

## Appendix 1 (as supplied by the authors): Patient interview topic guide for patients and carers

### *Interview strategy*

Given the exploratory nature of the study, the interview will be flexible and sensitive to the cues of the participant. It is essential to establish a good rapport with the respondent and to use their own language to explore their illness experience rather than imposing too rigid a framework. The interview will use patient cues to move the interview forward and will only introduce certain topics if appropriate.

I just want to be sure that you are happy with what this interview involves? I will ask you a few questions about your/ your husband/ wife/ partner/ friend's illness and the experiences you have had with it. I don't want the session to be too formal and I really just want to hear what you have to say so we can learn from your experiences.

You are free with to withdraw at any time.

Everything you say will be treated confidentially.

Some of the things I might ask you to talk about are quite personal so bear in mind that you don't have to answer any questions you are not comfortable with.

Let me know if there are any questions that you don't want to answer or if you feel tired or upset in any way then we can stop.

Can I just check that you are happy to go ahead and for me to record the interview?

Do you have any questions you would like to ask?

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How are you feeling in yourself today?

Can you tell me from the beginning about how you became ill?

### **Physical**

Can you tell me about your physical symptoms?

Do you think they have had an affect on how you live your life day to day?

Is there anything that you have found difficult to deal with?

Is there anything that has helped you to deal with them in any way?

What have the professionals said to you about your illness and what you can expect?

### **Staff and services**

Can you tell me which health services you are in contact with so far?

And are you finding them?

Are there any services that are particularly good?

Are there any services that are particularly bad?  
Have you found ways to deal with this?  
    What are they?  
How did you find out about these services?  
What other kinds of help and support (social services, aids and equipment, benefits, nursing support) are you receiving?  
Are there any services you feel you need that you are not receiving?  
    Any specific services or support for people in your situation/ with your diagnosis?

Are there any doctors, nurses or other health care staff that you are in touch with that are particularly helpful?  
    In what way?  
Is there anybody that is not helpful?  
    In what way?

Do you feel that you have a plan for your ongoing care?  
    Where would you like to be cared for? - for later interviews.

### **Practical**

Do you have any practical problems with day to day living since you have become ill?  
Do you find it difficult to get around from place to place?  
Do you have any problems getting to the hospital, GP or anywhere else related to your treatment?  
Do you have any problems getting to work?  
Do you find it difficult to get work done?  
Do you find it difficult to find people to help you with the children at all?  
Is there anything you did before you were ill that you have problems with now?  
    Could you say a bit more about that?

### **Financial**

Do you have any problems with money since becoming ill?  
Do you know if you have any benefits available to you?  
    How did you find out about them?  
    Have you found this helpful or not?  
Are there any other concerns or issues you have related to finances?

### **Information and communication**

Have you received any packs of information, leaflets or anything like that?  
Are you happy with the level of information?  
Is there anything that isn't useful?  
Is there anything you particularly value?  
Are there any other forms of information you would have liked that you did not receive?  
    What are they?  
Communication -  
Do you feel happy with the way the way the doctors have talked with you so far?  
Have they given you enough information?  
Have they talked to you in a way that you have been happy with?  
Is there anything they could have said or done that would have made the consultation easier for you?

What about the time you received your diagnosis? Do you feel the doctor told you about this was okay? How could it have been better?  
Is there anything you wish you did/ would like to do differently when consulting the doctor/ other healthcare staff.

### **Social/ family**

How has your illness affected your life?  
Are there family and friends in your life that have played an important role during your illness?  
Are there people beyond your immediate family?  
Are there any people with whom you have had a difficult time with in relation to your illness?  
    Could you say why you think that is?  
Are there aspects of handling social activities that have been difficult in any way?  
    Could you tell me a bit more about that?  
Have you had any problems in dealing with your partner?  
Have you had any problems in dealing with your children or other family/ friends?

### **Psychological/ emotional**

Have you found dealing with your illness hard to cope with?  
    What has helped you to cope?  
    What have been the most difficult things to cope with?  
Do you have any issues that have worried you?  
Is there any aspect of your illness that scares you?  
    Have you felt that there is someone to talk to about this or help in any way?  
  
Are you scared of dying? (if the issue of death and dying has been raised by the participant)

### **Spiritual/ existential**

Would you describe yourself as a spiritual person?  
Have you drawn on any aspect of this to help you deal with your illness?  
Would you say you are a religious person?  
    Could you tell me a bit about your religious faith and the role this has played for you?  
Would you say this has helped you or not?  
    How has it helped?  
What religious supports would you like available over the next months/ years?  
Do you feel that your faith is recognised and supported by the services you have been in contact with?  
Is religious support available to you when you were/ are in hospital?  
    Does this concern you?  
        Could you say a bit more about why this is?  
Do you ever think 'Why me?'

## **Service improvements**

Do you have any suggestions about how all services could be improved for people in your situation in the future?

Do you feel your family could have been helped more? How?

Do you feel anything else could be done to make your life better? (your day-to-day life, your quality of life)

Is there anything that could make your life easier?

Is there anything else you would like to say about any aspect of your experience? Do you want to add to anything that has already been said?

## **Taking part in interviews**

How did you feel about taking part in this interview?

Did you feel it was difficult for you?

Did you feel it was a comforting experience or not?

Did you feel it was a positive or negative experience?

Thank you for taking part in this interview.

## **Carers interviews**

Carers' interviews will be in a similar format to the patient interviews asking similar questions in relation to their experience as a carer. Additional questions will be asked about the experience of caring for a loved one.

What is it like to be a carer for \_\_\_\_\_? What are the physical, emotional, stress-related implications? Have you received sufficient information?

How would you see your role in sharing \_\_\_\_\_'s experience?

Have you experienced any difficulties?

How have you dealt with these?

Have you felt supported in your role?

By whom?

Have you felt your role has changed as time has gone on? How?

## **Subsequent interviews**

Subsequent interviews will cover similar topics to see how people's experiences have changed and what their main issues are at the stage they are at.

What are your main concerns at this stage?