

The IDEAL-2 Study **Living well and enhancing active life: the impact of COVID-19 (INCLUDE)**

Information for family members/friends

To be read out over the telephone

My name is [say name] and I work as part of a research team at Exeter University Medical School. I'd like to invite you to take part in a research project called INCLUDE.

I'm calling you because you have already taken part in the IDEAL-2 research study as a carer for a person who is experiencing changes in memory, other aspects of thinking, and ability to manage day-to-day activities, which may have been described as a type of dementia. You agreed that we could contact you again. This new project, INCLUDE, is an extra part of the IDEAL-2 study. May I tell you a bit about it?

We want to find out about people's experiences during the coronavirus (COVID-19) pandemic.

EITHER [For those who took part in the IDEAL COVID-19 Dementia Initiative (IDEAL CDI)] A few months ago you spoke with one of our researchers about your experiences during the initial lockdown period and we are now keen to find out about how this situation has affected you and [give name – the person you support] in the longer term.

OR [For those who did not take part in IDEAL CDI] This has been a difficult time for many people. We want to know how the restrictions on going out and seeing other people have affected you as a carer and [give name - the person you support], and how you are finding things now.

We would also like to talk to [give name – the person with dementia] as well.

This is so that we can recommend better ways of supporting people in the future.

You don't have to take part. It is up to you to decide. If you don't want to, that's alright. It won't make any difference to your health care or anything else.

If you do decide to take part, you can choose to withdraw at any time. Just tell the researcher. You don't have to say why. You can still continue to take part in the rest of the IDEAL-2 study.

I've explained that you don't have to take part if you don't want to, so next I'd like to tell you about what taking part involves.

If you agree to take part, [I/a researcher] will talk to you and ask you some questions about your experiences and feelings. We can do this on the telephone, or we can send you a link to click on and do it online. You can choose which is best for you. It will take about 45 to 60 minutes. We can either do it all in one go or we can talk

several times. It is up to you to choose. Your conversation with the researcher will be audio-recorded and some parts will be written out in full later.

We might ask you to talk to [a researcher] again a few weeks later and tell us more about your experiences. This would take up to 30 minutes and would be audio-recorded and later written out in full.

So this is what we would ask you to do if you decide to take part. Would it help to talk it through again? [The researcher will explain again if the participant so wishes].

Next I'd like to talk about how taking part could affect you.

We don't think there are any risks involved in taking part. If any of the questions make you feel uncomfortable, you don't have to answer them. Some people enjoy talking to a researcher and sharing their experiences.

Now I'd like to tell you about how we would look after any information you give us.

We will keep any personal details that you give us, such as your name or where you live, completely confidential. No-one outside of the research team will see this information, and no-one will be able to identify you personally from anything we say or write about the research.

We will store the other information you give us securely. We will look at your information along with the information from other people taking part. We will use this information to help us develop resources to support people better. At the end of the study, we will make the information available in anonymised form to other research teams.

That is everything I wanted to tell you about the research. Would you like to hear about the study again, or to ask me any questions?

To help you decide whether to take part, I can give you some more details about the research. You can find this information on our website at www.IDEALproject.org.uk, or I can send it to you by email or in the post. Would you like to see this information? [If yes] What would be the best way to organise that?

You can have as much time as you like to decide whether or not you want to take part. If you decide to go ahead, I will ask you to give your consent over the phone, and will audio-record it.

[The researcher will thank the potential participant, provide contact details, agree when and how the participant will receive or access further information, and **either** arrange to call back **or** if the participant indicates a clear decision to take part, may take consent at this point. If consent is taken at this point, the researcher will ensure the participant has access to the further information that is available.]