**INCLUSIVE REMOTE CARE**

**Study title:** Identifying the best ways to deliver health care for people from ethnic minority groups living with chronic obstructive pulmonary disease (COPD) and other health conditions.

**Research Ethics Committee Reference: 23/EE/0149**

Participant information sheet (Patient/Carer)

You are invited to take part in the INLCUSIVE REMOTE CARE 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?**

Health care is being offered more routinely by telephone, smartphone, apps, video link or online platforms (remote care delivery). It is important to find out whether remote delivery of care is acceptable and suitable for the care of people with chronic obstructive pulmonary disease (COPD) who have one or more other long-term conditions.



We would like to hear your views and experiences on this topic in an interview with the study researcher. The discussion will be to find out about the offer of care by remote delivery and support offered, reasons for taking it up or not and understand what worked well, what the challenges were and how experience of health care could be improved.

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

You have responded to the study advert on social media or via your local community, voluntary organization because you are a family member or friend providing help and support to a person with COPD at home from Indian, Pakistani, Bangladeshi, Black African, Black Caribbean or Other Black groups, Other minority groups e.g. Turkish, Romanian, Polish or from mixed ethnic groups.

**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 health care by remote delivery as per the needs of people with COPD, carers of people with COPD that is appropriate, suitable, and acceptable to them.

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

We do not foresee any risks if you decide to take part in the study.

**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, the researcher will ask you a few demographic questions, preferred spoken language, and about offer of remote care, type of remote care taken up or not.

We are looking to speak to about 15 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 invite 3-4 carers to take part in a 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 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,** the researcher within 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 pictures of your experience of receiving care remotely. These may be pictures of for example where you sit to have your remote consultation, what equipment you use to carry out the consultation, preparing for a remote consultation. You will then be invited to share these pictures with the researcher 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 why you took these pictures and what they meant to you.

Like the interview, the same measures will apply to the audio-recording of the discussion with the pictures. 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 education purposes.

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

The study duration is 14months. If you would like to hear about the progress of the study, 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 have a code number instead. 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 information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we will not be able to 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 [079 39 29 6667] or by sending email to the QMUL data protection team: 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 (31 May 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 the East of England - Cambridge Central Research Ethics Committee. Reference number. The reference number is 23/EE/0149.

**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

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

You can contact:

Dr Ratna Sohanpal

Centre for Primary Care

Queen Mary University of London

58 Turner Street

London, E1 2AB

ratna.sohanpal@nhs.net

r.sohanpal@qmul.ac.uk

079 3929 6667

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