

## **PARTICIPANT INFORMATION SHEET**

### **CAREVIS Long-Covid STUDY**

The CAREVIS Study  
PIS Carer V.4 20.4.22  
IRAS Project ID: 296159

# **Beyond Words: Co-creation And Evaluation of a Visual REsource to support Long-COVID Care in people with Intellectual Disabilities (CAREVIS Long-COVID)**

You are invited to take part in a research study. To help you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Please talk to us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

1. We aim to develop and explore the impact of using a **wordless book for people with** learning disabilities (also known as intellectual disabilities) who have, or have recently had, Long-Covid. We will ask people with a learning disability, and their carers, what having Long-Covid was like, how they got diagnosed and about the healthcare they received. We will use this information to develop an accessible picture book that will help people with a learning disability explain their symptoms of Long Covid to health professionals. It is hoped that by improving communication, people with a learning disability and Long-Covid will be able to access care across different medical and care services easier and faster. We will start using the wordless book across services within Hertfordshire Partnership NHS Foundation Trust (HPFT) and measure how well it is working.

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

2. You have been asked to take part because you are a carer of a person with learning disabilities who has, or recently has had, Long-Covid. You are ideally placed to tell us about your experiences of supporting someone, providing care and making decisions about their care, while they have Long-Covid.

### Do I have to take part?

3. No, it is entirely up to you to decide whether or not to take part. Please take time to read this information sheet and ask the researcher any questions you may have. If you 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 legal rights.

### What will happen if I take part?

4. If you are interested in participating in the study, please contact the researcher using the details provided below to express your interest and to ask any questions you may have about the study.

Next, the researcher will schedule a **phone or Zoom interview** with you for a time that is convenient for you. This interview will take up to an hour and will be a conversation about your experiences of supporting a person with learning disabilities and Long-Covid. If the person you care for is able to take part in the study, we will ask their permission to talk to you as it might be partly about them (your experiences supporting them).

It is your decision whether to take part in the study. If you agree to take part, you will be invited to participate in an audio recorded interview. We can conduct the interview with the person you care for (if you wish), or separately. This is up to you and the person you care for. They might want your support in the interview with them, but you might also wish to talk to us separately.

We will do the interview at a time that is convenient to you and should last no longer than an hour, but this is flexible according to your needs. You will only need to be interviewed once during the study. We can interview you by telephone or Zoom is more convenient.

You will need to provide verbal or written consent before the start of the interview to confirm that you agree to take part in the study. This consent process includes agreeing to an audio recording of the interview so that the researcher can produce an accurate account of what was said (a transcript) for analysis. The audio recording will be professionally transcribed. Once the transcript has been made it will be de-identified and the audio file will be deleted.

### What are the possible benefits of taking part? What are the possible disadvantages of taking part?

5. Benefits: We expect the findings to lead to greater understanding among healthcare leaders and policy makers about supporting people with a learning disability and Long-Covid to access to health care. Although this may not benefit you personally, information you give may help influence and shape services in the future and will contribute to our understanding of how best to provide care.

We would offer you a £10 gift token to show our appreciation for your participation.

Disadvantages: You will be asked to give up time to take part in the interview. During interviews, people sometimes become upset when discussing topics like being a carer. If you would like to stop or take a break during the interview at any time, please let the researcher know and they will stop the recorder for as long as you need.

### What will happen if I don't want to carry on with the study

6. You can stop at any time without giving a reason. If you would like to stop during the interview, please let the researcher know and they will stop the interview immediately.

In the unlikely event that serious safeguarding concerns are raised, the interviewer will immediately stop the interview and explain the next steps in terms of escalation, liaising with senior people in the care team as required. Such information may be shared in accordance with the law and local safeguarding procedures.

### How will we use information about you?

7. We will need to use information from you for this research project.

This information will be your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

### What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study within the University secure systems.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information by asking one of the research team or by calling the University of Hertfordshire's Data Protection Officer: [dataprotection@herts.ac.uk](mailto:dataprotection@herts.ac.uk)

### **What will happen to the results of the study?**

8. The results of the study will be written up in reports for professional bodies including Royal Colleges of Nursing and Psychiatry, and Royal College of Nursing Foundation, NHS England, and RADIANT, a network of carers and professionals who care for people with learning disabilities in the UK. The results will be published in professional journals and presented at conferences and dissemination workshops. We will email you a summary of the findings.

A public-facing report will be written and circulated to the funding charity, and for public involvement groups. We will publicise the findings from this research via blogs on institutional websites. You will not be identifiable from any published results.

### **Who is organising and funding the research?**

9. This study is being carried out by staff at the University of Hertfordshire, , Hertfordshire Partnership Foundation NHS Trustt and Hertfordshire County Council. The research is funded by Hertfordshire Partnership Foundation NHS Trustand sponsored by the University of Hertfordshire.

### **Who has reviewed the study?**

10. This project has been reviewed by Leicester Central NHS Research Ethics Committee (IRAS number: 296159) and a favourable opinion has been given.

### **Researcher Contact Details**

11. If you have any further questions about the study please contact Prof Natalie Pattison by email on [n.pattison@herts.ac.uk](mailto:n.pattison@herts.ac.uk), Dr Rajnish Attavar via his secretary ([t.glover1@nhs.net](mailto:t.glover1@nhs.net))\_or Dr. Helena Wythe by email on [h.f.wythe@herts.ac.uk](mailto:h.f.wythe@herts.ac.uk).

### **Independent Contact Details**

12. If you would like to discuss this study with someone independent of the study please contact: Dr Rosemary Godbold

Email: [r.godbold@herts.ac.uk](mailto:r.godbold@herts.ac.uk)

## Complaints

13. If you have a concern about any aspect of this study, please speak to me and I will do my best to answer your questions. If you remain unhappy and wish to complain formally you can do this through the University complaints procedure. If you have any complaints or concerns about any aspect of the way you have been approached or treated during this study, please contact the University of Hertfordshire Secretary and Registrar, (Sharon Harrison-Barker: [s.harrison-barker@herts.ac.uk](mailto:s.harrison-barker@herts.ac.uk)), University of Hertfordshire, College Lane, Hatfield, Hertfordshire, Herts AL10 9AB. You can also contact Patient Advice and Liaison (PALS) at Hertfordshire Partnership Foundation NHS Trust at The Colonnades, Beaconsfield Road, Hatfield, Herts, AL108YE, or call 01707 253916 or email: [hpft.pals@nhs.net](mailto:hpft.pals@nhs.net).

**Thank you very much for reading this information and  
considering taking part in this study**