

# Improving Care for People with Dementia

## Taking part in research



# **We are doing some research about life for people with dementia – Can You Help?**

## **Would you like to take part in some research?**

The hospital that provides your care is taking part in a research project. Would you like to get involved?

Who we are?

## **Who we are**

The research is being carried out by two researchers from the University of York Social Policy Research Unit:



Kate Gridley

and



Jenni Brooks



## What is the research about?

We want to understand how people at your hospital feel while they are in hospital and afterwards. We will compare this with information about people in another hospital. At the other hospital they do something called 'life story work', whereas at your hospital they don't. We want to find out which approach is best.

Kate and Jenni would like to gather some information from some patients on your ward and from some family carers.

**They would like to invite you to take part in this study.**

## What will happen if I take part?

### SOME QUESTIONS

Kate or Jenni will visit you at the start of the project, and three more times after, to ask you some questions. The questionnaires they will use are about how you feel ('quality of life') and your relationships with others. They will keep all your answers confidential.

## What other information will they collect?

Jenni and Kate would also like to collect information about what medication you are on, how often you use different services and whether you had any falls or other problems. They will collect this information from health records (they may use your NHS number for this).

## Deciding whether to take part

You do not have to take part in this research. It is entirely up to you. Please discuss any questions or concerns you have with Kate or Jenni. You can also talk to someone else about it – like a family member or friend.

## What if I do not want to take part?

That's fine - nothing will change.

## Support to take part

If you would like someone, like a friend, care worker or family member to be with you when we visit you, that's fine – please discuss this with a member of staff.



If you need help to hear or speak, or any other support to take part, please let us know.

## **Agreeing to take part**

If you would like to take part, we will ask you to sign a consent form. Someone else can sign this form for you if you prefer.

## **Changing your mind about taking part**

You can change your mind about taking part in the study at any time. You do not have to give a reason.

If you change your mind halfway through, we will still keep a record of the things we've learnt up to that point, but we will not ask you anything else.

## **Confidentiality**

We will not tell anyone you have taken part in this study without your permission and we will not use your name in any reports we write.

We will keep everything you say in a safe place for 5 years.



The only time we might have to speak to someone else is if you tell us that you or someone else is being hurt, but we would always try to speak to you about this first.

## How will the research be used?



We want to find out if life story work could make things better for people with dementia. The findings of this small study will be used to help plan a larger study about this. We will write a report for the National Institute of Health Research and talk about the research at conferences and in articles, but we will not use your name.

If you would like them to send you a summary of what we have learnt, please let us know who to send this to.

**This study is being conducted by the Social Policy Research Unit (University of York).** It was funded by the National Institute for Health Research and has been approved by the Social Care Research Ethics Committee for England.

## Further information

If you would like more information about this research please contact **Kate Gridley** at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321988

Email: [kate.gridley@york.ac.uk](mailto: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

Telephone: 07549 921901

Email: [nada@myid.org.uk](mailto:nada@myid.org.uk)

## Complaints

If you are concerned or would like to complain about this study, please contact: **Gillian Parker**, Director, Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321957

Email: [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)