



## **Personal Consultee information sheet**

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

#### **Invitation**

We would like to invite you to act as a personal consultee for your friend/relative to take part in the CHAPPI (**Care Home Activity Providers facilitating Public Involvement in research**) study. It is important to understand what being a 'personal consultee' would involve. It is also important to understand why the study is being undertaken and what it will involve for the person you are advising on behalf of. 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 does it mean to be a personal consultee?**

The Mental Capacity Act requires us by law to seek the advice of an appropriate personal consultee on occasions like this, as your friend/relative does not show the capacity to consent for themselves to take part in this research. Usually, this is a close family member or friend. You have been asked as the care home the person lives in suggested you would be the best person to fulfil this role.

We are asking you for advice: *In your opinion, would your friend/relative want to take part in the research if they could decide for themselves?* Please be guided by what you know about the person and ensure that the advice you give does not contradict



any advanced decisions the person may have made regarding research participation. Try to also think about the risks and benefits of them taking part.

If you do not wish to act as a personal consultee there is no obligation to do so. Please let the researcher know that you would prefer not to take this role.

### **What is the purpose of the 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).

### **Do they have to take part?**

No, taking part is voluntary and it is up to you to advise on whether your friend/relative would want to take part. You do not need to give a reason if you decide they would not want to take part.

If with your advice they took part, then at any point your friend/relative seemed unhappy or distressed about taking part we would stop their participation.



### **What will happen if they take part?**

We will observe public involvement activities lasting from 30 minutes to an hour, run by activity providers. We will look for signs that your friend/relative joins in with the activities. If you, and all those taking part agree, we will video record activity sessions. Using communication appropriate for your friend/relative we will encourage them to tell us about their experience, asking questions such as “what did you like/dislike about the activity”. Conversations with them will take between 5 and 30 minutes. With your consent, we would like to audio record conversations. If you prefer that we do not video or audio record activities or conversations, we will make notes throughout so that we clearly remember what we have seen and heard.

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

We do not think there are any big risks for residents who take part in the study. Your friend/relative may find it tiring to talk to us, in which case we would take a break. Your friend/relative may find the activity makes them think about difficult topics (like hospitals). If at any time they find the conversation difficult or distressing we will ask if they would like to end the conversation.

### **How will their taking part in the study be kept confidential?**

All information related to the person you are advising on behalf of and you as a result of this research will be kept confidential. The only time we would break confidentiality is if someone discloses that a resident or staff member is at risk of harm. We would then need to report this to the appropriate person or authority.

All information will be stored in a secure platform, which is only accessible by the research team. The consent information (e.g. contact name and details) and any recordings made 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. We will follow the Data Protection Act 2018 and GDPR.



### **What will happen if I don't want the person to carry on with the study after I have agreed for them to take part?**

If you decide that you would like your friend/relative to withdraw from the study, we will keep and continue to use all of their previously collected data. We will, however not collect any further data about them. This will not affect their care in any way. You can withdraw them by contacting Anne Killeth or Megan Davies at any time without giving a reason.

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

We will analyse the information from the study and share the findings with others to increase knowledge, share learning and have an impact on policy and practice. We will do this 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 Research Ethics Committee (reference number 23/NE/0141).



## How do I contact the researchers?

You can contact us directly:



Dr Anne Killett, [a.killett@uea.ac.uk](mailto:a.killett@uea.ac.uk), 01603 593319.



Dr Megan Davies [m.davies@uea.ac.uk](mailto:m.davies@uea.ac.uk)

**If you have a concern about any aspect of this study, you should ask 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](mailto:K.Crozier@uea.ac.uk)

*Tel:* [01603 597094](tel:01603597094)

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