Development and implementation of Realistic Medicine for severe stroke through Shared Decision Making at The Royal Infirmary of Edinburgh (RIE)

INFORMATION SHEET

Coproduction

We would like to invite you to participate in a research study, to plan and produce a new process to help doctors and nurses and therapists, patients and their families to make shared decisions about your care after severe stroke. The process will include discussing what information is most helpful to patients after severe stroke, and how to provide this in a sensitive way.

1) Why are we doing this study?

Currently making decisions about treatments after severe stroke is very difficult and complex, partly because patients are often too ill to talk about their preferences, families are shocked and upset at the time of a stroke, and some treatments might improve the chances of surviving but leave the patient with severe disability. We want to develop a system to help patients and families make difficult decisions about care, through a process called 'coproduction' whereby people affected by stroke, older people and health care professionals meet together, share experiences and jointly design a new process.

All participants will have the same 'say' in the process as the health care professionals.

2) Why am I being invited?

You have been invited because you have either had a stroke, you are involved in stroke care (as a professional or lay person) or are an older person without any personal experience of stroke.

3) Do I have to take part?

No. Your participation is voluntary.

Your care will not be affected if you don’t want to take part or if you change your mind.

You will sign a consent form if you agree

4) What happens in the study?

First, you will meet ‘virtually’ on Microsoft Teams (a platform that allows live video meetings online) with the research team leading the work to discuss what is involved and make sure that you have the time to participate in the workshops. The researcher will record the discussion with an audiorecorder. The recording will be stored on a secure NHS computer.

Then you will take part in four coproduction workshops -all on Microsoft Teams, with around 15 other people. The workshops will be led by experienced stroke researchers. There will be one workshop per month. Each one will take about an hour. Between workshops, you might be asked to read and consider information about stroke and communication.

The overall goal is to produce a process for helping health care professionals have better and more sensitive conversations with families and patients after a severe stroke.

The researcher will record the meetings on Microsoft Teams. The recordings will be stored on a secure NHS computer and destroyed up to 12 months after the study has ended.

5) What will be paid to take part?

We are not able to pay for your time; your participation will be voluntary.

6) What are the benefits of taking part?

You may find it helpful to express your experiences of stroke with other people.

The outcome of the meetings will help shape how stroke services develop in the future, in relation to communication after severe stroke

7) What are the possible risks of taking part?

Time. We estimate that this study will take about 10 hours of your time, in total.

It might be emotional to express your views. If you do get upset, you can drop out of the meeting and the researcher will check after the meeting that you are OK.

8) What if I do not want to carry on with the study?

You can stop taking part at any time

Any medical care you are receiving now or in the future will not be affected.

We will use information you gave us up until that point

9) What am I agreeing to?

- To take part in online workshops to discuss communication after stroke, and to develop better ways to do this.
- To have the audio recordings stored securely on NHS computers. These will be deleted once the study is completed.

10) Will my information be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

We will need to use information from you for this research project. This information will include your name and contact details to allow us to contact you for all workshops.

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.

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. 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
- by sending an email to sharedstrokedecisions@nhslothian.scot.nhs.uk

11) What happens to the results of the study?

Results will be written up as papers which will be published in journals. Results may also be presented in conferences. You will not be identified in published results

12) Who should you contact with questions?

Professor Gillian Mead (Researcher)

Gillian.e.mead@ed.ac.uk 0131 242 6927

If you wish, you could contact an independent person:

Dr Andrew Coull

Associate medical director

Royal Infirmary of Edinburgh

Andrew.coull@nhslothian.scot.nhs.uk

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For complaints:

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Thank you for reading this sheet and considering taking part in this study.