**Carers Study Topic Sheet**

**Introduction**

Good morning/afternoon. Thank you for agreeing to be interviewed today. My name is Ian Garner and I am a member of the team working on this study. COVID-19 continues to affect our everyday lives and places additional strain on those providing care for others. We have previously interviewed people who live with Parkinson’s about their experiences to better understand some of the challenges they face. Now we wish to understand some of the experience of people who provide informal care for those living with Parkinson’s.

The purpose of today’s interview is to understand in-depth your experiences of the COVID-19 pandemic, how things have changed for you both in terms of providing care and the impact it has had on you.

The interview is expected to take 30-45 minutes, but this could be less or more depending on the time you have available and the information you share. You and the information you share in this interview **will not be identifiable**, so please do not feel restricted when talking during the interview. You can stop the interview at any point, or not answer any questions you do not wish to. We can also have impromptu breaks if you need to. If there is anything you are unsure of during the interview, feel free to ask and I will clarify points I make.

Before we begin, can I confirm that you have read the information sheet? Are you okay with the interview being recorded? Do you have any questions about the study before we begin?

\*Start recording\*

**First Interview only:**

Before we fully jump into the interview, I would like to ask a few questions to gain some context about you and the person you provide care for if that is okay?

1. How long would you say you have provided care for the individual living with Parkinson’s?
2. Can you tell me a bit about the person you care for?
   1. How long has the person been diagnosed with Parkinson’s for?
   2. What does the person find difficult?
   3. What is their treatment path?
   4. How old is the person you provide care for?
   5. How much time do you spend providing care?
   6. What help do you provide?
   7. Does anyone else provide help?
3. How old are you?
4. Can you tell me your and your partner’s ethnicity?

**\*Please note that discussions point in each subject will loosely be followed, and that interviews will largely be directed based on participant responses.**

**Opening question for interview 1:** Can you tell me what it was like providing care before COVID-19?

**Opening question for interviews 2 & 3:** Can you tell a little bit about how things have been since we last spoke?

**Subject 1:** *Providing care during the COVID-19 pandemic.*

1. What were your experiences providing care during the COVID-19 pandemic?
   1. **Prompt (first interview only):** (i) through first lockdown; (ii) through second lockdown; (iii) through latest lockdown
   2. **Prompt (second and third interviews only):** (i) since we last spoke.
2. What was your experience of accessing support during COVID-19?
   1. **Prompt:** Why do you think you experienced this?
3. Can you describe your experience accessing healthcare during COVID-19?
   1. **Prompt:** What was this like for you?
4. Do you think COVID-19 may have impacted on health beyond Parkinson’s? and why?
   1. **Prompt:** (i) did lockdown affect health? (ii) have social restrictions impacted on health?
5. Have your caring responsibilities extended beyond the person living with Parkinson’s? If so, why do you think that is?
   1. **Prompt:** this may be providing support for others who you didn’t provide support for before COVID-19.
   2. **Prompt:** What has this been like for you?

**Subject 2:** *Balance of providing care and impact on you.*

1. How do you see your own health?
   1. **Prompt (first interview only):** (i) through first lockdown; (ii) through second lockdown; (iii) through latest lockdown
   2. **Prompt (second and third interviews only):** (i) since we last spoke.
2. What has been your experience of the impact providing care during the pandemic has had on you?
   1. **Prompt (first interview only):** (i) through first lockdown; (ii) through second lockdown; (iii) through latest lockdown
   2. **Prompt (second and third interviews only):** (i) since we last spoke.
   3. **Prompt:** (i) did the amount of time it took to complete tasks change?
3. What was your experience of providing care and considering the risk of contracting and spreading COVID-19?
   1. **Prompt:** (i) did you alter your behaviour? If so, in what way?
4. What was your experience of balancing providing care with other responsibilities?
   1. **Prompt:** (i) for example, working commitments.