

Welcome the Eurofamcare Project

Introduction

- 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.

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.

Many people who give support to an older person, especially husbands and wives do not see themselves as 'carers', although they may feel that they offer 'support' rather than care. As an interviewer you will need to be sensitive to this issue and choose the most appropriate term (care or support) for to use in the interview.

Some general points

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 tick the appropriate response. For example:

What is your relationship to ELDER?	Spouse / Partner ①	Child ②
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You tick the appropriate response

What is your relationship to ELDER?	Spouse / Partner ① <input checked="" type="checkbox"/>	Child ②
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Sometimes 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	<div style="border: 1px solid black; padding: 2px; text-align: center;">N/A</div> <input checked="" type="checkbox"/>
124 C124COPE	Does caregiving cause difficulties in your relationships with friends?	①	②	③	④	⑧



Completing 'Mode of recruitment'

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

Health or social care professional (e.g. Doctor or social worker)	① ✓
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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 tick ⑨. You then need to indicate the channel from which the snowball started, in this example 'door to door' recruitment ①.

Snowball	⑨ ✓
Snowball channel if known	1.



In this user guide [but not in real questionnaires] this picture highlights script that you need to say to your respondent. This script may introduce a section of the questionnaire, or advise respondents of particular circumstances we would like them to consider when answering the following section of questions. Please familiarise yourself with these short scripts



Again in the user guide we use this picture to indicate an instruction for you in the questionnaire. Of course once you are familiar with the questionnaire these sections become less significant, however, they are important and it is essential that you become familiar with all sections of the questionnaire

For example, the instruction to you that comes straight after the first question is crucial, it says:



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

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 choose 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

Each questionnaire in the study has an individual number and be given by the coordination centre

Questionnaire Number

QUESTIONUM

EUROFAMCARE

Questionnaire

Each country and each interviewer has a code number from the coordinating centre and this needs to be put on each questionnaire by the interviewer

46=Sweden;
44=Uk;
48=Poland;
30=Greece;
49=Germany;
39=Italy

1 G1NAME	NAME OF INTERVIEWER	<input type="text"/>
G1INTN	NUMBER OF INTERVIEWER (see National list of interviewers to insert appropriate code)	<input type="text"/>
2 G2CTRY	COUNTRY (see User Guide to insert appropriate code)	<input type="text"/>
3 G3REG	REGION (see User Guide to insert appropriate code)	<input type="text"/>
4 G4LOCA G4NAME	LOCALITY:	<p>If you do not know if your locality is metropolitan urban or rural write down the name of the area</p> <p>metropolitan ① urban ② rural ③</p>
5 G5SITE	SITE (write the name or code of the site)	<input type="text"/>
6 G6ID	CASE NUMBER (according to the list of the carers interviewed by each interviewer)	<input type="text"/>
7 G7DOI G7MOI G7YOI	INTERVIEW DATE: (DD / MM / YYYY)	<input type="text"/>
8 G8PRES	How was the carer recruited at the interview?	<input type="text"/>
9 G9REC G9SPEC	MODE OF RECRUITMENT (Tick only one mode of recruitment)	<p>Health or social care professional (e.g. Doctor or social worker) ①</p> <p>Priest/parish/religious organisations ②</p> <p>Door to door ③</p> <p>Voluntary organisation e.g. carer support group ④</p> <p>Advertisement (e.g. Newspaper, handbill/flyer/posters) ⑤</p> <p>Lists (e.g. of older residents, or electoral role) ⑥</p> <p><input type="text"/> ⑦</p> <p>Snowball (in this case go to question 10) ⑧</p>
10 G10SBC	SNOWBALL CHANNEL IF KNOWN:	<input type="text"/>

Coordinators need to complete region and locality for interviewers or ensure that the coding is correct

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

'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 given by the local coordinator

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 above



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.

11 C11NUMEL	How many people do you give support / care to for more than four hours a week who are 65 years old or more?	<input style="width: 50px; height: 20px;" type="text"/>
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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 WHERE QUESTIONN

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

12 C12HOUR	On average, how many hours a week do you gi	
13 C13NUMO	How many people who are not elderly [e.g. children etc] do you give care a	
14 C14HOURO	In total how many hours a week do you give care and support to all than ELDER, you care for?	

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

15 E15RELAT E15SPEC	What is your relationship to ELDER?	Spouse / Partner ① Sibling ③ Uncle/ Aunt ⑤ Cousin ⑦ Other, specify below: ⑧ Specification of other <input style="width: 100px;" type="text"/>
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Nephew/ Niece ⑥

Missing information = 999 for this question

16 E16SEX	What is ELDER's Gender?	Male ①
17 E17AGE	How old is ELDER?	

18 E18NAT E18CODE	What is ELDER's nationality?	
19 E19ETHN E19CODE	What is ELDER's ethnic origin?	
20 E20MARS	What is ELDER's marital status?	Married / Co Divorced / Se

You need to write in the carer's responses here and add the appropriate code from your national list, which your local coordinator will have. Local coordinators need to ensure that these questions are coded correctly. If you have missing data for either of these questions write 99 in the answer box

21 C21COHAB	Where do you and ELDER live?	In the same household ①
		In different households but the same building ②
		Within walking distance ③
		10 minutes drive / bus or train journey ④
		30 minutes drive / bus or train journey ⑤
		45 minutes drive / bus or train journey ⑥
		Over 1 hours drive / bus or train journey ⑦

'In their own home' includes older people who live with members of their families

22 E22HOME E22SPEC	Where does ELDER usually live?	At home ①
		In a care home ②
		In sheltered housing ③
		Other, specify below.. ④

Specification of other:

You need to ensure that you record a response for each of the options in this question

23	Who does ELDER live with? (ensure that all options are answered)			
E23ALONE	Alone	Yes ①	No ②	
E23CHILD	With their Children	Yes ①	No ②	N/A ③
E23PARTN	With their partner	Yes ①	No ②	N/A ③
E23PAID	With paid carers (in their own home)	Yes ①	No ②	N/A ③
E23OTHER	With others, please specify below...	Yes		
E23SPEC	...Specify others			<input style="width: 100px;" type="text"/>
24	FOR THOSE WHO DO NOT LIVE IN A CARE HOME OR WITH PAID CARERS			
E24NUMH	What is the total number of people in ELDER's household themselves?			<input style="width: 50px;" type="text"/>
E24NUMY	And how many of them are aged 14 years or less?			<input style="width: 50px;" type="text"/>

This question will help us to work out the economic costs of caring but should only be completed for those Elder's who do not live either in a care home or with the carer. You must ensure that you write 0 if there are no people under 14 in Elders household



WE WOULD NOW LIKE TO LOOK AT ELDER'S NEEDS FOR SUPPORT AND CARE IN A LITTLE MORE DETAIL.

25 E25REAS1	In your opinion what is the main reason that ELDER needs care and support? (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
	Write up to four more reasons here
26	Are there any other reasons? (list the four most important)

E26REAS2	
E26REAS3	
E26REAS4	
E26REAS5	

C) Would you like ELDER to have more help to meet these needs? (Tick as appropriate)

B) Who, if anyone, helps ELDER to meet their needs? ↓ (Tick as many as apply) ↓

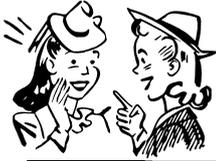
A) Does ELDER have a need for help with any of these areas (below) If so, do they rely partially or completely on others to meet that need? (Tick as appropriate) ↓		A			B	C	D	E	F		
		Completely	Partially	Does not have this need	No one	The interviewed Carer	Other informal carers	Service / support organisations (voluntary private or public)	Yes	No	Not Applicable
27 E27A- E27F	Health needs: (e.g. assistance with medication, medical treatment, rehabilitation, therapy etc)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①
28 E28A- E28F	Physical / Personal: (e.g. washing, dressing, eating or going to the toilet)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①
29 E29A- E29F	Mobility (e.g. inside or outside the house, transport)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①
30 E30A- E30F	Emo (e.g. c				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①
31 E31A- E31F	Dom (e.g. h				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①
32 E32A- E32F	Final (e.g. p ELDE				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①
33 E33A- E33F	Final (e.g. Supporting ELDER by providing them with money)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①
34 E34A- E34F	Organising and managing care & support: (e.g. contacting services)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	①

In this table we are asking three questions relating to the areas in the whiter column on the left hand side of the table.

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

If you have to tick ① or ② in column 'A' then you should complete column 'B' and 'C' for that item

If you tick ① in column 'A' then you do not need to complete either column 'B' or 'C' for that item



SOME OF THE MOST STRESSFUL SITUATIONS FOR CARERS ARE RELATED TO PROBLEMS WHICH AFFECT THE MEMORY AND BEHAVIOUR OF THE PERSON THEY CARE FOR. THE NEXT QUESTIONS RELATE TO THESE ISSUES.

35 E35MEM1	Has ELDER any memory problems? (Such as having difficulty in remembering what day it is, or recognising friends or neighbours)	Yes ①	No ②
		Complete grey section	Go to Q38
36 E36MEM2	IF 'YES', has the doctor given you any cause of ELDER's memory problems?	Yes ①	No ②
			Go to Q38
37 E37MEM3 E37SPEC	IF 'YES', please specify	Dementia ①	Other ②
		Specify 'other' here: <input type="text"/>	
38 E38BEHP	Does ELDER suffer from any behavioural problems? (Such as wandering, constantly repeating what is said, shouting inappropriately)	Yes ①	No ②

		Most of the time	Sometimes	Rarely	Never
	How frequently, if at all, does ELDER demonstrate any of these behaviours?				
39 E39BEHP1	Wander in or outside the home environment or behaving in a way that endangers their safety?				
40 E40BEHP2	Have difficulty holding normal conversation, have no insight their problems, or become uncooperative with your requests				
41 E41BEHP3	Do they behave in ways that you find upsetting? (For example constantly asking questions, following you around, repeat what has been said shout and scream for no particular reason or inappropriately dress or undress)	③	②	①	②

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.

42 E42DEP	How dependent is the person you care for?	
Severely Dependent – Unable to carry out most activities of daily living, without help (e.g. feeding themselves, or going to the toilet)		④
Moderately Dependent – Able to carry out some basic activities of daily living (for example, bathing, feeding, dressing) but unable without help to carry out most instrumental activities of daily living (e.g. shopping, cooking, housework)		③
Able to carry out most activities of daily living, but requires help with some (e.g. shopping, cooking, housework)		②
Able to carry out most activities of daily living, but may need some help occasionally		①

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 following activities?					
Tick as appropriate ↘		Unable	With some help		Without help
43 E43IADL1	Housework (clean floors etc.)	①	①		②
44 E44IADL2	Prepare their own meals	①	①		②
45 E45IADL3	Go shopping	①	①		②
46 E46IADL4	Handle their own money	①	①		②
47 E47IADL5	Use the telephone	①	①		②
48 E48IADL6	Take their own medicines	①	①		②
49 E49MOB	Walk outside	①	①		②
50 E50BAR1	Get around indoors	①	① In a wheelchair without help or walking with major physical help	② Walking with some help guided or supervised	③ May use any aid, e.g. stick, zimmer
Note the different response options here....					
51 E51BAR2	Manage stairs	①	①		②
52 E52BAR3	Move themselves from bed to chair, if next to each other	① Unable, no sitting balance	① Major help (1 or 2 people, physical)	② Minor help (verbal or physical)	③
53 E53BAR4	Use the toilet (or commode)	①	①		②
54 E54BAR5	Use the bath or shower	Here....		①	②
55 E55BAR6	Keep up their personal appearance (brush hair, shave, make up etc.)	①	①		②
56 E56BAR7	Dress themselves	①	①		②
57 E57BAR8	Feed themselves	①	①		②

		Yes, frequent accidents	Yes, occasional accident	No accidents (continent)
58 E58BAR9	Does ELDER have accidents with their bladder (incontinence of urine)?	① Once a day or more or needs catheter	① Less than once a day	②
And here....				
59 E57BAR10	Does ELDER have accidents with their bowels (incontinence of faeces)?	① Once a week or more or needs of enema	① Less than once a week	②

60-66 **Let's think about the last typical caring week for you: When in that week did you provide care or support for ELDER?**

INTERVIEWER - tick all the boxes that apply

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Early morning (approximately 5am to 9am)	<input type="radio"/> C60MO1	<input type="radio"/> C61TU1	<input type="radio"/> C62WE1	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> C66SU3
Morning (approximately 9am to 12noon)	<input type="radio"/> C60MO2	<input type="radio"/> C61TU2	<input type="radio"/> C62WE2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> C66SU4
Afternoon (approximately 12 noon to 5pm)	<input type="radio"/> C60MO3	<input type="radio"/> C61TU3	<input type="radio"/> C62WE3	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> C66SU5
Evening (approximately 5pm to 10pm)	<input type="radio"/> C60MO4	<input type="radio"/> C61TU4	<input type="radio"/> C62WE4	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Night (approximately 10pm to 5am)	<input type="radio"/> C60MO5	<input type="radio"/> C61TU5	<input type="radio"/> C62WE5	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Tick all that apply here. So, for example, if someone says they are caring for 24 hours a day every day, then you will tick all the boxes

You need to calculate this in months and therefore if the answer is given in years you will need to multiply this by 12 to give an answer in months

67 **How long have you been caring for ELDER?** Months:

68 **If you were ill is there anybody who would step in to help with ELDER?**

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 **If you needed a break from your caring role is there someone who would look after ELDER for you?**

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.

		YES	NO
70 C70FAC1	A security	<input type="radio"/> ①	<input type="radio"/> ②
71 C71FAC2	There was no alternative	<input type="radio"/> ①	<input type="radio"/> ②
72 C72FAC3	The cost of professional care would be too high	<input type="radio"/> ①	<input type="radio"/> ②
73 C73FAC4	Emotional bonds (love, affection)	<input type="radio"/> ①	<input type="radio"/> ②
74 C74FAC5	Caring for ELDER makes me feel good	<input type="radio"/> ①	<input type="radio"/> ②
75 C75FAC6	ELDER would not wish for anyone else to care for them	<input type="radio"/> ①	<input type="radio"/> ②
76 C76FAC7	Because of my religious beliefs	<input type="radio"/> ①	<input type="radio"/> ②
77 C77FAC8	I found myself in these circumstances almost by chance without making a decision	<input type="radio"/> ①	<input type="radio"/> ②
78 C78FAC9	There were economic benefits for me [Carer] and / or ELDER	<input type="radio"/> ①	<input type="radio"/> ②
79 C79FAC10	A personal sense of obligation toward ELDER as a family member	<input type="radio"/> ①	<input type="radio"/> ②
80 C80FAC11 C80SPEC	Other, please specify: <input type="text"/>	<input type="radio"/> ①	<input type="radio"/> ②
81 C81PRINC	What is the principle reason for caring among those you have indicated above? <i>INTERVIEWER: put the item number (from 70 to 80) in the box</i> → <input type="text"/>		

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

Don't forget to complete this last question



Here we look at the support that is available to you as a carer.

		Always	Often	Some-times	Never	N / A
82 C82COP1	Do you feel you cope well as a caregiver?	④	③	②	①	⊗
83 C83COP2	Do you find caregiving too demanding?	①	②	③	④	⊗
84 C84COP3	Does caregiving cause difficulties in your relationships with friends?	①	②	③	④	⑧
85 C85COP4	Does caregiving have a negative effect on your physical health?	①	②	③	④	⊗
86 C86COP5	Does caregiving cause difficulties in your relationship with your family?	①	②	③	④	⑧
87 C87COP6	Does caregiving cause you financial difficulties?	①	②	③	④	⊗
88 C88COP7	Do you feel trapped in your role as a caregiver?	①	②	③	④	⊗
89 C89COP8	Do you feel well supported by your friends and / or neighbours?	The 'not applicable' option is not available for all items in this instrument				⑧
90 C90COP9	Do you find caregiving worthwhile?					⊗
91 C91COP10	Do you feel well supported by your family?	④	③	②	①	⑧
92 C92COP11	Do you have a good relationship with the person you care for?	④	③	②	①	⊗
93 C93COP12	Do you feel well supported by health and social services? (for example, public, private, voluntary)	④	③	②	①	⑧
94 C94COP13	Do you feel that anyone appreciates you as a caregiver?	④	③	②	①	⊗
95 C95COP14	Does caregiving have a negative effect on your emotional well-being?	①	②	③	④	⊗
96 C96COP15	Overall, do you feel well supported in your role of caregiver?	④	③	②	①	⊗

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

97 C97QOL1	In general, would you say your health is:								
	Excellent ①	Very good ②	Good ③	Fair ④	Poor ⑤				
	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
98 C98QOL	and in good			⑤	④	③	②	①	①
99 C99QOL	and relaxed								①
100 C100QOL	and vigorous								①
101 C101QOL5	...wake up feeling fresh and rested			⑤	④	③	②	①	①
102 C102QOL6	...daily life has been filled with things that interest me			⑤	④	③	②	①	①
103 C103QOL7	Overall, how would you rate your quality of life in the last two weeks?								
	Very poor ⑤	Poor ④	Neither good nor poor ③	Good ②	Very good ①				

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

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.

	A. Let's begin with ELDER What services have ELDER (and YOU) used in the last 6 months?		B. Has the service met ELDER's / YOUR needs?		C. Do you or ELDER pay for this service when you utilise it?	
	SERVICES <i>INTERVIEWER: Refer to your national list of services</i>		Mostly Yes	Mostly No	Yes	No
	NAME OF SERVICE	A. (Number from list of services)	B		C	
104 SE104NAM SE104A- SE104G	<input type="text"/>	<input type="text"/>	①	①	①	①
105 SE105NAM SE105A- SE105G	<input type="text"/>	<input type="text"/>	①	①	①	①
106 SE106NAM SE106A- SE106G	<input type="text"/>	<input type="text"/>	①	①	①	①
107 SE107NA SE107A- SE107G	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.					
108 SE108NA SE108A- SE108G	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.					
109 SE109NA SE109A- SE109G	Then taking each of those services 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 and F.					
110 SE110NA SE110A- SE110G	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.					
111 SE111NA SE111A- SE111G						
112 SE112NA SE112A- SE112G	NB Only itemise services that the carer utilise as a direct consequence of their caring roles and responsibilities.					
113 SC113NA SC113A- SC113G	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.					
114 SC114NAM SC114A- SC114G	C A R E R	<input type="text"/>	<input type="text"/>	①	①	①
115 SC115NAM SC115A- SC115G		<input type="text"/>	<input type="text"/>	①	①	①
116 SC116NAM SC116A- SC116G		<input type="text"/>	<input type="text"/>	①	①	①
117 SC117NAM SC117A- SC117G		<input type="text"/>	<input type="text"/>	①	①	①
118 SC118NAM SC118A- SC118G		<input type="text"/>	<input type="text"/>	①	①	①

In the next 2 questions we are trying to understand

1. Why people chose not to use services that they need?
2. Why people stop using some services despite the fact that they still need them (We give some answer options but please specify if these options are insufficient)#
3. Why they do not access services at all

119	Are there any services that you or ELDER need but have not used so far?		
S119STOP	Yes <input type="radio"/> ①		No <input type="radio"/> ②
Ask questions in grey section		Move to question 120	
If yes, which ones? <i>INTERVIEWER: list the 3 most important, to be chosen from the national list of services</i>			
S119EXP1- S119EXP3	Too expensive	<input checked="" type="radio"/> S119EXP1	<input type="radio"/> S119EXP2
S119DIS1- S119DIS3	Too distant	<input type="radio"/> S119DIS1	<input type="radio"/> S119DIS2
S119QUA1- S119QUA3	Low quality of service	<input checked="" type="radio"/> S119QUA1	<input type="radio"/> S119QUA2
S119AV1- S119AV3	Any more	<input type="radio"/> S119AV1	<input type="radio"/> S119AV2
S119ENT1- S119ENT3	No longer entitled to use them	<input type="radio"/> S119ENT1	<input type="radio"/> S119ENT2
S119OTH	Other (specify)	<input type="text"/>	

If the respondent answers 'yes' write in the number of the service from your national list of services (See example in blue)

Then put a tick in the boxes that apply for each service. If the answer option you need is not available then choose 'other' and specify

This question is completed in the same way as the box above

120	Are there any services that you or ELDER need but have not used so far?		
S120NOUS	Yes <input type="radio"/> ①		No <input type="radio"/> ②
Ask questions in grey section		Move to question 121	
If yes, which ones? <i>INTERVIEWER: list the 3 most important, to be chosen from the national list of services</i>			
S120SER1- S120SER2- S120SER3		<input type="text"/>	<input type="text"/>
If yes, what were the reasons for your decision? <i>Please tick all boxes that apply</i>			
S120EXP1- S120EXP3	Too expensive	<input type="radio"/> S120EXP1	<input type="radio"/> S120EXP2
S120DIS1- S120DIS3	Too distant	<input type="radio"/> S120DIS1	<input type="radio"/> S120DIS2
S120QUA1- S120QUA3	Low quality of service	<input type="radio"/> S120QUA1	<input type="radio"/> S120QUA2
S120KNO1- S120KNO3	Didn't know about it	<input type="radio"/> S120KNO1	<input type="radio"/> S120KNO2
S120ENT1- S120ENT3	Are not entitled to use them	<input type="radio"/> S120ENT1	<input type="radio"/> S120ENT2
S120OTH	Other (specify)	<input type="text"/>	

121	ONLY FOR RESPONDENTS WHO USE NO SERVICES
	What are the reasons that you and ELDER do not access services? (List three most important)
S121REA1	
S121REA2	
S121REA1	

Please write clearly in answering these questions

122	ASK ALL RESPONDENTS THE FOLLOWING QUESTIONS
	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)
S122HEL1	
S122HEL2	
S122HEL3	

123	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)
S123DIF1	
S123DIF2	
S123DIF3	

124	Has caring resulted in any additional financial costs?				
F124ADAP	Adaptation of the Home environment and or furniture	Yes	①	No	①
F124TRAV	Travel costs	Yes	①	No	①
F124FOOD	Special food	Yes	①	No	①
F124MED	Medicines	Yes	①	No	①
F124OTHE	Other, specify below:	Yes	①	No	①
F124SPEC	Specification of other:	<input type="text"/>			

Tick either yes or no to all these options use the 'other' if needed

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.

	A. How important is support that gives you.....?	A				B. Is this currently being met for you?	
		Very important	Quite important	Not important	N / A	Mostly No	Mostly Yes
125 S125IMPA S125IMPB	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 S126IMPA S126IMPB	Information about the disease that ELDER has	②	①	①	X	①	①
127 S127IMPA S127IMPB	Training to help me develop the skills I need to care	②	①	①	X	①	①
128 S128IMPA S128IMPB	Opportunities to enjoy activities outside of caring	②	①	①	X	①	①
129 S129IMPA S129IMPB	Opportunities to take a holiday or break	②	①	①	X	①	①
130 S130IMPA S130IMPB	Opportunities for ELDER to do things they enjoy	②	①	①	X	①	①
131 S131IMPA S131IMPB	Opportunities for ELDER in the future	②	①	①	X	①	①
132 S132IMPA S132IMPB	The possibility to combine care giving with paid employment	②	①	①	⑧	①	①
133 S133IMPA S133IMPB	The opportunity to talk over my problems as a carer	②	①	①	X	①	①
134 S134IMPA S134IMPB	Opportunities to attend a carer support group	②	①	①	X	①	①
135 S135IMPA S135IMPB	More money to help provide things I need to give good care	②	①	①	X	①	①
136 S136IMPA S136IMPB	Opportunities to spend more time with my family	②	①	①	⑧	①	①
137 S137IMPA S137IMPB	Help to deal with family disagreements	②	①	①	⑧	①	①
138 S138IMPA S138IMPB	Help to make ELDER's environment more suitable for caring	②	①	①	X	①	①
139 S139IMP1	Of those types of support you have stated are very important which					Item-number:	<input type="text"/>
140 S140IMP2	The second most important	Write down the number of the 3 forms of support that the respondent finds most important				Item-number:	<input type="text"/>
141 S141IMP3	The third most important					Item-number:	<input type="text"/>

Regardless of the support you may or may not currently receive we are interested in finding out which service characteristics you value.

	A. How important are the following characteristics of a service for you?	B. Is this currently being met for you?					
		Not important	Mostly No	Mostly Yes	N/A		
142 S142CHAA S142CHAB	Help is available at most	②	①	①	①	①	⑧
143 S143CHAA S143CHAB	The help provided fits in with your own routines	②	①	①	①	①	⑧
144 S144CHAA S144CHAB	Help arrives at the time it is promised	②	①	①	①	①	⑧
145 S145CHAA S145CHAB	Care workers have the skills and training they require	②	①	①	①	①	⑧
146 S146CHAA S146CHAB	Care workers treat ELDER with dignity and respect	②	①	①	①	①	⑧
147 S147CHAA S147CHAB	Care workers treat you with dignity and respect	②	①	①	①	①	⑧
148 S148CHAA S148CHAB	Your views and opinions are listened to	②	①	①	①	①	⑧
149 S149CHAA S149CHAB	The help provided improves the quality of life of ELDER	②	①	①	①	①	⑧
150 S150CHAA S150CHAB	The help provided improves your quality of life	②	①	①	①	①	⑧
151 S151CHAA S151CHAB	The help provided is not too expensive	②	①	①	①	①	⑧
152 S152CHAA S152CHAB	Help is provided by the same care worker each time	②	①	①	①	①	⑧
153 S153CHAA S153CHAB	Help focuses on your needs as well as those of ELDER	②	①	①	①	①	⑧

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

154 S154IMP1	Of those characteristics you have stated are very important which would you rate as the most important to you?	Item-number: <input type="text"/>
155 S155IMP2	The second most important?	Item-number: <input type="text"/>
156 S156IMP3	The third?	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 C157FUT1	In the next year, are you willingly to continue to provide care to ELDER?	
	Yes, and I would even consider increasing the care I give if necessary	①
	Yes, and I would consider increasing the care I give for a limited time	②
	Yes, I am prepared to continue to provide care if the situation remains the same	③
	Yes, I am prepared to continue to provide care to ELDER but only if I have some more support (from services, family, friends etc.)	④
	No, I am not prepared to continue to provide care to ELDER, no matter what extra support I receive	⑤
158 C158FUT2	Would you be prepared to consider ELDER's placement in a care home?	
	No, not under any circumstances	①
	Yes, but only if ELDER's condition gets worse	②
	Yes, even if ELDER's condition remains the same as it is now	③

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"/> List: <input type="text"/>
163 C163ETHN C163CODE	What is your ethnic origin?	<input type="text"/>
164 C164MARS	What is your marital status?	Married / Cohabiting ② Divorced / Separated ④
165 C165RELI	Do you belong to a religious denomination?	Yes ① No ②
C165SPEC C165CODE	If yes, specify which one?	<input type="text"/> List: xx <input type="text"/>
166 C166RELI	Do you consider yourself to be...?	Not at all religious ① Quite religious ② Very religious ③
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

You may want to let the respondent read these options

Choose the nationality ethnic origin and religion from the national list you have been given and write down the code. If you find the option you need is not on the list write down what the respondent tells you

170 C170NUMH	Including yourself, what are the total number of people in your household?		<input type="text"/>
171 C171NUMY	And how many of them are children?		<input type="text"/>
<div style="border: 1px solid black; padding: 5px; width: fit-content; margin-left: auto; margin-right: auto;"> Include young people who are 14 year old in this numb </div>			
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	Are you currently employed?	Yes ①	No ②
		Ask questions in grey section	Go to question 179
C175HOUR	If yes, how many hours do you work in an average week?		<input type="text"/>
176 C176TYPE	If you are employed, are you.....?	A private sector employee ①	A public sector employee ②
C176SPEC		Self employed ③	Other, please specify ④
C176SPEC	Specification of other	<input type="text"/>	
177 C177WORK C177CODE	What type of work do you do?	<input type="text"/>	List: xx <input type="text"/>
178 C178WOR1	Has caring for ELDER caused any of the following restrictions to your working life or career?		
C178HOU	my working hours	Yes ①	No ②
C178INC	how many per week?	<input type="text"/>	
C178PON	is this made to your income per month	<input type="text"/>	
C178PON	or negative?	Positive ①	Negative ②

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)

ASK QUESTIONS 179 & 180 OF NON WORKING CARERS ONLY			
179 C179TYPE	If you are not working at present are you?	Retired ①	Unemployed and seeking work ②
C179SPEC		On long term sick leave but intending to return to work ③	Housewife / husband ④
C179SPEC		Other, please specify ⑤	<input type="text"/>
180	If you are not working. Has caring for ELDER caused any to your working life or career?		
C180WOR1	I cannot work at all	Yes ①	No ②
C180WOR2	I have had to give up work	Yes ①	No ②
C180HOUR	If yes, how many hour per week were you working before you gave up work?		<input type="text"/>

	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	①
181 C181WOR1		②
C181WOR2		③
C181WOR3		④

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

Specifica

Add up all sources, what is your household net income per month? If you don't know the exact figure, please give an estimate.

**NET INCOME MEANS:
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.**

F182CINC F182CAM	My household income per month is	①	<input type="text"/>	Specify the amount (F182CAM)	→ Go to question 184
	Don't know	②			→ Go to question 183
	No answer	③			→ Go to question 183
183 F183BAND	If you do not know exactly, perhaps you can tell me which range the household's net monthly income falls into? [Show card with options to respondent]				
	National figures	④		National figures	⑤
	National figures	⑥		National figures	⑦
	National figures	⑦		National figures	⑧
	National figures	⑧		National figures	⑨
	National figures	⑨		National figures	⑩
				No response	⑪

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

184	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.				
F184EINC F184EAM	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	③			→ Go to question 185
185 F185BAND	If you do not know exactly, perhaps you can tell me which range the household's net monthly income falls into? [Show card with options to respondent]				
	National figures	④		National figures	⑤
	National figures	⑥		National figures	⑦
	National figures	⑦		National figures	⑧
	National figures	⑧		National figures	⑨
	National figures	⑨		National figures	⑩
	National figures	⑩		National figures	⑪
	National figures	⑪		National figures	⑫
				No response	⑬

This question relates to the income of the cared for person and is answered in the same way as the one above. However, please skip this question if the cared for person lives with the respondent

