



Lived experiences of older people with pre-frailty

You are being invited to take part in a study designed to find out your experiences and opinions.

Before you decide if you would like to participate it is important for you to understand why the study is being done and how it is going to be done.

Please take time to read the following information carefully. Ask me for more information if there is anything you are not clear about.

Take time to decide whether or not you wish to take part. You may wish to discuss the study with family or friends before you decide to take part.

Purpose of the study

This study aims to explore the lived experiences of older people with pre-frailty.

Pre-frailty is a term used to describe a wide range of ongoing changes to mental, physical and social health and wellbeing; which can be the result of a wide variety of factors and influences. Examples could include things like:

- Jobs around the house and/or garden taking longer due to arthritis.
- Social life changes due to difficulties driving or using public transport.
- Using home delivery for groceries as going shopping is more difficult.
- Friends and/or family helping or supporting with some tasks.
- Feeling like you're 'slowing down' whilst still able to do most things.

I'm interested in learning about your experiences in order to understand your health and wellbeing needs, wants and priorities, as well as to explore your support networks.

Insights gained may inform improvements in health and social care professionals' ability to support pre-frail individuals to live well for longer.

Who is undertaking the study?

This study is led by Jemma James, a Registered Nurse and PhD student at Northumbria University, Department of Health and Life Sciences.



Why have you been invited?

You responded to a request for people to take part in this study, and have the lived experiences of pre-frailty needed to contribute to the study's findings.

What are you being asked to do?

You are being invited to:

1. Take part in individual interviews to explore and discuss your experiences of your health and wellbeing and support.

This can be a single interview, but may be up to three interviews to allow you time to express your views and experiences fully and explore issues around your day-to-day life, your health and wellbeing and any support and coping strategies/systems you have in place.

The interview(s) will be recorded on an electronic recording device and the recording(s) will be transcribed following the interview(s). Each interview will last approximately one hour and will take place at a location that is convenient for you. If you prefer to meet online, then online meetings will be arranged.

2. Complete a diary about your day-to-day experiences regarding your health, wellbeing and support. This will take a variable amount of time as it depends on what you feel is important to record. This will be given or sent to you after your first interview, and collected after your second interview.

Benefits of taking part?

You will have the opportunity to share your experiences and discuss your health and wellbeing priorities and views on what services/support structures you find useful. This will be used, along with other participant's information, to build a picture of what it is like to live as a pre-frail older person.

In turn, this may offer valuable insight for nurses and other health and social care professionals, service managers/developers and other key decision makers. It will enable them to refine and improve the design, implementation and assessment of pre-frailty identification and management, and hopefully contribute to improving the health and wellbeing of pre-frail older people.



Disadvantages of taking part?

Participation in the study will require up to 3 hours of your time, plus however long you choose to spend on your diary. Some people may have concerns that during interviews, or when writing their diaries, issues may be explored or raised which could cause distress or incur criticism or judgement. This is not the aim of the study.

If the study does raise issues which cause you distress, processes are in place to ensure that you will be well supported. Also, in the event that the study identifies unsafe or poor practice or significant risk of harm, this will be initially discussed with yourself and escalated where deemed appropriate to the local safeguarding team and/or relevant professional registration body to support you.

Do I have to take part?

No. It is up to you whether you would like to take part in the study. This information sheet is being provided to help you make that decision.

If you do decide to take part, remember that you can stop being involved in the study whenever you choose, without telling me why. You are completely free to decide whether or not to take part, or to take part and then leave the study before completion. Deciding not to take part, or leaving the study altogether, is at your discretion at any point during the research.

What will happen to the information that is gathered?

- The study findings will be used to complete my PhD thesis and you will have full access to a summary of the final output of this study.
- My thesis and any subsequent publications/presentations will include examples of what participants said, but you will not be named and no identifying information will be used.
- This study may also be reported in professional and academic publications and/or presented to professional and academic bodies.
- Your name will never appear in any documentation and no participants will be named in any reports or presentations about the research.
- All information will be kept confidential and stored in a secure place, including information used in reports and presentations.
- The information that is gathered will be analysed (including if you choose to withdraw from the study).
- Only the study team will handle the information gathered and it will be destroyed after a 5-year period.



Will my responses be kept confidential?

Anything said in the interviews or recorded in the diaries will be kept completely confidential. In the final written project, all participants names will be changed and substituted with numbers and no identifiable characteristics or information will be used.

How will my data be stored, and how long will it be stored for?

All paper data, including the typed-up transcripts from your interview(s) and your consent forms, will be kept in locked storage. The consent form you have signed will be stored separately from your other data.

All electronic data, including the recording(s) from your interview(s), will be stored on the University computer drives which are password protected. All data will be stored in accordance with University guidelines and the General Data Protection Regulation (GDPR).

What will happen to the findings of the study and could personal data collected be used in future research?

Anything participants say in this study will be kept strictly confidential and anonymised (see confidentiality for further details). The conclusions and findings from this study will be used solely for my PhD. Any participants who would like a summary of the findings can request one from me.

Who has reviewed this study?

Permission was obtained from Northumbria University Research Ethics Committee to do this study.

What are your rights as a participant in this study?

Minimal personal information is collected in this study (gender, age, ethnicity). The purpose of collecting this is to provide a background in the report about the viewpoint that is being presented.

You have a right of access to a copy of the information about the personal data we have collected about you (to do so you should submit a Subject Access Request to the data protection office at Northumbria University. I can explain how this is done).

If you are dissatisfied with the University's processing of personal data, you have the right to complain to the Information Commissioner's Office. For more information see the ICO website.



If you have any questions or would like further information about the project please contact:

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Alternatively, you can contact:

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For concerns about data protection please contact:

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