

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

PATIENT INFORMATION SHEET

Easy Access

We would like to invite you to participate in this research study. We want to find out what you think about the discussions you have had about your care with the doctors, nurses and therapists.

1) Why are we doing this study?

We don't know enough about how well doctors, nurses and therapists communicate with you about decisions concerning your care. Good communication is so important when caring for people who have had a stroke.

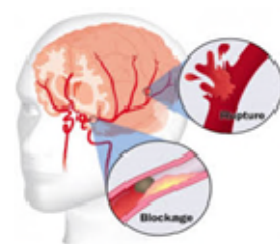


This research will tell us how well we are doing this.

2) Why am I being invited?

You have had a stroke.

We want to find out whether the clinical team have involved you in decision making.



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?

We need to look at your medical notes



Shortly after your stroke, we will ask you some questions about the communication you have had with the stroke team

Then we will ask you the same questions 2 weeks, 4 weeks and 8 weeks after your stroke.



We will interview some of you in more detail to find out about the quality of communication you have had with your doctors, nurses and therapists. If you are interviewed, we will transcribe what you discussed in the interview into written form.

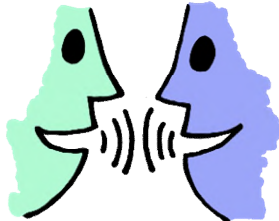


Six months after your stroke, we will telephone you to find out how you are getting on.



5) What will I be asked about?

What you think about how well you have been involved in decisions about your care



6) What are the benefits of taking part?

You may find it helpful to express your experiences

Your progress is important to our practice



7) What are the possible risks of taking part?

Time. This study will not take more than an hour of your time.



It might be emotional to express your views



You can take as much time as you need to discuss and think



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

You can stop taking part at any time



Your care is not affected

We will use information you gave us up until that point



9) Will information be given to my GP?

No, we are not going to contact your GP about your participation in the study



10) What am I agreeing to?

- For us to look at your notes, records and scans
- To store your name, contact details, date of birth and CHI number (hospital number) until we have collected all data we need (up to 12 months after study had ended)
- To anonymise and store your information securely after the end of the study for seven years.
- For relevant sponsors to access your notes to make sure research is conducted correctly



- To contact you at 2 weeks, 6 weeks and 8 weeks and in 6 months time.

- To contact your family for information if you were unable to participate



11) Will my information be kept confidential?

Yes, we follow strict laws to ensure your privacy.



You can find out more about how we use your information

- by asking one of the research team
- by sending an email sharedstrokedecisions@nhslothian.scot.nhs.uk

12) What happens to the results of the study?

Results will be written up as papers which will be published



Results may also be presented in conferences

You will not be identified in published results



13) 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:

NHS Lothian Patient Experience team

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Edinburgh EH1 3EG

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