

### INCLUDE structured interview for the person living with dementia

Introduction: Since we last saw you for the IDEAL study, we have all been through the coronavirus outbreak. First we had the lockdown where everyone had to stay at home, and then things opened up again but with some ongoing restrictions. I would like to talk about how the coronavirus outbreak has affected you and find out how you are doing at the moment.

Level	Domain	Type	IDEAL No.	Source	Question	Response options
					To start with I have a few questions about where you are living	
1	MELD-C	c	-	MoCA orientation	Can you tell me your current address? [Responses will be scored but not recorded]	1 point for town/city, 1 for other details
1	Demogr	m	-	-	Can I check - have you moved to live in a different place since [time of last IDEAL visit]? [IF YES establish what sort of accommodation it is e.g. own home]	Yes/no
1	Demogr	m	-	-	Are you living in your own home at the moment? [If no establish where the person is living] [If it is an ordinary residence (not a care home etc) ask] Does anyone else live there with you? [If YES] who else lives there with you?	Yes/no  Spouse/partner, other family [specify], other non-family [specify]
1	MELD-C	c	-	MoCA orientation	One additional thing – can you tell me today's date? [If answer incomplete, prompt] Tell me the [year; month; exact date; day of the week]	1 point for each correct element
					The next set of questions are about how the coronavirus outbreak has affected you.	
1	COVID	o	-	IDEAL CDI	Overall how do you feel the coronavirus outbreak has affected you?	
1	Health	m	-		[If not mentioned] Have you had the coronavirus? [If yes, establish whether tested and whether treated in hospital]	Yes/no

1	COVID	c	-		[If not mentioned] Has anyone close to you had the virus? [If participant says someone has died, interviewer will respond appropriately]	Yes/no
1	COVID	o	-	IDEAL CDI	[If not already clear] What have been the most difficult aspects of the coronavirus outbreak for you?	
1	COVID	o	-	ALWAYS	[If not already mentioned] During the lockdown period we were advised to stay at home. How do you feel this affected you?	
1	MELD-F	m	-	IDEAL CDI	[If not already mentioned] Some people have said that staying home during the lockdown affected their confidence. Do you feel it affected you in this way? [if yes ask for details]	Yes/no
1	COVID	c	-	ELSA	How worried, if at all, have you been about having enough food during the coronavirus outbreak?	Not at all Not very Somewhat Very Extremely
1	COVID	m	T4 Q127 adapted	IDEAL CDI	How easy or difficult was it to keep yourself occupied at home during the coronavirus lockdown?  What sorts of activities have you been doing (e.g. reading, listening to radio, television, puzzles, crafts, carpentry, DIY, gardening, volunteering, other)? Did you try any new activities during the coronavirus lockdown? If yes, which? Were there any activities that you found particularly interesting or stimulating?	Very easy Fairly easy Not very easy  Yes/no
1	COVID	m	-	ALWAYS	[If not already mentioned] Since the lockdown ended, we still have to live with various restrictions, like physical distancing or having to wear a mask on the bus. Have these restrictions affected you? [if yes ask for details] Which current restrictions have affected you the most? [If not mentioned] Why is that?	Yes/no
1	Social	c	-	ELSA	How do you feel your financial situation now compares to before the coronavirus outbreak? Are you worse off, better off or about the same?	Much worse off A little worse off About the same A little better off Much better off

1	COVID	o	-	IDEAL CDI	[If not already mentioned] Have there been any positive aspects or benefits of the coronavirus outbreak? [if yes ask for details]	Yes/No
1	COVID	o	-	IDEAL CDI	Overall how well do you feel you have coped since the coronavirus outbreak?	Very well Fairly well Not very well
1	COVID	o	-	IDEAL CDI	What would have made the situation easier for you to manage, or enabled you to cope better?	
					Now I'm going to ask a few questions about how you feel generally about your life at the moment.	
1	Living well	c	T4 Q87	ONS/ELSA	On a scale of 0 to 10, where 0 is "not at all" and 10 is "very", how satisfied are you with your life nowadays?	A number on a 0 – 10 scale
1	Living well	c	T4 Q88	ONS/ELSA	On a scale of 0 to 10, where 0 is "not at all" and 10 is "very", to what extent do you feel the things you do in your life are worthwhile?	A number on a 0 – 10 scale
1	Living well	c	T4 Q76	QoL-AD	When you think about your life as a whole, everything together, how do you feel about your life? Would you say it is poor, fair, good or excellent?	Excellent Good Fair Poor
					The next few questions are about how you feel in yourself.	
1	Living well	c	T4 Q77	WHO-5	In the last two weeks, how much of the time have you felt cheerful and in good spirits?	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
1	Psychol	c	T4 Q64	LOT-R	Overall, would you say you expect more good things to happen to you than bad?	Strongly agree Agree Neutral Disagree Strongly disagree

1	Psychol	c	T4 Q61	IDEAL	Do you feel you are still the same person you have always been?	Strongly agree Agree Neutral Disagree Strongly disagree
1	Psychol	c	T4 Q48	IDEAL	Do you feel sad or depressed?	Yes/No
1	Psychol	c	-	ELSA	On a scale of 0 – 10 where 0 is not at all and 10 is very, how happy overall did you feel yesterday?	A number between 0 and 10
1	Psychol	c	-	ELSA	On a scale of 0 – 10 where 0 is not at all and 10 is very, how anxious overall did you feel yesterday?	A number between 0 and 10
1	Psychol	c	T4 Q107	EQ-5D	Which of these options best describes your mood today? <ul style="list-style-type: none"> <li>• I am not anxious or depressed</li> <li>• I am moderately anxious or depressed</li> <li>• I am extremely anxious or depressed</li> </ul>	No problem Moderate Extreme
1	Psychol	m	T4 Q148	IDEAL [response scale changed to fit with ONS]	Do you feel lonely?  Has this changed during the coronavirus outbreak? [If yes, ask for details]	Often or always Some of the time Occasionally Hardly ever Never Yes/no
					Now I'd like to talk about the contact you have with other people	
1	Relationship	m	T4 Q158	PAI	[If carer participating] Thinking of [carer] how well do you get along together? [If no carer participating] Thinking of the person closest to you, how well do you get along together?  Has this changed since the coronavirus outbreak? [if yes, ask for details and establish whether they were together during the lockdown]	Extremely well Very well Well Quite well Not too well Not well at all Yes/no

1	Social	c	T4 Q149	Lubben	Considering the people to whom you are related by birth, marriage or adoption, how many relatives do you see or hear from at least once a month?	Any number
1	Social	c	T4 Q155	IDEAL	How satisfied are you with the support you receive from family?	Very satisfied Slightly satisfied Neither satisfied nor dissatisfied Slightly dissatisfied Very dissatisfied  Don't know
1	Social	c	T4 Q152	Lubben	Considering all your friends including those who live in your neighbourhood, how many friends do you see or hear from at least once a month? Has this changed since the coronavirus outbreak?	Any number  Yes/no
1	Social	c	T4 Q156	IDEAL	How satisfied are you with the support you receive from friends?	Very satisfied Slightly satisfied Neither satisfied nor dissatisfied Slightly dissatisfied Very dissatisfied Don't know
1		m	T4 Q137 – Q138 adapted	IDEAL	Do you have access to the internet at home Do you use the internet or social media (Twitter, Facebook) to keep in touch with people? If yes ask in what way (e.g. email, FaceTime, online meetings) Has this changed since the coronavirus outbreak started? [If yes, ask for details] What else do you use the internet for? (prompt: ordering online, banking, getting information from websites, entertainment, etc) Has this changed since the coronavirus outbreak started? [if yes, ask for details]	Yes/no Yes/no  Yes/no  Yes/no

					These questions are about how you manage with everyday activities at home	
1	MELD-F	c	T4 Q104	EQ-5D	Which of these options best describes your ability for self-care (things like washing and dressing yourself)? <ul style="list-style-type: none"> <li>• I have no problems with self-care</li> <li>• I have some problems washing and dressing myself</li> <li>• I am unable to wash and dress myself</li> </ul>	No problems Some problems Unable to do
1	MELD-F	c	T4 Q105	EQ-5D	Which of these options best describes your ability to do your usual activities (e.g. housework, family or leisure activities)? <ul style="list-style-type: none"> <li>• I have no problems with performing my usual activities</li> <li>• I have some problems with performing my usual activities</li> <li>• I am unable to perform my usual activities</li> </ul>	No problems Some problems Unable to do
					I'd like to ask about any help that you have at home	
1	Social	m	T4 Q162	CSRI	In the last 3 months have relatives or friends regularly helped you with tasks you had difficulty with or could not do? Has this changed since the coronavirus outbreak?	Yes/No
1	Social	c	T4 Q163	CSRI	In an average week, how much time do relatives or friends spend providing help for you with these tasks?	None Less than 1 hour Any other number of hours
1	Services-home care	m	T4 Q171 – 182 adapted	CSRI	Do you have any help at home apart from that provided by relatives and friends? [If yes establish what: home care, cleaner, meals on wheels, other]	Yes/no
1	Services-home care	m	-	-	Did any of these kinds of help you were receiving stop due to coronavirus? [if yes ask for details] Have they started again now?	Yes/no  Yes/no
1	Services-home care	m	-	-	Did you get any extra help at home during the coronavirus outbreak that you were not having before? [if yes ask for details]	Yes/no

					The next set of questions are about how much you get out and about	
1	Social	m	T4 Q139 adapted	IDEAL	Do you normally take part in social activities outside your home, such as support groups, church activities, choirs, art groups, or memory cafes? [if yes, ask what activities] [ONLY if yes] Most of these kinds of activities stopped due to coronavirus. How did this affect you? Did anyone keep in contact with you during that time? [If yes ask for details] Have any of these started up again now? [if yes, ask which]	Yes/no
1	Services	m	T4 Q217 – Q219 adapted	CSRI	Before the coronavirus outbreak, did you normally go to a day centre? [or equivalent] [If yes] when this closed due to coronavirus, did anyone keep in touch with you? Has it restarted now?	
1	MELD-F	c	T4 Q39 - 44	Life Space	During the past 3 days have you been <ul style="list-style-type: none"> <li>To places outside your immediate town or community?</li> <li>To places outside your immediate area, but within your town or community?</li> <li>To places in your immediate area, beyond your own home or place of residence?</li> <li>To an area outside your home or place of residence, such as a garden, yard, driveway or parking space?</li> <li>To an area immediately outside your home or place of residence, such as your porch, patio, hallway of an apartment building, or garage?</li> <li>To other rooms of your home or place of residence besides the room where you sleep?</li> </ul>	Yes/no Stop after the first 'yes' response
1	Demogr	c	-	-	[ONLY if answer yes to 1, 2, 3 and 4 of the above life space questions] Do you have a garden or outside area that you can spend time in?	Yes/no





1	Social	m	T1 Q337	IDEAL	How satisfied are you with your neighbourhood as a place to live?  Has this changed since the coronavirus outbreak? [If yes, ask in what way]	Very satisfied Slightly satisfied Neither satisfied nor dissatisfied Slightly dissatisfied Very dissatisfied Don't know
					Now I'm interested to find out about your memory and thinking skills	
1	MELD-C	c	T4 Q90	IDEAL	Compared to other people of your age, how would you describe your day-to-day memory?	Excellent Very good Good Fair Poor Very poor
1	MELD-C	m	T1 Q212 – Q219 adapted	RADIX	Since the coronavirus outbreak, have you noticed any changes in your ability to: <ul style="list-style-type: none"> <li>Remember everyday things</li> <li>Remember recent events</li> <li>Concentrate</li> <li>Say what you want to say</li> <li>Plan ahead</li> <li>Make decisions</li> </ul> [Once been through above list, if yes to any, ask for more details]	Yes/no for each If yes: Better than before Worse than before
					This next part is a short memory test.	
1	MELD-C	c	-	MoCA Memory/attention	I'm going to read a list of words for you to remember now and later on. Listen carefully. When I have finished, tell me as many words as you can remember. It doesn't matter in what order you say them. [Read words] I will ask you to remember those words again later.	Words recalled are listed - 1 point for each correct word

1	MELD-C	c	-	ALWAYS	Do you sometimes feel confused? Since the coronavirus outbreak, do you find yourself feeling confused more often, or about the same as before? When you experience confusion, is it worse than before, or about the same?	Yes/no  Yes/no Yes/no
1	MELD-C	c	-	MoCA Verbal fluency	Now I want you to tell me as many animals as you can think of. I will tell you to stop after one minute. Are you ready? [Repeat instructions if necessary] [Time person for 1 minute – if the person says two consecutive words starting with a different letter, remind the person to say words beginning with the letter T] [After 1 minute] Please stop now.	Animals generated: 0.5 point for each animal, up to max of 9 points
1	MELD-C	c	-	MoCA delayed recall	I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember.  Cued recall Was the word ****, ****, or **** etc	Score 2 points for each word spontaneously recalled/ 1 point for each recalled after cued recall (max 10)
					Now I'd like to ask about your health	
1	Health	c	T4 Q89	IDEAL	Overall, how would you rate your health in the past 4 weeks?	Excellent Very good Good Fair Poor Very poor
1	Health	m	-	-	Since the coronavirus outbreak, have you developed any new health problems? [If yes ask what these are]	Yes/no
1	Health	c	T4 Q106	EQ-5D	Which of these options best describe your level of pain/discomfort today? <ul style="list-style-type: none"> <li>I have no pain or discomfort</li> <li>I have moderate pain or discomfort</li> <li>I have extreme pain or discomfort</li> </ul>	No Moderate Extreme

1	Health	c	T4 Q103	EQ-5D	Which of these options best describe your mobility today? <ul style="list-style-type: none"> <li>• I have no problems in walking about</li> <li>• I have some problems in walking about</li> <li>• I am confined to bed</li> </ul>	No problems Some problems Major problems
1	Services - health	m	T4 Q204 – Q206 adapted	CSRI	Since the coronavirus outbreak started, have you been in contact with your GP? [If yes establish whether in person at surgery, home visit, or telephone consultation and frequency]	Yes/no
1	Services - health	m	T4 Q207 – Q216 adapted	CSRI	Since the coronavirus outbreak started, have you been in contact with any other health care workers such as a practice nurse, community nurse, physiotherapist, occupational therapist, optician or dentist? [If yes establish who and why]	Yes/no
1	Services – health	c	-	-	Did you avoid seeking help for any health issues because of the coronavirus? [If yes ask for details]	Yes/no
1	Services - health	m	T4 Q199 – Q203 adapted	CSRI	Since the coronavirus outbreak started, have you been to hospital as an outpatient to see a specialist or attend a clinic? [if yes ask for details]	Yes/no
1	Services - health	m	T4 Q183 – 198 adapted	CSRI	Since the coronavirus outbreak started, have you had to stay in hospital? [if yes ask for details]	Yes/no
1	Services - health	m	T4 Q164 – 170 adapted	CSRI	Since the coronavirus outbreak started, have you had to stay in a nursing home or care home? [if yes ask for details]	Yes/no
1	Services - health	m	T4 Q98 – Q100 adapted	CSRI	Are you taking any prescribed medication? [if yes ask for details]	Yes/no
1	Services - health	m	-	-	Were your healthcare needs affected by the coronavirus outbreak – for example, appointments postponed or planned operations delayed? [If yes ask for details]	Yes/no
1	Services - health	m	-	-	Did any healthcare services you were already receiving stop due to coronavirus? [if yes ask for details]	Yes/no

					[Optional, and only for participants who are managing well with the survey] If you feel up to it, I would like to ask your help with a few more questions	
2	Living well	c	-	IDEAL WS2	[Set A or Set B to be used alternately] I'd like to know how much you agree or disagree with the following statements. [EITHER Set A] I try to get something good out of each day I take each day as it comes I feel positive about the future I am generally happy I usually sleep well I feel afraid I take an interest in what is going on around me I continue to learn as much as possible I find that people treat me differently now I have good relationships with friends and family I have people to talk to I have someone I can call on in an emergency I like my community I worry about my finances I give help and support to others I like my home I am fit enough to do the things I want to I am able to stay active I have a poor appetite I am as independent as I can be I enjoy life	Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

					[OR Set B] I try to get the best out of life I live in the moment I worry about the future I feel good about myself I am able to relax I am worried things will change for the worse I feel engaged with what is going on in the world I keep my mind occupied I am doing well for my age I have a good social life I spend time with friends I can call on friends and family when I need them I like where I live I have enough money to live comfortably I feel useful I find my religious or spiritual beliefs help me cope My physical health problems limit what I can do I can get out and about when I want to I am able to eat well I am able to adapt to most situations I have a good sense of humour most of the time	
					Thank you for answering all these questions and telling me about your experiences.	
1	-	o	-	-	Is there anything else you'd like to tell me about, that we haven't covered?	
					Interviewer will explain that we will either be back in touch for another telephone conversation, or someone from the local NHS will be in contact to arrange another visit in the future. Interviewer will ask whether the interviewee is willing to be contacted by our team for other studies. If yes, interviewer will get agreement for further contact.	