**Checking Out – Topic guide for interviews with bereaved people**

**Introduction and consent process**

* Thank person for their participation
* Go through the participant information sheet and answer any questions
* Remind participants that there are no right or wrong answers.
* Remind participants that they do not have to answer any questions if they do not want to and that they are free to end the interview whenever they wish. Check if they have a time deadline.
* Get informed consent for use of audio recorder.
* Negotiate verbal informed consent – each statement is voluntary:

1. I confirm that I have received the information sheet dated 22.10.19 (version no.2) for the Checking Out project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.

3. I understand that anonymised sections of the data collected during the study may be looked at by members of the research Advisory Group. I give permission for these individuals to have access to the anonymised data.

4. I confirm that I consent to the researcher using an audio recorder / recording the video call during our interview.

6. I understand that audio recordings will be collected and stored by the researcher in a secure archive for a period of up to 12 months, and anonymised interview transcripts will be stored securely indefinitely for the purposes of research, as allowed within the Data Protection Act.

7. I confirm that I consent to the research team using verbatim quotes in any materials published from the study (e.g. academic publications, project website, media publications) provided I cannot be identified by their use.

8. I understand that the anonymised data may be used in teaching or training materials in University activities, public engagement activities or for training purposes.

9. I agree that my contact details can be kept securely and used by the researcher only to contact me about future research projects.

10. I agree to take part in the Checking Out project.

Thank you.

* Are you OK to go ahead with the interview now?
* Please feel free to suggest a break at any point, or let me know if you would prefer to continue another time.

**Background information**

1. Collect limited personal data (name, age, ethnicity)
2. Who do you live with?

* Age and gender of other household members

1. Can you tell me a bit about the area you live in, how long you’ve lived there and how you feel about living there?
2. What do you do for a living? What about other household members?

Explain the focus of the research

**Experience of bereavement**

1. Do you mind telling me about your experience of loss?
2. If appropriate – how much did you know about what was going to happen at different stages / how prepared did you feel?
3. Had you had any conversations with the person themselves, or with other family members, about preparing for their death?

* Reasons why/why not
* What do you think were their priorities at the time?

1. In what ways do you think worries or insecurity around things like money, housing, jobs, debt etc can impact on people going through this kind of situation?

* During the later stages of illness
* When dying
* Immediately after death
* When grieving

1. Are there any other ways that these kinds of issues affect people caring for someone at end of life?
2. Some people talk about a ‘good death’ – ways to make a death more comfortable or less distressing. Do you have any thoughts about this?

* At end of life and afterwards – the funeral process
* Whether there were aspects of the loss that could have been made less distressing

1. Is this something that you have thought about for yourself?

* What would be important to you?

**Sources of support and access to support**

1. Was there anything that helped you through this time? (People, community groups, charities, healthcare professionals)

* what was helpful about it?
* were there any particular things, big or small, that stick in your mind as having made a difference to you?

1. Were there any types of support or advice that were suggested to you or that you knew about but that you didn’t take up?

- Why was this?

1. Did you try to access any financial support at the time (e.g. DWP, other funds), or do you know of other people that have

* How was this?

1. Were there aspects of dealing with the loss that were particularly hard?

* Registering the death, paperwork, funeral arrangements, family/social aspects

1. From your experience, are there any kinds of support, advice or information that you think would be useful for people?

**Coronavirus**

1. In what ways has the virus / lockdown affected your experience (of bereavement or of grieving)?

- social isolation / ways of ‘community’

- enforced restrictions on funeral practices

1. Are there any changes that have been positive, or a relief in any way?

**General**

1. If you could change anything about the way we deal with end-of-life, or bereavement, in this country, what would it be?

* Attitudes towards preparing for end of life, information available, access to care, funeral practices

1. Is there anything else you would like to add, or that you think is important that we’ve not covered?

**Ending**

* Thank people for their time
* Ask if they would like to see the transcript and/or be kept informed about the research
* Offer payment in recognition of their time
* Do they know others who might want to participate?