# BHiRCH Better Health in Residents in Care Homes

# Information sheet & consent form for Residents

**IRAS ID: 2201211**

## Invitation to take part in a care home research project

We would like to invite you to take part in our research project which is taking place in your care home……. Before you say 'yes' or 'no' to taking part in the project, we would like you to know why the research is being done and what would happen if you were to take part.

<u>What is the research about?</u>

We want to try out a new way to improve health care in care homes. We want to ensure early detection and assessment of changes in residents' health. The care home where you live might try out this new way to improve health care in care homes. This may involve staff making a note of early signs of illness such as drowsiness or a change in your heart rate. If changes are noticed staff may investigate the problem further and, if appropriate, contact your GP.

Only half of the care homes that we're working with will try this new way of working. By providing training to half of the care homes we can see if the project improves the care that you receive.

What will taking part in the project involve?

You may be involved in the following activities:

- We will collect information from your care home records about how your health has been during the sixteen months of the project. This will include information about when you have seen the doctor or nurse, what medicines you are taking, and any medical tests that you have had.
- At a convenient time we will also complete a questionnaire with you about your quality of life, and ask some questions about your age and education. This will take about twenty minutes. We will ask you the same questions 3 times over 16 months to help us find out whether your health care has improved.

What if I can't make the decision?

If you are unable to decide for yourself if you would like to take part in the research project, we will ask someone who knows you to decide whether it would be in your best interests to take part in the project. We may also ask this person to tell us about how you have been.

Do I have to take part?

No you do not have to take part. Your participation in this project is completely up to you. If you do agree to take part you can refuse to

answer any questions that the researcher is asking. Just let us know. If you do not wish to participate, it will not affect your treatment or care in any way. If you do agree to take part you can withdraw from the project at any time without giving a reason.

## What are the potential benefits of taking part?

You will be helping to improve the care that care home residents receive in the future. You may enjoy speaking to the research team about your experiences.

## Are there any risks to taking part?

You may become tired when answering the questionnaires. If you do feel tired please let the researcher know and you can either take a break, or re-schedule for another time.

## Confidentiality and ID numbers

We will keep your personal information (name and date of birth) separate from other information we collect. We will use an ID number for any additional information we collect about you to ensure it cannot be linked to your name. You will not be identified in any reports or academic papers we write.

We will store all information securely. This will enable future researchers to continue to analyse the information we gather in this project. In the unlikely event that we discover serious issues of concern regarding your wellbeing, we will have to break patient confidentiality and inform the medical or social care authorities.

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

We will present the results of the research project at national and international meetings and write about them in academic journals. We will invite you to a feedback session where one of the research team will discuss the findings of the project. No individual will be identified in any publication or meeting.

## How can I be kept informed about the project?

We will provide project updates in a Newsletter. If you wish to receive this just ask one of the researchers.

## What will happen if I don't want to carry on with the project?

You can withdraw from the project at any time. This will not affect your care in any way. If you wish to withdraw from the project, we would use the information collected up to the time of your withdrawal unless you tell us that you want all information to be destroyed.

Will my General Practitioner/Family doctor (GP) be involved?

With your permission we will inform your doctor that you will be taking part. This is because your GP is responsible for your care and they must be kept up to date with any changes.

What if there is a problem?

If you wish to know more or are concerned about any aspect of this project, please speak to Dr Alan Blighe on (01274) 236284, email: a.blighe@bradford.ac.uk or Dr Catherine Powell on (01274) 236338, email: c.powell2@bradford.ac.uk. If you remain unhappy, or wish to make a complaint about the conduct of the project, you can contact Professor Murna Downs on (01274) 233991, email: m.downs@bradford.ac.uk.

University College London (UCL) holds insurance against claims from participants for harm caused by their participation in this project. Participants may be able to claim compensation if they can prove that UCL has been negligent.

Who is organising and funding the research?

The research project is funded by the National Institute of Health

Research and is sponsored by University College London.

## Who has reviewed and approved this project?

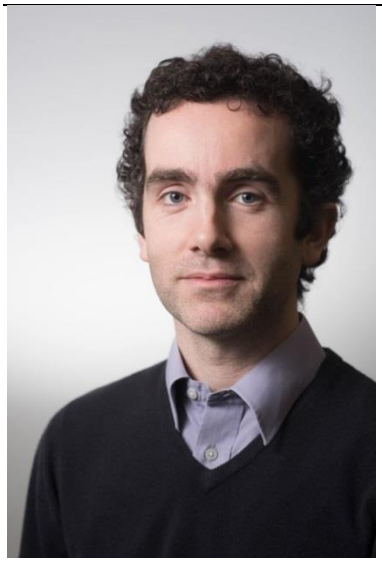
This research has been looked at by a group of people who are not involved in the project, called a Research Ethics Committee. These people are there to make sure you are kept safe and your rights are respected.

## What do I do now?

Thank you for taking the time to consider the project and for reading this information. If you do decide that you would like to take part you will be given this information sheet to keep and be asked to sign a consent form at the end of the document.

## Who do I contact for information or advice?

If you would like further information please ask a member of staff in your care home who will be able to put you in contact with someone who can help you. You can also contact:



Dr Alan Blighe

Room 4.04

Centre for Applied Dementia Studies

Faculty of Health Studies

University of Bradford

Horton A Building, Richmond Road, Bradford BD7 1DP

Tel: (01274) 236284

Email: a.blighe@bradford.ac.uk

Or

Dr Elizabeth Sampson

Marie Curie Palliative Care Research Department
Division of Psychiatry
University College London
6th Floor, Maple House, 149 Tottenham Court Road, London W1T 7NF

Tel: 020 7679 9730 (Internal 09730)

Email: e.sampson@ucl.ac.uk

If you would like to speak with someone not connected to the project please contact:

Professor Jan Oyebode

Centre for Applied Dementia Studies

Faculty of Health Studies

University of Bradford

Bradford BD7 1DP

Tel: 01274 236330

Email: J.Oyebode@bradford.ac.uk

Thank you for reading this information sheet.

## BHiRCH Better Health in Residents in Care Homes

Participant Identification Number for this trial:

**Consent form for Residents** **Please initial box**

1. I confirm that I have read the information sheet dated..... (version.....) for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.2. I understand that my involvement may include: ☐

- collection of information from my care home records about how my health has been during the sixteen months of the project, and
- completing a questionnaire about my quality of life 3 times over 16 months. This will be completed by myself, or by someone who knows me if I am unable to complete it for myself.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

4. I understand that relevant sections of my medical notes (information about medical tests, treatment, medication usage, and contact with GPs, consultants, etc.) and data collected during the project (questionnaires), may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these ☐

individuals to have access to my records.

5. I understand that information I give will be stored **with an ID number and not my name**. ☐

6. I agree to my General Practitioner being informed of my participation in the project. ☐

7. I would like to be kept informed of the progress of the project via the newsletter and to be invited to attend the feedback session at the end. ☐

8. I agree to take part in the above project.

| Name of Participant | Date | Signature |
|---|---|---|
| Name of Person taking consent | Date | Signature |