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Easy read information sheet

SONNET Study

Social connection in long-term care home residents (Aim 3)

Why have I got this leaflet?



We are inviting you to take part in research to find out what is important for social connection for people who live in care homes.

You can talk with your family, friends, carers, doctor and me to help to decide whether to take part.

If you have any questions about this leaflet, please contact Dr Andrew Sommerlad (020 7679 9248, a.sommerlad@ucl.ac.uk) for further information.

Why are we doing this study?

We want to be able to measure resident's social connection accurately so that researchers and other professionals can find out what helps social connection. Our team have looked at different ways of measuring social connection (called "tools)" and none were very good.

So we created a new measurement tool that we would now like you to complete. We would also like to ask a family member, friend or care staff to complete a few questionnaire about you to help us evaluate the tool.

We have asked you because you are a care home resident.

What will we do?



If you are interested in taking part in the study, we will meet with you, answer any questions you have, and ask for you to agree to take part in the study by signing a consent form. If you are unable to make a decision about participating, then we will follow the law by asking someone who knows you well.



We will then meet with you for an interview. We will collect some basic information about you (e.g. your age, gender etc) and ask you to complete a questionnaire to assess your social connection. This will take around 15 minutes. We will also ask one of your family or care staff to complete a few questionnaires about your dementia, social functioning, activities of daily living and quality of life.

For some participants who are willing to do so, we will return after 2-4 weeks to ask you some of the questions again.

Do I have to take part?

No, you do not need to take part.



If you say no, you do not have to say why. It will not change the care you get.



If you say yes, I will ask you to sign a consent form or will record you agreeing to take part.

What if I do not want to carry on with the study?



You can stop the study at any time, without giving a reason.

We will keep information about you that we have already, but we will not collect any new information.

If you stop taking part this will not affect the care you get.



If you take part in the interview we will give you a £20 gift certificate as a token of our thanks for your time.

What if I feel upset taking part?

We find most people enjoy taking part but it may be upsetting talking about the topics we discuss.



You may choose not to answer any question and you can also choose to stop at any time or to start again at a later time or date.

If you are upset, you can speak to us or call the Alzheimer's Society helpline on 0333 150 3456.

What happens after the research stops?



The researcher will stop contacting you, unless you have agreed that we can contact you again in future about other research projects.



If you would like to receive information about the results of the study, then you will be able to tell us of your wishes for this and we will then keep your contact details so that we can send you a summary of the results once the study has finished.

Will my taking part be kept private?



Yes, the information you give will be confidential (private).

We will not talk to anyone else about you unless we are worried about your safety.

How will we use your information?



Personal information like your name, address, phone number or date of birth will be kept safely and separately from the other information we collect.

We will give a number which we will use when we are looking at the findings so no one will know it is you. We will keep any information you give safely and securely.

If you have any questions about the information you give us, you can speak to the principal researcher:

Dr Andrew Sommerlad

Tel: 020 7679 9248

Email: <u>a.sommerlad@ucl.ac.uk</u>

You can find out about how we use your information at: www.hra.nhs.uk/information-about-patients/

What if there is a problem?



If you are worried about any part of this study, you can speak to Dr Andrew Sommerlad

Tel: 020 7679 9248

Email: a.sommerlad@ucl.ac.uk

If you remain unhappy, or wish to make a complaint you can contact UCLH/UCL Joint Research Office, R&D Directorate, Roseheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB

Thank you for reading this leaflet