

### **Care Home Manager – Information Sheet**

# Care Home Activity Providers facilitating Public Involvement in research (CHAPPI)

#### Invitation

We would like to invite the care home that you manage to take part in the CHAPPI (**C**are **H**ome **A**ctivity **P**roviders facilitating **P**ublic **I**nvolvement in research) study. It is important to understand why the study is being undertaken and what it will involve. This leaflet explains how your home can participate and what this would mean for your home. Please read the following information carefully and discuss it with others if you wish. Contact us if you have any questions or would like more information before you decide.

Contact details for the research team can be found at the end of the leaflet.

#### Who is involved in this study?

The CHAPPI study is led by Dr Anne Killett at the University of East Anglia, with a team from the National Activity Providers' Association (NAPA), University of Hertfordshire, Auburn Mere Care Home, London Borough of Barnet, and Skills for Care.

#### What is the purpose of this study?

The CHAPPI study aims to understand how activity providers in care homes and researchers can work with care home residents to enable them to become involved in research as members of the public, and have their voices heard.

We know that lived experiences can influence research, making it more meaningful and relevant. However, public involvement in care home research rarely involves residents living in care homes. We have been working with the National Activity Providers' Association to change this. In previous projects activity providers ran public involvement activities with care home residents, using provider feedback and resident insight to inform research. We want to find out if this is positive for residents, care home staff and researchers.

We plan to use what we learn to produce a 'how to' guide for conducting research involvement activities with care home residents for activity providers and researchers to use in the future.



#### Who is funding the research?

The CHAPPI study is funded by the National Institute for Health and Care Research (NIHR).

#### Why has the care home I manage been invited to take part in the study?

Your care home has been invited because your activity provider has told NAPA they are interested to run public involvement activities.

#### Does my care home have to take part?

No, taking part is voluntary. Your care home does not have to take part if you do not wish for it to, and you do not need to give a reason.

#### What will happen if I agree for the care home that I manage to take part?

Firstly, public involvement sessions, lasting 30 minutes to an hour, would be run by your activity provider. These are designed by the CHAPPI team in discussion with your activity provider to present research studies to residents in a way that is meaningful and is suitable to the needs and preferences of the residents. Activities will use written words, pictures, videos and games to explain studies to residents and to help them to use their experience to influence the research.

A researcher from the study will be present in the home to observe some of the public involvement sessions. Observations will be made of people who consent to take part, which may be video recorded if consent is given by all participants. If consent to video is not given, we will write notes to remember what we have observed. (Residents could choose to take part in the public involvement activity and not to take part in the research about that activity.)

Following this, we will conduct 1:1 interviews, lasting between 5 and 30 minutes each, with the activity provider, residents (up to 10 people), relatives (up to 3 people) and care home staff (up to 3 people) who consent to take part, to hear their experiences and views about the public involvement sessions. During the interview we will ask them, for example, how it was to take part in the activity session and what they did or didn't like about it. If they agree we will make a voice recording of the interview. If they do not agree we will write notes. If they use signs to help communication, we will make a video recording of the conversation, if they agree. Only the research team will listen to or watch any recordings. All recordings will be destroyed at the end of the project



We will ask activity providers to have initial discussions with residents about participating in research. This will give us an idea of who might be interested in taking part. CHAPPI researchers will then talk to residents who have capacity and wish to take part to:

- Provide them with information about taking part.
- Answer any questions about taking part.
- Gain their consent to participate.

We will also need the home's help by sending information to the family members of residents without capacity to consent to take part, to invite them to act as personal consultees as set out in the section of the Mental Capacity Act (2005) section 32 about research.

For residents who do not have family or if the consultee does not respond within two weeks, a care home staff member may be better placed to provide advice about participation as a nominated consultee. If care home staff do not feel able to act as a nominated consultee we could identify an independent nominated consultee, such as a retired GP or admiral nurse. Consultees will be asked to sign a declaration form after giving their advice.

As a thank you at the end of the study, all study participants will be offered a shopping voucher to the value of £20.

#### What are the possible disadvantages or risks of taking part?

We do not think there are any big risks for residents or care homes who take part in the study. This study is **<u>not</u>** about judging or evaluating the care provided in your home. Residents may find taking part tiring, in which case they could take a break at any point. There is a small chance that some residents might find that the activity made them think about difficult topics (like hospitals). If at any time they found the conversation difficult or distressing we would invite them to stop.

## How will the identity of the home and residents taking part in this study be kept confidential?

All research information relating to residents and the home will be kept confidential in adherence with the Data Protection Act 2018 and GDPR. The only time we would break confidentiality is if we heard or saw something that indicated that someone was at risk of harm. We would report this to you as the registered manager. Personal information obtained during the study will be anonymised, and any information noted during observations, conversations or interviews will be pseudonymised to protect all participants and the care home. In writing



up the research, we will use only pseudonymised information and will take care to change any features of the participants which could be identifying.

All data will be stored in a secure platform, which is only accessible by the research team. The consent information (e.g. contact name and details) from your residents and their consultees as well as any audio or video recordings will be kept securely on the University of East Anglia servers and will be deleted within 12 months of the end of the study. Paper copies of the consent forms will be stored securely at the University of East Anglia offices in locked filing cabinets and shredded within 12 months of the end of the study.

No resident medical or care information will be requested during the study.

#### What will happen if I withdraw the care home that I manage from the study?

If you wish to withdraw the care home from the study, we will keep and continue to use all information previously collected during observations, conversations and interviews. We will, however, not collect any further information. You can withdraw by contacting Anne Killett or Megan Davies (details below).

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

We will analyse all information collected during observations, conversations and interviews and share the findings by:

- Writing a report for the funder of this research.
- Publishing the findings in academic journals.
- Presenting the results at conferences and commissioner and provider events.
- Sharing summaries of the results with the care homes, staff and residents that took part in the research.
- Trying to raise awareness of the results using social media and linking with local organisations.

The information collected will also form the 'how to' guide for future research involvement activities with care home residents, aimed at researchers and activity providers.

#### Who has reviewed the study?

This study has been reviewed by Newcastle & North Tyneside 2 Ethics Committee (reference number 23/NE/0141).



#### How do I contact the researchers?

You can contact us directly:

Dr Anne Killett, <u>a.killett@uea.ac.uk</u>, 01603 593319, Dr Megan Davies, m.davies2@uea.ac.uk





If you have a concern about any aspect of this study, please to speak to Anne Killett or Megan Davies, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Kenda Crozier, who is the Dean of the School of Health Sciences at the University of East Anglia and independent from the CHAPPI study. Contact Details can be found below.

Professor Kenda Crozier Email: K.Crozier@uea.ac.uk Tel: 01603 597094

Thank you very much for reading this information and considering whether to take part in this study.