**Full title: COVID Oximetry @home (CO@h): A rapid patient experience study**

**Short title: CO@h patient experience**

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**Protocol version number and date:** Version 1 (15th December 2020)

**R&D / Sponsor Reference Number(s): EDGE ID: 138343**

**Study Registration Number: EDGE ID: 138343**

## PROTOCOL VERSIONS

| Version Stage | Versions No | Version Date | Protocol updated & finalised by; | Appendix No detail the reason(s) for the protocol update |
|---|---|---|---|---|
| Current | Version 1.2 | 10/02/2021 | Dr Holly Walton (Research fellow) | Addressing REC feedback |
| Previous | Version 1.1 | 29012021 | Dr Holly Walton (Research fellow) | N/A |
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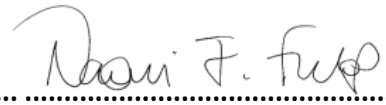
## DECLARATIONS

The undersigned confirm that the following protocol has been agreed and accepted and that the investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the Research Governance Framework 2005 (as amended thereafter), the Trust Data & Information policy, Sponsor and other relevant SOPs and applicable Trust policies and legal frameworks.

I (investigator) agree to ensure that the confidential information contained in this document will not be used for any other purposes other than the evaluation or conduct of the clinical investigation without the prior written consent of the Sponsor.

I (investigator) also confirm that an honest accurate and transparent account of the study will be given; and that any deviations from the study as planned in this protocol will be explained and reported accordingly.

**Chief Investigator:**

**Signature:**.....  **Date 29/01/2021**

**Print Name(in full):**.....**NAOMI J FULOP**.....

**Position: Professor of Health Care Organisation & Management**

**On behalf of the Study Sponsor:**

**Signature:**  **Date 29/01/2021**

**Print Name(in full): Pushpsen Joshi**

**Position: Research Governance Manager**

## STUDY SUMMARY

| **Identifiers** | |
|---|---|
| IRAS Number | 294011 |
| REC Reference No | **21/HRA/0155** |
| Sponsor Reference No | 138343 |
| Other research reference number(s) (if applicable) | |
| | |
| Full (Scientific) title | COVID Oximetry @home (CO@h): A rapid patient experience study |
| Health condition(s) or problem(s) studied | COVID-19 |
| Study Type i.e. Cohort etc | Mixed methods study comprising a national survey and interviews with patients and carers from selected case study sites. |
| Target sample size | • Interviews – 72 patients / carers (6 patients or carers from each of the 14 NHS sites)<br>• survey (not yet known – as many responses from as many patients in as many sites as possible) |
| | |
| **STUDY TIMELINES** | |
| Study Duration/length | 5 months |
| Expected Start Date | January 2021 |
| End of Study definition and anticipated date | June 2021 |
| Key Study milestones | • *Study design*: September/November 2020<br>• *Data collection for national study of patient experience begins*: January 2021<br>• *Data collection for in-depth case studies of patient experience begins*: February 2021<br>• *Sharing emerging findings, including interim quantitative findings*: February/March 2021<br>• *Data collection for patient experience study ends*: May 2021<br>• *Submission of final report*: June 2021 |
| **FUNDING & Other** | |
| Funding | This project was funded by the National Institute for Health Research, Health Services & Delivery Research programme (RSET Project no. 16/138/17; BRACE Project no. 16/138/31). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR, NIHR, NHS or the Department of Health and Social Care |
| Other support | |
| **STORAGE of SAMPLES (if applicable)** | |

| | |
|---|---|
| Human tissue samples | N/A |
| Data collected / Storage | N/A |
| **KEY STUDY CONTACTS** | |
| Chief Investigator | Professor Naomi Fulop,<br>Professor of Healthcare organisation and management<br>UCL Department of Applied Health Research<br>n.fulop@ucl.ac.uk |

## KEY WORDS

Rapid, remote monitoring, patients, qualitative, survey, experience, engagement, COVID-19

## LIST OF ABBREVIATIONS

BRACE – Birmingham, RAND and Cambridge Evaluation Team
CO@H – Covid Oximetry @ home
GDPR – General Data Protection Regulation
HRA – Health Research Authority
HS&DR – Health Services and Delivery Research
ICU – Intensive care unit
MS – Microsoft
NASSS - non-adoption, abandonment, and challenges to the scale-up, spread, and sustainability
NHS – National Health Service
NHS – NHS England
NIHR – National Institute for Health Research
PALS – Patient advice and liaison service
RAP – Rapid Assessment Procedures
RSET – Rapid Service Evaluation Team
SMS – Short Message Service
UCL – University College London
UK – United Kingdom
US – United States

## CONTENTS

# 1 INTRODUCTION

During the first wave of the COVID-19 pandemic, some patients were not admitted to hospital until they were displaying advanced symptoms of COVID-19. These patients may then have received invasive treatments and/or been admitted to intensive care. Monitoring patients at home may help to reduce these delays and identify patients earlier. In the UK, a healthcare service called COVID Oximetry @home has been nationally rolled out by NHS England and Improvement. Some services implemented COVID Oximetry@home (also known as virtual wards) during the 1st wave of the pandemic in England (Vindrola-Padros et al. 2020a). Within this service, patients are given an oximeter and asked to record their oxygen levels regularly either digitally or using paper-based diaries. Patients are monitored and sent for further care if problems arise.

This research aims to explore patient experiences of receiving and engaging with the COVID care at home.

To understand how patients and staff have experienced COVID care at home, we will do two things.

a) First, we will conduct a national survey with patients and carers in as many NHS trusts across the country as possible. The surveys will explore patient experiences of receiving and engaging with COVID care at home. We will analyse this data using descriptive statistics (e.g. percentages).

b) Secondly, we will complete further data collection in 14 purposively selected NHS case study sites. We will speak with patients who have received COVID care at home, or who have withdrew from receiving care or declined care. These interviews will help us to find out more about how people experienced receiving COVID care at home and the things that help or get in the way.

This research is important as it will help us to find out if healthcare services that require patients to monitor at home are effective, affordable, suitable and practical for both patients and healthcare professionals.

# 2 BACKGROUND AND RATIONALE

Delays in the escalation and admission of patient cases during the COVID-19 pandemic has led to the admittance of patients with advanced course of the disease, requiring invasive treatment and potential admission to ICU. Research suggests that delays in admission increases patient mortality (Alaa et al, 2020). Remote home monitoring models (sometimes referred to as 'virtual wards') seek to remotely monitor patients considered high-risk of deterioration at home to: 1) avoid unnecessary hospital admissions (appropriate care at the appropriate place), and 2) escalate cases of deterioration at an earlier stage to avoid invasive ventilation and ICU admission. Remote home monitoring models have been implemented in the US, Australia, Greece and UK, with some variation in the frequency of patient monitoring, modality (telephone or video calls and use of applications or online portals), patient criteria and use of pulse oximetry (Margolius et al. 2020; Karampela et al. 2020; Thornton 2020; Hutchings et al. 2020; Kricke et al. 2020; Annis et al. 2020; O'Keefe et al. 2020; Ford et al. 2020; Nunan et al, 2020). There is emerging evidence that community oxygen saturation predicts outcomes, including mortality and ICU admission (Inada-Kim et al, 2020).

In the UK, several remote home monitoring models have been documented with the aim outlined above (this does not include models operating as a step-down service following hospital inpatient stay). These models have mainly involved the following processes: 1) patient triage through 111, GP

practice, hot hub (or emergency department (ED) for those in secondary care), 2) patient provided with pulse oximeter, patient information (including escalation warning signs and what to do) and mechanism for recording observations regularly (app or paper diary) (potential observations being symptoms, pulse, heart rate, temperature, O2), 3) patient receives regular monitoring calls from staff (either primary or secondary care depending on model). Symptoms and trends of O2 saturations are monitored. Modality/frequency of surveillance at clinician discretion. Calls are used to identify cases of deterioration and inform patient of next steps, and 4) Patients expected to 'check out' around 14 days mark (when recovery expected) - follow up to check symptoms and have oximeter and diary returned. Some services implemented COVID Oximetry@home (also known as virtual wards) during the 1st wave of the pandemic in England (Vindrola-Padros et al. 2020a; Clarke et al, 2020).

The national roll out of remote home monitoring models was launched by NHS England in November 2020 to support the development and implementation of these models of care, including the purchase and distribution of pulse oximeters which clinical commissioning groups across England will be able to access. To date, many sites have been set up across England across primary and secondary care. Despite previous research on the use of remote home monitoring models for other conditions, there is a lack of studies on the impact (effectiveness) and implementation of remote home monitoring models for COVID-19 patients, including in-depth analyses of patients' and staff's experiences of receiving and delivering care. This mixed-methods evaluation of remote home monitoring models in England will seek to address this gap by exploring patient experiences of remote home monitoring. The study will have a particular focus on inclusivity of these services and potential impact on inequalities.

# 3 OBJECTIVES

## 3.1 Aim

The aim of this study is to explore the experiences and behaviours (i.e. engagement with COVID care at home, use of other services) of patients and carers who have received the COVID care at home service.

## 3.2 Research questions

1. What are the experiences and behaviours (i.e. engagement with COVID care at home, use of other services) of patients in COVID care at home?
2. Do these experiences and behaviours vary by type of model, patient characteristics, mode of remote monitoring?

By behaviours, we refer to the behaviours and actions that participants need to do as part of the COVID care at home service. During the survey and interviews we will explore several relevant behaviours, including: engagement with the service (e.g. do participants understand and are they able to use the service?), using the oximeter, recording their readings, providing readings to healthcare professionals/members of the CO@H team, self-escalating care (seeking further healthcare) when necessary and use of other services.

When we refer to 'type of model', we are referring to the different ways in which COVID care at homemodels may be set up and delivered. For example, some models are pre-hospital models (community referrals/emergency department referrals) and others are hospital early discharge models (e.g. referral onto the COVID care at home pathway after being discharged from hospital).

By 'mode of remote monitoring', we refer to the different ways in which patients can be asked to record their readings (e.g. through a paper diary or through a digital solution such as a mobile application).

# 4 STUDY DESIGN

This is a multi-site study that will combine qualitative and quantitative approaches to analyse patients' experiences of receiving and engaging with COVID care at home. The design of this evaluation was informed by the findings from phase 1 (evaluation of remote home monitoring for Covid-19 patients during the first wave of the pandemic in England (Vindrola-Padros et al. 2020a) a systematic review (Vindrola-Padros et al. 2020b, discussions with the project clinical advisory group, sites running or planning to implement remote monitoring, and with evaluation partners in relation to their proposed studies.

**In addition to this research project of patient experience, we are also conducting a separate service evaluation to explore effectiveness, cost-effectiveness, implementation and staff experiences of delivering COVID Oximetry @home. This work is described in a separate protocol that has been deemed to be a service evaluation (using the HRA checklist and agreement with the Joint Research Office).**

**METHODS**

The evaluation comprises the two workstreams outlined below.

***WORKSTREAM 1: NATIONAL STUDY OF PATIENT EXPERIENCE***

The aim of this workstream is to analyse patient experiences of care in sites across the country.

**Patient/carer survey**

*Design, data collection and sampling*

We will conduct a national survey of patients and carers. The aim of the survey will be to capture the experiences of patients who received COVID care at home, patients who refused COVID care at home and patients who disengaged with COVID care at home, and their engagement with the COVID care at home service. If patients are not able/willing to take part in the survey, they will be able to allow their carer (such as family member or friend) to complete the survey on their behalf, reflecting on the patient's experience with the service. The survey will be sent to patients who have received care at participating sites by NHS staff. The survey will include a number of closed questions focused on: socio-demographic characteristics, the service that patients have received, their experience with the service and their engagement with the service (See Appendix 2). These questions will be followed by a single open text question at the end to give participants the opportunity to share any wider thoughts. To reduce burden and maximise response rates, the online survey will take between 15 and 30 minutes to complete. Case study sites will be asked to keep record of the number of surveys they have sent out to determine patient response rates. It will be delivered using the online platform REDCap. We will aim to pilot the survey via a small number of sites with some patients/carers who have received COVID care at home to determine whether questions are appropriate and relevant, while identifying areas for further refinement prior to circulation nationally. NHS case study sites will circulate the

surveys to patients, patients will then return completed surveys directly to the study team for analysis, either electronically through REDCap or via post using pre-paid envelopes.

*Data analysis*

The quantitative survey data will be analysed using statistical software. Descriptive statistics will be used and depending on the number of responses received, we will use univariate analyses to compare patient experiences of the service across patient groups and service models (as reported by patients and carers). We will offer to carry out site-specific analyses of patient experience data for sites that request this information.

***WORKSTREAM 2: IN-DEPTH CASE STUDIES OF PATIENT EXPERIENCE***

The aim of this workstream will be to explore patient experiences of care in a sample of 14 sites. This workstream will provide a more in-depth exploration of patient experience, capturing the experiences and behaviours (i.e. engagement with COVID care at home, use of other services, knowledge of escalation processes, safety-netting, etc.) of patients who received the COVID care at home service, and where possible, include those who withdrew from the service and those who were offered the service, but declined participation. It will draw out potential implications for these models of care for patients with conditions other than COVID-19. Patient interview guides will be piloted with a small number of sites to determine whether questions are appropriate and relevant to research questions and their experience of engaging with patients while delivering COVID care at home, and identifying areas for further refinement prior to circulation nationally. The interviews will be semi-structured, audio recorded (subject to consent being given), transcribed verbatim by a professional transcription service, anonymised and kept in compliance with the General Data Protection Regulation (GDPR) 2018 and Data Protection Act 2018.

**Patient/carer and Carer Interviews**

*Data collection*

We will conduct interviews with patients and carers who have been offered and/or received COVID care at home The interviews with patients and carers will focus on documenting their journeys of remote home monitoring, their experiences of being ill and monitored at home, experiences with escalation and discharge, their engagement with the service, and recommendations for improving these models (see Appendix 3).

If patients are not able/willing to take part in the interview, we will ask patients if we can approach their carer (if they have one) to capture their perceptions of the patient's journey and overall experience with the service. During the interview, we will ask patients/carers some brief questions relating to socio-demographic characteristics including whether they are a patient or carer, age, gender, ethnicity, how many people they live with, education and qualifications, employment status, English as a first language, disability and postcode (the latter to be used as indicator of social deprivation). We will emphasise that as with all parts of the interview, these questions are optional. In addition, we will also ask some of the patients who have used digital solutions to narrate the process of using the technology (think aloud methodology).

We anticipate that interviews will last between 30-60 minutes, but may take longer than this depending on how much participants have to say.

*Interview sampling*

The semi-structured interviews with patients will also follow a purposive sampling approach. Patients will be sampled in relation to their age, gender, ethnicity, deprivation score (by postcode), employment status, comorbidities, mechanism for onboarding, type of monitoring approach, remote length of stay, and outcome (including those who withdrew from the 'virtual ward' and those who were escalated) in order to be inclusive and capture as wide a range of responses as possible. These same patient characteristics will be taken into consideration when developing the sampling for the carers. If possible, we will also seek to include patients who refused to receive care through a virtual ward and patients who dropped out (and their carers if patients are not able/willing to take part).

We will purposively select and sample patients and families from 14 pilot sites. At each site we will aim to recruit up to six interviewees (four who have accepted receipt of the COVID care at home service and two who refused to receive COVID care at home or have withdrawn). This sampling strategy will ensure that we hear from a range of patients who have and have not engaged with COVID care at home.

*Data analysis for the interviews*

Data collection and analysis will be carried out in parallel and facilitated through the use of Rapid Assessment Procedures (RAP) sheets as explained in Vindrola-Padros et al. (2020c). RAP sheets will be developed per site to facilitate cross-case comparisons and per population (to make comparisons between sub-groups). The categories used in the RAP sheets will be based on the questions included in the interview topic guide, maintaining flexibility to add categories as the study is ongoing.

**Integration of findings across all workstreams**

The RAP sheets mentioned above will be developed at site level (1 per research site) and at population level (including sub-groups of patients) for the 14 sites involved in workstream 2. Data from both workstreams (and the separate service evaluation) will be added to these to facilitate processes of triangulation. Findings on local barriers and facilitators to patient experiences will aid the interpretation of findings from our service evaluation on outcomes, service use and costs. Quantitative data on resource allocation will be understood in relation to qualitative data on staff experiences of planning and delivering services. Data from the case studies will be used to explain the survey findings (representing experiences and trends at a national scale). In addition, emerging findings from this study will be discussed in relation to those from the two other evaluation partners (Imperial and IAU).

**THEORETICAL LENS**

We will analyse remote home monitoring models in the social and political context where these are designed and implemented (including the clinic and home), the multiple realities, assumptions and values that play a role in their implementation, the organisational structures that shape experiences of receiving and delivering care and the sociopolitical issues that frame the development, diffusion and use of technology (Leheoux and Blume 2000). This lens goes beyond an analysis of remote home monitoring solely as a technological innovation to consider dimensions such as: self-management,

accountability and clinical responsibility, 'personalised care', inequalities in access to care and 'caring at a distance' (Greenhalgh et al. 2015, 2017; Powell et al. 2010).

Furthermore, Greenhalgh et al. (2017) provide an example of a suitable framework with a socio-technical lens that incorporates non-adoption, abandonment, and challenges to the scale-up, spread, and sustainability (NASSS) of technologies for health and social care. This includes expected and necessary changes/adaptation to staff working practices and the context for widespread use of the technology. This framework (informed by theory and evidence) describes the barriers to successful uptake of innovations and provides a guide to the type of issues that should be considered by evaluators (Greenhalgh et al., 2017).

We will use these frameworks as a sensitising device, to inform the development of questions in the surveys and interviews, and to help in the interpretation of findings.

# 5 STUDY SCHEDULE

This study will take place between November 2020 and August 2021 (see Figure 1).

- *Study design*: September/November 2020
- *Data collection for national study of patient experience begins*: January 2021
- *Data collection for in-depth case studies of patient experience begins*: February 2021
- *Sharing emerging findings, including interim quantitative findings*: February/March 2021
- *Data collection for patient experience study ends*: May 2021
- *Submission of final report*: June 2021

*Figure 1.* Gannt Chart

| | **2020** | | | | **2021** | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Sept | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun |
| **Study design** | | | | | | | | | | |
| **Data Collection & analysis** | | | | | | | | | | |
| *National study of patient experience* | | | | | | | | | | |
| *In-depth case studies of patient experience* | | | | | | | | | | |
| **Sharing emerging findings** | | | | | | | | | | |
| **Submission of final report** | | | | | | | | | | |

*these dates are dependent on HRA approvals of patient experience elements, gaining access to sites and response rates. The timeline could vary due to engagement with the study and barriers created by COVID-19, including delivery of vaccination programme.

The study schedule for recruitment and consent procedures is shown in Table 1.

Table 1. Recruitment and consent procedures for workstreams 1 and 2

| Workstream | Activity | Who/numbers | Recruitment channels | Potential Participant Identification Centres (discussed so far) | Recruitment and consent channels | What do participants do? | Approx. time | Recruitment study months |
|---|---|---|---|---|---|---|---|---|
| 1 | Patient survey | As many patients/carers as possible from up to 25 sites | NHS sites (up to 25) | 1. NIHR CRN: North West London<br>2. Gloucestershire CCG<br>3. Hampshire and Isle of Wight STP (Portsmouth CCG)<br>4. Hampshire and Isle of Wight STP ( Isle of Wight CCG)<br>5. Cheshire & Merseyside<br>6. West Leicestershire CCG<br>7. NHS East Lancashire CCG<br>8. Basingstoke (North Hampshire CCG)<br>9. Royal Free London NHS Foundation Trust<br>10. Tees Valley CCG<br>11. Dorset CCG<br>12. Salford Royal NHS Foundation Trust (SRFT) | Participants approached by NHS staff upon discharge to take place online or through a paper questionnaire. Patients will complete the questionnaire and return it to the research team. | Complete the questionnaire | 15-30 minutes | January 2021-April 202-1 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | 13. West Hertfordshire hospitals NHS trust<br>14. Bristol, North Somerset and South Gloucestershire CCG<br>15. Derby & Derbyshire CCG<br>16. BaNES, Swindon and Wiltshire CCG (including Medvivo)<br>17. North Bristol NHS Trust<br>18. Whittington health NHS Trust<br>19. Shropshire, Telford and Wrekin STP Shropshire CCG)<br>20. Shropshire, Telford and Wrekin STP (Telford and Wrekin CCG)<br>21. West Hampshire CCG<br>22. Wigan (Wrightington, Wigan and Leigh | | | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | Teaching Hospitals NHS Foundation Trust)<br>23. Cornwall partnership NHS Foundation Trust<br>24. Wakefield CCG<br>25. NHS Devon CCG<br>26. NHS East Berkshire CCG<br>27. Royal Cornwall Hospitals NHS trust | | | | |
| 2 | Patient interviews | 72 patients or family members who have received COVID Oximetry@home | 12-14 NHS sites | 1. NIHR CRN: North West London<br>2. Gloucestershire CCG<br>3. Hampshire and Isle of Wight STP (Portsmouth CCG and Isle of Wight CCG)<br>4. Cheshire & Merseyside<br>5. West Leicestershire CCG<br>6. NHS East Lancashire CCG<br>7. Basingstoke (North Hampshire CCG) | Participants identified by NHS site staff. Interested individuals contact researcher and receive information sheets and study summary. Allows at least 48 hours before contacting them to ask for agreement to participate. Participant completes written consent form (by hand or digitally) | Take part in a telephone/online interview with one researcher | 30 minutes – 60 minutes | February 2021-May2021 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | 8. Royal Free London NHS Foundation Trust<br>9. Tees Valley CCG<br>10. Dorset CCG<br>11. Salford Royal NHS Foundation Trust (SRFT)<br>12. West Hertfordshire hospitals NHS trust<br>13. Bristol, North Somerset and South Gloucestershire CCG<br>14. Derby & Derbyshire CCG | | | | |

# 6 CONSENT

The study protocol and materials for the patient survey and interviews will be submitted to the UCL/UCLH JRO for sponsorship review and to the HRA for review and approval. We are aware of the sensitive nature of this research for organisations and individuals. The research team has experience in conducting research on similar sensitive topics. We will maintain the independence of the research, follow an informed consent process, and maintain the anonymity of participants and organisations. Site names and digital solutions will be replaced with pseudonyms for analysis and dissemination purposes.

**Workstream 1:** Both survey options (online and paper) will include prefacing information with a background to the study, potential risks, indicating voluntary participation, anonymity and a description of how the data will be used (see Appendix 6/7). This page also includes boxes that patients or carers can tick to indicate their consent to take part in the study.

**Workstream 2 (interviews):** Participant information sheets (Appendix 4) will be developed by the research team to explain the purpose of the interviews, how long the interviews will last and how data (personal or research) will be stored securely and not used beyond the analysis. Information sheets will also include details about who to contact should any questions or problems occur and details about participant withdrawal. Participants will be informed that taking part is voluntary and that they are free to withdraw at any point (e.g. prior to the interview, or during the interview). Participants will be informed about the limits of confidentiality (e.g. if someone is at risk of harm). Additionally, participants will be informed that they are free to withdraw their data after it has been collected and prior to the anonymised publication of findings. Data will be fully anonymised.

If the patient/carer is contacted via phone, they will be asked if a participant information sheet and consent form can be sent via email. If they prefer post, both of these documents will be sent via post with a pre-paid addressed envelope so they can return the signed consent form to the team. The researcher will then contact them to arrange a time to carry out the interview. Interviews will be carried out via telephone or an online platform (e.g. Zoom or MS Teams) as preferred by the patient. If patients are not able/willing to take part in the interview, we will ask patients if we can approach their carer (if they have one) to capture their perceptions of the patient's journey and overall experience with the service.

If the patient is contacted via email, the participant information sheet and consent form will be sent in a subsequent email and the patient will be given the option to schedule a call with the researcher to discuss the study. The participant information sheet will contain information on the study, potential risks and a description of how the data will be used to ensure informed and voluntary participation. If the patient/carer agrees to take part in the study, they will be instructed to email back the signed consent form (scanned forms or typewritten/electronic signature) (Appendix 5). As part of the consent process, participants will be asked to provide consent for audio-recording. The HRA approve of electronic consent as a valid form of consent (HRA, 2018).

Interviews will be carried out via telephone or an online platform (e.g. Zoom or MS Teams) as preferred by the patient. If patients are not able/willing to take part in the interview, we will ask patients if we can interview their carer alone. As interviews will take place remotely, we will also check with the participants if they are still happy to consent to take part at the start of the interview.

# 7 ELIGIBILITY CRITERIA

To participate in our study, participants will need to be 18 or over, proficient in English, eligible to receive COVID care at home, and must also have been offered and either received or refused the COVID care at home service, or care for someone who was eligible to receive COVID care at home , and who received or refused COVID care at home.

National and local eligibility for COVID care at home may vary. We will be flexible within our sampling to take into account both national and local eligibility criteria. For reference, the national eligibility guidelines are as follows: To be eligible for receiving COVID care at home, patients must have a confirmed or suspected diagnosis of COVID-19 plus be one of the following:

(a) Symptomatic with COVID-19 & aged 65 years or older,

b) Symptomatic with COVID-19 & under 65 years but 'clinically extremely vulnerable' (using the Clinically extremely vulnerable to COVID list) to COVID (CO@h Standard operating procedure, 2020).

# 8 RECRUITMENT

**Workstream 1 (survey):** When a patient is discharged from the remote home monitoring service in any of the sites that have decided to take part in the national-level study, they will be approached by NHS staff to take part in a survey in one of two different ways: 1) if the patient was monitored through the use of an app, they will receive a SMS with a link to the online survey, 2) if the patient was monitored through regular phone calls and a paper-based recording method, they will receive the survey in the post (with a pre-paid addressed envelope). Whilst most surveys will be distributed at discharge, some sites may choose to distribute the paper survey at onboarding and then remind patients at discharge to complete the survey. NHS staff will distribute the online and paper version of the survey so the research team will have no access to patient information.

The feasibility of the research team's recruitment strategy is currently under consideration with a number of potential NHS sites. The method of administering the survey i.e. NHS staff sending to patients means that there will be no reminders. Due to limited capacity, we are unable to conduct the survey with patients over the phone. NHS staff will be asked to record the number of surveys that they have distributed allowing us to determine response rate.

**Workstream 2 (interviews):** Staff leads will first contact potential patients to see if they are happy to be approached by a researcher. This will include patients who have received the CO@H service, those who have withdrawn and those who have declined the service. If they agree, the researcher will then contact the patient/carer via telephone or email to discuss the study. If the patient/carer is contacted via phone, they will be asked if a participant information sheet and consent form can be sent via email. If they prefer post, both of these documents will be sent via post with a pre-paid addressed envelope so they can return the signed consent form to the team. The researcher will then contact them to arrange a time to carry out the interview. Interviews will be carried out via telephone or an online platform (e.g. Zoom or MS Teams) as preferred by the patient. If patients are not able/willing to take part in the interview, we will ask patients if we can approach their carer (if they have one) to capture their perceptions of the patient's journey and overall experience with the service.

# 9 PATIENT AND PUBLIC INVOLVEMENT (PPI)

Members of the study team met with service user and public members of the BRACE Health and Care Panel and patient representatives from RSET to discuss the study, what research with patients might explore, and methods of patient recruitment to ensure inclusivity. Patient facing documents, such as the consent form, topic guides, patient survey and patient information sheet will also be reviewed by this group. We will incorporate their feedback into the study documents prior to data collection, while interpreting findings, and throughout the study. We might also engage in conversations with existing patient groups and organisations to request feedback on the study, collect additional data and/or cross-check our interpretations.

# 10 FUNDING AND SUPPLY OF EQUIPMENT

The study funding has been reviewed by the UCL Research Office, and deemed sufficient to cover the requirements of the study.

The research costs for the study have been supported by the National Institute for Health Research, Health Services & Delivery Research programme (RSET Project no. 16/138/17; BRACE Project no. 16/138/31).

# 11 DATA HANDLING AND MANAGEMENT

The study is compliant with the requirements of General Data Protection Regulation (2016/679) and the Data Protection Act (2018). All investigators and study site staff will comply with the requirements of the General Data Protection Regulation (2016/679) with regards to the collection, storage, processing and disclosure of personal information, and will uphold the Act's core principles. UCL/UCLH is the data controller; the UCL/UCLH Data Protection Officer is Alex Potts (a.potts@ucl.ac.uk).The data processors are Chris Sherlaw-Johnson, Theo Georghiou, Cecilia Vindrola, Sonila M Tomini, Holly Walton, Manbinder Sidhu, Jo Ellins, Kelly Singh, Jenny Bousfield, Nadia Crellin, Lauren Herlitz, Stephen Morris.

**DATA MANAGEMENT**

Data will be managed in line with legal and regulatory requirements, including the General Data Protection Regulation (GDPR) and the Data Protection Act (2018), and necessary research approvals.

Professor Naomi Fulop will act as the data controller for this study. She will process, store and dispose of all data in accordance with all applicable legal and regulatory requirements, including the General Data Protection Regulation (GDPR) and the Data Protection Act (2018) and any amendments thereto. Data will not be transferred to any party not identified in this protocol and are not to be processed and/or transferred other than in accordance with the patients' consent.

In line with GDPR guidelines on data minimisation, we are only collecting personal data that is relevant and necessary for the purposes of this study.

**Workstream 1 (survey):**

The research team will develop the survey using an online platform (REDCap). A paper copy of the patient survey will also be available. Surveys will be sent to patients by the individual NHS sites. NHS

sites will be asked to circulate the survey using their individual site ID. Therefore, researchers will not have access to any patient contact details. Surveys will be returned to the research team, either electronically through REDCap, or by posting completed surveys in pre-paid envelopes to our RSET team members at the Nuffield Trust. As we are in lockdown, the offices at Nuffield Trust and UCL are currently closed. However, we describe here the process with which we will store the paper versions of the survey. Surveys received via post will be stored securely in locked filing cabinets within the secure Nuffield Trust office. Data from patient surveys sent via post will be either inputted into REDCap by members of the research team or securely transferred into the Data Safe Haven (using the Data safe haven file transfer portal). Data from the patient surveys will be directly stored in the UCL Data Safe Haven via REDCap, as this will include identifiable information (postcode data). Data from the completed surveys will be stored securely using password protected spreadsheets to which only the RSET and BRACE researchers will have access to.

**Workstream 2 (Interviews):**

Patient interviews (qualitative data) will be recorded on an encrypted, password-protected digital recorder (only the researcher will know the password). Data will be collected by a team of qualitative researchers from RSET (University College London and Nuffield Trust) and BRACE (University of Birmingham and RAND Europe).

Patient consent forms and audio-recordings of interviews will be securely transferred using the Data Transfer portal onto the UCL Data safe Haven (a secure electronic environment, certified to ISO27001 information security standard and conforms to the NHS Information Governance Toolkit). Once transferred onto the Data Safe haven, the data will be cleared from the Dictaphone. Patient consent forms received via post will be posted to our RSET team members at the Nuffield Trust. Patient consent forms received via post will be stored securely in locked filing cabinets within the secure Nuffield Trust office.

Digital audio-recordings of patient interviews will be sent to a UCL-approved contractor for transcription (TP transcription limited). Transcripts will be fully anonymised (names and places) and organised by participant codes. Anonymised transcripts and other relevant data will be stored in a secure folder to which only the named researchers (RSET and BRACE qualitative team) have access. Only the research team will have access to participants' personal data (i.e. name and contact details). A password protected spreadsheet of interviewees and their contact details will also be held on the Data Safe Haven. Participant identifier codes will be stored in the DSH and kept separate from study data. Data will be shared between UCL and University of Birmingham researchers using the DSH.

## 12 PEER AND REGULATORY REVIEW

The study has been peer reviewed in accordance with the requirements outlined by UCL/UCLH. This study has been peer reviewed within UCL, by an independent and relevant peer reviewer on 7th December 2020. The Sponsor has accepted these reviews as adequate evidence of peer review.

Additionally, the study has been reviewed by our clinical advisory group and the NHS Digital CO@h Evaluation Workstream Group.

# 13 ASSESMENT AND MANAGEMENT OF RISK

Conducting interviews with patients regarding their experience of receiving COVID Oximetry @home may potentially cause distress – as these will involve patients discussing their experience of receiving care whilst experiencing COVID-19. To address these concerns and ensure that questions within the topic guides are sensitively presented, we have sought feedback on the interview topic guides from the research team and the BRACE and RSET PPI members. We will also state in the information sheet that participation is voluntary, and that participants are free to withdraw. We will also seek to signpost patients to relevant support groups (where necessary and relevant).

Secondly, we are asking patients to reflect on their experiences of receiving a care service and thus may be hesitant to raise criticism. To address this, the participant information sheet will highlight that the research team are independent of those delivering the care service and will also highlight that there are no right or wrong answers, and that the information will be fully anonymised (including names and places). We will also emphasise that it is important to learn about the things that do not work as well, in order to improve these for future patients. We will signpost participants to the patient advice and liaison service (PALS) and/or external services if required.

Additionally, this project may be subject to recruitment risks. These are shown in Table 2.

**Table 2: Potential risks and mitigation strategies**

| | Risk | Impact | Likelihood | Mitigation |
|---|---|---|---|---|
| WS 1&2 | Increased demand on NHS workforce as a result of the Covid-19 pandemic | High | High | The project team will be prepared for the potential likelihood that NHS general practice and acute trust staff could suspend participation in this evaluation if the transmission of the virus increases either locally and/or nationally and/or need to focus their attention predominantly on the national vaccination programme. The principal investigator for the project will communicate with senior NHS leads, and seek guidance from NHS Digital and NIHR HS&DR if such a situation occurs and will act accordingly. |
| WS1&2 | Loss of key staff | High | Low | There is a large project team, in the event of one member leaving there is capacity and resources for this person to be replaced from the wider team or to bring other researchers in. |
| WS 1&2 | Non-engagement from sites | High | Medium | The research team has built relationships with the national NHS COVID Oximetry@ Home Learning Network and other regional networks, and already received a number of expressions of interest from sites to take part in the evaluation. Team members will have on-going meetings with site delegation teams/gatekeepers, to discuss the contribution required from each party for the duration of the evaluation. |
| WS1 | Low response rates from patient surveys | High | Medium | Given our proposed method of administering the surveys (distributed by sites not the research team) means that we will not be able to send reminders, there is a risk that the study team encounters a low response rate from patients completing surveys. In addition, patients may only return partially completed surveys.<br><br>At each participating site staff leads will be asked to remind staff to ask patients to complete surveys at discharge. The team will have designated team members to communicate with each case study site to maintain engagement with site leads. |

| | | | | |
|---|---|---|---|---|
| WS2 | Inability to recruit participants for interview | High | Medium | There is a risk the study may be delayed in recruiting participants because it will be the responsibility of case study sites to identify staff and patients to interview on behalf of the evaluation team<br><br>At each case study site, the team will identify a key point of contact regarding participation and will be in regular contact with them. The team will produce detailed, descriptive information sheets to inform potential participants of the importance of the evaluation, why we have asked them to take part, their involvement, and associated risks and benefits. |

## 14 MONITORING AND AUDITING

The Chief Investigator will ensure there are adequate quality and number of monitoring activities conducted by the study team. This will include adherence to the protocol, procedures for consenting and ensure adequate data quality.

The Chief Investigator will inform the sponsor should he/she have concerns which have arisen from monitoring activities, and/or if there are problems with oversight/monitoring procedures.

This study is part of a wider evaluation of three teams: this one, The Institute of Global Health Innovation at Imperial College London & Imperial College Healthcare and The Improvement Analytics Unit at the Health Foundation. We will meet weekly with the NHS Digital CO@h Evaluation Workstream Group chaired by Professor Jonathan Benger and work in close partnership with the other evaluation teams. As a shared governance structure, we will ensure the work of the three evaluations remains joined up to garner learning as the evaluation progress. In addition, we will operate a policy of ensuring stakeholders are aware of developments of the research as it progresses through weekly stand-up meeting and have early sight of outputs for comment and agreement of publication strategy.

We will continue to work closely with the NIHR 70@70 Senior Nurse Research Leaders and our Clinical Advisory Group throughout the project to ensure the evaluation is relevant and conducted in a way that involves expert clinical input as required. The Clinical Advisory Group will be led by Dr Karen Kirkham (Integrated Care System Clinical Lead, NHSE/I Senior Medical Advisor Primary Care Transformation, Senior Medical Advisor to the Primary Care Provider Transformation team), Dr Matt Inada-Kim (Clinical Lead Deterioration & National Specialist Advisor Sepsis, National Clinical Lead - Deterioration & Specialist Advisor Deterioration, NHS England & Improvement) and Allison Streetly (Deputy National Lead Healthcare Senior Public Health Advisor, Public Health England). The team will work with research nurse leaders from the NIHR 70@70 programme to seek advice on data collection and recruitment in relation to staff and patient survey and interviews.

The team will meet weekly throughout the duration of the evaluation. The evaluation will be discussed as a standing item at monthly NIHR RSET and NIHR BRACE meetings, in terms of progress against project milestones and to address any practical or methodological issues, and to help maintain the independence of the evaluation.

## 15 TRAINING

The Chief Investigator will review and provide assurances of the training and experience of all staff working on this study. Appropriate training records will be maintained in the study files.

## 16 INTELLECTUAL PROPERTY

All intellectual property rights and know-how in the protocol and in the results arising directly from the study, but excluding all improvements thereto or clinical procedures developed or used by each participating site, shall belong to UCL. Each participating site agrees that by giving approval to conduct the study at its respective site, it is also agreeing to effectively assign all such intellectual property rights (“IPR”) to UCL and to disclose all such know-how to UCL. with the understanding that they may

use know-know gained during the study in clinical services and teaching to the extent that such use does not result in disclosure of UCL confidential information or infringement of UCLIPR.

## 17 INDEMNITY ARRANGEMENTS

University College London holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach in the hospital's duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

## 18 ARCHIVING

UCL and each participating site recognise that there is an obligation to archive study-related documents at the end of the study (as such end is defined within this protocol). The Chief Investigator confirms that he/she will archive the study master file at UCL for the period stipulated in the protocol and in line with all relevant legal and statutory requirements. The Principal Investigator at each participating site agrees to archive his/her respective site's study documents in line with all relevant legal and statutory requirements. Study documents will be archived for a minimum of 5 years from the study end, and no longer than 20 years from the study end.

## 19 PUBLICATION AND DISSEMINATION POLICY

Outputs for this patient experience research will include an analysis of patients' experiences of these models, including findings in relation to inclusivity of these services.

We will regularly share feedback with stakeholders on: patient views and experiences of CO@H. We will offer to carry out site-specific analyses of patient experience data for sites that request this information. Dissemination to sites will be facilitated through existing and new national and regional networks (e.g. the Communities of Practice group, COVID Oximetry@ Home Learning Network).

We aim to present findings are relevant conferences and publish findings in peer reviewed journals. We will submit a final report to the National Institute for Health Research, Health Services and Delivery Research programme (NIHR HS&DR)

In addition, we plan a range of dissemination methods to reach different audiences. These will be developed with input from the Nuffield Trust communications team and National Voices to disseminate to organisations that represent NHS staff as well as patients and carers. These may include:

- A range of slide packs to share findings with a range of key audiences including primary and secondary care clinicians, commissioners, policymakers and patients/carers facilitated through existing (the NHS Communities of Practice group, COVID Oximetry@ Home Learning Network) and new networks
- Appropriate non-expert forms of dissemination e.g. videos, blogs, podcasts.

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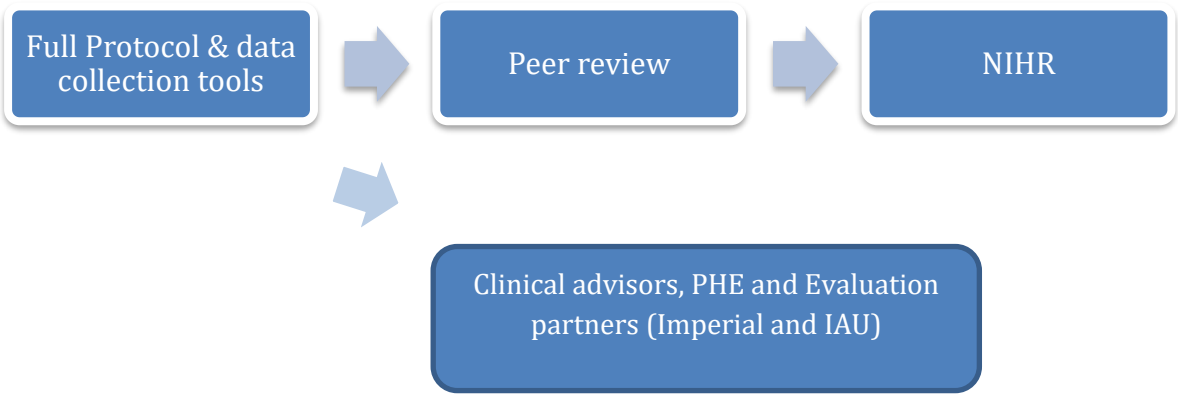
## 21 APPENDICES

***Appendix 1.*** Flowchart of study review processes

1. **Full protocol**




2. **Research Protocol:** Patient experience study (survey and interviews)


3. **Service Evaluation Protocol**: Service evaluation of effectiveness, cost-effectiveness, implementation and staff experience (not included in this protocol – included in a separate protocol)

***Appendix 2.*** **Patient survey**

**Site ID: [xxx]**

| **Group of questions** | **Questions to cover** |
|---|---|
| Section 1. Demographic characteristics (possibly move questions 2-12 to the end of the survey) | - Patient who received COVID care at home or carer? *(patient / carer)*<br>  ○ (If family member) – relationship with patient *(spouse or partner / son or daughter/ son or daughter in law/brother or sister/ friend / other)*<br>  ○ (If family member) - family member's role in supporting patient (open text)<br>- Gender of patient (and family member if applicable)<br>- Sexuality of patient/carer (bisexual, gay/lesbian, heterosexual/straight, don't know, prefer not to say, other)<br>- Age of patient (and family member if applicable) *(18-24/25-29/30-34/35-39/40-44/45-49,50-54/55-59/60-64/65-69/70-74/75-79/80-84/85+/do not wish to answer)*<br>- *How many people do you live/co-habit with? (patient/family member) (numerical options / do not wish to answer)*<br>- *Which of these best describes your living arrangement? (patient/family member) Please select one answer (I own my home outright, I own my home with a mortgage, I rent from local authority/housing association, I rent privately, Other (e.g. living with family/friends), prefer not to say)*<br>- Ethnicity of patient (and family member if applicable)<br>- At what age did you complete your continuous full time education? *(patient/family member) (__ years/never went to school, do not wish to answer)*<br>- Which of these best describes your highest educational qualification? *(patient/family member)* (Please select one answer) *(No formal qualification, GCSE/CSE/O level or equivalent, A level/AS level or equivalent, Degree level or higher, Other (please specify), do not wish to answer)*<br>- Which of these best describes your current work situation? *(patient/family member) (please tick all that apply) (Working full time, working part time, self-employed, student in higher education, unemployed, homemaker, retired, furloughed under COVID-19, Full time carer (of dependent child or adult), not in work due to poor health or disability,, Other (if other please describe), do not wish to answer).*<br>- Is English your first language? *(patient/family member) (yes/no/do not wish to answer)*<br>- Prior to your current illness, are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?? (Includes problems which are due to old age.) *(patient/family member) yes, limited a lot/yes, limited a little, no/do not wish to answer)*<br>- What is your Postcode? *(patient/family member) (optional)* |
| Section 2. Questions about the service received | - Did you receive an oximeter? *(yes/no)*<br>  ○ Were you given information on how to use the oximeter? *(yes/no)*<br>  ○ Were you given information on how to record your observations? *(yes/no)*<br>  ○ Were you given information about what to do if your oxygen levels dropped below the recommended levels? (yes/no)<br>  ▪ *Was this information provided to you in your first language? (Yes/no)*<br>  ▪ *If No, what is your first language?* |

| | |
|---|---|
| | - Did you have anyone who could help you to use the oximeter if needed? *(yes/no/not applicable)*<br>- Were you asked to record your symptoms and outcomes using a paper diary or an app? *(paper diary/app/both)*<br>[If paper diary or both]<br>o Were you happy to record using a paper diary? *(yes/no)*<br>o Did you use the same method throughout? *(yes/no)*<br>o How easy was the paper diary to use? *(very easy-not at all easy)*<br>o Were you given the choice between using an app or a paper diary? *(yes/no)*<br>o Did you have anyone to support you with recording observations, if needed? *(yes/no/not applicable)*<br>[If app or both]<br>a. Did you have access to a smart phone to use the app? *(yes/no)*<br>b. Were you happy to record using an app? *(yes/no)*<br>c. Did you use the same method throughout? *(yes/no)*<br>d. How easy was the app to use? *(very easy – not at all easy)*<br>e. Were you given the choice between using a paper diary or app? *(yes/no)*<br>f. Did you have anyone to support you with recording observations, if needed? *(yes/no/not applicable)*<br>- Did you receive any medications as part of the COVID care at home service (those discharged from hospital (yes/no/don't know/not applicable)<br>- Were you given oxygen as part of the COVID care at home service? (yes/no/don't know/not applicable)<br>- How often did you speak with the person taking your readings?<br>o How would you rate your contact with the person taking your readings? *(Excellent to poor)*<br>- Which activities were you asked to do *(Select all that apply): (take readings using oximeter, fill in diary, record observations in an app, review symptoms, seeking further help if observations are lower than the recommended threshold)*<br>- Did you understand what would happen after being discharged from COVID care at home? *(yes/no)*<br>- Were you asked to return the oximeter once discharged from COVID care at home? *(yes/no)* |
| Section 3. Patients' experiences of receiving CO@h | - Please rank your experience of receiving COVID care at home *(positive to negative)*<br>- How did receiving COVID care at home make you feel? *(Reassured - worried)*<br>- How helpful have you found receiving COVID care at home in relation to your COVID symptoms? *(very helpful to not at all helpful)*<br>- Would you recommend COVID care at home to your friends and family? *(yes/no)* |
| Section 4. Patients' engagement with CO@h | - **How easy information on the following things was to understand** *(likert scale – very easy to very difficult):*<br>o What COVID care at home is and what it would involve<br>o What an oximeter is<br>o How to use the oximeter<br>o How to record observations using the app/diary<br>o How to provide results to the service<br>o How to seek further help if you have concerns about your health (escalating care)<br>o Who to contact if needed at different times of day and days of the week<br>o What happens at discharge (leaving information, knowing how to get help if needed and advice on how to return the oximeter)<br>o Knowing how to access services following discharge |

| | |
|---|---|
| | - **How did you find the training on how to use the oximeter?** *(likert scale – very helpful to not at all helpful)*<br>- **How have you found it to actually do the following things in practice** *(likert scale – very easy to very difficult)*:<br>  o Using the oximeter<br>  o Recording your observations using the app/diary<br>  o Providing results to healthcare professional<br>  o Seeking further help if have concerns about health (Escalating care) (if necessary)<br>  o Contacting professional (if needed)<br>  o Returning the oximeter (once discharged)<br>- **Did you experience any problems with the following things** *(select all that apply*): *Using the oximeter / Recording your observations / Providing results to your healthcare professional / Seeking further help if you had concerns about your health / Contacting professionals when needed / Returning the oximeter (if discharged)*<br>  o [if yes to the above question]. Did you tell a member of the medical team about these problems? *(yes/no)*<br>  ▪ [if yes to the above question]. Did these problems get resolved? *(yes/no).* |
| Barriers/facilitators *(MCQ)* | - What helped you to engage with COVID care at home? (select all that apply)<br>- What got in the way with you engaging with COVID care at home? (select all that apply)<br>- What could be changed to make it easier for you to engage with COVID care at home**?** *[Open text]* |
| Use of other services | - Which of the following scenarios best described your experience while receiving COVID care at home *(Stayed at home the whole time /Asked to go to the emergency department / Admitted to hospital)* |
| Open text question | - Is there anything else you'd like to tell us about your experience of receiving COVID care at home? *(Please write in the box below)* |

## *Appendix 3*. Patient interview topic guides

### INTRODUCTION

The interview should last between 30 and 60 mins, but may take longer than this, depending on how much you would like to say. We will ask questions about how you found the experience of monitoring and recording your COVID symptoms at home, and any further advice you received – we call this "COVID care at home". We will feedback the results of this evaluation to local and national NHS and public health services, and results will be made available to the general public too.

If you do not want to answer a question, you do not have to, and if you feel uncomfortable or tired we can stop the interview at any point. Let us know if you'd like a break or to come back later. We can also carry out the interview in two halves if that is easier for you to manage. Have you got any questions before we start?

**Questions for those who have received CO@h**

| Main question | Follow up questions (prompts) |
|---|---|
| 1. Please tell me a bit about yourself, | • Do you live by yourself or with others?<br>• How long have you lived in your neighbourhood?<br>• Do you have any family or friends living close by?<br>• Is English your first language? If N, ask what is their first language. |
| **FINDING OUT ABOUT THE SERVICE**<br>2. Can you tell me the story of how you ended up being referred to COVID care at home? | a. How were you referred to the service? *(may include some referrals following positive test)*<br>b. Who did you speak to and when? (virtual/face to face? How were you involved in the assessment process?) *(for assessment/triage)*<br>c. When you were first told about the service, how was it described to you?<br>d. What were your first impressions of COVID care at home? *(prompt about whether they found it reassuring or not)*<br>a. Positive impressions?<br>b. Did you have any concerns/worries? |
| **DESCRIBING COVID CARE AT HOME**<br>3. COVID care at home is carried out slightly differently in different parts of the country. Please can you tell me about what receiving COVID care at home has involved for you? | a. What equipment were you given?<br>b. How/when was the pulse oximeter delivered to you? Can you tell me how it works?<br>c. What symptoms did you have to monitor? For each, ask how often.<br>d. How did you have to record your symptoms? (e.g. paper, digital app, telephone line) |

| | |
|---|---|
| | e. Were you offered a choice in how you recorded your symptoms?<br><br>f. Who did you speak to? (& how often – monitoring)<br><br>g. Have family members/carers been involved? If so, how? (if relevant)<br><br>h. Overall, how did you feel about recording and monitoring your symptoms? *(prompt about whether they found it reassuring or not)*<br><br>i. Did you receive any medications as part of COVID care at home (for those early discharged from hospital)?<br>a. If yes. How did you find it?<br>j. Were you given oxygen as part of the COVID care at home service?<br>a. If yes, how did you find it? |
| **INFORMATION RECEIVED ON COVID CARE AT HOME AT ONBOARDING**<br><br>4 a. Did you receive information on COVID care at home **in person** from a member of the care team?<br><br>If no, move to 4b.<br><br>4b. Did you receive information on COVID care at home **over the telephone or a video call** from a member of the care team?<br>If no, move to 4c.<br><br>4c. Were you directed to any information **to read or watch on a website** on COVID care at home?<br><br>If no, move to 4d. | a. i) If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)*<br>ii) Who gave you the information? Was it in your first language?<br>iii) How easy was it to understand the information?<br>iv) Did the person you spoke to describe the readings and what they mean in relation to your everyday symptoms and experience?<br><br>b. i) If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)*<br><br>ii) Who gave you the information?<br>iii) Was it in your first language?<br>iv) How easy was it to understand the information?<br><br>c. i) If yes, were you able to access the information you needed on the website?<br>ii) If no, why not?<br>If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice*?)<br><br>iii) Was it in your first language?<br>iv) How easy was it to understand the information? |

| | |
|---|---|
| 4d. Were you directed to any information **to read or watch on an app** on COVID care at home?<br><br>If no, move to 5. | d. i) If yes, were you able to access the information you needed on the app?<br>If no, why not?<br>If i) is yes, what information did you receive? *(Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)*<br><br>iii) Was it in your first language?<br>iv) How easy was it to understand the information? |
| **CARRYING OUT THE MONITORING**<br><br>**OXIMETER**<br>5. How did you find using the oximeter to monitor your oxygen levels? *(may like to prompt about how often they used it)* | a. What helped you to use it?<br>b. What got in the way?<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>What could be changed to make it easier to use the oximeter? |
| **OTHER SYMPTOMS**<br>6. Overall, how did you find monitoring your other symptoms (pulse heart rate/temperature/symptoms) at home? *(may like to prompt about how often they monitored other symptoms)* | a. What worked well?<br>b. What got in the way?<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>d. What could be changed to make it easier to monitor your other symptoms?<br>e. Was there any parts of monitoring that you were uncertain about?<br>f. Did you seek further advice from anyone about monitoring your symptoms? Prompt – who, when, how? |
| **CARRYING OUT RECORDING**<br>7. Overall, how did you find recording your readings (blood oxygen levels/symptoms/pulse heart rate/temperature)? *(using an app / diary / both) (prompt about how often they recorded their readings)* | a. What worked well?<br>b. What got in the way?<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>d. What could be changed to make it easier to monitor your other symptoms?<br>e. Was there any part of recording your symptoms that you were uncertain about? *(prompt about whether they felt confident)*<br>r. Did you seek further advice from anyone about recording? Prompt – who, when, how? |
| **COMMUNICATING READINGS TO MEMBER OF THE TEAM**<br>**8. How have you found sending or communicating your symptoms and readings to the COVID care at home team? (if needed)** | a. What worked well?<br>b. What got in the way?<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>d. What could be changed to make it easier to communicate your readings to the COVID care at home team?<br>e. Was there any part of communicating your readings to a member of the team that you were uncertain about? |

| | |
|---|---|
| | r. Did you seek further advice from anyone about communicating your readings? Prompt – who, when, how? |
| **SEEKING FURTHER ADVICE**<br>8. Have you had to seek further support and help (escalate your care) because of the readings given by your oximeter or because of other things such as a change in symptoms? | a. How did this go?<br>b. What did this involve?<br>c. What was your experience of being sent for further support and help (e.g. escalated or admitted to hospital)?<br>d. What were you instructed to do? (i.e. dial 111, dial 999, go to A&E)?<br>e. Did you self-escalate your care (seek further health care) if necessary? Why or why not? *(prompt on how they made the decision that they needed to seek further help)*<br>f. What helped you to seek further support?<br>g. What got in the way of seeking further support?<br>h. What could be changed to make it easier? |
| **DISCHARGE**<br>9. What was your understanding about what would happen once you are discharged from COVID care at home? | a. How did you feel after being discharged from COVID care at home? (prompt about whether they found it reassuring or not?)<br>b. Since being discharged from COVID care at home, what other services/support have you accessed? *(If discharged from COVID care at home).*<br>i. What were these?<br>ii. How often have you had to access these? |
| **RECOMMENDATIONS**<br>10. If a friend who was in a similar position to you at the start of your illness was offered COVID care at home, would you recommend it to them<br>a) over hospital care?<br>b) over no monitoring, with the option to access usual services as needed.<br><br>11. Do you have any recommendations to improve the service? | A) If yes, why? If no, why not?<br><br>B) If yes, why? If no, why not?<br><br>If yes, what? |
| 12. Is there anything else that you would like to say about what we have talked about? | |

**If participants did not want to receive COVID care at home**

Could ask Q1-5, and then:

| Main question | Follow up questions (prompts) |
|---|---|
| 1. Please tell me a bit about yourself | • Do you live by yourself or with others?<br>• How long have you lived in your neighbourhood?<br>• Do you have any family or friends living close by?<br>• Is English your first language? If N, ask what is their first language. |
| **FINDING OUT ABOUT THE SERVICE**<br>2. Can you tell me the story of how you ended up being referred to COVID care at home? | a. How were you referred to the service?<br>b. Who did you speak to and when? (virtual/face to face? How were you involved in the assessment process?) *(for assessment/triage)*<br>c. When you were first told about the service, how was it described to you?<br>d. What were your first impressions of COVID care at home? *(prompt about whether they found it reassuring or not)*<br>a. Positive impressions?<br>e. Did you have any concerns/worries? |
| | **f.** |
| **EXPECTATIONS OF COVID CARE AT HOME**<br>**3.** Please tell me about what you thought receiving COVID care at home would involve | a. What equipment would you be given?<br><br>c. What symptoms would you have had to monitor? For each, ask how often.<br><br>d. How would you have had to record your symptoms? (e.g. paper, digital app, telephone line)<br><br>e. Were you offered a choice in how you could have recorded your symptoms?<br><br>f. Who did you speak to?<br><br>h. Overall, how did you feel about the prospect of recording and monitoring your symptoms? *(prompt about whether they found it reassuring or not)* |
| **INFORMATION RECEIVED ON COVID CARE AT HOME AT ONBOARDING**<br><br>4 a. Did you receive information on COVID care at home **in person** from a member of the care team?<br><br>If no, move to 4b. | a. i) If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)*<br>ii) Who gave you the information? Was it in your first language?<br>iii) How easy was it to understand the information?<br>iv) Did the person you spoke to describe the readings and what they mean in relation to your everyday symptoms and experience?<br><br>b. i) If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)* |

| | |
|---|---|
| 4b. Did you receive information on COVID care at home **over the telephone or a video call** from a member of the care team?<br>If no, move to 4c.<br><br>4c. Were you directed to any information **to read or watch on a website** on COVID care at home?<br><br>If no, move to 4d.<br><br>4d. Were you directed to any information **to read or watch on an app** on COVID care at home?<br><br>4. If no, move to 5. | ii) Who gave you the information?<br>iii) Was it in your first language?<br>iv) How easy was it to understand the information?<br><br>c. i) If yes, were you able to access the information you needed on the website?<br>ii) If no, why not?<br>If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice*?)<br><br>iii) Was it in your first language?<br>iv) How easy was it to understand the information?<br><br>d. i) If yes, were you able to access the information you needed on the app?<br>If no, why not?<br>If i) is yes, what information did you receive? (Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)<br><br>iii) Was it in your first language?<br>iv) How easy was it to understand the information?<br>a. |
| | a. |
| **REASONS FOR DECLINING**<br>5. Why did you choose not to take part in the CO@h remote monitoring?<br><br>6. Could anything be changed to make you want to receive COVID care at home more? | Did anything get in the way? If so, what?<br>How did this get in the way?<br><br>If so, what?<br>How would this help? |
| **OTHER CARE/SERVICES ACCESSED**<br>7. Did you have any other type of monitoring? | If so, what?<br>How did you find this? |
| 8. Have you had to seek further support and help? (e.g. GP or A&E) | If so, what? |
| 9. Is there anything else you'd like to say about what we have talked about? | How would this help? |

**If participants withdrew from receiving COVID care at home**

| Main question | Follow up questions (prompts) |
|---|---|
| 1. Please tell me a bit about yourself | • Do you live by yourself or with others?<br>• How long have you lived in your neighbourhood?<br>• Do you have any family or friends living close by? |

| | |
|---|---|
| | • Is English your first language? If N, ask what is their first language. |
| **FINDING OUT ABOUT THE SERVICE**<br>2. Can you tell me the story of how you ended up being referred to COVID care at home? | a. How were you referred to the service?<br>b. Who did you speak to and when? (virtual/face to face? How were you involved in the assessment process?) *(for assessment/triage)*<br>c. When you were first told about the service, how was it described to you?<br>d. What were your first impressions of COVID care at home? *(prompt about whether they found it reassuring or not)*<br>a. Positive impressions?<br>Did you have any concerns/worries? |
| **DESCRIBING COVID CARE AT HOME**<br>**3.** COVID care at home is carried out slightly differently in different parts of the country. Please can you tell me about what receiving COVID care at home has involved for you? | a. What equipment were you given?<br>b. How/when was the pulse oximeter delivered to you? Can you tell me how it works?<br>c. What symptoms did you have to monitor? For each, ask how often.<br>d. How did you have to record your symptoms? (e.g. paper, digital app, telephone line)<br>e. Were you offered a choice in how you recorded your symptoms?<br>f. Who did you speak to? (& how often – monitoring)<br>g. Have family members/carers been involved? If so, how? (if relevant)<br>h. Overall, how did you feel about recording and monitoring your symptoms? *(prompt about whether they found it reassuring or not)* |
| **INFORMATION RECEIVED ON COVID CARE AT HOME AT ONBOARDING**<br><br>4 a. Did you receive information on COVID care at home **in person** from a member of the care team?<br><br>If no, move to 4b.<br><br>4b. Did you receive information on COVID care at home **over the telephone or a video call** from a member of the care team? | a. i) If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)*<br>ii) Who gave you the information?<br>Was it in your first language?<br>iii) How easy was it to understand the information?<br>iv) Did the person you spoke to describe the readings and what they mean in relation to your everyday symptoms and experience?<br><br>b. i) If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)*<br>ii) Who gave you the information?<br>iii) Was it in your first language? |

| | |
|---|---|
| If no, move to 4c.<br><br>4c. Were you directed to any information **to read or watch on a website** on COVID care at home?<br><br>If no, move to 4d.<br><br>4d. Were you directed to any information **to read or watch on an app** on COVID care at home?<br><br>If no, move to 5. | iv) How easy was it to understand the information?<br><br>c. i) If yes, were you able to access the information you needed on the website?<br>ii) If no, why not?<br>If yes, what information did you receive? (*Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice*?)<br><br>iii) Was it in your first language?<br>iv) How easy was it to understand the information?<br><br>d. i) If yes, were you able to access the information you needed on the app?<br>If no, why not?<br>If i) is yes, what information did you receive? (Monitoring symptoms? Using oximeter? Recording symptoms? Seeking further advice?)<br><br>iii) Was it in your first language?<br>iv) How easy was it to understand the information?<br>a. |
| **REASON FOR WITHDRAWING FROM CO@H**<br>**i.** Why did you choose to withdraw from receiving COVID care at home? | - Did anything get in the way? If so, what?<br>- How did this get in the way? |
| **CARRYING OUT THE MONITORING (if applicable)**<br><br>**OXIMETER**<br>i. How did you find using the oximeter to monitor your oxygen levels?<br><br>**OTHER SYMPTOMS**<br>i. Overall, how did you find monitoring your other symptoms (pulse heart rate/temperature/symptoms) at home? | a. What helped you to use it?<br>b. What worked less well?<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>What could be changed to make it easier to use the oximeter?<br><br>a. What worked well?<br>b. What worked less well<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>d. What could be changed to make it easier to monitor your other symptoms? |
| **CARRYING OUT RECORDING (If applicable)**<br>v. Overall, how did you find recording your readings (blood oxygen levels/symptoms/pulse heart | a. What worked well?<br>b. What worked less well?<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>d. What could be changed to make it easier to monitor your other symptoms?<br>e. Was there any part of recording your symptoms that you were uncertain about? |

| | |
|---|---|
| rate/temperature)? *(using an app / diary / both)* | r. Did you seek further advice from anyone about recording? Prompt – who, when, how? |
| **COMMUNICATING READINGS TO MEMBER OF THE TEAM (If applicable)**<br>9. How have you found sending or communicating your symptoms and readings to the person taking the readings (if needed) | a. What worked well?<br>b. What worked less well?<br>c. What did you do when you had problems? (prompt about type of support and usefulness)<br>d. What could be changed to make it easier to communicate your readings to a member of the team?<br>e. Was there any part of communicating your readings to a member of the team that you were uncertain about?<br>f. Did you seek further advice from anyone about communicating your readings? Prompt – who, when, how? |
| **SEEKING FURTHER ADVICE (If applicable)**<br>**v.** Have you had to seek further support and help (escalate your care) because of the readings given by your oximeter or because of other things such as a change in symptoms? | a. How did this go?<br>b. What did this involve?<br>c. What was your experience of being sent for further support and help (e.g. escalated or admitted to hospital)?<br>d. What were you instructed to do? (i.e. dial 111, dial 999, go to A&E)?<br>e. Did you self-escalate your care if necessary? Why or why not?<br>f. What helped you to seek further support?<br>g. What got in the way of seeking further support?<br>h. What could be changed to make it easier? |
| **OTHER CARE/SERVICES ACCESSED**<br>10. Did you have any other type of monitoring? | - If so, what?<br>-How did you find this? |
| 11. Have you had to seek further support and help? (e.g. GP or A&E) | - If so, what? |
| **RECOMMENDATIONS**<br>12. Could anything be changed to make you want to receive COVID care at home more?<br><br>13. If a friend who was in a similar position to you at the start of your illness was offered COVID care at home, would you recommend it to them<br>a) over hospital care?<br>b) over no monitoring, with the option to access usual services as needed.<br><br>14. Do you have any recommendations to improve the service? | a. If so, what?<br>b. How would this help?<br><br>A) If yes, why? If no, why not?<br><br>B) If yes, why? If no, why not?<br><br>If yes, what? |
| 15. Is there anything else you'd like to say about what we have talked about? | |

**Interview questions on demographic characteristics (asked at the end of the interview)**

- Patient or carer? (relationship with patient, if carer)
- Gender
- Age
- How many people do you live/cohabit with?
- Which of these best describes your living arrangement? *Please select one answer (I own my home outright, I own my home with a mortgage, I rent from local authority/housing association, I rent privately, Other (e.g. living with family/friends), prefer not to say)*
- Ethnicity of patient (and family member if applicable)
- At what age did you complete your continuous full time education? *(__ years/never went to school, do not wish to answer)*
- Which of these best describes your highest *educational* qualification? *(Please select one answer) (No formal qualification, GCSE/CSE/O level or equivalent, A level/AS level or equivalent, Degree level or higher, Other (please specify), do not wish to answer)*
- Which of these best describes your current work situation? *(please tick all that apply) (Working full time, working part time, self-employed, student in higher education, unemployed, homemaker, retired, furloughed under COVID-19, Full time carer (of dependent child or adult), not in work due to poor health or disability,, Other (if other please describe), do not wish to answer).*
- Is English your first language? *(yes/no/do not wish to answer)*
- Prior to your current illness, are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?? (Includes problems which are due to old age.) (yes, limited a lot/yes, limited a little, no/do not wish to answer)
- Sexuality
- What is your Postcode? (optional)

## Appendix 4. Participant Information sheet for patient interviews

LONDON'S GLOBAL UNIVERSITY

IRAS: 294011

**Participant Information Sheet: Interviews**

**Title of Project:** COVID care at home: A rapid patient experience study

We would like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read this information and discuss it with others if you wish. If anything is not clear, or you would like more information, please ask us.

**What is the study about?**

- The COVID care at home patient experience study is trying to find out ***how patients and carers experienced receiving COVID care at home.***
- This interview study is part of a larger piece of work, which aims to explore the ***impact of COVID care at home***, which was put in place during the COVID-19 pandemic.
- In this study, we are ***conducting telephone or online interviews*** with patients to understand your experiences of receiving COVID care at home.
- Researchers from two teams are conducting this study: the Rapid Service Evaluation team (RSET) at University College London, and the Birmingham, RAND and Cambridge Evaluation (BRACE) team at the University of Birmingham.

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

You have been invited to take part because you have been offered and/or received the COVID care at home service as a patient or as a family member. As part of this service, you may have been given something called an oximeter. Oximeters are used to measure your blood oxygen levels. You may also have been asked to take and record your results using a diary or a mobile application. You may also have been given other devices to record your health and well-being.

**Do I have to take part?**

No, participation is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part, you can change your mind and withdraw at any time (prior to publication of the results), without reason. Withdrawing will not affect your healthcare.

**What would taking part involve?**

If you decide to take part you will be given this information sheet, and asked to sign a consent form (either by hand or electronically) and send this to the researcher before the interview.

During the interview, we will ask you about your experiences of receiving COVID care at home, things that helped and things that got in the way, your use of other healthcare services and

recommendations for improving COVID care at home. You do not have to answer any questions you do not want to answer.

We will audio-record the interview. Audio-recordings will be professionally typed up. All names will be removed. The recordings will be used only for analysis and no other use will be made of them without your written permission. The interview will take place over the telephone, Zoom or Microsoft teams at a time/date that is convenient for you. The interview will last between 30 and 60 minutes, depending on how much you would like to say.

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

No direct benefits will be received by participants and no expenses or reimbursements will be included. There are no immediate benefits for participants, but it is hoped that these findings will inform service improvements to COVID care at home.

**What are the possible disadvantages of taking part?**

There are no known disadvantages in taking part, but you may find it emotional to discuss your, or your family member's condition and care. If this happens, you are free to stop and/or withdraw from the study up to 14 days after the date that your interview took place. If you decide to withdraw from the study, the information you have provided until that time will be deleted.

**Will my taking part in this project be kept confidential?**

Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else. We will not tell anyone that you have taken part or pass your contact details onto anyone else. All information collected during the study will remain anonymous. Short, anonymised sections of the interview (direct quotes) may be used in written reports, publications, or any other materials produced for the study.

**How will my data be stored/managed?**

We will record the interview on an encrypted, password-protected digital audio recorder. Only the researcher will know the password. Recordings and consent forms will be saved locally to the researcher's computer before being transferred onto a secure computer network and deleted from the recorder. Recordings will be typed up by a professional company, who have a service and confidentiality agreement in place with University College London. Personal names will be removed before analysis takes place. Transcripts may still include information that could identify you. Identifiable information will not be shared with anyone outside of the research team and will not be included in reports or publications. Apart from the professional transcription company who have access to the recordings, only named team members have access to recordings via password-protected computers, and personal data (i.e. name, email address). Our research team is made up of named individuals from University College London, University of Birmingham, Nuffield Trust and RAND Europe. Paper-based data (e.g. signed consent forms) will be stored in locked filing cabinets. Your identifiable data will be stored securely for up to three years after the

end of the project and then destroyed securely. Anonymised data will be archived for up to 20 years.

**What will happen to the results of the research project?**
Findings will be shared in a variety of ways including reports, academic publications and presentations and to a variety of audiences. The study findings will be made publically available. Once published, you will be able to access the findings on the BRACE and RSET websites.

**Who has reviewed this study?**
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the xxx Research ethics committee (Project ID number: xxx).

**Who is organising and funding the research?**
The study is funded by the National Institute for Health Research-NIHR (Health Services and Delivery Research, 16/138/17 – Rapid Service Evaluation Research Team; or The Birmingham, RAND and Cambridge Evaluation (BRACE) Centre Team (HSDR16/138/31). The study is managed by Professor Naomi Fulop, Professor of Healthcare Organisation and Management at University College London. The research will be conducted and analysed by researchers at University College London, University of Birmingham, Nuffield trust and RAND Europe.

**What if something goes wrong?**
If something goes wrong and you want to make a complaint about the conduct of the research, or would like help or advice following your participation, you can contact the study's principal investigator, Professor Naomi Fulop (n.fulop@ucl.ac.uk). If you are not satisfied with the response you receive then you can contact the study Sponsor at the Joint Research Office, UCL: randd@uclh.nhs.uk.

UCL holds insurance against claims from participants for harm caused by their participation in this research. Participants may be able to claim compensation if they can prove that UCL has been negligent.

**Who should I contact with questions about the study?**
If you would like to take part, would like this information in a different format or have any questions, please contact: Researcher name, **Email:** Researcher email, **Tel:** telephone

**Other information**
For general support you may find the following resources useful:

- Patient Advice and liaison service: https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/

**Data Protection Privacy Notice**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

**CORE RESEARCH TEAM**
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Dr Jenny Bousfield, RAND Europe (NIHR BRACE) jennyb@randeurope.org
Dr Lauren Herlitz (NIHR RSET), l.herlitz@ucl.ac.uk
Dr Ian Litchfield, University of Birmingham, I.Litchfield@bham.ac.uk

**Thank you for reading this information sheet and for considering taking part in this research study. If you take part, you will be given a copy of this information sheet to keep and you will be asked to sign two copies of a consent form - one of which you will keep.**

## Appendix 5. Patient consent form for interviews

LONDON'S GLOBAL UNIVERSITY

**Participant Consent Form: Interviews**

| | |
|---|---|
| **IRAS ID:** | 294011 |
| **Study number:** | |
| **Participant identification number:** | |

**Title of Project:** COVID Oximetry@home (CO@h): A rapid patient experience study

This study has been approved by the NHS Research Ethics Committee. Project ID number:

XXXX

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research. You will be given a copy of this Consent Form to keep and refer to at any time.

**Name and Contact Details of the Researcher(s):**
Dr Cecilia Vindrola Padros, University College London, c.vindrola@ucl.ac.uk
Dr Holly Walton, University College London, holly.walton@ucl.ac.uk
Dr Manbinder Sidhu, University of Birmingham, m.s.sidhu@bham.ac.uk
Kelly Singh, University of Birmingham, k.e.singh@bham.ac.uk
Jenny Bousfield, RAND Europe, jennyb@randeurope.org
Dr Jo Ellins, University of Birmingham, j.l.ellins@bham.ac.uk
Dr Lauren Herlitz (NIHR RSET), l.herlitz@ucl.ac.uk
Dr Ian Litchfield, University of Birmingham, I.Litchfield@bham.ac.uk
**Name and Contact Details of the Principal Researcher:**
Prof. Naomi Fulop, University College London, n.fulop@ucl.ac.uk

**Name and Contact Details of the UCL Data Protection Officer:**
Alex Potts, data-protection@ucl.ac.uk

Note: One copy for the participant and one copy to be retained by the researcher
Patient interview consent form_V1.2 11/02/2021

I understand that by initialling or ticking each box below, I am consenting to this part of the study. If I leave a box blank it will be assumed that I DO NOT consent to that part of the study. I understand that if I do not give consent for one or more parts I may not be eligible to take part.

| | | Please initial/tick |
|---|---|---|
| 1. | I have read the Participant Information Sheet for the above study (dated xxx, version xxx). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| 2. | I understand that my participation in an interview is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. If I decide to withdraw from the study, I can do so up to two weeks from the date of the interview. I understand that if I withdraw, the data I have provided up until that time will be deleted. | |
| 3. | I give consent to the interview being audio-recorded. | |
| 4. | I understand that all personal information will be used for purposes explained to me, will remain confidential and that all efforts will be made to ensure I cannot be identified. | |
| 5. | I understand that any identifiable data gathered in this study (e.g. recordings and transcripts) will be stored securely and will not be shared with anyone outside of the research team, except from the professional transcription company. | |
| 6. | I am happy for my anonymised quotes to be used in written reports, academic publications, conference presentations, or any other material produced for the research study. | |
| 7. | I am aware of who to contact if I wish to complain about any aspect of the study. | |
| 8. | I give permission for the identifiable data I provide to be archived at University College London for up to three years after the end of the project. The anonymised data will be archived for up to 20 years. | |
| 9. | I agree to take part in this interview study. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing, and , 'research purposes' will be the lawful basis for processing special category data. | |

| | | |
|---|---|---|
| Name of participant | Date | Signature |
| Name of researcher | Date | Signature |

2

Note: One copy for the participant and one copy for researcher
V1.2 11/02/2021

## Appendix 6. Patient information sheet for survey

LONDON'S GLOBAL UNIVERSITY

IRAS: 294011

**Participant Information Sheet: Survey**

**Title of Project:** COVID Care at Home: A rapid patient experience study

We would like to invite you to take part in our research study evaluating the COVID care at home service. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read this information and discuss it with others if you wish. If anything is not clear, or you would like more information, please ask us.

**What is the study about?**

- The COVID care at home patient experience study is trying to find out ***how patients and carers experienced receiving COVID care at home.***
- This national survey is part of a larger piece of work, which aims to explore the ***impact of COVID care at home***, which was put in place during the COVID-19 pandemic.
- In this study, we are ***conducting a national survey*** with patients and carers to understand your experiences of receiving COVID care at home.
- The study is being undertaken by two national Rapid Evaluation Centres: RSET (based at University College London and the Nuffield Trust) and BRACE (based at the University of Birmingham and RAND Europe). It is funded by the National Institute for Health Research (NIHR) and NHS England and Improvement.

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

You have been invited to take part because you have been offered and/or received the COVID care at home service as a patient or as a family member. As part of this service, you may have been given something called an oximeter. Oximeters are used to measure your blood oxygen levels. You may also have been asked to take and record your results using a diary or a mobile application. You may also have been given other devices to record your health and well-being.

**Do I have to take part?**

No, participation is entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part, you can change your mind and withdraw from the study up to 14 days after taking the survey, without giving a reason. Withdrawing will not affect your healthcare.

**What would taking part involve?**

You will be sent an email from your NHS service with a link to complete a survey online. The survey will ask you about your experiences of receiving COVID care at home. As part of the survey we will first ask you to share some basic demographic details and then answer questions about the

service itself, your experiences receiving and engaging with the service, and your use of other services. The survey should take between 15 and 30 minutes to complete. We will ask you to provide consent at the start of the survey.

**How long will the study last?**
The total duration of the study will be approximately six months but your involvement will only be the duration of completing the survey. You may also be given the option to take part in a one-to-one interview with a researcher.

**Can I stop being in the study?**
You can withdraw from the study up to 14 days after the date you complete the survey. If you decide to withdraw from the study, any data you may have provided will be destroyed following UK Data Protection Act (2018) and General Data Protection Regulation (GDPR) 2018 guidelines.

**What are the possible benefits of taking part?**
No direct benefits will be received by participants and no expenses or reimbursements will be included. There are no immediate benefits for participants, but it is hoped that these findings will inform service improvements to COVID care at home.

**What are the possible disadvantages of taking part?**
There are no known disadvantages in taking part, but you may find it emotional to answer questions about your, or your family member's condition and care. If this happens, you are free to stop and/or withdraw from the study up to 14 days after the date that your interview took place. If you decide to withdraw from the study, the information you have provided until that time will be deleted.

**Will my taking part in this project be kept confidential?**
The information that you provide when completing the survey will remain anonymous. This is a very low risk study. NHS trusts will be pseudonymised when reporting the study findings.

**How will my data be stored/managed?**
The information obtained from surveys will be stored securely and managed in accordance with the UK Data Protection Act (2018) and General Data Protection Regulation (GDPR) 2018 and in accordance with the University College London, Nuffield Trust RAND Europe, and University of Birmingham's policies for data storage and management. Identifiable data (your name and contact details) may be stored at the named organisations. All data will be stored on password-protected computers and servers, and will only be accessible to members of the research team. Our research team is made up of named individuals from University College London, University of Birmingham, Nuffield Trust and RAND Europe. Only these named researchers will have access to the data.

Paper survey copies will be sent to and stored at the Nuffield Trust. Paper copies will then be scanned into the UCL Data Safe Haven. Online survey responses will be directly sent to the UCL Data Safe Haven. Your identifiable data will be stored securely for up to three years after the end of the project and then destroyed securely. Hard copies of research data will be shredded and electronic data will be destroyed. Shredded data will be securely disposed of in confidential waste. Anonymised data will be archived for up to 20 years. We will ensure that any personal information gathered for this research study is kept confidential, unless we learn of serious risk to patients or staff from the information disclosed.

**What are the costs of taking part in this study? Will I be paid for taking part in this study?**
There are no costs to you for taking part in this study. You will not be paid for taking part in this study.

**What are my rights if I take part in this research study?**
Taking part in this study is your choice. You may choose either to take part or not to take part in the study. No matter what decision you take, there will be no consequences to you in any way.

**Who is organising and funding the research study?**
The study is funded by the National Institute for Health Research-NIHR (Health Services and Delivery Research, 16/138/17 – Rapid Service Evaluation Research Team; or The Birmingham, RAND and Cambridge Evaluation (BRACE) Centre Team (HSDR16/138/31). The study is managed by Professor Naomi Fulop, Professor of Healthcare Organisation and Management at University College London. The research will be conducted and analysed by researchers at University College London, University of Birmingham, Nuffield Trust and RAND Europe.

**Who has reviewed the research study?**
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the xxx Research ethics committee (Project ID number: xxx).

**What will happen to the results of the research project?**
Findings will be shared in a variety of ways including reports, academic publications and presentations and to a variety of audiences. The study findings will be publically available. Once published, you will be able to access the findings on the BRACE and RSET websites.

**"What if there is a problem" or "What happens if something goes wrong?"**
If something goes wrong and you want to make a complaint about the conduct of the research, or would like help or advice following your participation, you can contact the study's principal investigator, Professor Naomi Fulop (n.fulop@ucl.ac.uk). If you are not satisfied with the response you receive then you can contact the study Sponsor at the Joint Research Office, UCL: randd@uclh.nhs.uk.

UCL holds insurance against claims from participants for harm caused by their participation in this research. Participants may be able to claim compensation if they can prove that UCL has been negligent.

**Who should I contact with questions about the study?**
If you would like to take part, would like this information in a different format or have any questions, please contact: Researcher name, **Email:** Researcher email, Tel: Researcher telephone

**Other information**
For general support you may find the following resources useful:

- Patient Advice and liaison service: https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/

**Data Protection Privacy Notice**
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

**CORE RESEARCH TEAM**
**Principal Investigator:** Prof Naomi Fulop n.fulop@ucl.ac.uk

Dr Cecilia Vindrola, UCL (NIHR RSET) c.vindrola@ucl.ac.uk
Dr Manbinder Sidhu, University of Birmingham (NIHR BRACE) m.s.sidhu@bham.ac.uk
Kelly Singh, University of Birmingham (NIHR BRACE) K.E.Singh@bham.ac.uk
Dr Jo Ellins, University of Birmingham (NIHR BRACE) J.L.Ellins@bham.ac.uk
Dr Holly Walton, UCL (NIHR RSET) holly.walton@ucl.ac.uk
Dr Jenny Bousfield, RAND Europe (NIHR BRACE) jennyb@randeurope.org
Nadia Crellin, Nuffield Trust (NIHR RSET) nadia.crellin@nuffieldtrust.org.uk
Dr Lauren Herlitz (NIHR RSET), l.herlitz@ucl.ac.uk
Dr Ian Litchfield, University of Birmingham (NIHR BRACE), I.Litchfield@bham.ac.uk

***THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION AND FOR CONSIDERING HELPING WITH OUR STUDY***

## Appendix 7. Patient consent information for survey

Patient consent survey_v1.1 28012021
IRAS: 294011

**Blurb on front page of patient survey & consent questions**

**PAGE 1**

**Please read this information before completing the survey**

Thank you for taking the time to look at our survey. If you decide to complete this survey, the responses you provide will help us to understand more about the experiences of patients and carers who have received COVID care at home via the COVID oximetry@ home service. The survey is part of a larger study which is looking at the impact of COVID oximetry@home.

The survey may take between 15 and 30 minutes to complete.

The questions in the survey will ask you about yourself, the service that you received and your experience receiving and engaging with the service.

The survey is part of a larger study which is funded by the UK National Institute for Health Research (NIHR). This study has been reviewed and given favourable opinion by the xxx Research ethics committee (Project ID number: xxx).

The principal investigator for this study is Professor Naomi Fulop (n.fulop@ucl.ac.uk). If you have any questions about the survey, please contact [researcher name] by email: [email], by phone: .

**Important information about your data**

**By completing this questionnaire, you are giving your consent for the information you have provided to be used by researchers at University College London, University of Birmingham and RAND Europe.**

The information obtained from surveys will be stored securely and managed in accordance with the UK Data Protection Act (2018) and General Data Protection Regulation (GDPR) 2018 and in accordance with the University College London, RAND Europe, Nuffield Trust and University of Birmingham's policies for data storage and management.

Your personal data will be handled securely and anonymised after analysis and before publication. You can withdraw your data up until 14 days after the date that you complete the survey.

For more information about the survey, please read the Participant information sheet (date: xxx version xxx)

Thank you so much for taking time to read this information.

If you would like to complete this survey, please click on the 'next' button.

If you would not like to complete the survey, please close your browser.

**PAGE 2**

**Consent**

By ticking each box below, you are providing consent to take part in this survey:

1. I have read the information provided for this study (Information sheet dated xxx, version xxx). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation in this survey is voluntary and that I am free to withdraw up to 14 days after completing the survey. I understand if I withdraw, the data I have provided up until that time will be deleted.
3. I understand that all personal information will be used for purposes explained to me, will remain confidential and that all efforts will be made to ensure I cannot be identified.
4. I understand that any identifiable data will be stored securely and will not be shared with anyone outside of the research team.
5. I give permission for the identifiable data I provide to be archived at University College London for up to three years after the end of the project. The anonymised data will be archived for 20 years.
6. I agree to take part in this survey