	Yes, and I would even increase the amount of care I give.	①
	Yes, and I would even increase the care I give for a limited time	②
	Yes, if the situation remains the same	③
	Yes, but only if I have some more support (from services, family, friends etc.)	④
	No, no matter what extra support I receive	⑤
158 C272FUT	<b>Would you be prepared to consider ELDER's placement in a care home?</b>	
	No, not under any circumstances	①
	Yes, but only if ELDER's condition gets worse	②
	Yes, even if ELDER's condition does not get worse	③

You may want to let the respondent read these options

Finally, we would like to ask you some questions about you, your roles and responsibilities, and how caring has affected your personal circumstances.

160 C160AGE	How old are you?		<input type="text"/>
161 C161SEX	What is the carers gender?	Male ①	Female ②
162 C162NAT C162CODE	What is your nationality?	<input type="text"/>	Lis xx <input type="text"/>
163 C163ETHN C163CODE	What is your ethnic origin?	Just write in what the respondents says is their nationality and religious denomination	
164 C164MARS	What is your marital status?		
165 C165RELI	Do you belong to a religious denomination?		
C165SPEC C165CODE	If yes, specify which one?	<input type="text"/>	Lis xx <input type="text"/>
166 C166RELI	Do you consider yourself to be...?	Not at all religious ①	②
		Quite religious ①	②
		Very religious ②	②
167 C168KID	Do you have any children?	Yes ①	No ②
168 C168KIDN	If yes, how many children do you have?		<input type="text"/>
169 C169GRAN	Do you have any grandchildren ...	Yes ①	No ②
170 C170NUMH	Including yourself, what are the total number of people in your household?	Include young people who are 14 years old in this number	<input type="text"/>
171 C171NUMY	And how many of them are children aged 14 years or less?		<input type="text"/>
172 C172EDU1	What is your highest educational attainment?	Specify: <input type="text"/>	
173 C173EDU2	Are you currently in Education?	Yes ①	No ② Go to question 175
174 C174HOUR	If yes, how many hours do you spend in education per week?		<input type="text"/>

175 C175EMPL	<b>Are you currently employed?</b>	Yes ①	No
C175HOUR	<b>If yes, how many hours do you work in an average week?</b>	Ask questions in grey section	Go to question 179
176 C176TYPE	<b>If you are employed, are you.....?</b>	A private sector employee ①	A public sector employee ②
		Self employed ③	Other
	<b>Specification of other</b>	<input type="text"/>	
177 C177WORK C177CODE	<b>What type of work do you do?</b>	<input type="text"/>	
178	<b>Has caring for ELDER caused any restrictions to your working life or career?</b>		
C178WOR1	<b>I have had to reduce my working hours</b>	Yes ①	No ②
C178HOUR	<b>If yes, by how many per week?</b>	<input type="text"/>	
C178INC	<b>And what difference has this made to your income per month</b>	<input type="text"/>	
C178PONE	<b>Is the difference positive or negative?</b>	positive ①	negative ②
	<b>any of the following restrictions to your working life or</b>		
	<b>reduce my working hours</b>	Yes ①	No ②
	<b>If yes, by how many per week?</b>	<input type="text"/>	
	<b>difference has this made to your income per month</b>	<input type="text"/>	
C178PONE	<b>Is the difference positive or negative?</b>	positive ①	negative ②

Write in what the respondent says

If the respondents income has changed due to reducing their hours of work we need to know if their income each month has increased (e.g. more allowances) or decreased (e.g. loss of earnings)

<b>ASK QUESTIONS 179 &amp; 180 OF NON WORKING CARERS ONLY</b>			
179 C179TYPE	<b>If you are not working at present are you?</b>	Retired ①	Unemployed and seeking work ②
		On long term sick leave but intending to return to work ③	Housewife / husband ④
		Other	
180	<b>If you are not working. Has caring for ELDER caused any of the following restrictions to your working life or career?</b>		
C180WOR1	<b>I cannot work at all</b>	Yes ①	No ②
C180WOR2	<b>I have had to give up work</b>	Yes ①	No ②
C180HOUR	<b>If yes, how many hour per week were you working before you gave up work?</b>	<input type="text"/>	

<b>ASK ALL CARERS</b>	
181 C181WOR1	I can/could not develop my professional career or studies Yes ① No ②
C181WOR2	I can/ could work only occasionally Yes ① No ②
C181WOR3	Other specify below Yes ① No ②
C181SPEC	

The next questions we are going to ask relate to the finances of the respondent and the person they care for. Please be sensitive to the response of the respondent to these questions. Ask question 182 but if the respondent is reluctant or does not know the answer go to 183 and offer them the card with income bands this allows them to be less specific in their response

182 F182CINC	<b>If you add up all sources, what is your household net income per month? If you don't know the exact figure, please give an estimate.</b>
	<b>NET INCOME MEANS</b>
	<i>AMOUNTS AS YOU RECEIVE IT, WHICH IS NORMALLY AFTER TAX AND CONTRIBUTIONS TO SOCIAL INSURANCE AND PENSIONS. IF INCOME VARIES BETWEEN MONTHS, PLEASE GIVE AN AVERAGE.</i>
	Don't know ① →Go to question 183
	Refuse response ⑧ →Go to question 183
	<b>Don't know exactly, perhaps you can tell me which range the household's net monthly income falls into?</b> [Show card with options to respondent]
	0-£600 ① £2,100 - £2,400 ⑧
	£601 -£800 ② £2,401 - £2,900 ⑨
	£801 - £1,100 ③ £2,901 - £4,200 ⑩
	£1,101 - £1,400 ④ £4,201 + ⑩
	£1,401 - £1,700 ⑤ No response ⑨ ⑨
	£1,701 - £2,100 ⑦

This definition is provided to help you and the respondent to understand what information we are seeking

questions 184-185 are not to be completed if ELDER lives with carer.

184 F184EINC F184EAM	<b>If you add up all sources, what is ELDER's household net income per month? If you don't know the exact figure, please give an estimate.</b>
	Elder's household income per month is ① : <input type="text"/> Specify the amount F184EAM →Go to question 186
	Don't know ② →Go to question 185
	Refuse response ⑨ →Go to question 185
185 F185BAND	<b>If you do not know exactly, perhaps you can tell me which range the household's net monthly income falls into?</b> [Show card with options to respondent]
	0 - £300 ① £1,401 - £1,700 ⑦
	£301 - £600 ② £1,701 - £2,100 ⑧
	£601 - £700 ③ £2,101 - £2,400 ⑨
	£701 - £800 ④ £2,401 - £2,900 ⑩
	£801 - £1,100 ⑤ £2,901 + ① ①
	£1,101 - £1,400 ⑥ Refuse response ⑨ ⑨

186 F186ESUP	<b>Does ELDER receive any pension or financial support of any kind from the state?</b>	Yes ①	No ②
-----------------	--	-------	------

	Do you or ELDER receive any financial support, or allowances because of your caring situation as shown on the list below ? A	ELDER		CARER	
		Yes	No	Yes	No
187 F187SUPA F187SUPE F187SUPC	<b>Attendance allowance</b> For older people who need personal help or supervision from someone else. Paid to the older person themselves	①	②	X	X
188 F188SUPA F188SUPE F188SUPC	<b>Direct payments</b> Local authorities, instead of providing services, can give older people money to organise and buy the care they need as assessed by the local authority	①	②	X	X
189 F189SUPA F189SUPE F189SUPC	<b>Help with care home fees</b> Local authorities can pay towards care home fees for older people who have less than £19,000 in savings	①	②	X	X
190 F190SUPA F190SUPE F190SUPC	<b>Carers allowance</b> Given to carers where Elder is receiving attendance allowance. Paid directly to people who give care for at least 35 hours a week	X	X	①	②
	<b>specify</b>	①	②	①	②
	<b>benefits received because of the caring situation per month</b>	[ ]		[ ]	
	<b>Per? (Please circle relevant time unit)</b>	Week	①	Week	①
		Month	②	Month	②
		Year	③	Year	③

These are a list of the benefits available to carers and older people specifically because of their caring situation. There are of course many more they could claim but these would be available to other people who were not caring, cold weather payments for example. But if respondents mention an allowance and your

You need to make sure that we understand how much people get so if they get a weekly sum from one benefit and they get another sum monthly it is important that report both sums weekly i.e. divide the monthly sum by 4

If all benefits are received monthly just add the total write it in the appropriate box and tick monthly

<b>We would like to know how you feel about the person you care for</b>		<b>A lot</b>	<b>Some</b>	<b>A little</b>	<b>Not at all</b>
194 UKMUT1	To what extent do you and Elder see eye to eye?	④	③	②	①
195 UKMUT2	When you really need it, how much does Elder comfort you?	④	③	②	①
196 UKMUT3	How much do you confide in Elder?	④	③	②	①
197 UKMUT4	How much do you and Elder laugh together?	④	③	②	①
198 UKMUT5	How much does Elder express feelings of appreciation for the things you do?	A great deal ④	Quite a bit ③	Sometimes ②	Not very much ①
199 UKMUT6	How close do you feel to Elder?	Not at all ④	Somewhat ③	Quite ②	Very ①
200 UKMUT7	Did you have a good relationship with Elder before you took on the caring role?	Always ④	Often ③	Some-times ②	Never ①

Here we want you to check once again if respondents are willing to be contacted by a member of the research team in 12 months time and if so to get their telephone number

201 UKREJE	<b>To what extent has Elder accepted or rejected the service?</b>
	Completely accepting services ①
	Mostly accepting services ②
	Neither accepting or not ③

202	<b>We have come to the end of the questionnaire and I would like to thank you for all your help today. As you know we would like to contact you by telephone again in a years time to see how things have changed for you and Elder. Would you be happy for a member of the research team to contact you and to undertake a short telephone interview? (15 minutes)</b>
UKFUP1	Yes ①      No ②      Go to 203
UKFUP2	<b>If yes, could I please have your telephone number</b> <input type="text"/>

203	<b>Finally, do you know of anyone else who cares / supports someone over 65 years old who may be willing to take part in our study?</b>
UKSNOW1	Yes ①      No ②
	<b>If yes, could I please take some contact details?</b>

**THANK, CLOSE, AND CHECK CONSENT [PAGE 2] HAS BEEN COMPLETED**