**Participant Information Sheet**

**Project title**

Life after Stroke: lessons from personal narratives of survival, managing change and overcoming adversity.

**Invitation**

We would like to invite you to take part in a PhD research study.

The aim of this study is to find out how stroke survivors manage life after stroke. The results of this study will help us to better understand the important issues that affect life after stroke. By doing this, we can encourage the development of new approaches that can help survivors adjust following stroke.

Before you decide whether you would like to take part in this study, we would like to tell you more about it. We will also explain what this study will involve for you, if you choose to take part.

The lead investigator, Joe Hall, is available to contact if you have any questions regarding any information on this sheet. His contact details are present at the end of this information sheet.

**Why have I been invited?**

Stroke affects thousands of people across the UK. Survivors of stroke are often faced with the long-term consequences that change everyday life. Adjusting to life following stroke can be a complex challenge, one that is not fully understood.

You have been invited to partake in this study as you have spent over a year readjusting to life after stroke. We are very interested in hearing the lessons you have learned following stroke. We believe that your experiences and the knowledge you have gained can help us to beneficially impact the lives of stroke survivors across the country.

**Who are we looking to talk to?**

We are looking to speak to a variety of individuals who have had different experiences in adjusting to life following stroke. However, all participants involved in the project must:

* **Be aged 18 years or older.**
* **Have been recovering to life after stroke for 1 year or more.**
* **Live in the United Kingdom**.

**What will taking part involve?**

If you choose to be a part of this study, you will be asked to partake in an interview. Before you do this, we would need you to fill out a questionnaire.

**Questionnaire**

This questionnaire will help us to ensure that we have talked to stroke survivors from a variety of different backgrounds.

For this reason, while we believe all survivors have an important story to tell, it may be possible that if we have a large number of people who represent a similar background you may not be selected.

**Participant Interviews**

Joe will ask you to share your story about how stroke has affected your life. This will involve questions about how your life has changed, how well you think you have adjusted following stroke and what you find most important now.

This discussion will last between **60 to 90 minutes**. This does not need to be completed within a single interview. It is possible for the discussion to be split over multiple sessions if that would be preferable.

To conduct the interview, Joe can visit you individually at your home or at a place that is convenient for you. The interview can also take place over the phone or an internet communication platform, such as Skype.

You may also prefer to have someone with you, perhaps your spouse, a family member, your carer or a friend.

**Privacy**



We would like to record the discussions that take place during interviews.

All information taken during the course of the study will be strictly confidential.

Any recording or written copy of discussions will be stored in a safe location within GCU. The only people who will have access to this information are members of the research team. No personal details will be attached to confidential information.

Direct quotes from interviews may be used within the study paper, however, all personal information will be removed.

After the study has been completed all recordings and other information will be destroyed, according to University guidelines.

**Do I have to take part in the study?**

No, taking part is up to you. There is no problem with you deciding not to take part.

Even if you choose to take part within the study, you are free to change your mind at any point. You do not require a reason for why you no longer wish to participate. Any information you have given to the research team will be destroyed.

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If you would like to, please read over the questionnaire attached to the information sheet. If you feel comfortable answering the questions, please answer them and return them to Joe at the supplied address.

If you would like an electronic copy of the questionnaire, or have any other questions in regard to this, please contact Joe (details are at the end of this information sheet).

**Who is funding the research?**

This research is funded by Glasgow Caledonian University.

**What happens after the interviews?**

The interviews make up the first part of a larger project. There are three key parts of the project:

1. Participant interviews (as detailed in this information sheet): We will speak to stroke survivors and learn important lessons from their stories and experiences.
2. Focus group: We intend to hold a focus group with stroke survivors to determine the best ways to spread the important lessons we have learned from the interviews. The hope is to communicate with key stakeholders, such as: fellow stroke survivors, their family and friends, carers, health care professionals and policy makers. We also hope to spread these important lessons to the wider public as well.
3. Spreading the message: Through the activities and methods discussed in the focus groups, we will spread the lessons learned from part one of the project. This will most likely include public events and social media posts, but this will be decided together with those who take part in the focus groups.

This invitation is for the **first part** of the project. However, for those who are willing, they are also invited to participate in part two and three.

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You **do not** have to agree to join every part of the project in order to take part in the participant interviews. By agreeing to be contacted about the next stages of the project, you are also not obligated to take part.

**How long will the project last?**

The entirety of the project is expected to last between 12 to 18 months. Part one will take about 5 to 7 months to complete. Part two will take about 2 to 4 months to complete. Finally, part three will take about 5 to 7 months to complete.

**What happens next?**

Think over whether you would like to partake in the study. If you are unsure about taking part, it may help to discuss with your family and friends.

If you decide to take part, please fill out the questionnaire and return it to the address below.

If you are selected for the project, informed consent will be required from you before the interview takes place. This will most likely happen just before the interview. Joe will go through the information sheet with you in person and you can ask any questions you may have.

If you would like an electronic copy of these forms, or have any questions at all, please contact Joe. His contact details are provided below.

**Thank you very much for your time**

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