**Participant Information Sheet**

NHS Research Ethics Committee Approval ID Number: 22/LO/0227

**Title of Study:** Optimising self-management of long-term multi-morbidity in people who are

experiencing socioeconomic deprivation

**Department:** Primary Care and Population Health, University College London (UCL)

**Chief Investigator:** Megan Armstrong megan.armstrong@ucl.ac.uk

**Researcher:** Dr Abi Woodward: abigail.woodward@ucl.ac.uk

You are being invited to take part in our research project. Before you decide, it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. One of our team will also go through this information sheet with you and answer any questions you have. Please let us know if you would prefer if we read this to you. This should take about 10 minutes. Thank you for reading this.

**Why is the study being done?**

We want to explore how we can improve the self-management of long-term health conditions by identifying the difficulties that people experience. Most of the funding for health is spent on long-term health conditions and it is important to understand how we can best support people to manage their conditions, as well as they can. By doing this, we can help to reduce the inequality in healthcare.

People who are experiencing social and economic deprivation are more likely to have a long-term health condition, for it to be more severe, and to have multiple long-term conditions. We will explore how education, income, access to information, expectations, Covid-19 and attitudes to health and government policies might impact self-management.

**Why have I been chosen?**

You are someone who has been identified as experiencing two or more long-term conditions that require more than medication management. We would really value the contribution you can make to this study.

**Do I have to take part in the project?**

Taking part in the project is entirely voluntary. If you do decide to take part, you will be given this information sheet to keep and will also be asked to provide written consent to taking part (we will give you a form to complete). If you do not take part, your care will not be affected.

**What do I have to do if I participate?**

If you agree to participate in the project, we will invite you take part in an interview with a researcher. The interview will take place in a location of your choice – this could be in your home or in a public or community venue (or over the phone/video call on zoom depending on your preference and Covid-19 restrictions). The interview will be an informal conversation and should last no more than 90 minutes (including breaks if needed). In the interview, you will be asked some questions about your overall health and well-being and how you self-manage your long-term conditions. You will be able to stop the interview at any time or choose not to answer questions that you are not comfortable with.

We will ask you to complete a short questionnaire so that we can collect important information about you. As a thank you for your time, you will receive a £50 voucher.

We may also ask you whether you have an informal (unpaid) carer who supports you that we could contact to interview them too. If you do not have a carer or would prefer we do not speak to them, you can still take part in this study.

**How will we use information about you?**

We will need to use information from you for this research project. This information will include your age, gender, ethnicity, educational attainment, employment status/job role, income band and long-term conditions. We will collect this through the short questionnaire mentioned above. We are also asking people who are being interviewed to be audio recorded. This helps us to accurately recall all the information you give us. These recordings will be transcribed (written out), with any names or identifying information removed. Interview transcripts will be used in our analysis and anonymised. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym (different name) instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports, conference presentations, lecture material and academic publications in a way that no-one can work out that you took part in the study. The reports may be publicly available but transcripts and original audio recordings will not be shared with anyone outside the project.

**What are my choices about how my information is used?**

If you do decide to take part, you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. You do not have to give a reason for withdrawing from the study. If you withdraw from the study, any care/support you receive will not be affected in any way.

**What are the possible disadvantage and risks of taking part?**

We do not anticipate any risks or harm to you as a result of taking part in this project, though it is possible that the conversations may touch on some difficult subjects. We will ensure that if this is the case, we are able to signpost you to appropriate support if needed.

**What are the possible benefits of taking part?**

We are hoping that the project will result in better support for people with multiple long-term conditions. We are also hoping that the project will help with the development of interventions suitable for people from lower socioeconomic status groups with multi-morbidity.

**What if something goes wrong?**

If you have a concern about any aspect of this project, in the first instance you should ask to speak to a member of the project team who will do their best to answer your questions. However, if you feel your complaint has not been handled to your satisfaction you can contact the Bromley Research Ethics Committee - bromley.rec@hra.nhs.uk.

**Will my taking part in this project be kept confidential?**

All the information that we collect about you during the research will be kept strictly confidential. You will not be able to be identified in any reports or publications that we produce, and we will use pseudonyms (change your name).

**Limits to confidentiality**

Please note that confidentiality will be maintained as far as it is possible, unless if during our conversation I hear anything that makes me worried that someone might be in danger of harm, I might have to inform relevant agencies of this. If this were the case, we would inform you of any decisions that might limit your confidentiality.

**What will happen to the results of the research project?**

The results gathered from you and other participants will help us identify the challenges and facilitators to self-managing multiple long-term conditions so that we can suggestions for tailoring patient care and support. The results will also be published in academic journals, at conferences and lectures. You will be advised where you can access a summary of the results.

**Audio recordings**

Your interview will be audio recorded by the researcher interviewing you. This will be stored on a password protected Dictaphone and uploaded to a secure UCL system as soon as reasonably possible. The audio recording will then be deleted from the Dictaphone. The audio recordings will be sent to a UCL approved transcription company in which a confidentiality agreement will be in place. Only the approved transcription company and UCL staff members working on this project will have access to the audio recordings. Once the audio recordings have been transcribed, the audio recording will be deleted from UCL secure systems. The transcriptions will be anonymized with all identifying information removed.

**Where can I find out more about how my information is used?**

You can find out more about how we use your information by sending an email to the UCL Data Protection Officer at data-protection@ucl.ac.uk.

**Data Protection Privacy Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This ‘local’ privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our ‘general’ privacy notice:

<https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>

If you are concerned about how your personal data is being processed, please contact Dr Megan Armstrong in the first instance. If still concerned you should contact UCL at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner’s Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

The legal basis used to process your *personal data* will be performance of a task in the public interest.

***Your personal data will be processed so long as it is required for the research project***. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. The project team will keep your name and contact details confidential and will not pass this information to any other organisation. We will only use this information to contact you about the project and to link your interviews. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. All information that identifies you will be deleted before the data is analysed.

All information collected during the project will be combined, and no individual will be identified in any report or publication.

**Who is organising and funding the project?**

This project has been funded by the National Institute for Health Research (NIHR). It is a collaborative project led through the Research Department of Primary Care and Population Health and the Centre for Ageing Population Studies (CAPS) at UCL. The project is sponsored by University College London.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Bromley Research Ethics Committee.

**Contact for further information**

Dr Abi Woodward: abigail.woodward@ucl.ac.uk or Dr Megan Armstrong: megan.armstrong@ucl.ac.uk

**Thank you for reading this information sheet and for considering taking part in this research study. The information sheet is for you to keep.**