**Participant Information Sheet**

**Title of Project: Physical rehabilitation interventions for people with advanced dementia**

**Invitation and summary:**

Thank you for taking the time to read this participant information sheet. It will provide information about the study and your potential involvement. If you have any questions about the study, please contact us and we would be happy to meet with you to discuss further.

**Purpose of the research:**

Our research aims to try to understand how best to provide physical rehabilitation with people who break their hip and have advanced dementia.

We will interview health care professionals, to ask:

* What treatments work better for people with more advanced dementia?
* Do treatments need to be adapted for people with advanced dementia? Or do standard treatments following hip fracture still work?
* What needs to be considered when providing education to other healthcare professionals treating people with advanced dementia?

With this information, we will determine what an intervention to provide rehabilitation to people with advanced dementia following hip fracture might consist of.

**Why have I been approached?**

We are inviting several health and care professionals who have experience of treating people with dementia to take part in this research. You have been identified as having the skills and experience that would be of significant benefit to assist with this research.

**What would taking part involve?**

If you decide to take part in the research, we will contact you via email or phone to talk more about the study and answer any questions.

With your written consent, you will be asked to take part in a focus group (via Microsoft Teams – if you do not have the software available, we will organise an alternative method of joining the call such as dialling in by telephone)) about your experiences of treating people with advanced dementia and explore options for potential physical rehabilitation techniques that might be effective in improving their physical abilities. The focus groups will follow clear ground rules, which will be provided prior to the focus group. There will be at least one member of our Patient and Public Involvement and Engagement team in the meeting to consider the discussion from a patient perspective.

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

Your participation in a focus group will help us understand your perspectives on physical rehabilitation interventions for people with advanced dementia. This will help to inform the development of an intervention which we will explore further in a future study.

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

We are not aware of any disadvantages or risks to you if you take part in this research other than the time it will be required to take part – which we anticipate being approximately 90 minutes.

**What will happen if I don't want to carry on with the study?**

Taking part is voluntary and you are free to withdraw at any time, without giving a reason. If you withdraw, we will delete your contact details from our records, but any information you have already given will remain part of the research. Analysis of data will begin in August 2022 so requests to withdraw data would need to be submitted before this date. If after this date, the anonymised data would not be able to be withdrawn.

**How will my information be kept confidential?**

The University of Exeter processes personal data for the purposes of carrying out research 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 do 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 informationgovernance@exeter.ac.uk or at http://www.exeter.ac.uk/ig/

All information collected in this study will be kept strictly confidential and stored either on an encrypted password protected computer. You will be allocated a unique participant number, to ensure your information will be protected and cannot be identified outside of the research team. Any personally identifiable information will be stored separately and securely from information obtained from the research, it will only be kept for a limited time (until the findings have been written up) and securely destroyed (when the findings are published).

Your rights to access, to change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you feel that any quotes may compromise your anonymity, you will be given the opportunity to change the quote to ensure your confidentiality is maintained. In this case, you will be asked to inform the researcher. Should the researcher feel that a direct quote might compromise your anonymity, you will be contacted and asked if you wish to change your wording. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

**Are there any circumstances in which confidentiality would be broken?**

Please be aware that the researcher has a duty to inform relevant NHS Services, and/or your employer should you disclose any information indicating evidence of malpractice or risk of harm.

**Will I receive any payment for taking part?**

There is no payment for taking part in this research.

**What will happen to the results of this study?**

This information will be used to inform our understanding of the needs and treatments that might benefit people with advanced dementia who experience a hip fracture. This understanding will enable us to develop and refine our theory of how physical rehabilitation interventions may help people with advanced dementia. The findings from our current study will be written up as a report and provided to the funders, and we will also publish the results in healthcare journals for healthcare professionals. Participants can request a copy of the report also.

**Who is organising and funding this study?**

This study is funded by the National institute for Health Research School of Primary Care Research. Members of the Patient and Public Involvement and Engagement (PPIE) group were invited to advise this study.

**Who has reviewed this study?**

This project has been reviewed by the College of Medicine and Health Research Ethics Committee at the University of Exeter (Reference Number 515745).

**Further information and contact details**

Dr Abi Hall of the University of Exeter is an experienced healthcare researcher.

If there is anything that is not clear to you after reading this, please ask for clarification:

**Researcher Name: Dr Abi Hall**

**Email: a.hall4@exeter.ac.uk**

If you have a concern about any aspect of this study, you should ask to speak to the researchers (contact details above) who will do their best to answer your questions. If you remain unhappy and wish to make a formal complaint you can through the sponsor for this study at the University of Exeter, and the person to contact there is:

Gail Seymour, Research Ethics and Governance Manager

[g.m.seymour@exeter.ac.uk](mailto:g.m.seymour@exeter.ac.uk), 01392 72662

Or the Research Ethics and Governance Mailbox [cgr-reg@exeter.ac.uk](mailto:cgr-reg@exeter.ac.uk)

**Thank you for your interest in this project**