



PARTICIPANT INFORMATION SHEET (Version 4, 28/08/2024)

PROJECT TITLE: Psychological and Social Factors Influencing Wellbeing and Distress in Long COVID

INTRODUCTION:

- You are being asked to join this study about how people cope with having Long COVID.
- This study is survey based and takes approximately 15 minutes. You can do this on your own, either on paper (if you have been provided a paper pack) or online through following this link: <https://tinyurl.com/5jae9h2d>
- Before you decide, it is important you know why we are doing this research and what it will involve. Please take time to read the information here carefully.

WHO IS LEADING THIS STUDY?

- Ronan McGrath, NHS Trainee Clinical Psychologist, is leading this study as part of his professional training course in Clinical Psychology.

WHAT IS THE PURPOSE OF THE STUDY?

- The aim of the study is to explore how people cope with challenging Long COVID symptoms and how this relates to their mood.
- This can help healthcare professionals to better support people struggling with Long COVID.
- Please note: this research **is not** being done to explore if mental health problems are the reason people have Long COVID.

CAN I TAKE PART IN THIS STUDY?

You can take part in this study if:

- You are 18 or over

- You live in the UK
- A healthcare worker in the UK has told you that you have any of the following: 'Long COVID', 'Ongoing symptomatic COVID-19' or 'Post-COVID-19 Syndrome' and you still have the condition
- You are fluent in English.

Please note, you will not be able to take part in this study if you:

- Had a mental health difficulty and did **not** consider yourself recovered within the 12 months before getting COVID
- Have another long term health condition (besides Long COVID) that significantly impacts your quality of life such as:

-Chronic pain conditions such as fibromyalgia, Rheumatoid arthritis etc.

-Heart disease

-Cancer

-Acquired brain injury

-Functional neurological disorder

-Other conditions which significantly impacts your quality of life

DO I HAVE TO TAKE PART?

No – it is entirely up to you. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your healthcare or legal rights.

WHAT HAPPENS IF I DECIDE TO TAKE PART?

- If you chose to take part, you will be asked to complete the Consent Form on the next page to show you understand your rights and you are happy to take part.
- In this survey, there will be questions about your condition of Long COVID, your mood and some basic demographic questions.
- The survey takes about 15 minutes to complete in one go, but you can take as long as you want and at a time that suits you. It is best to take the survey somewhere quiet where you can focus.

WHAT MIGHT BE THE BENEFITS OF TAKING PART?

There are no direct benefits to you, but you will help us to better understand how people cope with Long COVID and how healthcare workers can better support people with the condition.

ARE THERE ANY RISKS OR DISADVANTAGES OF TAKING PART?

- There are no big risks from taking part. There is a small risk that you may find some of the questions upsetting.
- At the end of this sheet and at the end of the survey, some sources of support will be shared.

WILL MY TAKING PART BE KEPT CONFIDENTIAL?

- All the information we collect during the course of the research will be kept confidential. There are strict laws that protect your privacy at every point.

HOW WILL WE USE INFORMATION ABOUT YOU?

- We will record your age, gender, ethnicity and occupation, but you do not have to leave any information that can identify you as an individual. This means that your participation will be kept anonymous.
- All collected responses will be analysed and written up as a report which may be published, this will only discuss group findings.
- With your consent, your anonymised data will also be kept for potential future research. This will be kept secure as anonymous data in long term data storage approved by the University of Edinburgh.
- For further information about data privacy for research participants please refer to <https://data-protection.ed.ac.uk/privacy-notice-research>

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

- You can stop taking part in the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

The University of Edinburgh is the co-sponsor for this study along with NHS Lothian, based in the United Kingdom. We will be using the information you provide in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep this anonymised information about you for 10 years after the study has finished.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH?

The results of this research will be written up as a doctoral thesis submitted to the University of Edinburgh. This will also take the form of an article submitted to a peer-reviewed journal and may be presented at academic conferences. If you would like to access the results of this study, please see <https://sites.google.com/view/live-research-long-covid/home>.

WHO IS ORGANISING THE RESEARCH?

This study has been organised by Ronan McGrath as part of his doctoral professional training course in Clinical Psychology. Two Clinical Psychologists are part of the research team and supervise the project: David Gillanders (Senior Lecturer in Clinical & Health Psychology, The University of Edinburgh) and Dr Emily Revell (Clinical Psychologist with the Mental Health after COVID Hospitalisation (MACH) Service, NHS Lothian). The study is co-sponsored by the University of Edinburgh and NHS Lothian.

WHO HAS REVIEWED THE STUDY?

The study proposal has been reviewed by the Ethics committee in the Schools of Health and Social Sciences from The University of Edinburgh. All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. A favourable ethical opinion has been obtained from North East - Tyne & Wear South Research Ethics Committee (reference number: 24/NE/0053). NHS Management Approval has also been given.

WHO CAN I CONTACT?

If you have any further questions about the study, please contact the lead researcher, Ronan McGrath at r.mcgrath-6@sms.ed.ac.uk.

If you want to talk about this study with someone independent of the study team, please contact Dr Tim Bird (Tim.Bird@ed.ac.uk).

If you want to make a complaint about the study, please contact the Head of School for Health and Social Sciences, Professor Matthias Schwannauer (headofschool.health@ed.ac.uk). Please include the study title and put your concerns about the study in your complaint email.

Or, you can contact the Patient Experience Team at:

NHS Lothian
2nd Floor
Waverley Gate
2-4 Waterloo Place

Edinburgh
EH1 3EG
Tel: 0131 536 3370
Email: feedback@nhsllothian.scot.nhs.uk

Please keep this information sheet for your own records.

Further Support

For any health related queries or concerns then please contact your General Practitioner (GP).

For further support or information, then please see the following resources:

- NHS long COVID website: <https://www.yourcovidrecovery.nhs.uk/i-think-i-have-long-covid/>
- Chest Heart and Stroke Scotland have a range of support and information for those with Long COVID.

Tel: 0808 801 0899

Website: <https://www.chss.org.uk/long-covid/#5>

- Samaritans: a general support service (not specifically for those with Long COVID), they are there 24 hours a day, 365 days a year. You can call 116 123 for free if you are going through a difficult time and want someone to talk to.

Website: <https://www.samaritans.org/?nation=scotland>