**COPD and Assistive technology**

**Study title:** Understanding the potential of assistive technology (AT) in people with chronic obstructive pulmonary disease (COPD) to support independence and wellbeing: A qualitative study

**Research Ethics Committee Ref:** **23/LO/0660**

Participant information sheet (Carer)

You are invited to take part in the COPD and Assistive technology research study. Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**1. What is the purpose of the study?**

Assistive technology is devices or equipment that that helps people with disability or those who have difficulty in carrying out daily routine activities. People with chronic obstructive pulmonary disease (COPD) can have difficulty in performing routine activities such as cooking or cleaning or walking up the stairs due to shortness of breath, cough, or tiredness.

Assistive technology is wide-ranging from personal alarms to home adaptations like stairlifts and includes digital technology like Alexa.

This type of technology can help people to carry out daily routine activities more easily and safely in their home and surroundings.

But there is not enough information on how assistive technology can help people with COPD and in what way.

We would like to hear your views and experiences on this topic in an interview with the study researcher (Farhin)

Aim: To support independence and wellbeing

* Find out what works best
* How we can assist in improving life for COPD patients and their carer
* Explore any challenges

**2. Why have I been invited to take part?**

You have been invited through your local GP practice, hospital, community clinic or social care organisation / or you have responded to the study advert on social media or via your health or social care, community, or voluntary organisation because you are a family member or friend providing help and support to a person with COPD at home and are from White, Black, Indian, Pakistani, or Bangladeshi ethnic group. You may be supporting or have supported your family member or friend with COPD with assistive technology.

**3. What are the benefits to taking part?**

There might be no direct benefits to you taking part in the study, but we hope you may find it helpful to share your experience and get your voice heard. Your contribution could help to improve and create opportunities to access assistive technology as per the needs of *carers of people with COPD* that is timely, appropriate, and suitable to them.

**4. What are the risks or disadvantages of taking part?**

It is unlikely that you will find taking part in the study difficult, but if you do become distressed, we will offer to support you by contacting your GP or healthcare professional with your permission so that you receive the care you may need.

If we are concerned about you or someone else experiencing abuse or neglect, we may need to follow the University safeguarding policy and report our concerns to your local authority.

.

**5. What will happen if I am interested** **to take part in the study?**

If you express an interest in taking part in the study, Farhin will ask you a few demographic questions, preferred spoken language, and about any experience you may have had with assistive technology.

We are looking to speak to about 10 carers in total of different age-groups, gender, ethnicity, living circumstances, having other medical conditions. Of those that take part in the interview, we will invite3-4 carers to take part in a one-off photography activity.

If you are selected, you will have the opportunity to ask any further questions about the study before deciding whether you would like to take part in the interview or take part in the interview and the photography activity.

**6. What will happen if I take part?**

The researcher will take your written or verbal permission before the start of the interview and the photography activity.

**If you decide to take part in the interview,** the researcher will arrange a date and time that is convenient to you. The interview will take place at your preferred location, and this could be by telephone or online (via MS teams or zoom) or face-to-face (e.g., in your home or in a meeting room at the university and following COVID-19 related guidance). We will arrange your travel if required.

The interview will last up to one hour and will be audio-recorded. You will be able to take a rest or a break at any time if you need to. The recording will be typed up in full either by a study team member or by a confidential third-party transcription service contracted to work on the study. The secure transfer of the recording and the typed document between the study team and the transcription service will be done by secure email transfer or by using the Royal Mail Signed for Special Delivery Service. The recording or the typed document will not be heard or seen by anyone other than the study team and the study transcriber and will be kept securely. You may listen to the recording or read the document if you wish to do so.

**If you decide to take part in the photography activity,** Farhinwithin three months of the interview will re-confirm your interest to take part in the photography activity. If yes, they will provide you with a camera and they will ask you to take photos related to your experience of assistive technology. These may be photos of for example of different technology you may have, use, or not use, how the technology helps or not. You will then be invited to share these photos with Farhin only or with three other people who also live with COPD or care for someone with COPD. This is called ‘Photovoice.’ During this discussion, we will invite you to talk about the photos and what they meant to you.

Like the interview, the same process will apply to the audio-recording of the discussion with the pictures. If you take part in the small group discussion, confidentiality will be expected but may not be guaranteed. The pictures will not have any personal details and will only be seen by the study team. We will ask for your permission to use the pictures for public display or for future research and educational purposes.

As a thank you for your time and contribution to the study, we will offer you a £30 love2shop voucher for taking part in the interview and a £30 love2shop voucher for taking part in the photography activity.

The study duration is 15months. If you want to hear about the study's progress, we will provide updates by post or email as per your preference.

**7. Do I have to take part in the study?**

No. It is entirely up to you if you want to take part. If you decide to take part, please inform the study researcher. You are free to withdraw from the study at any time and without giving a reason and this will not affect any of your rights. If you decide to withdraw after the interview or after the photography activity, the study sponsor (Queen Mary University of London) will retain any information about you that has already been provided in the anonymised form. The information collected from you in the interviews and the discussion following the photovoice activity will not have your name or contact details. Any personal contact details will not be retained and will be deleted.

Please be aware that if you are taking part in research, or information about you is used for research, your rights to access, change or move information about you are limited under the UK General Data Protection Regulation. <https://www.hra.nhs.uk/information-about-patients> https://understandingpatientdata.org.uk/introducing-patient-data

**8. How will we use information about you?**

We will need to use information from you for this research project. This information will include your contact details held by the study team to arrange the interview and photography activity**.**

People who do not need to know who you are will not be able to see your name or contact details. Your data will be identified by a mix of letters and numbers such as C01 where C denotes carer. We will keep all information about you safe and secure.

Once we have finished the study, we will keep the data to write the study results and study reports, and this will include use of direct quotations. We also plan to produce various outputs in the form of study summary report for you, presentations (or short videos or blogs or in conferences) and journal publications in a way that no-one can work out that you took part in the study.

The information collected may be used to support other research in the future and if so, the information will be shared in anonymised form with other researchers.

The data collected during the study, may be looked at by individuals from Queen Mary University of London or regulatory authorities where it is relevant to your taking part in this research. We will ask your permission for these individuals to have access to your records.

**9. What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep the information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means we cannot let you change the data we hold about you.

You can find out more about how we use your information by sending an email to [ratna.sohanpal@nhs.net], by ringing us on [07940422954] or by sending email to the QMUL (Queen Mary University of London) data protection team: [data-protection@qmul.ac.uk](mailto:data-protection@qmul.ac.uk)

**10. When and how long will my information be stored for?**

The recording will be destroyed at the end of the study (30 September 2024) and the typed document, and the pictures will be kept securely at Queen Mary University of London for 5 years in anonymised form in line with the study sponsor regulations and guidance.

**11. Who has reviewed the study?**

This study has been reviewed by an independent NHS research ethics committee and approved by Research Ethics Committee. The reference number is 23/LO/0660.

**12. What should I do if I have any concerns about this study?**

Queen Mary University of London has insurance to protect research study participants. Your wellbeing will always be our priority. We believe that this study is safe and do not expect you to suffer any harm or injury because of your participation. However, Queen Mary University of London has agreed that if you are harmed because of your participation in the study, you will be compensated. In such a situation, you will not have to prove that the harm or injury which affects you is anyone’s fault. These special compensation arrangements apply where harm is caused to you that would not have occurred if you had not taken part in the study. These arrangements do not affect your rights to pursue a claim through legal action. You can ask more questions about this to us.

For independent advice and support, you can contact the NHS Patient Advice and Liaison Service:

The Royal London & Mile End Hospitals - 0203 594 2040 RLHpals.bartshealth@nhs.net

Whipps Cross Hospital - 0208 535 6438 WXpals.bartshealth@nhs.net

Newham University Hospital - 0207 363 9292 nuhpals.bartshealth@nhs.net

St Bartholomew's Hospital - 0203 465 5919 SBHpals.bartshealth@nhs.net

For any data concerns, please contact the QMUL data protection team: data-protection@qmul.ac.uk

For any concerns about the conduct of interview or photographic activity, you can speak to another member of the research team:

Professor Stephanie Taylor,

Centre for Primary Care

Queen Mary University of London

58 Turner Street

London, E1 2AB

s.j.c.taylor@qmul.ac.uk

**13. Who can I contact if I have any questions about this study?**

You can contact:

|  |  |
| --- | --- |
| **Study Lead** | **Study Researcher** |
| Dr Ratna Sohanpal  [ratna.sohanpal@nhs.net](mailto:ratna.sohanpal@nhs.net)  07940422954  Centre for Primary Care, Queen Mary University of London, 58 Turner Street, London, E1 2AB | Farhin Ahmed  [farhin.ahmed@qmul.ac.uk](mailto:farhin.ahmed@qmul.ac.uk)  07940422954  Centre for Primary Care, Queen Mary University of London, 58 Turner Street, London, E1 2AB |

**Thank you for taking the time to read this information.**