Address of host organisation and NHS clinic/GP practice (where appropriate)

**REMO CARE**

**Study title: Exploring the potential opportunities & challenges in REMOte CARE for COPD**

**Research Ethics Committee Ref:** **22/EM/0061**

Participant information sheet (Patient/Carer)

You are invited to take part in the REMO 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?**

Healthcare has shifted to remote delivery (via websites, video link, smartphone, telephone) and some are predicting that remote consultations will continue even after the pandemic. As restrictions are gradually being eased it is timely to consider whether remote consulting is acceptable, and appropriate for the care of patients with chronic obstructive pulmonary disease (COPD) who often also have other conditions.

We would like to hear your views, opinions and insights on this topic. In a one-off interview with the study researcher, the discussion will be to find out about the offer of care by remote delivery, reasons for taking it up or not and understand what worked well, what the challenges were and how experience of care could be improved.

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

You have been invited through your local GP practice, hospital or community clinic because you are living with a long-term lung condition (also known as chronic obstructive pulmonary disease (COPD)) or *you might be a family member or friend caring for a person living with a long-term lung condition.*

**3. What are the possible benefits of taking part?**

There might be no direct benefits to you taking part in the study but your contribution could help to improve and create opportunities to access care remotely according to the needs and preferences of people with COPD and in a way 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 joining the study, Ratna will ask you a few demographic questions and about offer of remote care, type of remote care taken up. We are looking to speak to about 15 patients in total of different age-groups, gender, living circumstances, being on oxygen, having other medical conditions. *We are looking to speak to 6-8 family member or friend caring for patients who take part in the study.* If you are selected, you will have the opportunity to ask any further questions about the study before deciding whether or not you would like to take part.

**6. What will happen if I decide to take part in the study?**

If you decide to take part, Ratna will suggest some dates and time and arrange a date and time that is convenient to you for the interview. 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). Ratna will arrange your travel if necessary.

Ratna will take your written permission before the start of the interview. It 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.

As a thank you for your time and contribution to the study, we will offer you a £30 voucher.

The study duration is of one year. 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 up to you to decide whether you wish to take part. If you decide to take part, please inform Ratna. 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, the study sponsor (Queen Mary University of London) will retain any information about you that has already been provided in the anonymised form (you will not be identifiable in any way). 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>

**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**.**

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. 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 from this interview 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 won’t 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 (30 Sep 2022) and the typed document 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. 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 as a result 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.

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

You can contact:

Dr Ratna Sohanpal

Centre for Primary Care, Wolfson Institute of Population Health

Queen Mary University of London

Yvonne Carter Building

58 Turner Street

London, E1 2AB

ratna.sohanpal@nhs.net

r.sohanpal@qmul.ac.uk

079 39 29 6667

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