

Dementia Carers Instrument Development: DECIDE

INFORMATION FOR CARERS

We would like to invite you to take part in a research study that is developing a new questionnaire to measure carers' quality of life. The aim of this part of the study is for us to talk with a range of carers about their experiences so that we can build the new questionnaire upon real life experiences. The questionnaire will be used to help staff in services be aware of carers' needs, to help evaluate services or supports, and to inform policies.

This information sheet explains what taking part would involve. Please read it carefully and discuss it with others if you wish. A researcher will contact you in a few days to answer any questions and to find out whether you would like to take part. Thank you for reading this information sheet.

Why have I been invited?

We are inviting you to take part because you care for someone who lives with dementia. You are being given this information sheet because you are connected with a local service, which has agreed to help us contact carers. We understand you have said you may be interested in taking part.

Can I choose whether or not to take part?

It is up to you to decide whether or not you want to take part. If you do, we will give you this information sheet to keep and we will ask you to sign a consent form. If you change your mind, you can pull out at any time and you do not have to say why. If you decide not to take part or to pull out, this will not make any difference to the services you or your relative receive and it will not affect your rights in any way.

What will happen if I decide to take part?

If you decide to take part, the researcher will contact you to ask some initial questions to find out a little more about you (e.g. your age, your ethnicity) and the person you care for (e.g. their relationship to you, how long ago they developed dementia). This is because we hope to interview a wide range of carers. If we already have other carers who are similar to you in several ways, we might tell you we do not need to interview you on this occasion. If this is so, we will ask if you would be willing for us to contact you again when we reach the next stage of our study, as you might be able to help with that.

Otherwise, the researcher will arrange to interview you. This will take place at a time and place that suits you, at your own home or elsewhere. The researcher will spend 45-60 minutes with you (or longer if you have more you would like to say). The researcher will ask you about your experiences

of caring for your relative with dementia, including the most rewarding and most trying aspects, and the impact on your own life.

The researcher will ask your consent to audio-record the interview. This will allow us to study what you say and help us put together well-worded items for the questionnaire.

What are the possible disadvantages and risks of taking part?

We do not think that taking part will involve any disadvantages or any specific risks to you. Should you become upset by talking about your situation, the researcher will offer to pause or stop the interview.

What are the possible benefits of taking part?

You may find it interesting to talk with the researcher about your experiences as a carer. The information from the interviews will help to make sure the questionnaire we develop is based on real-life experiences. This means that by taking part you will be contributing to a useful questionnaire that will be used by researchers and service providers in the future.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspect of your part in the study, we would ask you first to speak to one of the research team, so that we can try to address your concerns and find a solution. You can talk to the researcher (see contact details below) or to Professor Jan Oyeboode, who is leading this part of the study (School of Dementia Studies, University of Bradford, Bradford, BD7 1DP. Phone: 01274 236330. E-mail: j.oyebode@bradford.ac.uk) or you can contact the Chief Investigator, Dr Penny Wright (Psychosocial Research Group, Level 03, Bexley Wing, St James's Institute of Oncology, Beckett Street. Leeds LS9 7T, Phone: 0113 2068488. Email: e.p.wright@leeds.ac.uk).

If you are not satisfied with our response you can make a complaint to an independent professional – Clare Skinner. Clare is the Faculty Research Manager for Medicine and Health at the University of Leeds and will be able to give you independent advice about any problems you are encountering with the research.

Clare Skinner – tel: 0113 343 4897
Email: governance-ethics@leeds.ac.uk

Will my taking part in the study be kept confidential?

Your taking part will be confidential.

All information that we collect will be kept strictly confidential and stored securely. Only those in the research team will have access to your personal information. After your interview, we will type up a transcript of what was said. The person typing this up will take out all names and identifying information. The transcript will be kept separate from your personal details, and will only be linked to you using a code. Only the researchers will have access to that code. We will keep the audio recordings securely on University of Leeds computers for the length of the research and then erase them once the project is completed. The transcript of your interview may be accessed by other researchers, but we will remove any information that could be used to identify you. No-one will ever be able to identify you personally from anything that we write or say in public about the research.

The only situation in which we might need to share information about you with others would be if the researchers observe or hear anything that causes very serious concern about the health, safety or well-being of you or the person you care for. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

We will ask you if you are willing for us to keep your contact details (name, address, telephone number and email address) on record for 2 years after the end of the study. This is because it is possible that in the future we may be able to obtain funding for further work about caregiving. You do not have to agree to this. If you do agree, your contact details will be kept securely and only the original research team will be able to access them.

If in the two weeks following your interview you would like to withdraw it from the study, then please contact Dr Simon Pini on the details provided. After this time the transcripts we gather, along with the other anonymised information you give us, will be stored securely at the University of Leeds for 5 years. They will be made available to other researchers if these researchers make a good case and have an ethical approach. This is a way of making good use of valuable information rather than 're-inventing the wheel'.

What will happen if I change my mind about taking part?

You can withdraw from the interview at any time without giving a reason. If you withdraw it will not affect any services you receive in any way. We will continue to use the information collected before you decided to withdraw, unless you tell us that you do not want us to do so.

What will happen to the results of the research study?

When the study is complete, we will publish the questionnaire and make it freely available to health and social care staff, and researchers. We will present the results at scientific conferences, publish them in scientific journals, and present them to carers. If you would like to know the results, we

will be very happy to provide these to you, or you can find up to date information about the study on our website www.decideproject.co.uk. We expect the results to be available by July 2018 at the latest.

Who is organising and funding the research?

This research project is led by Dr Penny Wright from the University of Leeds. The research is funded by the Medical Research Council. This funding covers the running costs of the research project.

Who has reviewed the study?

The quality of our proposed research has been reviewed and approved by the Medical Research Council. Also, our research is connected with the NHS, as we are contacting some carers to take part through NHS services. All research connected with the NHS is reviewed by a Research Ethics Committee, to protect the safety, rights, well-being and dignity of those taking part. This study has been reviewed and approved by the South Central (Oxford B) Research Ethics Committee.

Who can I contact for further information?

For more information, please contact: [contact details removed when archiving]

Thank you for reading this information sheet and for considering taking part in this research study.