IDEAL-2 COVID-19 INITIATIVE: TELEPHONE INTERVIEW GUIDE

**Interview style**

Interviews may involve both carer and person living with dementia as joint participants if requested, or either one or the other as a single participant. Interviewers will adjust their approach to accommodate this difference, being particularly conscious to facilitate both participants’ contribution in joint interviews. The aim is for interviews to be conversational and allowed to flow in a way that follows the issues and concerns arising from participants’ own lived experience. Therefore, the questions set out above may not be asked sequentially and may be adapted to make use of specific words, phrases, examples and reference points used by participants.

The qualitative interviews will aim to elicit data in four broad topics:

* Negative impacts in terms of disruption to daily routines; and emotional and social consequences of social distancing measures including where relevant self-isolation and shielding.
* Coping strategies and support found to be helpful in mitigating negative impacts.
* Unmet needs and additional support that might have been helpful in mitigating negative impacts.
* Any positive impacts in terms of unexpected benefits; and how they might be maintained.

**Interviewers’ introduction**

Interviewers will open the interview with the following script:

*We are trying to find out how people who are living with dementia and their carers are being affected by the coronavirus pandemic and the measures that have been put in place to manage it. We are interested in how you are coping with social distancing measures; anything that you have found particularly difficult; and any support that you’ve found particularly helpful. We are also interested in any gaps in support – so anything you would have found helpful but has not been available to you. The aim is to get a better understanding of how best to support people during the crisis and after it has passed.*

**Initial interviews**

Interviewers will ask a general open ended question:

**Q.1. Tell me about how you have been affected by the coronavirus situation:**

This will be followed by a series of more specific questions:

**Q.2. Let me ask you about day to day things in a little more detail:**

* *In what ways have your daily routines been affected?*
* *What things have you found particularly difficult?* 
  + *Why was that?*
* *What things have you done to try to overcome these difficulties?*
* *What support have you had to overcome these difficulties?*
  + *How effective was it? Why was that?*
  + *Is there any additional support that you would have found helpful but wasn’t available to you? Tell me about it.*

**Q.3. I want to ask about any emotional and social effects on you now:**

* *Has the coronavirus situation made a difference to how you have been feeling?*
  + *In what ways?*
  + *How have you coped with that?*
  + *Have you had any support that has helped you to cope better?*
  + *Is there any additional support that you would have found helpful but wasn’t available to you? Tell me about it.*
* *Have you felt more cut off from other people than you did before?*
  + *How have you coped with that?*
  + *Have you had any support that has helped you to cope better?*
  + *Is there any additional support that you would have found helpful but wasn’t available to you? Tell me about it.*

**Q.4. The last questions are about any unexpected benefits and whether it is possible to build upon them:**

* *Have you found anything beneficial or better than it was before because of the corona virus situation?*
  + *What is that and why is that?*
  + *Do you think that is something that could be continued after the crisis stage has passed?*
* *What other things do you think are important to help people in your situation as things get back to normal?*

**Follow up interviews**

Questions specific to the content of the original interviews, will be asked using the following topics:

* Current general welfare and circumstances
* Discussion of themes that had emerged from each interviewee’s initial interview
* Changes in issues previously raised – better the same or worse
* Availability and suitability of post lockdown support

**Q.1. I would like to know how you have been since I last spoke to you.**

* *How are you now?* 
  + *What are your current circumstances?*

**Q.2. Last time you talked about [ ] and [ ] (Discussion of themes that had emerged from each interviewee’s initial interview)**

**Q.3. Thinking about what you said about [ ], has that changed?**

* *Is that better or worse or the same?*

*(repeat for other key issues raised)*

**Q.4. I want to next ask about any support/services you may have had since we last spoke.**

* What support arrangements/services are available to you now?
  + *Have any support arrangements / services re-started?*
  + *Has any new support/services that started during lockdown continued?*
  + *Have you had any different support / services since restrictions were eased?*

**Q.5. Lastly I want to know what your views are about the guidance you have received?**

* *How well informed do you feel about post-lockdown guidance?*
  + *To what extent does post-lockdown guidance or other information received address personal circumstances?*