

Study Documentation: Work Package 2/Chapter 4

1a. Participant Information Leaflet (Carer in Receipt of Admiral Nursing)



THE UNIVERSITY of York



Evaluating Support for Carers of People with Dementia

Participant Information Leaflet

This leaflet contains information for family carers of people with dementia considering taking part in a focus group or interview for a research project. Please read it all before consenting to take part.

The research is about Admiral Nursing and similar types of support for carers of people with dementia. It is being conducted by the Social Policy Research Unit, University of York, in partnership with Dementia UK, and is funded by the National Institute for Health Research.

Invitation to take part in a focus group or interview

We would like to invite you to take part in a focus group or interview about support for carers. You have been contacted because you care for someone with dementia. Before you decide whether or not to take part, you need to understand why the research is being done and what taking part would involve.



If you have any questions after reading this information leaflet please contact Kate Gridley who will be happy to discuss the project with you (see contact details in the box on the right). If you do decide to take part, there will be further opportunity to ask questions on the day.

Kate Gridley, Researcher
Social Policy Research Unit

Tel: [REDACTED]
9 am – 5 pm

Monday to Wednesday

What is the research about?

This research is about support for carers of people with dementia. One example of specialist support for carers is Admiral Nursing. We want to find out how effective services like Admiral Nursing are. In order to do this, we first need to know what outcomes the people using this service want to see.

How can I contribute?

You can choose to:

a) Be part of a focus group discussion with other carers

OR

b) Be interviewed on your own (either face-to-face with a researcher, or over the telephone)

Purpose of the focus groups and interviews

The purpose of the focus groups and interviews will be to hear what outcomes you would like to see from Admiral Nursing and how best we can measure these. We will be talking to carers from four areas of England.

a) What would taking part in a focus group involve?

You would meet at a local venue with six or seven other carers to discuss:

- what support carers of people with dementia need
- how services would know if they had met these needs

The discussion would last about two hours, with fifteen minutes at the start for questions and a break with refreshments in the middle. The discussion would be run by Kate Gridley, a researcher for the Social Policy Research Unit. You would be given directions and have your travel expenses paid.

The focus group dates will be fixed once all carers have responded, but if you cannot make the date agreed, we can arrange an individual interview (see below).

b) What would taking part in an interview involve?

If you cannot come to the focus group, a researcher can meet you at a venue of your choosing, or come to your home, to ask you some questions from the same list of topics. If you would prefer to do the interview over the telephone that would be fine too.

How would my views be recorded?

Focus group discussions and interviews will be audio-recorded (with your written consent) so that we have a full record of the views of carers. **If you do not want to have your voice recorded you will not be able to take part.** All recordings will be kept on a secure computer drive and/or in a locked cabinet, and will only be listened to by the researcher. When the project ends all the information you provided will be securely archived and retained for 10 years, then destroyed.

Will I receive anything for taking part?

Yes. We will give you a gift of £20 to say thank you for helping us with this research. You will also receive a summary of the research findings when they are available.

Will you pay for substitute care so that I can take part?

Yes. If you need to arrange for someone to support the person you care for on the day of the focus group or interview, we can reimburse the cost of this.

Will you cover my expenses?

Yes. We will reimburse your travel expenses to enable you to get to a focus group or interview. Please keep all tickets and receipts. Similarly, if you require any other support to take part, such as help with communication, this can be arranged. Please tell us about any extra support needs on your response form.

Do I have to take part?

No. It is entirely up to you whether you take part in this research. We will talk through this information leaflet with you in advance and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form.

To respond to this invitation

If you are interested in taking part, or would like more information, please complete and return the enclosed response form or go to [REDACTED] to complete the form online. If you do not want to take part, please indicate this on the form or go to [REDACTED] so that we know not to contact you again.

ADMIRAL NURSING WILL NOT BE INFORMED of your response, it will be kept confidential.

Can I withdraw from the study later?

You can withdraw from the study at any time before or during the focus group or interview without giving a reason. However, if you withdraw after the discussion has started, any contributions already made may be retained and used anonymously.

Will my taking part in this study be kept confidential?

We will not tell anyone you have taken part in this study without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without your permission. As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

What will happen after the focus group/interviews?

At the end of each group discussion or interview, we will feed back what we have learnt and work with you to finalise the outcomes you would like us to take forward to the next stage of work. After the sessions are complete, we will listen to all the recordings and pull together the responses of all the carers who took part.

In the next stage of the study, we will design a questionnaire to help Admiral Nursing and other service providers measure the outcomes of the support they provide. There will be an opportunity for you to comment on the draft questionnaire in a follow-up interview. More information about these follow-up interviews and how to get involved will be available at the focus group and initial interview sessions.

The project is due to end in July 2017, after which time we will send you a short summary of all findings.

Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the study methods have been approved by the Health Research Authority for England.

Further information and contact details

For more information about this research, please contact: **Kate Gridley**

[Redacted contact information]

Tel: [Redacted] Email: [Redacted]

If you are concerned or would like to complain about any aspect of this study, please contact the project leader: **Gillian Parker** [Redacted]

[Redacted contact information] Tel: [Redacted]

Email: [Redacted]

1b. Participant Information Leaflet (Carer in Area without Nursing Carer)



THE UNIVERSITY *of York*



Evaluating Support for Carers of People with Dementia

Participant Information Leaflet

This leaflet contains information for family carers of people with dementia considering taking part in a focus group or interview for a research project. Please read it all before consenting to take part.

The research is about specialist nursing support for carers of people with dementia. It is being conducted by the Social Policy Research Unit, University of York, in partnership with Dementia UK, and is funded by the National Institute for Health Research.

Invitation to take part in a focus group or interview

We would like to invite you to take part in a focus group or interview about support for carers. You have been contacted because you care for someone with dementia.

Before you decide whether or not to take part, you need to understand why the research is being done and what taking part would involve.



If you have any questions after reading this information leaflet please contact Kate Gridley who will be happy to discuss the project with you (see contact details in the box on the right). If you do decide to take part, there will be further opportunity to ask questions on the day.

Kate Gridley, Researcher
Social Policy Research Unit

Tel: [REDACTED]

9 am – 5 pm
Monday to Wednesday

What is the research about?

This research is about support for carers of people with dementia. An example of this would be nurses who specialise in supporting carers of people with dementia. We want to find out how effective services like these are. In order to do this, we first need to know what outcomes carers like you want to see.

How can I contribute?

You can choose to:

a) Be part of a focus group discussion with other carers

OR

b) Be interviewed on your own (either face-to-face with a researcher, or over the telephone)

Purpose of the focus groups and interviews

The purpose of the focus groups and interviews will be to hear what outcomes would like to see from support services for carers of people with dementia, and how best we can measure these. We will be conducting focus groups and interviews with carers from four areas of England.

a) What would taking part in a focus group involve?

You would meet at a local community centre with six or seven other carers to discuss:

- what support carers of people with dementia need
- how services would know if they had met these needs

The discussion would last about two hours, with fifteen minutes at the start for questions and a break with refreshments in the middle. The discussion would be run by Kate Gridley, a researcher for the Social Policy Research Unit. You would be given directions and have your travel expenses paid.

The focus group dates will be fixed once all carers have responded, but if you cannot make the date agreed, we can arrange an individual interview (see below).

b) What would taking part in an interview involve?

If you cannot come to the focus group, a researcher can meet you at a venue of your choosing, or come to your home, to ask you some questions from the same list of topics. If you would prefer to do the interview over the telephone that would be fine too.

How would my views be recorded?

Focus group discussions and interviews will be audio-recorded (with your written consent) so that we have a full record of the views of carers. **If you do not want to have your voice recorded you will not be able to take part.** All recordings will be kept on a secure computer drive and/or in a locked cabinet, and will only be listened to by the researcher.

Will I receive anything for taking part?

Yes. We will give you a gift of £20 to say thank you for helping us with this research. You will also receive a summary of the research findings when they are available.

Will you pay for substitute care so that I can take part?

Yes. If you need to arrange for someone to support the person you care for on the day of the focus group or interview, we can reimburse the cost of this.

Will you cover my expenses?

Yes. We will reimburse your travel expenses to enable you to get to a focus group or interview. Please keep all tickets and receipts. Similarly, if you

require any other support to take part, such as help with communication, this can be arranged. Please tell us about any extra support needs on your response form.

Do I have to take part?

No. It is entirely up to you whether you take part in this research. We will talk through this information leaflet with you in advance and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form.

To respond to this invitation

If you are interested in taking part, or would like more information, please complete and return the enclosed response form or go to [REDACTED] to complete the form online. If you do not want to take part, please indicate this on the response form or go to [REDACTED] so that we know not to contact you again. **TIDE WILL NOT BE INFORMED of your response, it will be kept completely confidential.**

Can I withdraw from the study later?

You can withdraw from the study at any time before or during the focus group or interview without giving a reason. However, if you withdraw after the discussion has started, any contributions already made may be retained and used anonymously.

Will my taking part in this study be kept confidential?

We will not tell anyone you have taken part in this study without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without your permission. As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

What will happen after the focus group/interviews?

At the end of each group discussion or interview, we will feed back what we have learnt and work with you to finalise the outcomes you would like us to take forward to the next stage of work. After the sessions are complete, we will listen to all the recordings and pull together the responses of all the carers who took part.

In the next stage of the study, we will design a questionnaire to help Admiral Nursing and other service providers measure the outcomes of the support they provide. There will be an opportunity for you to comment on the draft questionnaire in a follow-up interview. More information about these follow-up interviews and how to get involved will be available at the focus group and initial interview sessions.

The project is due to end in July 2017, after which time we will send you a short summary of all findings. When the project ends all the information you provided will be securely archived and retained for 10 years, then destroyed.

Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the study methods have been approved by the Health Research Authority for England.

Further information and contact details

For more information about this research, please contact: **Kate Gridley**

[Redacted contact information]

Tel: [Redacted] Email: [Redacted]

If you are concerned or would like to complain about any aspect of this study, please contact the project leader: **Gillian Parker** [Redacted]

[Redacted contact information]

Tel: [Redacted] Email: [Redacted]

2. Consent Form (Focus Group with Carers)

Evaluating Specialist Support for Carers

Consent Form (focus group)

This form is for you to state whether or not you agree to take part in the study. Please read and answer every question. If there is anything you do not understand or if you would like further information please ask the researcher.

Please tick if you agree

	Yes	No
I have read and understood the study information sheet (V3, 13 th Jan 2016).	<input type="checkbox"/>	<input type="checkbox"/>
I have had an opportunity to ask questions about the study.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my participation is voluntary. I also understand that I am free to withdraw at any time, without giving a reason. If I withdraw, this will not affect the services that I, or the person I support, receive.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to the focus group being recorded.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to anonymised information being used in reports, publications and presentations.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that data collected during the study may be looked at by individuals from the University of York or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the study.	<input type="checkbox"/>	<input type="checkbox"/>

All data is held by SPRU in accordance with the Data Protection Act.

Your name (in BLOCK letters): _____

Your signature: _____

Researcher's signature: _____

Date: _____

3. Demographic Form (Carer)

ID Number:

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THE UNIVERSITY of York



Evaluating Support for Carers of People with Dementia

About You

1. Age group (tick one box only)

18-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐

60-65 ☐ 66-75 ☐ 75-85 ☐ 85+ ☐

Prefer not to say ☐

2. Gender

Male ☐ Female ☐ Prefer not to say ☐

3. Ethnicity (tick one box only)

Asian/Asian British ☐ Black/Black British ☐

Mixed ☐ White British ☐

White Other ☐ (please specify) _____

Any other ethnic background (please specify) _____

Prefer not to say ☐

4. Are you a current or former carer? (For the purposes of this research a person caring for someone living in residential care would be classed as a current carer.)

Current ☐ Former ☐

5. Do you live with the person you care for?

Yes ☐ No ☐ I am a former carer ☐

6. Relationship to the person you care(d) for (please state below)

4. Focus Group Topic Guide (Carers)

Evaluating Support for Carers of People with Dementia

Focus Group Instructions (for researcher)

Before the focus group begins:

- Check that all participants have read and understood the information leaflet and would like to take part. Answer any remaining questions and reiterate that involvement is optional, and that they can change their minds at any time.
- Ask those who would like to take part to sign a consent form (this will include consenting to the focus group being audio-recorded)

Explain to the group:

- a) That the discussion should be grounded in mutual respect (everyone's view is valid, it is important to listen and not interrupt etc.) and that we are not looking for consensus - people can have very different views and this is fine
- b) That everything said in the focus groups should be kept confidential/not talked about in a way that makes other people identifiable outside the room (but they can talk to people about what they themselves said/felt – and Kate will be available after the session if they do want to talk about anything that came up in the discussion)
- c) The audio-recording of the discussion will be stored securely at SPRU and participants' names will not be included in any reports that come from it
- d) Participants are free to withdraw from the focus group at any time
- e) It is fine for participants to ask questions or take breaks during the focus group

The focus of this discussion is you!

This research is about the support provided to *carers* of people with dementia and how best to evaluate this. Most services focus on supporting the person with dementia themselves. We know this is very important to you, but today we want to focus on you and your needs, and how we can tell if these needs have been met.

There has been a lot of research about the needs of carers. As far back as 1988, the King's Fund said that carers have the following 'core needs':

- *Information and advice about caring*
- *Assessment or review of carers' own needs and of those of the person they are supporting*
- *Financial support*
- *Training*
- *Help in the tasks of caring, including respite*
- *Emotional support*

We have added:

- *Support to remain in or take up paid work*

This list of core needs was identified over 25 years ago. We want to talk to you about:

- Whether these needs are still relevant today?
- Do carers have any other support needs that are not covered here?
- What difference would it make to have these needs met?

Structure (2 hours in total)

Ice Breaker (15 minutes)

Talk to the person next to you:

- Introduce yourself and ask them to do the same
- Try to find two things you have in common

After about 5 minutes, you will be asked to introduce your neighbour to the group and share one of the things that you have in common. Your neighbour will then do the same for you.

Explanation and initial discussion (15 minutes)

Show the table (overleaf) on a large screen, explain the example (*Support to remain in or take up paid work*) and discuss as a group the potential outcomes of this and what could happen if support is lacking.

Group work (30 minutes)

Split participants into two groups and give each some flipchart paper. Ask each group to consider three of the remaining six inputs (half each) in the same way (looking at potential outcomes and what could happen if support is lacking) until the break.

Break for refreshments (15 minutes)

Feedback and discussion (30 minutes)

Ask each group in turn to feed back and discuss their suggestions for the three inputs they were considering. Ensure participants have opportunity to comment on inputs considered by the other group.

Round up and final points (15 minutes)

Summarise key points from the discussion and ask:

- Have we missed anything? (Are there any inputs or outcomes that did not feature in the discussion that you think are important?)
- What information should be collected to evaluate specialist nursing services for carers of people with dementia?
- Anything else?

Finish

Input (Type of support)	Outcome (What was gained/kept)	What happens if this support is lacking?
<i>Support to remain in or take up paid work</i>	E.G's: Money, self-esteem, identity, ability to pay for care, social contact.....	E.G's: Have to give up job, or work in an undesirable job, or undesirable hours. Lose social contacts. Money problems.....
<i>Information and advice about caring</i>		
<i>Assessment or review of carers' own needs and of those of the person they are supporting</i>		
<i>Financial support</i>		
<i>Training</i>		
<i>Emotional support</i>		
<i>Help in the tasks of caring, including respite</i>		

After the focus group has finished:

- Thank all participants for their contribution
- Ask if the group (or any particular members) have any questions or concerns – **hand out sources of support resource pack**
- Explain the next stages of the project (listening to the tape, analysis, drafting a data collection tool, cognitive interviews)
- Invite members to take part in the next stage of WP2 (cognitive interviews to develop the data collection tool) – **hand out invitation packs**
- **Hand out thank you letters with £20 gift**
- Stay long enough to answer any concerns people still have about this focus group or the next stage of the project and how to get involved.

5. Interview Topic Guide (Carer)

Evaluating Support for Carers of People with Dementia

Interview Instructions (for researcher)

Before the interview begins:

- Check that the participant has read and understood the information leaflet and would like to take part. Answer any remaining questions and reiterate that involvement is optional, and that they can change their mind at any time.

If face-to-face:

- Ask them to sign a consent form (this will include consenting to the interview being audio-recorded)

If conducting the interview over the telephone:

- Ask them to confirm on tape that they have signed and returned a consent form (this will have included consenting to the interview being audio-recorded)

Refer the participant to the document overleaf entitled:

'The focus of this discussion is you!'

Complete the 'About You' demographic form.

The focus of this discussion is you!

This research is about the support provided to *carers* of people with dementia and how best to evaluate this. Most services focus on supporting the person with dementia themselves. We know this is very important to you, but today we want to focus on you and your needs, and how we can tell if these needs have been met.

There has been a lot of research about the needs of carers. As far back as 1988, the King's Fund said that carers have the following 'core needs':

- *Information and advice about caring*
- *Assessment or review of carers' own needs and of those of the person they are supporting*
- *Financial support*
- *Training*
- *Help in the tasks of caring, including respite*
- *Emotional support*

We have added:

- *Support to remain in or take up paid work*

This list of core needs was identified over 25 years ago. We want to talk to you about:

- Whether these needs are still relevant today?
- Do carers have any other support needs that are not covered here?
- What difference would it make to have these needs met?

Topics to Cover

Show the table (overleaf) explain the example (*Support to remain in or take up paid work*) and discuss the potential outcomes of this and what could happen if support is lacking.

Consider the remaining six inputs in the same way (looking at potential outcomes and what could happen if support is lacking).

Specific questions:

- What difference would/does it make to you to have these needs met?
- What might change (or has changed) for you as a result of receiving support?
- How does it feel when support is lacking?
- What might happen as a result?
- Do carers of people with dementia have any other support needs that are not covered here?

Reflect on the outcomes identified so far by the interviewee.

Feed these back and ask:

- Have we missed anything?
 - Any more outcomes/consequences of receiving support?
 - Any more consequences of not receiving support?
- What, ultimately, would happen if you did not get the support you required?
- What, ultimately, would be the result if you got really good support?
- Of the outcomes discussed, which are most important?
 - Why?
- What information should be collected to evaluate services for carers of people with dementia?

Input (Type of support)	Outcome (What was gained/kept)	What happens if this support is lacking?
<i>Support to remain in or take up paid work</i>	E.G.'s: Money, self-esteem, identity, ability to pay for care, social contact.....	E.G.'s: Have to give up job, or work in an undesirable job, or undesirable hours. Lose social contacts. Money problems.....
<i>Information and advice about caring</i>		
<i>Assessment or review of carers' own needs and of those of the person they are supporting</i>		
<i>Financial support</i>		
<i>Training</i>		
<i>Emotional support</i>		
<i>Help in the tasks of caring, including respite</i>		

After the interview has finished:

- Thank the participant for their contribution
- Ask if they have any questions or concerns – **give sources of support resource pack** (*for telephone interviewee, ask whether they would prefer these to be posted out or emailed*)
- Explain the next stages of the project (listening to the tape, analysis, drafting a data collection tool, cognitive interviews)
- Invite interviewee to take part in the next stage of WP2 (cognitive interviews to develop the data collection tool) – **give invitation pack** (*for telephone interviewees, ask whether they would prefer these to be posted out or emailed*)
- **Give thank you letter with £20 gift**
(*for telephone interviews, explain that this will follow in the post*)

6. Thank you Letter (Carer Focus Group)

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KG/AL

Direct line: [REDACTED]

E-mail: [REDACTED]

Dear focus group member

Re: Evaluating Support for Carers of People with Dementia

Thank you for taking part in a focus group for our research.

Your contribution was very helpful and will help us to understand better the outcomes carers want from support services. Please be certain that everything we talked about will be dealt with anonymously.

We would like to send you a summary of our findings when the research is complete (towards the end of 2017) so if your contact details change before then, please do let us know. In the meantime, if you have any questions or comments about the research, please do not hesitate to contact me on [REDACTED] or use the email address above.

Many thanks again for your interest and support for the project.

Yours sincerely

[Electronic signature]

Kate Gridley
Research Fellow

7. Covering Letter for Cognitive Interviews (Carer)

PRINTED ON LETTERHEADED PAPER

KG/DR

Direct line: [REDACTED]

E-mail: [REDACTED]

Dear Carer

Re: Evaluating Support for Carers of People with Dementia: Refining the Questionnaire

Thank you for helping us to understand more about what carers want from the services they receive. Our aim is to help organisations that support carers to evaluate their services more effectively. To do this we are designing a questionnaire and we would like your help again to make it more relevant and meaningful to carers.

CAN YOU HELP US TO IMPROVE OUR QUESTIONNAIRE?

We would like to invite you to take part in a follow-up interview. In this interview, we will go through the draft questionnaire with you and ask you what you think of each question. Please read the enclosed information leaflet carefully. If you would like to take part again, please let us know like before, by filling in the enclosed response form and returning it in the Freepost envelope provided (you do not need a stamp).

Once again, if you need to arrange for someone to support the person you care for on the day of the interview, we can reimburse the cost of this.

If you have any questions, please do not hesitate to contact me on the above details.

Yours faithfully

[Electronic signature]

Kate Gridley
Research Fellow

Encs.

8. Participant Information Leaflet (Cognitive Interviews with Carers)

THE UNIVERSITY *of York*



Evaluating Support for Carers of People with Dementia

Refining the Questionnaire Participant Information Leaflet

Thank you for helping us to think about the difference that carers support services can make to carers of people with dementia. The next stage of this research is to design a questionnaire, which could be used to evaluate such services. Could you help us to do this?

Please read this leaflet before consenting to take part in this next stage of the research.

Invitation to help improve the questionnaire

We would like to meet with you when the questionnaire has been drafted to hear your opinion about filling it in. You have been invited because you took part in a focus group or interview for the first stage of this project and told us what outcomes you wanted to see from support services.



If you have any questions after reading this information leaflet please contact Kate Gridley who will be happy to discuss this stage of the project with you (see contact details in the box below). If you do decide to take part, there will be further opportunity to ask questions on the day.

Kate Gridley, Researcher, Social Policy Research Unit
[Redacted] Tel: [Redacted]
(My working hours are 9am – 5pm Monday to Wednesday)



The Evaluating support for carers of people with dementia project is funded by the National Institute for Health Research HS&DR

What is the research about?

How can I contribute?

We are developing a questionnaire, which can be used to evaluate services for carers of people with dementia. We are inviting you to meet with the researcher, Kate Gridley, to go through the draft questionnaire and tell her what you think about it. This kind of meeting is called a 'cognitive interview'.

What would taking part in a cognitive interview involve?

This would be a one-off interview at a location of your choice. Kate would bring the draft questionnaire and go through the questions with you. However, she would not be recording the answers. Instead, she would be interested in your opinions about the questions themselves:

- Does the wording make sense?
- What do you think each question is asking?
- How would you answer each question?
- How would answering these questions make you feel?

If you would prefer to do the interview over the telephone this could be arranged.

How would my views be recorded?

Kate will write notes during the interview on paper and on the questionnaire.

Will I receive anything for taking part?

Yes. We will give you a gift of £20 to say thank you for helping us with this research. You will also receive a summary of the research findings when they are available.

Will you pay for substitute care so that I can take part?

Yes. If you need to arrange for someone to support the person you care for on the day of the focus group or interview, we can reimburse the cost of this.

Will you cover my expenses?

Yes. We will reimburse your travel expenses to enable you to get to an interview. Please keep all tickets and receipts. Similarly, if you require any other support to take part, such as help with communication, this can be arranged. Please tell us about any extra support needs on your response form.

Do I have to take part?

No. It is entirely up to you whether you take part in this stage of the research. We will talk through this information leaflet with you and answer any questions you have. If you agree to take part, we will then ask you to sign a consent form.

To respond to this invitation

If you are interested in taking part in this stage of the research, or would like more information, please complete and return the enclosed response form or go to [REDACTED] to complete the form online.

If you do not want to take part please indicate this on the response form or go to [REDACTED] so that we know not to contact you again.

No other organisation will be informed of your response - it will be kept completely confidential.

Can I withdraw from the study later?

You can withdraw from the study at any time before or during the cognitive interview without giving a reason. However, if you withdraw after the discussion has started, any contributions already made may be retained and used anonymously.

Will my taking part in this study be kept confidential?

We will not tell anyone you have taken part in this study without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without your permission.

As with all assurances of confidentiality, we may have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

What will happen after the cognitive interview?

Once we have been through the questionnaire with a number of carers we will pull together their comments and make any changes that they have suggested to make the questionnaire more useful and/or easier to understand.

In the next stage of the study, we will use the finished questionnaire to evaluate some support services for carers of people with dementia. This is why it is so important that we make the questionnaire relevant and meaningful to carers like you.

The project is due to end in July 2017, after which time we will send you a short summary of all findings.

When the project ends all the information you provided will be securely archived and retained for 10 years, then destroyed.

Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the study methods have been approved by the Health Research Authority for England.

Further information and contact details

This research is being conducted by the Social Policy Research Unit, University of York, in partnership with Dementia UK, and is funded by the National Institute for Health Research.

For more information, please contact the lead researcher **Kate Gridley**

[Redacted contact information for Kate Gridley]

Tel: [Redacted] Email: [Redacted]

If you are concerned or would like to complain about any aspect of this study, please contact the principal investigator **Gillian Parker**

[Redacted contact information for Gillian Parker]

Tel: [Redacted] Email: [Redacted]

9. Consent Form (Cognitive Interviews with Carers)

Evaluating Specialist Support for Carers

Consent Form (cognitive interview)

This form is for you to state whether or not you agree to take part in the study. Please read and answer every question. If there is anything you do not understand or if you would like further information please ask the researcher.

Please tick if you agree

	Yes	No
I have read and understood the study information sheet (V3, 13 th Jan 2016).	<input type="checkbox"/>	<input type="checkbox"/>
I have had an opportunity to ask questions about the study.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my participation is voluntary. I also understand that I am free to withdraw at any time, without giving a reason. If I withdraw, this will not affect the services that I, or the person I support, receive.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to notes being taken during the interview.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to anonymised information being used in reports, publications and presentations.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that data collected during the study may be looked at by individuals from the University of York or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the study.	<input type="checkbox"/>	<input type="checkbox"/>

All data is held by SPRU in accordance with the Data Protection Act.

Your name (in BLOCK letters):

Your signature:

Interviewer's signature:

Date:

Study Documentation: Work Package 4/Chapter 7

10. Participant Information Leaflet (Professionals in Areas with Admiral Nursing)



Evaluating Support for Carers of People with Dementia

Participant Information Leaflet

This leaflet contains information for professionals considering taking part in an interview for a research project. Please read it all before consenting to participate.

The research is about Admiral Nursing and similar types of support for carers of people with dementia. It is being conducted by the Social Policy Research Unit, University of York, in partnership with Dementia UK, and is funded by the National Institute for Health Research.

Invitation to take part in an interview

We would like to invite you to take part in an interview about the impact of having an Admiral Nurse or similar service in your area. We are particularly interested in the effect (if any) that this service has on other health and social care services in your area, or the system as a whole.

You have been contacted because you are involved in providing or commissioning services for people with dementia and/or their carers. Before you decide whether or not to take part, you



The Evaluating support for carers of people with dementia project is funded by the National Institute for Health Research HS&DR

need to understand why the research is being done and what taking part would involve.

If you have any questions after reading this information leaflet please contact Kate Gridley, who will be happy to discuss the project with you (see contact details in the box on the right). If you do decide to take part, there will be further opportunity to ask questions on the day.

Kate Gridley, Researcher
Social Policy Research Unit
[REDACTED]
Tel: [REDACTED]
9 am – 5 pm
Monday to Wednesday

What is the research about?

This research is about support services for carers of people with dementia. One example of specialist support for carers is Admiral Nursing. We want to find out how effective services like Admiral Nursing are. These services may affect individual carers, but it is also possible that they have wider effects on health and social care services.

We want to hear about the effects services like Admiral Nursing have on wider services or the system as a whole.

How can I contribute?

You can take part in an interview, either in person or over the telephone. You can also help us to identify other stakeholders in your area who could contribute to the research.

Purpose of the interviews

The purpose of the interviews is to hear what you think the effects are (if any) of having Admiral Nursing in your area. More specifically, we will cover the following topic areas:

- current provision for carers of people with dementia in your area,
- impact (if any) of this support on health and social care services (hospital services, residential care services, voluntary sector organisations, etc.),
- the balance between the costs and benefits of supporting carers,
- future plans for (further) developing support for carers of people with dementia.

What would taking part in an interview involve?

If you would like to take part in an interview, a researcher can meet you at your place of work or another venue of your choosing to ask you some questions from a set list of topics. If you would prefer to give an interview over the telephone, this can be arranged instead. The interview would take no longer than an hour.

How would my views be recorded?

The interviews would be audio-recorded (with your written consent) so that we have a full record of what is said. **If you do not want to have your voice recorded, you will not be able to take part.** All recordings will be kept on a secure computer drive and transcriptions will be stored in a locked cabinet. Recordings will only be listened to by the researcher and a transcriber who has signed a confidentiality, data storage and data transfer agreement with the Social Policy Research Unit.

Will my taking part in this study be kept confidential?

We will not tell anyone you have taken part in this study without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without your permission.

As with all assurances of confidentiality, we may have to pass on information if you indicate to us that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

Do I have to take part?

No. It is entirely up to you whether you take part in this research. We will talk through this information leaflet with you in advance and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form.

To respond to this invitation

If you are interested in taking part, or would like more information, please email [REDACTED] or ring Kate Gridley on [REDACTED].

If you do not want to take part, please indicate this on the response form or in an email to [REDACTED] so that we know not to contact you again.

No-one outside the research team will be informed of your response: it will be kept completely confidential. We will not tell your employer whether you have taken part and it will not affect your job in any way.

Can I withdraw from the study later?

You can withdraw from the study at any time before or during the interview without giving a reason. However, if you withdraw after the interview has started any contributions already made may be retained and used anonymously.

What will happen after the interview?

At the end of the interview, we will ask you whether you know of any other professional stakeholders in your area who we might contact about taking part in an interview. The recording of your interview will be written up and analysed together with transcripts from other interviews. We will use the learning from these interviews to explore the perceived system-wide impact of providing Admiral Nursing services, against the support available in areas without Admiral Nursing.

When the project ends all the information you provided will be securely archived and retained for 10 years, then destroyed.

Getting research into practice

The final stage of our project will be a stakeholder workshop that will present the findings of all elements of our research. There will be a full-day event to draft a statement about current evidence, how different models of support might influence outcomes, and how to collect data at a local level so that it informs service development and evaluation. For information about how to register your interest in this workshop, please contact [REDACTED]

After the workshop, the draft guidelines will be circulated to participants and other stakeholders for comment before they are finalised and disseminated. We will then write a full report and send you a short version of this once the report has been approved (we estimate that this will be in the autumn of 2017).

Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the study methods have been approved by the Health Research Authority for England.

Further information and contact details

For more information about this research, please contact: **Kate Gridley**

[Redacted contact information]

Tel: [Redacted] Email: [Redacted]

If you are concerned or would like to complain about any aspect of this study, please contact the project leader: **Gillian Parker** [Redacted]

[Redacted contact information]

Tel: [Redacted] Email: [Redacted]

11. Participant Information Leaflet (Professionals in Areas without Admiral Nursing)



THE UNIVERSITY of York



Evaluating Support for Carers of People with Dementia

Participant Information Leaflet

This leaflet contains information for professionals considering taking part in an interview for a research project. Please read it all before consenting to participate.

The research is about services that support carers of people with dementia. It is being conducted by the Social Policy Research Unit, University of York, in partnership with Dementia UK, and is funded by the National Institute for Health Research.

Invitation to take part in an interview

We would like to invite you to take part in an interview about the impact of having support services for carers of people with dementia in your area. We are particularly interested in the effect (if any) that these services have on other health and social care services in your area, or the system as a whole.

You have been contacted because you are involved in providing or commissioning services for people with dementia and/or their carers. Before you decide whether or not to take part, you need to understand why the research is being done and what taking part would involve. If you have any questions after reading this information leaflet please contact Kate Gridley, who



will be happy to discuss the project with you (see contact details in the box on the right). If you do decide to take part, there will be further opportunity to ask questions on the day.

Kate Gridley, Researcher
Social Policy Research Unit

Tel: [REDACTED]

9 am – 5 pm

Monday to Wednesday

What is the research about?

This research is about support services for carers of people with dementia. One example of specialist support for carers is Admiral Nursing, but there are other examples and we would like to hear about these. We know that there is no Admiral Nursing service in your area: we want to find out what services there *are* for carers of people with dementia in your area and how effective these services are. These services may affect individual carers, but it is also possible that they have wider effects on health and social care services.

We want to hear about the effects support services for carers of people with dementia have on wider services or the system as a whole.

How can I contribute?

You can take part in an interview, either in person or over the telephone. You can also help us to identify other stakeholders in your area who could contribute to the research.

Purpose of the interviews

The purpose of the interviews is to hear what you think the effects are (if any) of having support services for carers of people with dementia in your area. More specifically, we will cover the following topic areas:

- current provision for carers of people with dementia in your area,
- impact (if any) of this support on health and social care services (hospital services, residential care services, voluntary sector organisations, etc.),
- the balance between the costs and benefits of supporting carers,
- future plans for (further) developing support for carers of people with dementia.

What would taking part in an interview involve?

If you would like to take part in an interview, a researcher can meet you at your place of work or another venue of your choosing to ask you some questions from a set list of topics. If you would prefer to give an interview over the telephone, this can be arranged instead. The interview would take no longer than an hour.

How would my views be recorded?

The interviews would be audio-recorded (with your written consent) so that we have a full record of what is said. **If you do not want to have your voice recorded, you will not be able to take part.** All recordings will be kept on a secure computer drive and transcriptions will be stored in a locked cabinet. Recordings will only be listened to by the researcher and a transcriber who has signed a confidentiality, data storage and data transfer agreement with the Social Policy Research Unit.

Will my taking part in this study be kept confidential?

We will not tell anyone you have taken part in this study without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without your permission. As with all assurances of confidentiality, we may have to pass on information if you indicate to us that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

Do I have to take part?

No. It is entirely up to you whether you take part in this research. We will talk through this information leaflet with you in advance and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form.

To respond to this invitation

If you are interested in taking part, or would like more information, please email [REDACTED] or ring Kate Gridley on [REDACTED]

No-one outside the research team will be informed of your response: it will be kept completely confidential. We will not tell your employer whether you have taken part and it will not affect your job in any way.

Can I withdraw from the study later?

You can withdraw from the study at any time before or during the interview without giving a reason. However, if you withdraw after the interview has started any contributions already made may be retained and used anonymously.

What will happen after the interview?

At the end of the interview, we will ask you whether you know of any other professional stakeholders in your area that we might contact about taking part in an interview.

The recording of your interview will be written up and analysed together with transcripts from other interviews. We will use the learning from these interviews to explore the perceived system-wide impact of providing support for carers of people with dementia in areas like yours against areas with Admiral Nursing services. When the project ends all the information you provided will be securely archived and retained for 10 years, then destroyed.

Getting research into practice

The final stage of our project will be a stakeholder workshop that will present the findings of all elements of our research. There will be a full-day event to draft a statement about current evidence, how different models of support might influence outcomes, and how to collect data at a local level so that it informs service development and evaluation. For information about how to register your interest in this workshop, please contact [REDACTED]

After the workshop, the draft guidelines will be circulated to participants and other stakeholders for comment before they are finalised and disseminated. We will then write a full report and send you a short version of this once the report has been approved (we estimate that this will be in the autumn of 2017).

Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the study methods have been approved by the Health Research Authority for England.

Further information and contact details

For more information about this research, please contact: **Kate Gridley**

[Redacted contact information]

Tel: [Redacted] Email: [Redacted]

If you are concerned or would like to complain about any aspect of this study, please contact the project leader: **Gillian Parker** [Redacted]

[Redacted contact information]

Tel: [Redacted] Email: [Redacted]

12. Consent Form (Interviews with Professionals)

Evaluating Specialist Support for Carers

Consent Form (staff interview)

This form is for you to state whether or not you agree to take part in the study. Please read and answer every question. If there is anything you do not understand or if you would like further information please ask the researcher.

Please tick if you agree

	Yes	No
I have read and understood the study information sheet (V3, 13 th Jan 2016).	<input type="checkbox"/>	<input type="checkbox"/>
I have had an opportunity to ask questions about the study.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my participation is voluntary. I also understand that I am free to withdraw at any time, without giving a reason. If I withdraw, this will not affect me or my job in any way.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to the interview being recorded.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to anonymised information being used in reports, publications and presentations.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that data collected during the study may be looked at by individuals from the University of York or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the study.	<input type="checkbox"/>	<input type="checkbox"/>

All data is held by SPRU in accordance with the Data Protection Act.

Your name (in BLOCK letters): _____

Your signature: _____

Interviewer's signature: _____

Date: _____

13. Topic Guide (Interviews with Professionals in Areas with Admiral Nursing)

Evaluating Support for Carers of People with Dementia

Professional Interview Instructions (for researcher)

Before the interview begins:

- *Check that the participant has read and understood the information leaflet and would like to take part. Answer any remaining questions and reiterate that involvement is optional, and that they can change their minds at any time.*
- *Ask them to sign the consent form.*

Topics to cover – ADMIRAL NURSING AREA

The purpose of the interviews is to hear what local stakeholders in health and social care think the effects are (if any) of having Admiral Nursing in their area.

Current provision for carers of people with dementia in the area (*try to form a picture of the general dementia care landscape and how AN fits in*):

- Admiral Nursing (AN)
 - Why was the service commissioned?
 - What are the goals of the service?
- Other relevant (dementia/carer) services covering the locality

Impact (if any) of AN services on other health and social care services:

- How does the AN service interact with other services for carers of people with dementia?
 - Observed outcomes (including influence on culture, training, organisational or individual practice etc.)
 - Measured outcomes?
 - How do you know if the goals are achieved?

- Are any systems in place to monitoring performance of the service?
- If so, what are these, how are they measured and how often?
- Are they reported on, if so to whom, and how often?

Ask if we could have these reports on a confidential basis.

- How does the AN service interact with wider (i.e. general) services (such as residential care, hospitals, social care or voluntary sector provision)?
 - Observed outcomes (including influence on culture, training, organisational or individual practice etc.)
 - Measured outcomes?

Impact (if any) of other services for carers of people with dementia:

- How do other services interact with each other?
 - Observed outcomes (including influence on culture, training, organisational or individual practice etc.)
 - Measured outcomes?

The balance between the costs and benefits of AN services:

- How is the service funded: health, local authority, health and social care integrated budget, charity funding etc.? If more than one, the proportion each contributor makes to the overall budget.
- What is the expenditure on the service per annum/quarter/month (delete as appropriate)?
 - How is the service staffed?
 - manager?
 - nurses?
 - other staff?
- What are their qualifications, grades and time (FTE)?
- What are the other costs of delivering the service?

- travel
- training
- office costs: computer equipment, consumables, utilities, office space, administrative support, including financial administrative input.
- How many people does the service serve per annum/quarter/month (delete as appropriate)?
- Are users (carers) expected to make a contribution to the costs? If so, how much?
- Who decides on the funds allocated to this service?
- What is the added value of the AN service to the wider service sector?
 - E.G.'s: Impact on admissions, in-reach into other settings, knowledge/understanding of non-AN staff?
- Does your organisation pay anything towards the cost of AN?
- Are there any hidden costs?
- Does AN provide value for money?

Opportunity cost – Question for commissioners only

The objective of these questions is to understand the opportunity cost of providing the service. The opportunity cost is the benefits of the services that cannot be provided given the investment in funding the existing service.

Imagine that the government provided additional funds specifically for the service, and therefore the funds now spent in the service could be used to fund something else.

How would these funds be spent?

For example, would you fund another service for dementia, or would it fund a service in another disease area?

The balance between the costs and benefits of other services for carers of people with dementia:

- What is the added value of other service(s) to the wider service sector?
 - E.G.'s: Impact on admissions, in-reach into other settings, knowledge/understanding of staff?

- Does your organisation pay anything towards the cost of this/these other service(s)?
- Are there any hidden costs?
- Do(es) this/these service(s) provide value for money?

Future plans for (further) developing support for carers of people with dementia:

- Does your organisation have any plans to develop/change the support they provide to carers of people with dementia?
- Are you aware of any other plans to develop/change the support provided to carers of people with dementia locally?

Anything else

- Is there anything else relevant to this project that you would like to tell us?

Finish

After the interview has finished:

- Thank the participant for their contribution
- Ask if they have any questions or concerns
- Explain the next stages of the project (transcription of the tape, analysis, stakeholder workshop)
- Give thank you letter

14. Topic Guide (Interviews with Professionals in Areas without Admiral Nursing)

Evaluating Support for Carers of People with Dementia

Professional Interview Instructions (for researcher)

Before the interview begins:

- *Check that the participant has read and understood the information leaflet and would like to take part. Answer any remaining questions and reiterate that involvement is optional, and that they can change their minds at any time.*
- *Ask them to sign the consent form*

Topics to cover – AREAS WITHOUT ADMIRAL NURSING

The purpose of the interviews is to hear a) what support there is locally for carers of people with dementia (i.e. what is 'usual care' in this area); and b) what local stakeholders think the wider effects are (if any) of this support

Current provision for carers of people with dementia in the area (i.e. what is 'usual care' for carers of people with dementia in this area?)

- Why was the service commissioned?
- What are the goals of the service?

Impact (if any) of carer support services on other health and social care services:

- How do carer support services interact with other services for carers of people with dementia?
 - Observed outcomes (including influence on culture, training, organisational or individual practice etc.)
 - Measured outcomes?
 - How do you know if the goals are achieved?
 - Are any systems in place to monitoring performance of the service?

- If so, what are these, how are they measured and how often?
- Are they reported on, if so to whom, and how often?

Ask if we could have these reports on a confidential basis.

- How do carer support services interact with wider (i.e. general) services (such as residential care, hospitals, social care or voluntary sector provision)?
 - Observed outcomes (including influence on culture, training, organisational or individual practice etc.)
 - Measured outcomes?

The balance between the costs and benefits of services for carers of people with dementia:

- How is the service funded: health, local authority, health and social care integrated budget, charity funding etc.? If more than one, the proportion each contributor makes to the overall budget.
- What is the expenditure on the service per annum/quarter/month (delete as appropriate)?
 - How is the service staffed?
 - manager?
 - nurses?
 - other staff?
- What are their qualifications, grades and time (FTE)?
- What are the other costs of delivering the service?
 - travel
 - training
 - office costs: computer equipment, consumables, utilities, office space, administrative support, including financial administrative input.
- How many people does the service serve per annum/quarter/month (delete as appropriate)?

- Are users (carers) expected to make a contribution to the costs? If so, how much?
- Who decides on the funds allocated to this service?
- What is the added value of carer support services to the wider service sector?
 - E.G.'s: Impact on admissions, in-reach into other settings, knowledge/understanding of staff?
- Does your organisation pay anything towards the cost of this/these service(s)?
- Are there any hidden costs?
- Do(es) this/these service(s) provide value for money?

Opportunity cost

The objective of these questions is to understand the opportunity cost of providing the service. The opportunity cost is the benefits of the services that cannot be provided given the investment in funding the existing service.

Imagine that the government provided additional funds specifically for the service, and therefore the funds now spent in the service could be used to fund something else.

How would these funds be spent?

For example, would you fund another service for dementia, or would it fund a service in another disease area?

If no service available:

Imagine that the government made it mandatory for you to provide a service to support dementia carers, but did not provide any additional funds? Would these funds be diverted from services in the area of dementia, or would they be obtained from savings across the health service in your area?

Future plans for (further) developing support for carers of people with dementia:

- Does your organisation have any plans to develop/change the support they provide to carers of people with dementia?
- Are you aware of any other plans to develop the support provided to carers of people with dementia locally?

Anything else

- Is there anything else relevant to this project that you would like to tell us?

Finish

After the interview has finished:

- Thank the participant for their contribution
- Ask if they have any questions or concerns
- Explain the next stages of the project (transcription of the tape, analysis, stakeholder workshop)
- Give thank you letter