

Engaging people with dementia in research

Best practice and person centred approaches considered in accordance with the demands for ethical scrutiny

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Introduction

- ▶ Meeting ethical requirements
- ▶ Engaging participants in the design of ethical documents
- ▶ Designing the documentation
- ▶ Developing the research relationship



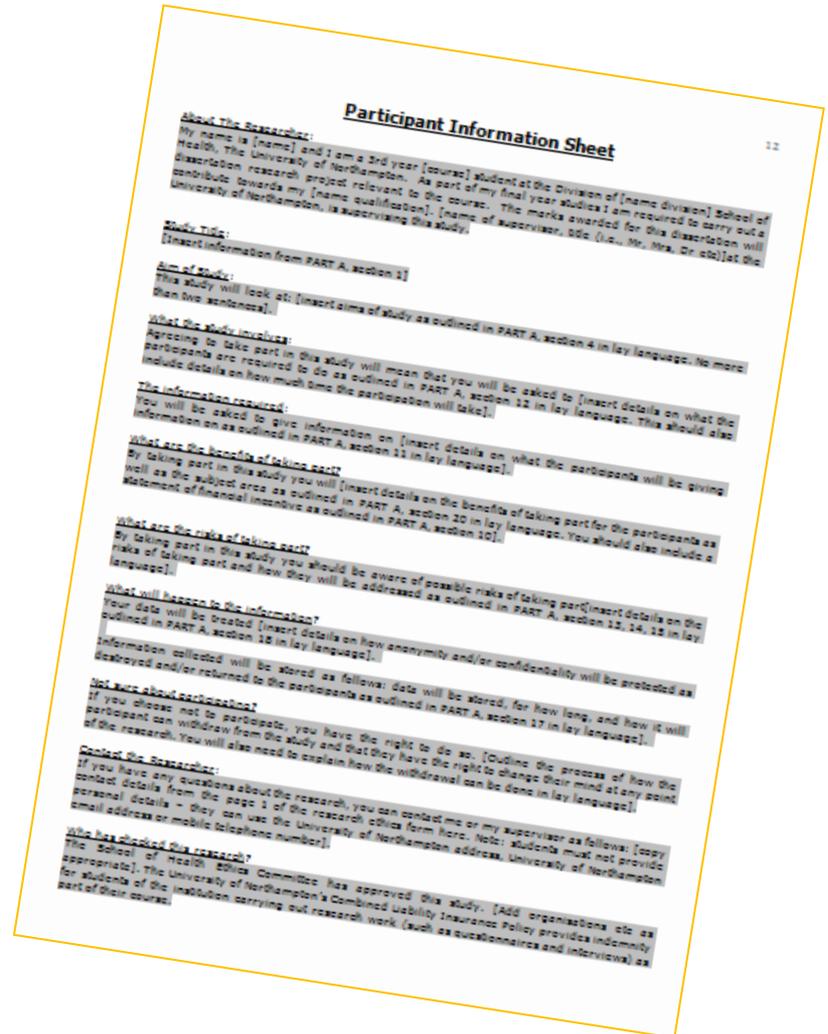
Ethical requirements – why?

- ▶ Information
- ▶ Protection
- ▶ Regulation
 - ▶ Ethical committees
 - ▶ Data Protection act
 - ▶ Mental capacity act
 - ▶ Funding requirements
- ▶ Gathering quality data



Participant Information Sheet

- ▶ NHS recommendations
 - ▶ Invitation
 - ▶ Purpose of the study
 - ▶ Taking part – do I have to; what will I be doing
 - ▶ Risks, benefits
 - ▶ What happens to the results
 - ▶ Confidentiality
 - ▶ Data storage
 - ▶ Reporting problems
 - ▶ Up to 22 different factors



What's been done already

- ▶ **Enabling a better understanding** (Knight, 2007)
 - ▶ Use of yellow
 - ▶ Use of images
 - ▶ Use of a booklet
 - ▶ Written/Video/Audio
- ▶ **Written literature should be supported with face to face contact** (Dewing, 2007; Meulenbroek et al., 2010)
- ▶ **Physical environment recommendations which may be transferable:**
 - ▶ Avoid patterned backgrounds
 - ▶ Contrasting colours for signage



How did we look at it

- ▶ Tested a variety of designs
- ▶ Consultation with public (carers/people with dementia/professionals)
 - ▶ Agreement that the participant information could be made more friendly
- ▶ Used the feedback
- ▶ Development of participant information sheets



Participant Information Sheet Design Ideas

Information about the research
Drama and Storytelling Research with Young Onset Dementia

I would like to invite you to take part in a PhD research project to explore the experience of taking part in a 10 week drama and storytelling project for people with young onset dementia and their partner/carer.

Workshops will be run at the University of Northampton during July 2015. Each workshop will be 1-2hrs.

As part of the workshops you will be asked to take part in a research project which will include three interviews and a diary.

Before you decide to take part, I would like you to spend some time to meet with you and your partner/carer to go through an information booklet and answer any questions you have about 30mins.

Part 1 tells you about the purpose of the study and what will happen if you take part.

Part 2 will provide more information about the conduct of the study.

Please ask if there is anything that is not clear.

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Faculty of Health and Wellbeing

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I would like to invite you to take part in a PhD research project to explore the experience of taking part in a 10 week drama and storytelling project for people with young onset dementia and their partner/carer.

Workshops will be run at the University of Northampton during June and July 2015. Each workshop will be 1-2hrs.

As part of the workshops you will be asked to take part in a research project which will include three interviews and a photography diary.

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Language

- ▶ Clear
- ▶ Short sentences
- ▶ One point at a time
- ▶ Friendly words
- ▶ Explain terminology
- ▶ Is your understanding of a word universal? Will participants read this differently?
- ▶ Ensure participants understand the information presented – talk this through
 - ▶ Consider phrasing timeframes - e.g. 30 min interview - could cause concern when the time starts to run out and they want to say more.
 - ▶ Appreciated - “Please ask if there is anything that is not clear”
 - ▶ Did not like the use of words such as ‘therapy’ or ‘workshops’



Images

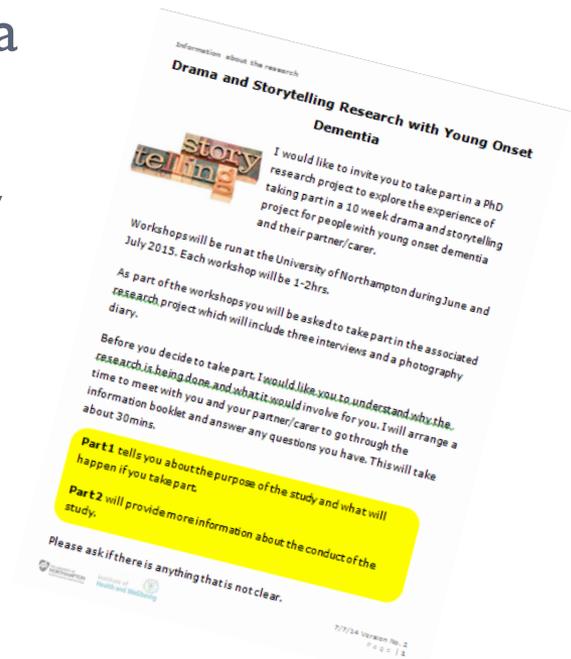




Colours

▶ Colour

- ▶ Caregivers and professionals were not keen on bright yellow – suggested blue/red
- ▶ Mixed response from people with dementia
- ▶ Text in black
- ▶ Little support for the whole page as yellow
- ▶ Consider flexibility in use of colour, maybe personalise to the individual



General Issues Raised

- ▶ Give people time to ask questions about the study.
- ▶ Making sure people know they can drop out.
- ▶ The inclusion of potential benefits was appreciated.
- ▶ Consider selling the project up front stress what the participant can get out of it.
- ▶ Consider the 'selling' of the study and the legalities/ethics as two separate elements.



Outcome

► Ethical approval

Information about the research

Drama and Storytelling Research with People with Young Onset Dementia and their Carers

I would like to invite you to take part in a 10 week drama and storytelling project. This is designed for people with young onset dementia (aged under 65 years) and their partner/family member. This is part of a PhD research project.

Ten drama sessions will be run at the University of Northampton during June and July 2015. Each drama and storytelling session will be up to 2 hours.

As part of the sessions you will be asked to take part in a research project which will include:



3 Interviews



Photo Diary

Before you decide to take part, I would like you to understand why the research is being done and what it would involve for you. I will arrange a time to meet with you and your partner/carer to go through the information booklet and answer any questions you have. This will take about 30 minutes. We can talk for longer if needed.

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Information about the research

The Research

Interviews



I would like to hear your story about taking part in the drama sessions. I will ask what you thought of the sessions, if you enjoyed the sessions and what attending meant to you. Interviews will be with both the person with dementia and the carer. I will meet with you three times.

Interview 1: We will meet before the drama sessions begin. I would like to understand a little more about you and what taking part in the sessions means to you. This will help me plan for the first session.

Interview 2: We will meet 1 month after the drama sessions. We will look at the photographs you have taken during the photo diary and talk about taking part in the sessions.

Interview 3: We will meet 6 months after the drama sessions. We will talk about what I have learnt from the research. You will have the opportunity to let me know if these ideas reflect your experiences. We will use the storybook in our discussion.

Each interview will take up to an hour and will be at a time convenient for you.

Information about the research

Thank you for taking time to read this.

Please ask if you have any questions.

For further information, please contact:

Alison Ward, PhD Student
The University of Northampton, Boughton Green Road,
Northampton NN2 7AL

 alison.ward@northampton.ac.uk

 01604 893559 or 07967227571



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Reflections on the process

- ▶ There is no one size fits all.
- ▶ Need to be able to respond to individual needs
- ▶ This is just the beginning of an on-going process
- ▶ Information sheets are just a piece of paper – communication with the individual is key
- ▶ Informed consent should not be just a tick box exercise but seen as the start of the research relationship
- ▶ Ethics is fundamentally about people and not about procedure.



Importance of the Research Relationship



Acknowledgements

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