

## **Study Information Sheet for Stroke Survivors and their Carers**

**What are the views of stakeholders on how motivation of stroke survivors and support from therapists help with rehabilitation including self-managed practice?**

### **Introduction**

You are invited to take part in a workshop to **share your experiences about rehabilitation** (including physiotherapy, occupational therapy and speech and language therapy) after stroke. We are interested to hear your views on the importance of stroke survivors' motivation and support from therapists in rehabilitation, including home-based exercises and activities. The study is being conducted Stefanie Schnabel at Glasgow Caledonian University and is supervised by Prof. Frederike van Wijck and Prof. Lisa Kidd. Stefanie is carrying out the study as a part of an educational course for the award of a doctoral degree.

Before you decide whether or not to take part, it is important for you to understand what participation in the study will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact us at the address below if you would like more information.

### **Why is this study important?**

I aim to investigate **what helps stroke survivors like you during rehabilitation and when practising by yourself**. The purpose of the workshop is to hear your views about your **motivation** and the role of the **therapist's support** to engage in rehabilitation, including home-based exercises and activities. We would like to know if the study findings from a previous study reflect what people like yourself have experienced and what is important to them to engage in rehabilitation. Including your views about the motivation you had and the support of therapists to engage in rehabilitation, will help us better understand how we can improve rehabilitation for other people like you.

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

We would like to ask you to take part in a **two-part workshop** (within 2-3 weeks) and each will last for approximately **2 hours**. The workshops will consist of **5-6 participants** and will be held by Stefanie **online** (we will provide guidance to help you with this) and to be completed **at the end of March 2024**. The

workshops will ask you for your views on the importance of motivation and the support of therapists during rehabilitation, including home-based exercises and activities.

These are the steps we will follow before you sign up for the workshops:

1. You will get the opportunity to **ask** Stefanie **any questions** about the study and participation before you decide to take part.
2. You will be given **time (about one week) to read the form** and to ask Stefanie any questions about it.
3. Once all your questions have been answered and you have decided that you want to take part in the study, we ask you to **sign the consent form** prior to the first workshop starting.
4. To provide written informed consent, we will send you the consent form electronically or by post (as you prefer). This informed consent form will ask you some questions.
5. You can return the consent form electronically as a scanned copy or photograph or by post. You will be able to keep a copy of the signed consent form or we can send you one.

If you have difficulties signing the consent form, you can give us verbal consent either over the phone or through video call. This needs to be done in the presence of a witness, who will sign the form on behalf of you. Either way, we will help you with providing consent.

Once consent has been completed, we will invite you to attend the workshops **online** to discuss the study findings from a previous study with other stroke survivors and their carers. Prior to the workshops we will send you a very short document for you to read in preparation for the workshops. If you need help with this, we will be happy to assist you.

The **workshops** include the following: in **workshop one** a short introduction of the study and the ideas will be given. We will then talk about **idea 1**, which is about the **motivation of stroke survivors** to engage in rehabilitation including home-based exercises and activities.

In **workshop 2** we will talk about **idea 2**, which is about the **importance of the support of therapists** to engage in rehabilitation including home-based exercises and activities.

We are interest in your views on each of these ideas and to hear which of these ideas you think should be the first for us to study further.

### **Do I have to take part?**

No, taking part in the workshops is **voluntary** and also you decide whether or not you want to take part. If you decide to take part, you will be asked to sign a consent form.

You can **stop taking part in the study at any time, without giving a reason.**

Declining to take part in the workshops or withdrawing from the study will not affect your medical care or legal rights. If you decide to **withdraw** during the workshops, your data will be destroyed. However, once your data is anonymised and analysed, we cannot delete your contribution.

### **What are the possible risks with taking part?**

Although we do not anticipate possible risks to you, taking part in the workshops and discussing your experiences might be distressing for you. If this happens, you have the option to take a break as long as you need, leave the workshops or stop engaging in the discussion. With your consent the researcher can guide you to the GP, the local stroke nurse or other professionals to obtain support or signpost you to online resources that offer help and emotional support.

Another unlikely risk is that data protection is breached and we accidentally share your information.

Measures are in place to prevent the breach of data such as all electronic data we collect will be stored on encrypted GCU devices and data on paper will be kept in locked filing cabinets. We will inform you if the risk of data breach occurred and if you no longer want to participate in the study, you can leave and are not required to give a reason.

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

We can't promise the study will help you personally. Talking about your experience may be helpful for you. However, with your contribution to the workshops you will be able to help us to improve our understanding of how we can improve rehabilitation for people like you in the future.

### **What happens when the study stops?**

Written reports of the study findings will be available after the study results have been analysed. We will send you a **summary report of the study findings if you wish**. Further written reports of the study findings will be available and can be requested from Stefanie.

### **What if there is a problem?**

If you are concerned about your participation in the workshops and would like to speak with someone out with the study team, please contact **Prof. Maggie Lawrence** from the School of Health and Life Sciences, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA Scotland, UK; Tel.: 0141 331 8863; Email: [Maggie.Lawrence@gcu.ac.uk](mailto:Maggie.Lawrence@gcu.ac.uk) .

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

This section will explain what happens to the information you given during the study and how it will be protected. The following **personal data will also be collected during this study**: your name, gender, occupation (if applicable), onset and severity of stroke, age, being with or without carer and the mode of rehabilitation experienced e.g. in-patient, home-based or self-managed. These personal data will be anonymised by using **pseudonyms** and **kept confidential**; your name will not appear on any study reports or publications. Only the study team will have access to your personal data and this will be destroyed as soon as the study is completed.

With your consent, verbal discussions in the workshops will be **audio-recorded**, transcribed word by word and analysed by the PhD candidate Stefanie and discussed within the study team. Audio-recordings will be destroyed as soon as they have been transcribed and checked. All data will be stored on encrypted Glasgow Caledonian University devices and stored in line with the sponsor's policy guidelines for a minimum of 5 years and destroyed confidentially.

This study complies with the Data Protection Act (2008) and the General Data Protection Regulation (GDPR). The data controller is Glasgow Caledonian University.

Information is being processed on the basis of Article 6(1)(e) of the General Data Protection Regulation and to perform a task carried out in the public interest.

Enquiries specifically relating to data protection should be made to **the University's Data Protection Officer (DPO)**. The DPO can be contacted by email: [dataprotection@gcu.ac.uk](mailto:dataprotection@gcu.ac.uk). If you are unhappy with the response from the University, you have the right to lodge a complaint with the Information Commissioner's Office (ICO). The ICO can be contacted by email: [casework@ico.org.uk](mailto:casework@ico.org.uk).

GDPR also gives study participants the right to ask for their personal data to be erased. If you would like us to stop using your personal data, then you can contact Stefanie by email: [Stefanie.Schnabel@gcu.ac.uk](mailto:Stefanie.Schnabel@gcu.ac.uk) and ask for your personal data to be erased. However, it will only be possible to erase data that has not been anonymised and/or 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 and funded by Glasgow Caledonian University.

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

The study results will be available to a range of people including e.g. health professionals, researchers, and the public (e.g. via publications, conferences and professional meetings). It will not be possible to identify any individual participant from these reports or publications. You will also be sent a copy of the study findings if you wish.

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

All studies involving human participants carried out at Glasgow Caledonian University are reviewed by an ethics committee. The role of the ethics committee is to protect the safety, rights, wellbeing, and dignity of study participants. This study was reviewed by the School of Health and Life Sciences Allied Health Science departmental committee and given ethical approval on 06/11/23 under the following approval code: HLS/PSWAHS/23/003.

### **What happens next?**

If you are interested in participating and would like to know more then please contact Stefanie Schnabel

Email: [Stefanie.Schnabel@gcu.ac.uk](mailto:Stefanie.Schnabel@gcu.ac.uk) .

### **How do I make contact with the study team?**

Name: Stefanie Schnabel (Primary researcher)

Email: [Stefanie.schnabel@gcu.ac.uk](mailto:Stefanie.schnabel@gcu.ac.uk)

Name: Prof. Frederike van Wijck (Director of Studies)

Email: [Frederike.vanWijck@gcu.ac.uk](mailto:Frederike.vanWijck@gcu.ac.uk)

Name: Prof. Lisa Kidd

Email: [Lisa.Kidd@gcu.ac.uk](mailto:Lisa.Kidd@gcu.ac.uk)

Thank you for taking the time to read this information.