

Participant Information Sheet

Invitation to take part in a research study to share your thoughts about how to measure Quality of Life when medicines are stopped

As we get older our bodies are less able to handle some medicines. Medicines that were once effective and safe may no longer work as well but could still cause side effects.

Researchers are working with older adults, family and friends and healthcare professionals to design and test new ways of safely stopping medicines that may no longer be working. Measuring the effect of stopping medicines on a person's Quality of Life is a priority. But at the moment there are no good ways to measure Quality of Life in this situation.

If you are 65 years or older and take 5 or more medicines we want to hear your thoughts about the most important things to think about when measuring a person's Quality of Life when they stop taking a medicine. We will do this by talking about it with you in a **1 hour online or telephone interview**. In the interview we will ask you what you think is important to think about when measuring a person's Quality of Life when they stop taking a medicine. We will also ask you to look at two different Quality of Life surveys and then tell us your thoughts about whether or not they are a good way of measuring Quality of Life when a person stops taking a medicine. **You will get a £60 Amazon voucher as a thank you for taking part. This study does NOT involve you stopping any of your medicines.**

To help you decide whether you want to take part further information about research study is on the following pages.

SIGN UP

How to take part

If you decide you would like to take part please let us know by completing this short [expression of interest form](#).

Who is organising and funding the study?

The study is being organised by researchers at the University of Leicester. The study is also being done in Canada by the University of British Columbia and in Denmark by the University of Southern Denmark.

The study is being funded by the United States Deprescribing Network which is part of the United States of America's National Institute on Aging. The funding has been given to the University of British Columbia who are leading this research.

What will happen if I take part?

Before your interview you will be asked to fill out a consent form to confirm that you have read the information in this sheet. You will then answer some questions about you like how old you are and how many medicines you take. We will also ask you to let us know when you would like to do the interview and whether you want to do it online using Microsoft Teams or over the telephone.

At your 1 hour interview we will do two things. First we will spend about 30 minutes asking you to tell us your thoughts about how medicines affect your daily life. Then we will spend the rest of the interview asking you to look at two different Quality of Life surveys and then tell us your thoughts about whether or not they are a good way of measuring Quality of Life when a person stops taking a medicine.

The researcher you talk to will audio record the interview discussion so that it can be typed up to make sure we don't miss anything important. Nothing that can identify you will be typed up and then the recording will be deleted.

What are the possible benefits of taking part?

You will be helping to design a way to measure the effect of stopping medicines on a person's Quality of Life. This will help the NHS and policy makers to understand whether or not new ways of safely stopping medicines that may no longer be working improve people's Quality of Life. This will help them to decide whether any new ways of safely stopping medicines are a good idea to make them available across the NHS.

You will get a £60 Amazon voucher as a thank you for taking part.

What are the possible disadvantages of taking part?

We do not think that there are any major disadvantages to taking part but you will be giving up some of your time to attend the 1-hour interview.

What about confidentiality?

Your information will be treated with absolute confidence and will only be shared with members of the research team at the University of Leicester and the University of British Columbia (Canada) who need to see it. The information shared with the University of British Columbia will not identify you in any way.

People who do not need to know who you are will not be able to see your name or contact details. Information collected about you will be securely stored for 6 years after the study has ended.

The University of Leicester is the data controller for this study which means that they are responsible for looking after your information and using it properly. 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 study to be reliable and accurate. This means that we won't be able to let you see or change the data we hold about you.

To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how the University of Leicester manages Personal Data by visiting www.le.ac.uk/ias. Principles of the General Data Protection Regulations 2018 will be followed with respect to data storage, processing, and destruction.

What happens when the study ends?

We will publish what we learn from the study in scientific journals and news articles for the public. We might use direct quotes from what you say but will remove any information that could identify you. We will send you a summary report of our findings if you tell us you would like a copy.

Who has reviewed the research?

This research has been reviewed and approved by an independent group of people based at the University of Leicester, called a Research Ethics Committee. They are committed to protect the rights, safety, dignity and wellbeing of research participants.

What if I change my mind?

You can stop being part of the research study at any time, without giving a reason. If you choose to stop, we will keep the information that we have collected up to the point of withdrawal.

What if there is a problem

If you have a concern about any aspect of the study you can speak to the study team (see contact details below), who will do their best to answer your questions. If you have concerns about any aspect of the way you have been approached or treated during the course of the study, you may wish to contact the Chair of the University of Leicester Research Ethics Committee on ethics@le.ac.uk. If you have any concerns about how your information is used, you may wish to contact the University of Leicester's Data Protection Officer on DPO@le.ac.uk.

In the unlikely event that you feel that you have been harmed during the study and that this is due to someone's negligence, then you may have grounds for a legal action for compensation against the University of Leicester. However, you may have to pay your legal costs as there are no special compensation arrangements for this study.

For more information

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