Version 4, January 20, 2025

## Participant Information Sheet for Adults with LTNCs

**Learning from the COVID-19 pandemic: exploring the care and support needs of adults with long-term neurological conditions during the COVID-19 pandemic for emergency preparedness.**

### Introduction

The study aims to understand the care and support needs of adults with long-term neurological conditions (LTNCs), such as Parkinson's, Dementia, and others, and their unmet healthcare needs during the COVID-19 pandemic. It is being carried out by Ebere Ugwuodo (EU) as phase 3 of a project for the award of a Doctor of Philosophy (PhD) degree. The study is supervised by Dr Pauline Campbell, Dr Julie Cowie, and Professor Lorna Paul at Glasgow Caledonian University.

Before deciding whether to take part, it is important you understand what the study will involve. Please read the following information carefully and talk about it with others if you want to. If you need more information, please don't hesitate to contact us at the address below for more details.

### Why is this study important?

The Covid-19 pandemic resulted in widespread disruption of healthcare services which we were not prepared for. This was particularly true for neurological services. I am conducting this study to hear the views and experiences of people with long-term neurological conditions to see how the Covid-19 pandemic impacted on their lives. I hope to be able to identify any gaps in the care and support and identify their met and unmet healthcare needs during the COVID-19 pandemic. This information will be used to help us be better prepared for any future pandemic or global healthcare crisis.

### Why have I been invited?

You have been invited because you have experience of living with a long-term neurological condition during the Covid-19 pandemic. Your experience and perspectives are really important to provide a clear picture of what it was like for someone living with a neurological condition during the COVID-19 pandemic

**What will I have to do if I take part?**

If you are interested in participating, you will be invited to consent. I will email you a consent form before the interview, for you to sign and return to me before the interview. If you prefer, I can send you this in the post with a self-addressed envelope. You can also take a picture of the signed document and email back to me. Alternatively, you can also give verbal consent during the interview if you prefer.

You will be interviewed by myself, Ebere, at a time that suits you. Interviews will be conducted using an online meeting tool, Microsoft Teams or through phone calls. There is also an opportunity for an email interview if you wish or have difficulty talking on Microsoft Teams. I will explain the procedure and send you a copy of the interview questions beforehand. However, I will send you the meeting link if you wish to discuss using Microsoft Teams. During our interview, I will ask you some questions about your experiences of living with a neurological condition during Covid-19. There are no right or wrong answers, I'm just keen to hear your own experiences and thoughts on the care you received during this time. The interview will be recorded using a password-secured device. The interview will take no longer than around 45-60 minutes.

**Do I have to take part?**

Participating in this study is entirely your choice. You can change your mind and withdraw your consent at any time. Please be assured that your data will be treated with the utmost confidentiality and will be deleted and destroyed securely.

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

There are no known risks to participation. Speaking about experiences during the pandemic may bring up some upsetting memories. However, there will be an opportunity to take a break during the interview, and you are not compelled to continue a conversation that makes you uncomfortable. The interview will take 45-60 minutes to conduct. If you feel uncomfortable about any of the topics raised, you can let me know if you do not wish to discuss the issue or if you wish to stop or terminate the interview. We can reschedule at any time that suits you. Your safety and well-being is important to us. If a significant risk to yourself or another person becomes apparent, I may have to discuss with my supervisor how best to support you. I will also signpost you to national helplines or G.P. Before the interview. I will send you a short information sheet showing relevant support service information (such as charities and helplines) or we can also go through that before the interview. After the interview, there will be a de-brief; this will be in the form of a short conversation to check that you are okay and to remind you of options for support if you need it.

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

There are no direct benefits to taking part but your experiences may help services respond differently in the future.

Considering that the COVID-19 pandemic significantly impacted people with LTNC, this research will contribute to knowledge related to lessons learned during the pandemic and preparedness against future crises. Your response will help neurology practices prepare for emergencies whenever they occur.

**What happens when the study stops?**

Written reports of the study findings will be available. When the study is finished I will email or post a copy of the findings to you if you are interested.

**What if there is a problem?**

If you are concerned about your participation in the study and would like to speak with someone other than the study team, please contact Professor Marian Brady at [Email:m.brady@gcu.ac.uk ].

**What will happen to the information given during the study?**

This section will explain what happens to the information you provided during the study.

Your data will be collected without any personal identifiers and stored securely. We will follow the University's policy on data protection to destroy data when the study ends (https://www.gcu.ac.uk/aboutgcu/universitygovernance/data-protection). All your personal information will be stored securely following the General Data Protection Regulation (2018) in GCU one drive and will only be accessed by research team members. Hard copy materials will be locked in a cabinet in a locked/secured office, which will be destroyed confidentially 10 years after the study. The audio recording of your interview will be transcribed anonymously. The audio will be erased right after transcription. We will keep identifiable information (like your name and email) separate from the recording and transcript to protect your privacy. This identifiable information will only be used to contact you and will not appear in any documents or the final report.

Glasgow Caledonian University is responsible for your data. We process your information under Article 6(1)(e) of the General Data Protection Regulation, which allows us to do this for public tasks. If you have questions about data protection, please reach out to the University's Data Protection Officer (DPO) at this email: dataprotection@gcu.ac.uk. If you are unhappy with the response from the University, you have the right to complain to the Information Commissioner's Office (ICO). The ICO can be contacted by email: casework@ico.org.uk.

GDPR also gives study participants the right to ask for their data to be erased. If you want us to stop using your data, you can contact the lead investigator and ask for your data to be erased. However, it will only be possible to erase data that has yet to be published. Further information about your rights can be found at: https://www.gcu.ac.uk/dataprotection/rights

**Who is organising and funding the study?**

This study is being organised by Ebere Ugwuodo and funded through a Glasgow Caledonian University PhD Studentship.

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

The results will also be published in academic journals and presented at scholarly conferences. However, your details will not be identifiable from these reports, presentations, or publications.

**Who has reviewed the study?**

All studies involving human participants carried out at Glasgow Caledonian University are reviewed by an ethics committee. The committee's role is to protect study participants' safety, rights, well-being, and dignity. This study was reviewed by the School of Health and Life Sciences nursing departmental committee at Glasgow Caledonian University.

**What happens next?**

If you are interested in participating and would like to know more, please get in touch with Ebere Ugwuodo at Ebere.Ugwuodo@gcu.ac.uk.

**How do I contact the study team?**

You can get more study information or discuss the project with the research team:

| **Lead investigator (PhD Student)** | **Director of Studies** |
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| Mrs Ebere Ugwuodo<br>School of Health and Life Sciences<br>Glasgow Caledonian University<br>Cowcaddens Road<br>Glasgow, G4 0BA<br><br>e-mail: Ebere.Ugwuodo@gcu.ac.uk<br>phone: 01413318750 | Dr Pauline Campbell<br>School of Health and Life Sciences<br>Glasgow Caledonian University<br>Cowcaddens Road<br>Glasgow, G4 0BA<br><br>e-mail: Pauline.Campbell@gcu.ac.uk<br>phone: 0141 2731934 |
| **Independent staff member (separate from the research team)** | |
| None | |

Thank you for taking the time to read this information