



Living well and enhancing active life: The IDEAL-2 study

Living well and enhancing active life: the impact of
COVID-19

INCLUDE

LONG INFORMATION SHEET FOR PARTICIPANT

More information about the study

We are inviting people who have taken part in the IDEAL-2 research study to take part in a new study, INCLUDE, which is an extra part of the IDEAL-2 study. In the INCLUDE study we are contacting people by telephone instead of visiting in person. This is to remove any risk of coronavirus (COVID-19) infection. You may already have spoken to an IDEAL-2 researcher on the telephone.

In the INCLUDE study, we want to find out about people's experiences since the coronavirus (COVID-19) outbreak started. 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, and how you are finding things now. This is so that we can recommend better ways of supporting people in the future.

Do I have to take part?

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. 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.

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.

What is involved in taking part?

If you agree to take part, 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 30 – 45 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.

How will taking part affect me?

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.

How will the researchers look after my information?

We will look after any information you give us very carefully.

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.

When do I have to make a decision?

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, the researcher will ask you to give your consent over the phone, and will audio-record it.

Further details

There are some more details about the INCLUDE study and about how we will look after the information you give us on the following pages. You can also find this information on our website at www.IDEALproject.org.uk.

Thank you for reading this information.

Why are we doing this research?

We are running a large research programme called IDEAL-2 which looks at how to improve the experience of people who have difficulties with memory or other aspects of thinking, or changes in their ability to manage day-to-day activities. People taking part in IDEAL-2, and their families and close friends, may face particular challenges as a result of the restrictions brought in to control the COVID-19 pandemic, such as social distancing. We have secured funding for this extra project called INCLUDE, which is an added part of IDEAL-2, so that we can find out about people's experiences during this time. We will use the results to recommend better ways of supporting people while these restrictions continue, and in the future.

Who is responsible for the research?

Exeter University is responsible for making sure the research is conducted properly.

Who is paying for the research?



The Economic and Social Research Council (ESRC) is funding the INCLUDE project. ESRC is part of UK Research and Innovation (UKRI).

Alzheimer's Society is funding the main IDEAL-2 study.



Who has reviewed the study?

This study has been reviewed and authorised by Wales 5 NHS Research Ethics Committee and the Health Research Authority.

What if something goes wrong?

If you have any concerns about the way you have been approached or treated while taking part in the study, please talk to your researcher first of all.

If you are still unhappy, you can contact:

- the Programme Manager, Dr Claire Pentecost, tel. 01392 724653, e-mail c.pentecost@exeter.ac.uk; or the Chief Investigator, Professor Linda Clare, tel. 07485 042117, e-mail l.clare@exeter.ac.uk.

If you are not satisfied with the response you receive, you can make a complaint to the Sponsor Representative:

- Ms Pam Baxter, Research Ethics and Governance Office, University of Exeter, Lafrowda House, St Germans Road, Exeter, Devon, EX4 6TL. Tel. 07485 042117, e-mail p.r.baxter2@exeter.ac.uk.

In the unlikely event that you are harmed by taking part in this study, or because someone is negligent, you may be able to take legal action.

Protecting your personal data and safeguarding your rights

How do we manage your personal data?

Due to recent regulatory changes in the way that data is processed (General Data Protection Regulation 2018 and the Data Protection Act 2018) the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data is controlled and managed for this study then you can also contact the Sponsor Representative, Pam Baxter, Senior Research Governance Officer, Research Ethics and Governance Office, University of Exeter, Lafrowda House, St Germans Road, Exeter, Devon, EX4 6TL. Tel. 07485 042117, e-mail p.r.baxter2@exeter.ac.uk.

How will my information be stored?

For the purposes of this study we will also use consent to protect your confidentiality and provide you with choice in your participation. We will

keep all information collected in this study strictly confidential and stored either on an encrypted password-protected computer, or in a locked cabinet at the University, which can only be accessed by members of the research team. You will be allocated a unique participant number, which will ensure the information from your interviews is protected and cannot be identified by anyone else. We will store any personally identifiable information, such as your contact details, separately from information obtained from the interviews.

What will happen to my information if I withdraw from the study?

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. If this happens, to safeguard your rights, we will use the minimum possible amount of personally-identifiable information.

What will happen to my information after the end of the study?

After the study ends, we will add the information gained from the research to a national data archive so that other scientists can also make use of it. This is a condition of our research funding. We will make sure that none of your personal information is included. No-one will be able to identify you personally from the data we add to the archive. We will securely destroy your personal information 5 years after the end of the IDEAL-2 study.

Where can I find more information?

You can find more information on our websites at www.IDEALproject.org.uk and www.INCLUDEproject.org.uk. You can email the research team at IDEAL@exeter.ac.uk. You may already receive IDEAL project newsletters with updates about our findings, but if not, please ask your researcher about them.

Contact us

If you want more information about the study and taking part then please contact:

The research team by calling Tel. [01392 724653](tel:01392724653) or e-mail IDEAL@exeter.ac.uk

If you have a complaint contact the research team in the first instance or

the Programme Manager, Dr Claire Pentecost, Tel. [01392 724653](tel:01392724653), e-mail c.pentecost@exeter.ac.uk or

the Chief Investigator, Professor Linda Clare, tel. 07485 042117, e-mail l.clare@exeter.ac.uk.

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The Sponsor Representative, Pam Baxter. Research Ethics and Governance Office, University of Exeter, Lafrowda House, St Germans Road, Exeter, Devon, EX4 6TL. Tel. [07485 042117](tel:07485042117), e-mail p.r.baxter2@exeter.ac.uk.

Thank you for considering taking part in this research.

END OF INFORMATION SHEET