

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

## **INFORMATION SHEET**

### **Welfare Attorney/Welfare Guardian or Nearest Relative**

You are invited to agree, on behalf of your ward/relative, for them to be included in a research study. To help you decide whether or not you can agree to your ward/relative being included in the research study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. We would then ask that you put your own views about the research aside and to consider and take into account, the past and present wishes and feelings of the person you are consenting for, had they been able to consent for themselves

This study would involve you giving permission for the person you are consenting for to take part in a research study, because the data we want to collect is about their medical care. As their legal representative or closest family, we would like you to provide consent on their behalf. This is permissible under the Adults with Incapacity Act (Scotland 2000).

#### **1) Why are we doing this study?**

After a stroke, it can be difficult to decide what treatments are suitable for individual patients. Some treatments may not always be helpful, and some (for example, feeding tubes) may be uncomfortable. We want to find out how well the clinical team (doctors, nurses and therapists) involve patients and their loved ones in discussions about their care.

## **2) Why have I been invited?**

Your ward/relative has had a severe stroke. . We would like to collect medical data about them which will be used along with the additional questions we will ask you (you will be given a second information sheet regarding these questions)

## **3) Do you have to agree to your ward/relative being included in this study? take part?**

No. Participation is voluntary.

Not taking part or withdrawing at any time will not affect the standard of care the person you are consenting for will receive.

If you decide to consent on behalf of your ward/relative, you will be asked to sign a consent form.

## **4) What happens in the study?**

We will access the medical notes and hospital notes of your ward/relative in order to get more information about their background, the stroke and progress in hospital. We are asking to you consent on their behalf to access their medical notes.

## **5) What are the benefits of taking part?**

There are no direct benefits to your ward/relative. The aim of this study is to improve the way that the clinical team communicates with patients who have severe stroke, and their families in the future. The medical information collected on your ward will be used as part of this study.

## **6) What are the possible risks of taking part?**

There are no dangers to you or the health of the person you are consenting for.

### **7) What if I do not want to carry on with the study?**

You may change your mind about taking part in the study at any time. This does not affect the care the person you are consenting for will receive.

We would like to use the information we have collected up until you stop taking part

### **8) Will information be given to my relatives GP?**

We will not be contacting your GP or the GP of the person you are consenting for with regards to your participation in the study.

### **9) What am I giving consent to?**

- Access to medical notes, brain scans and GP records to find out information about the stroke, previous medical history and social circumstances of your ward/relative
- For the sponsor and university to access these records to ensure that research is being carried out properly

### **10) Will the information collected 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 you and your ward/relative's privacy at every stage.

We will need to use information from your ward/relative's medical notes for this research project. This information will include name, date of birth and CHI number (NHS numbers). People will use this information to do the research or to check your relative's records to make sure that the research is being done properly.

People who do not need to know who you or your ward/relative is will not be able to see their name, date of birth or CHI number. The data will have a code number instead.

We will keep all information about your ward/relative 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.

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](mailto:sharedstrokedecisions@nhslothian.scot.nhs.uk)

### 11) What will happen to the results of the study?

The study will be written up and papers will be published. Results may also be presented in conferences. You or your ward/relative will not be identifiable in any published results.

### 12) Who should you contact with questions?

Professor Gillian Mead (Professor of Stroke and Elderly Care Medicine)

[Gillian.x.mead@nhslothian.scot.nhs.uk](mailto:Gillian.x.mead@nhslothian.scot.nhs.uk)

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If you wish, you could contact an independent person:

For complaints:

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 Associate medical director  
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**We would like to thank you for reading this information sheet and considering taking part in this study.**