

Life Stories Research

Information Leaflet for Consultees

Background

[Comparison site] has teamed up with the University of York to do some research about life story work. They want to understand whether life story work makes a difference for people with dementia and those who care for them, and whether this difference can be measured. The research is being conducted by the Social Policy Research Unit, (University of York), in partnership with [Comparison site], and is funded by the National Institute for Health Research.

Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



Why have I been contacted?

We believe thatis unable to make an informed decision about getting involved in a research project taking place on Jubilee Ward. We are contacting you for advice on whether you think he/she would want to take part – if you agree to give this advice, this would make you a 'consultee'.

This information leaflet explains what the research is about and what it means to be a consultee.

What does it mean to be a consultee?

A consultee is someone who knows a person well and is willing and able to offer an opinion as to what that person's wishes would be. A consultee is not asked for their personal views about the research but what they think the person's wishes would have been if they were able to make a decision.

Why have I been asked to be a consultee?

You have been contacted because the person you care for is eligible to take part in the study and we are seeking your advice as to whether you think they would have agreed to take part if they had the capacity to do so.

Personal consultees

You may have been chosen because you know the person personally and they would trust you to help with this decision. This would make you a 'personal consultee'.

Nominated consultees

Or, you may be a member of the care team who looks after the person and have their best interests in mind, in which case you are a 'nominated consultee'.

Do I have to be a consultee?

No, you do not have to act as a consultee if you do not want to. Please let us know (see contact details below) if you do not want to act as a consultee and we will find an alternative.

What is the life stories research about?

In some hospitals, support to make a life story is a routine part of care. At present, [Comparison site] do not offer life story work to any patients. [Comparison site] would like to learn more about the well-being of patients who do not get support to make a life story.

There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this. Researchers at the University of York want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them.

This study is a small preliminary study which we will use to design a bigger piece of research. Kate and Jenni will try out a range of ways of assessing the difference between outcomes for people on wards that do and do not do life story work. The person you are a consultee for is **on a ward that does not do life story work**. If they take part in this research they would therefore be in the comparison group.

When we say 'life story work', we mean:

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

AND

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

What would taking part involve for the person I am a consultee for?

Kate and Jenni would like to collect some information about the person from their medical records and their main carer, and ask the person with dementia themselves some questions (if they are able to answer). The information they collect will be kept confidential and will be stored in a safe place (see below).

Kate or Jenni will visit the person on four occasions over a 6 month period to collect this information (once at the start of the project, and again 1 month, 2 months and 6 months afterwards).

Assessing quality of life:

We would like to assess the person's quality of life. We could do this by asking them directly, or if they are unable to understand and answer questions we will ask a family member or friend to answer on their behalf.

Asking about relationships:

If they are able to answer questions we will also ask them about their relationship to their main carer (if they have one). Again, if they are unable to answer these questions we will only ask the carer.

Information from medical records:

We would like to collect information about the medication the person takes, the sorts of care they have received and whether anything untoward (like a fall) has happened to them. This information will be collected from medical records by hospital staff (no-one from the research team will have access to the person's records directly). It may require the use of the person's NHS number.

Does the person have to take part?

No. We are asking you whether you think the person would want to take part. If you think they would prefer not to that is fine, they will not be included. This will not alter the care they receive in any way.

Support for the person

If you think that the person could take a more active role in the research if they had some support, such as a communication aid, or the help of a friend or interpreter, then please let us know.

Will information be kept secure and confidential?

We will keep the information we collect safe and secure and it will not be shared with anyone without your permission. We may refer to information about the person in reports, articles or presentations, but they will not be named and no details will be given that could identify them. The information about them, including that you acted as their consultee, will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if it appears that the person, or someone else, is at risk of serious harm. In such a situation, we would try to talk to you before passing on any information.

What will happen to the results of the study?

We will write a report about everything we learn for the National Institute of Health Research, (part of the NHS) which will be circulated widely. We will also talk about what we have learnt at conferences and in academic papers. No names will be used in anything we produce. The report should be available in spring 2015. If you

would like to be sent a copy, please give your preferred contact details to a member of the research team.

How do I respond to this consultation?

Please contact Kate Gridley on 01904 3212988 kate.gridley@york.ac.uk to let her know whether you would be happy to act as a consultee, or ask a member of staff at the care home to pass on your contact details so that Kate or Jenni can contact you. They will answer any questions you have over the phone or in person. If you think the person would have no objections to taking part in the research, you will be asked to sign a 'record of consultation' form.

If you feel unable to give advice about the person's wishes, please say so.

What if I change my mind?

You can withdraw the person from the study at any time. This will not affect the care that they receive. If you withdraw them after the study has started, any information already provided will be retained, but no more will be collected.

Further information and contact details

If you would like further information or have questions about this study please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD tel: 01904 321988 Email: kate.gridley@york.ac.uk

Independent advice

If you would like to discuss this project with an organisation that supports people with dementia to get involved in research please contact:

Nada Savitch at Innovations in Dementia, Tel: 07549 921901

Email: nada@myid.org.uk