

EUROFAMCARE

Questionnaire

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:	metropolitan ① urban ② rural ③
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	DATE OF INTERVIEW: (DD / MM / YYYY)	<input type="text"/> / <input type="text"/> / <input type="text"/>
8 G8PRES	ELDER present at the interview?	Yes ① No ②
9 G9REC G9SPEC	MODE OF RECRUITMENT (Tick only one mode of recruitment)	
	Health or social care professional (e.g. Doctor or social worker)	①
	Priest/parish/religious organisations	②
	Door to door	③
	Voluntary organisation e.g. carer support group	④
	Advertisement (e.g. Newspaper, handbill/flyer/posters)	⑤
	Lists (e.g. of older residents, or electoral role)	⑥
	Other, specify: <input type="text"/>	⑦
	Snowball (in this case go to question 10)	⑧
10 G10SBC	SNOWBALL CHANNEL IF KNOWN:	<input type="text"/>



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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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.

12 C12HOUR	On average, how many hours a week do you give care and support to ELDER?	<input style="width: 50px; height: 20px;" type="text"/>
13 C13NUMO	How many people who are not elderly [e.g. children etc] do you give care and support?	<input style="width: 50px; height: 20px;" type="text"/>
14 C14HOURO	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?	<input style="width: 50px; height: 20px;" type="text"/>

15 E15RELAT E15SPEC	What is your relationship to ELDER?	<table style="width: 100%; border: none;"> <tr> <td style="width: 50%;">Spouse / Partner ①</td> <td style="width: 50%;">Child ②</td> </tr> <tr> <td>Sibling ③</td> <td>Daughter- / Son-in-law ④</td> </tr> <tr> <td>Uncle/ Aunt ⑤</td> <td>Nephew/ Niece ⑥</td> </tr> <tr> <td>Cousin ⑦</td> <td>Other, specify below: ⑧</td> </tr> <tr> <td colspan="2">Specification of other <input style="width: 150px; height: 20px;" type="text"/></td> </tr> </table>	Spouse / Partner ①	Child ②	Sibling ③	Daughter- / Son-in-law ④	Uncle/ Aunt ⑤	Nephew/ Niece ⑥	Cousin ⑦	Other, specify below: ⑧	Specification of other <input style="width: 150px; height: 20px;" type="text"/>	
Spouse / Partner ①	Child ②											
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Uncle/ Aunt ⑤	Nephew/ Niece ⑥											
Cousin ⑦	Other, specify below: ⑧											
Specification of other <input style="width: 150px; height: 20px;" type="text"/>												
16 E16SEX	What is ELDER's Gender?	Male ① Female ②										
17 E17AGE	How old is ELDER?	<input style="width: 50px; height: 20px;" type="text"/>										
18 E18NAT E18CODE	What is ELDER's nationality?	<table style="width: 100%; border: none;"> <tr> <td style="width: 70%;"><input style="width: 100%; height: 20px;" type="text"/></td> <td style="width: 5%; text-align: center;">List:</td> <td style="width: 25%;"><input style="width: 30px; height: 20px;" type="text"/></td> </tr> <tr> <td></td> <td style="text-align: center;">xx</td> <td></td> </tr> </table>	<input style="width: 100%; height: 20px;" type="text"/>	List:	<input style="width: 30px; height: 20px;" type="text"/>		xx					
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19 E19ETHN E19CODE	What is ELDER's ethnic origin?	<table style="width: 100%; border: none;"> <tr> <td style="width: 70%;"><input style="width: 100%; height: 20px;" type="text"/></td> <td style="width: 5%; text-align: center;">List:</td> <td style="width: 25%;"><input style="width: 30px; height: 20px;" type="text"/></td> </tr> <tr> <td></td> <td style="text-align: center;">xx</td> <td></td> </tr> </table>	<input style="width: 100%; height: 20px;" type="text"/>	List:	<input style="width: 30px; height: 20px;" type="text"/>		xx					
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	xx											
20 E20MARS	What is ELDER's marital status?	<table style="width: 100%; border: none;"> <tr> <td style="width: 50%;">Married / Cohabiting ①</td> <td style="width: 50%;">Widowed ②</td> </tr> <tr> <td>Divorced / Separated ③</td> <td>Single ④</td> </tr> </table>	Married / Cohabiting ①	Widowed ②	Divorced / Separated ③	Single ④						
Married / Cohabiting ①	Widowed ②											
Divorced / Separated ③	Single ④											

21 C21COHAB	Where do you and ELDER live?	<table style="width: 100%; border: none;"> <tr> <td style="width: 50%;">In the same household ①</td> <td style="width: 50%;">①</td> </tr> <tr> <td>In different households but the same building ②</td> <td>②</td> </tr> <tr> <td>Within walking distance ③</td> <td>③</td> </tr> <tr> <td>Within 10 minutes drive / bus or train journey ④</td> <td>④</td> </tr> <tr> <td>Within 30 minutes drive / bus or train journey ⑤</td> <td>⑤</td> </tr> <tr> <td>Within 1 hours drive / bus or train journey ⑥</td> <td>⑥</td> </tr> <tr> <td>Over 1 hours drive / bus or train journey ⑦</td> <td>⑦</td> </tr> </table>	In the same household ①	①	In different households but the same building ②	②	Within walking distance ③	③	Within 10 minutes drive / bus or train journey ④	④	Within 30 minutes drive / bus or train journey ⑤	⑤	Within 1 hours drive / bus or train journey ⑥	⑥	Over 1 hours drive / bus or train journey ⑦	⑦
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Within 1 hours drive / bus or train journey ⑥	⑥															
Over 1 hours drive / bus or train journey ⑦	⑦															

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:	<input type="text"/>

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 ⑧
E23PARTN	With their partner	Yes ①	No ②	N/A ⑧
E23PAID	With paid carers (in their own home)	Yes ①	No ②	N/A ⑧
E23OTHER	With others, please specify below...	Yes ①	No ②	N/A ⑧
E23SPEC	...Specify others	<input type="text"/>		
24	FOR THOSE WHO <u>DO NOT</u> LIVE IN A CARE HOME OR WITH THE CARER...			
E24NUMH	What is the total number of people in ELDER's household, including ELDER themselves?	<input type="text"/>		
E24NUMY	And how many of them are aged 14 years or less?	<input type="text"/>		

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)
	<input type="text"/>
	<input type="text"/>
26	Are there any other reasons? (list the four most important)
E26REAS2	<input type="text"/>
E26REAS3	<input type="text"/>
E26REAS4	<input type="text"/>
E26REAS5	<input type="text"/>

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) ↓		Completely	Partially	Does not have this need	No one	The interviewed Carer	Other informal carers	Service / support organisations (voluntary private or public)	F		
									Yes	No	Not Applicable
		A			B	C	D	E	F		
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	⑧
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	⑧
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	⑧
30 E30A- E30F	Emotional / Psychological / Social: (e.g. companionship, reassurance)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	⑧
31 E31A- E31F	Domestic: (e.g. housework)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	⑧
32 E32A- E32F	Financial management: (e.g. paying bills for the cared for from ELDER's own money)	②	①	①	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	①	①	⑧
33 E33A- E33F	Financial support: (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	⑧
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	⑧

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?	③	②	①	②
40 E40BEHP2	Have difficulty holding normal conversation, have no insight into their problems, or become uncooperative with your requests	③	②	①	②
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

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 <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)		③
Slightly Dependent –		
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)		②
Independent –		
Able to carry out most activities of daily living, but may need some help occasionally		①

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
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	①	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
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"/> C63TH1	<input type="radio"/> C64FR1	<input type="radio"/> C65SA1	<input type="radio"/> C66SU1
Morning (approximately 9am to 12noon)	<input type="radio"/> C60MO2	<input type="radio"/> C61TU2	<input type="radio"/> C62WE2	<input type="radio"/> C63TH2	<input type="radio"/> C64FR2	<input type="radio"/> C65SA2	<input type="radio"/> C66SU2
Afternoon (approximately 12 noon to 5pm)	<input type="radio"/> C60MO3	<input type="radio"/> C61TU3	<input type="radio"/> C62WE3	<input type="radio"/> C63TH3	<input type="radio"/> C64FR3	<input type="radio"/> C65SA3	<input type="radio"/> C66SU3
Evening (approximately 5pm to 10pm)	<input type="radio"/> C60MO4	<input type="radio"/> C61TU4	<input type="radio"/> C62WE4	<input type="radio"/> C63TH4	<input type="radio"/> C64FR4	<input type="radio"/> C65SA4	<input type="radio"/> C66SU4
Night (approximately 10pm to 5am)	<input type="radio"/> C60MO5	<input type="radio"/> C61TU5	<input type="radio"/> C62WE5	<input type="radio"/> C63TH5	<input type="radio"/> C64FR5	<input type="radio"/> C65SA5	<input type="radio"/> C66SU5

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

68 C68ILL	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 C69BREAK	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.

	What factors influenced your decision to care for ELDER? <i>INTERVIEWER (ensure that there is an answer 'yes', or 'no' for each item)</i>	YES	NO
70 C70FAC1	A sense of duty	①	①
71 C71FAC2	There was no alternative	①	①
72 C72FAC3	The cost of professional care would be too high	①	①
73 C73FAC4	Emotional bonds (love, affection)	①	①
74 C74FAC5	Caring for ELDER makes me feel good	①	①
75 C75FAC6	ELDER would not wish for anyone else to care for them	①	①
76 C76FAC7	Because of my religious beliefs	①	①
77 C77FAC8	I found myself in these circumstances almost by chance without making a decision	①	①
78 C78FAC9	There were economic benefits for me [Carer] and / or ELDER	①	①
79 C79FAC10	A personal sense of obligation toward ELDER as a family member.	①	①
80 C80FAC11 C80SPEC	Other, please specify: <input type="text"/>	①	①
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"/>		

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	<input type="checkbox"/>
83 C83COP2	Do you find caregiving too demanding?	①	②	③	④	<input type="checkbox"/>
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	<input type="checkbox"/>
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	<input type="checkbox"/>
88 C88COP7	Do you feel trapped in your role as a caregiver?	①	②	③	④	<input type="checkbox"/>
89 C89COP8	Do you feel well supported by your friends and / or neighbours?	④	③	②	①	⑧
90 C90COP9	Do you find caregiving worthwhile?	④	③	②	①	<input type="checkbox"/>
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	<input type="checkbox"/>
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	<input type="checkbox"/>
95 C95COP14	Does caregiving have a negative effect on your emotional well-being?	①	②	③	④	<input type="checkbox"/>
96 C96COP15	Overall, do you feel well supported in your role of caregiver?	④	③	②	①	<input type="checkbox"/>

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			
	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
98 C98QOL2	I have felt cheerful and in good spirits		⑤	④	③	②	①	①
99 C99QOL3	I have felt calm and relaxed		⑤	④	③	②	①	①
100 C100QOL4	I have felt active and vigorous		⑤	④	③	②	①	①
101 C101QOL5	I woke up feeling fresh and rested		⑤	④	③	②	①	①
102 C102QOL6	My 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		

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	②	①	②	
105 SE105NAM SE105A- SE105G	<input type="text"/>	<input type="text"/>	①	②	①	②	
106 SE106NAM SE106A- SE106G	<input type="text"/>	<input type="text"/>	①	②	①	②	
107 SE107NAM SE107A- SE107G	<input type="text"/>	<input type="text"/>	①	②	①	②	
108 SE108NAM SE108A- SE108G	<input type="text"/>	<input type="text"/>	①	②	①	②	
109 SE109NAM SE109A- SE109G	<input type="text"/>	<input type="text"/>	①	②	①	②	
110 SE110NAM SE110A- SE110G	<input type="text"/>	<input type="text"/>	①	②	①	②	
111 SE111NAM SE111A- SE111G	<input type="text"/>	<input type="text"/>	①	②	①	②	
112 SE112NAM SE112A- SE112G	<input type="text"/>	<input type="text"/>	①	②	①	②	
113 SC113NAM SC113A- SC113G	<input type="text"/>	<input type="text"/>	①	②	①	②	
114 SC114NAM SC114A- SC114G	<input type="text"/>	<input type="text"/>	①	②	①	②	
115 SC115NAM SC115A- SC115G	<input type="text"/>	<input type="text"/>	①	②	①	②	
116 SC116NAM SC116A- SC116G	<input type="text"/>	<input type="text"/>	①	②	①	②	
117 SC117NAM SC117A- SC117G	<input type="text"/>	<input type="text"/>	①	②	①	②	
118 SC118NAM SC118A- SC118G	<input type="text"/>	<input type="text"/>	①	②	①	②	

119	Are there any services that you or ELDER still need that you have <u>stopped</u> using?			
S119STOP	Yes ① <i>Ask questions in grey section</i>		No ② <i>Move to question 120</i>	
If yes, which ones? <i>INTERVIEWER: list the 3 most important, to be chosen from the national list of services</i>				
S119SER1 S119SER2 S119SER3				
If yes, what were the reasons for your decision? <i>Please tick all boxes that apply</i>				
	↘	Service 1	Service 2	Service 3
S119EXP1- S119EXP3	Too expensive	<input type="radio"/> S119EXP1	<input type="radio"/> S119EXP2	<input type="radio"/> S119EXP3
S119DIS1- S119DIS3	Too distant	<input type="radio"/> S119DIS1	<input type="radio"/> S119DIS2	<input type="radio"/> S119DIS3
S119QUA1 – S119QUA3	Low quality of service	<input type="radio"/> S119QUA1	<input type="radio"/> S119QUA2	<input type="radio"/> S119QUA3
S119AV1- S119AV3	Not available any more	<input type="radio"/> S119AV1	<input type="radio"/> S119AV2	<input type="radio"/> S119AV3
S119ENT1- S119ENT3	No longer entitled to use them	<input type="radio"/> S119ENT1	<input type="radio"/> S119ENT2	<input type="radio"/> S119ENT3
S119OTH	Other (specify)			

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

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

122	<u>ASK ALL RESPONDENTS THE FOLLOWING QUESTIONS</u> 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)
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"/>			

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	①	①	①
126 S126IMPA S126IMPB	Information about the disease that ELDER has	②	①	①	①	①	①
127 S127IMPA S127IMPB	Training to help me develop the skills I need to care	②	①	①	①	①	①
128 S128IMPA S128IMPB	Opportunities to enjoy activities outside of caring	②	①	①	①	①	①
129 S129IMPA S129IMPB	Opportunities to have a holiday or take a break from caring	②	①	①	①	①	①
130 S130IMPA S130IMPB	Opportunities for ELDER to undertake activities they enjoy	②	①	①	①	①	①
131 S131IMPA S131IMPB	Help with planning for the future care	②	①	①	①	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	①	①	①
134 S134IMPA S134IMPB	Opportunities to attend a carer support group	②	①	①	①	①	①
135 S135IMPA S135IMPB	More money to help provide things I need to give good care	②	①	①	①	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	①	①	①
139 S139IMP1	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 S140IMP2	The second most important?					Item-number:	<input type="text"/>
141 S141IMP3	The third?					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?	A			B. Is this currently being met for you?		
		Very important	Quite important	Not important	Mostly No	Mostly Yes	N/A
142 S142CHAA S142CHAB	Help is available at the time you need it 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
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"/>

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: xx <input type="text"/>
163 C163ETHN C163CODE	What is your ethnic origin?	<input type="text"/> List: xx <input type="text"/>
164 C164MARS	What is your marital status?	Married / Cohabiting ① Widowed ② Divorced / Separated ③ Single ④
165 C165RELI	Do you belong to a religious denomination?	Yes ① No ② → Go to question 166
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 ② Quite religious ① 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

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 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 <i>Go to question 175</i>
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
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 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: <input type="text"/> xx
178 C178WOR1	Has caring for ELDER caused any of the following restrictions to your working life or career?	I have had to reduce my working hours Yes ① No ②
C178HOUR	If yes, by how many per week? <input type="text"/>	
C178INC	And what difference has this made to your income per month <input type="text"/>	
C178PONE	Is the difference positive or negative?	Positive ① Negative ②

<u>ASK QUESTIONS 179 & 180 OF NON WORKING CARERS ONLY</u>		
179 C179TYPE	If you are not working at present are you?	Retired ① Unemployed and seeking work ② On long term sick leave but intending to return to work ③ Housewife / husband ④ Other, please specify ⑤ <input type="text"/> C179SPEC
180	<u>If you are not working.</u> 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"/>	

ASK ALL CARERS		Has caring for ELDER caused any of the following restrictions to your working life or career?	
181 C181WOR1	I can/could not develop my professional career or studies	Yes ①	No ⑩
C181WOR2	I can/ could work only occasionally	Yes ①	No ⑩
C181WOR3	Other, specify below...	Yes ①	No ⑩
C181SPEC	Specification of other: <input type="text"/>		

182 F182CINC		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.	
<i>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.</i>			
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	⑨	→ 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 ①		National figures ⑥
	National figures ②		National figures ⑦
	National figures ③		National figures ⑧
	National figures ④		National figures ⑨
	National figures ⑤		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	⑨	→ 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 ①		National figures ⑦
	National figures ②		National figures ⑧
	National figures ③		National figures ⑨
	National figures ④		National figures ⑩
	National figures ⑤		National figures ⑪
	National figures ⑥		National figures ⑫
			No response ⑬

186 F186ESUP	Does ELDER receive any pension or financial support of any kind from the state?	Yes ①	No ②
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	Do you or ELDER receive any financial support, or allowances <u>because of your caring</u> situation as showed on the list?	ELDER		CARER	
		Yes	No	Yes	No
	A	E		C	
187 F187SUPA F187SUPE F187SUPC	<input type="text"/>	①	②	①	②
188 F188SUPA F188SUPE F188SUPC	<input type="text"/>	①	②	①	②
189 F189SUPA F189SUPE F189SUPC	<input type="text"/>	①	②	①	②
190 F190SUPA F190SUPE F190SUPC	<input type="text"/>	①	②	①	②
191 F191SUPA F191SUPE F191SUPC	<input type="text"/>	①	②	①	②
192 F192TOTE F192TOTC	Total amount	<input type="text"/>		<input type="text"/>	
193 F193TIME F193TIMC	Per? (Please tick relevant time unit)	Week	①	Week	①
		Month	②	Month	②
		Year	③	Year	③

Thank the respondent for their participation in the study:

Interviewer notes or comments