PARTICIPANT INFORMATION SHEET

TITLE OF PROJECT: To what extent do Long- Covid patients perceive the treatment available appropriate?

VERSION NUMBER: 1 **DATE:** 09/12/24

This research has been approved by the Health and Sciences Research Ethics Panel in line with the University's Research Ethics Policy. Ethical approval reference number: 22022000980

Invitation

The researcher would like to invite you to take part in a research project which involves completing an anonymous online survey. Before you decide whether to take part, it is important that you understand why the research is being done, what it will involve for you, what information the study will ask from you, and what the researcher will do with that information. Please take time to read the following information carefully. Thank you for reading.

Who is undertaking the research?

Name: Tillie Kendrick
Position: BSc (Hons) Physiotherapy Student
Role on the project: Researcher

What is the purpose of the research?

This study aims to identify whether patients who are diagnosed with Long-Covid and provided with physical treatment (not including medication intervention) believe the treatment is appropriate (*something to be suitable and proper in the circumstances)* for them and their condition.

Covid-19 spread quickly across the world and healthcare professionals for a long time were unsure on the treatments. Similarly, long-covid *(a syndrome characterized by the persistence or development of symptoms attributed to Covid-19, typically including extreme fatigue, breathlessness, and muscle weakness, more than twelve weeks after initial infection)* was unknown to the medical profession and therefore treatments were put in place with minimal research supporting them. The researcher is interested to find out whether the people who are involved, or have been involved in physical treatments such as pulmonary rehabilitation classes or physiotherapy sessions believe they are properly catered towards helping their quality of life and symptoms improve. Additionally, the researcher would like to hear the opinions of people living with long Covid about if they believe there is a gap in appropriateness, the treatment should be better catered towards them, enabling them to engage better and enjoy the benefits of the treatment advertised.

Why have I been invited to take part?

You have received this invitation because you are a part or involved in the long-covid support group, and therefore may be appropriate to take part in the survey enclosed. If you are 18+, have Long-Covid, live in England and have received physical treatment for your condition (excluding medication treatment), and you would like to help me get a better understanding of how the people directly involved, the receiving end of the treatment feel about the appropriateness then I would love to herd from you via the survey. The researcher hopes to recruit *20 participants* for this study.

What will happen if I agree to take part?

If you agree to take part you will be asked to complete an anonymous survey. The survey will be attached to this email, you will need to follow the secure link to reach the survey. The survey will include both open ended questions where you will be able to give as much or as little detail as you wish in the answer box, as well as questions that will be 'on a scale of 1-5 how far would you agree'. All questions are completely optional or will have a 'prefer not to say' box. You are under no obligation to finish the survey if you decide you no longer want to participate, no responses will be sent to the researcher unless you press the final submit button allowing you the option to withdraw at any point during the survey. The survey will take approximately 20-30 minutes to complete.

Do I have to take part?
No. It is up to you to decide whether or not you want to take part in this study. Your participation is entirely voluntary.

If you do decide to take part, you will be asked at the start of the survey to agree to a number of statements to indicate that you are over 18 years old, have read and understood this information and agree to take part in the survey. By submitting the survey, you are providing consent for the data you have given to be used in the study.

You can withdraw from the study by closing the browser page down without submitting your responses and your data will not be saved. Please note that once you have submitted your survey responses you will be unable to withdraw your data as participation is anonymous and there will be no way of indentify which responses are yours.

What are the benefits for me in taking part?
Although there will be no direct benefits to you from participating in this research it is hoped the research will better my understanding, and other physiotherapists and students understanding when we are prescribing treatment for Long-Covid in practice. It will also give the researcher an understanding from people who have experienced it first hand which the researcher can share with people who are potentially anxious or unsure about getting involved. Additionally, if any issues arise, such as people feeling treatments are not appropriate, the researcher will be able to gain a better understanding of this hearing first hand from people living with Long-Covid.

Are there any risks for me if I take part?
The researcher does not anticipate any risks occurring during this research or survey, however, if you were to feel uncomfortable or upset by any of the questions in the survey you can choose to skip the questions you do not wish to answer, without needing to justify why.

What will you do with my data?
The data you submit will be treated confidentially at all times. No personal identifiable information will be obtained during or as part of the study. Your answers will be completely anonymous.

The researcher anticipates that the results of the research will be written up used within my dissertation project solely.

During the project, all data will be kept securely. Specifically it will be stored on a password protected device only accessible by me. In line with the University's Policy for the Effective Management of Research Data and its Information Security Policy. It will not be shared with anyone other than myself.

How long will you keep my data for?
At completion of the project the researcher will destroy all data relating to the project.

Thank you for taking the time to read this information

If you have any questions or would like further information, please contact:

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Or
Research Supervisor: g.hayden@worc.ac.uk

The University is registered with the Information Commissioner’s Office and the University Data Protection Officer is Helen Johnstone. For more on the University approach to Information Assurance and Security visit: https://www.worcester.ac.uk/informationassurance/index.html.

Allegations of Research Misconduct

To view University of Worcester’s Procedures for Dealing with Allegations of Research Misconduct please click here. For information about who to contact please click here.

If you would like to speak to an independent person who is not a member of the research team, please contact the University of Worcester, using the following details:

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