

DA VINCI: INTERVIEW GUIDE FOR RELATIVES/CARERS AND PEOPLE WITH MEMORY PROBLEMS

Aim: to explore the views of people with dementia and their relatives/carers on the use of visual identification systems such as symbols, documents and training in providing care for people with memory problems

Consent: Check that everyone is happy to take part and that they know how long the interview will last. Talk through the information leaflet and consent form.

Ask the person with memory problems if they would like to take part and check that they understand the research is about and assess whether they have capacity to take part.

1. The researcher will read through the information sheet and will then explain the purpose of the study, reasons why the participant has been approached, and what taking part involves.
2. The researcher will ask if the participant has any questions about the study or their involvement.
3. The researcher will then ask the participant:
‘To make sure you understand what taking part involves, could I check that you know:
 - a. What the study is about? (answer: visual symbols and memory problems in hospital or having a memory problem in hospital or similar)
 - b. Why you’ve been asked to take part (answer: to find out how I feel about being in hospital and/or having a memory problem in hospital)
 - c. What we are we asking you to do (answer: to take part in an interview/have a chat)If the person with dementia gives correct answers to all three questions, they will be deemed to have capacity. If not, ask relatives /carers if they consent to take part to be interviewed from their perspective.

Introduction

This research is about people with dementia experiences of being in hospital.

I want to start by checking that you are happy for me to use the term dementia. If not what would you prefer?

Could you tell me about a time when you [or your relative –as appropriate] went to hospital?

Probe for why admitted, how long they were in, how often they have been in hospital



Thinking about your most recent hospital stay [If relative – could you think about the most recent hospital stay when you were able to visit your relative], were you worried about problems you might have in hospital because of your dementia? What did you worry about?

What was your experience of being in hospital like? What was good and what was not so good? Ask for examples

- Did you feel that you were treated kindly? What was it that made you feel this?
- Did you feel staff talked to you about what was happening?
- Did you ever get upset or distressed? What made you upset or distressed?
- Did you feel safe [OR did you feel your relative was safe]? Why?

Did you feel that staff understood you and your needs when you were in hospital? What helped with this? (e.g. 'this is me'/patient profile)

Was there anything that you felt the hospital did to help to make your stay easier for you and other people with dementia?

Is there anything you would have liked to have been done differently?

Visual identifiers in hospital

We are interested in your views about using labels such as a flower or a butterfly or wristbands to identify you as having dementia.

Show examples of visual identifiers

Did you have a label to indicate you had dementia, such as a flower or a wristband in hospital? Can you describe what it was? If wristband - what colour? At what point did you get it during your hospital stay?

What were you told about why the hospital was using these labels?

How did you feel about having a label like this?

- What do you think it is useful for? Does it help make your care better? How?
- Is it important for staff in hospital to know you have dementia? Why? When does it really matter that staff know you have dementia?
- Can you give an example from your own experience about when it helped that staff knew you had dementia?
- Is there anything bad about being labelled as someone with dementia in hospital? Can you give examples from your own experience?

Do you think it matters if other patients or relatives on the ward can see the label? Will they find out that you have dementia? Does this matter?

When the staff put the flower by your bed / gave you a wristband, were you asked whether you agreed to have it or not? Do you think it's important to ask people, before giving them a visible label like this? Why?



Closing

How does it feel to be a person with dementia?

For relatives: How does it feel to have a family member with dementia?

If you had to go back into hospital what would you like staff to know about you? Why do you think this is important?

What else do you think is important in making sure that you, and other people with dementia, get good care in hospital?

Do you have anything else you would like to add?

Thank participant

