

Life Stories in Dementia Care

Focus Groups

Information Sheet - Professionals

This sheet contains information for professionals considering taking part in a focus group about life story work in dementia care. Please read it all before consenting to take part in a focus group.

The research is being conducted by the Social Policy Research Unit (SPRU), University of York, and is funded by the National Institute for Health Research (NIHR).

Our invitation to you

The aim of this research is to understand more about the outcomes and costs of life story work for people with dementia, in order to plan a formal evaluation of the effectiveness of this approach. We also want to establish core elements of good practice in using and applying life story work with people with dementia. You have been contacted because we understand you are involved in life

story work in dementia care and we would like to invite you to take part in a focus group discussion with other professionals about this.

Before you decide whether or not to take part, you need to understand why the research is being done and what taking part in a focus group would involve. If you have any questions after reading this information sheet please contact Kate Gridley on 01904 321988 or email

kate.gridley@york.ac.uk. Kate will be happy to discuss the project with you. If you do decide to take part in a focus group, there will be further opportunities to ask questions on the day.

Purpose of this research

There have been no large-scale, rigorous studies of life story work in dementia care and we have little evidence about whether, in what

ways or why life story work might improve care for people with dementia. It is not even clear, at this stage, what outcomes could or should be measured to assess the effectiveness of life story work. There is also little evidence about what might constitute good practice in life story work or how much it might cost to use life stories as a routine part of dementia care.

The purpose of this research is to carry out the preliminary investigations required to design a full evaluation of life story work for people with dementia. The first step towards this is to develop a theoretical model of life story work, including its potential outcomes, and establish core elements of good practice in using and applying the approach. We plan to do this by running focus groups with people with dementia, carers and professionals with experience of life story work as well as bringing together all the research evidence already available on the subject and reviewing it in a systematic way. You are being invited to take part in one of the focus groups with professionals.

The purpose of the focus groups will be to hear what outcomes are experienced or expected from life story work, for whom, under what circumstances, and the reasons for

this. We also want to hear what you think are core elements of good practice in life story work, what challenges it might present and how these can be overcome. In the professional focus groups we will also be asking what resources might be needed to make life story work a routine part of dementia care and what implications it might have for costs.

Do I have to take part?

No. It is entirely up to you whether you take part in a focus group. We will talk through the study with you and discuss any concerns you have in advance. If you agree to take part, we will then ask you to sign a consent form. You can still withdraw after this point, but any contributions already made may be retained so as not to undermine the contributions of others.

What would taking part involve?

If you would like to take part, or you want more information before making a decision, please contact Kate Gridley on 01904 321988 or email kate.gridley@york.ac.uk. She will give you further details of the focus groups, including dates and venues, and can answer any remaining questions you have. Three focus group sessions for professionals have been planned in total, and where possible you will

be given a choice of which one to attend. Travel expenses incurred as a result of taking part in a focus group will be reimbursed if you keep all tickets and receipts.

Each focus group session will have no more than ten participants and will last no longer than two hours, with fifteen minutes at the start and finish for questions. The discussion will be facilitated by Kate Gridley and will cover an agreed list of topics. Please ask if you would like us to send this to you in advance.

Focus group discussions will be audio-taped (with your consent) and transcribed so that we have a full record of everything said. **If you do not want to be tape recorded you will not be able to take part.** All recordings and transcripts will be kept on a secure drive and/or in a locked cabinet, and will only be seen/ listened to by the project team and transcribers.

What if I change my mind about taking part?

You can withdraw from the study at any time before or during the focus group discussion without giving a reason. However, if you withdraw after the discussion has started, any contributions already made may be retained so as not to

undermine the contributions of others.

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 discussing this with you first.

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 before passing on any information.

What will happen to the results of the study?

After the focus group we will send you a summary of key points from the discussion. At this point you still have the opportunity to clarify specific issues by ringing us or sending an email. The data from all the focus groups will then be analysed thematically and considered together with the findings from the literature review to produce an account of what works, for whom, and in what circumstances, from the

perspectives of people with dementia, carers and professionals.

The next stage of the research will be a national survey of carers and care providers, followed by a pilot study of costs and outcomes in care home and hospital settings.

The project is due to end in January 2015, after which time we will send you a short summary of all findings. If your contact details change in the meantime and you would still like a copy of the findings please do let us know so that we can update our records.

Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the focus group methods have been approved by the Social Care Research Ethics Committee for England.

Further information and contact details

If you would like to take part in a focus group, or would like further information about any part of this research, please contact:

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If you are concerned or would like to complain about any aspects of this study please contact the director of the social Policy Research Unit:

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