

(Quantitative) Information for Participants

You are being invited to take part in a research study. Before you decide, 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. My telephone number and contact details are available at the end of this document so please call me if there is anything that is not clear or if you would like more information.

What is the purpose of this study?

The purpose of this study is to examine how people who have had GBS have experienced the disease and whether it has affected aspects of their lives now that they are recovering. It is hoped that by gaining enough information, the findings can be shown to healthcare professionals so as to improve the treatment, recovery and support of those with GBS and their families.

Why you have been chosen?

You have been chosen because you have had an episode of GBS with or without paralysis. I am looking for volunteers to answer a series of questionnaires so that I can gain as much information as possible about general trends in groups of people who have had GBS.

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. Even if you decide to take part you are still free to withdraw at any time and without giving a reason. Any decision that you make will not affect the standard of care that you receive.

What will happen if you take part?

If you agree to take part the questionnaires can be downloaded from the GBS support group website <http://www.gbs.org.uk> and sent once completed to the address detailed at the end of this document. Alternatively the questionnaires can be sent to your home address by the researcher, Catherine Harrison.

What will the questionnaires and interviews be looking at?

They will look at different aspects of your mood that may have been affected by GBS as well as the time you spent in hospital, the impact upon your family, your daily living and your job.

What happens to the results?

The results from the questionnaires will be analysed to see how people who have had GBS have been affected. The study is being conducted as part of a Clinical Doctorate requirement for Catherine Harrison and is being supervised by Prof. Mike Wang at the University of Leicester. It is hoped that this research will help to raise the awareness of GBS as well as provide information on the impact of GBS upon sufferers and their families. These findings will also be shared with healthcare providers so as to further support patients with GBS.

What will happen after I complete the questionnaires?

A summary of the findings will be disseminated at the Annual GBS conference in 2010. It is also hoped that the findings will be shared with the University of Leicester and published within an academic journal when the study has been completed.

Will my participation in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it. If you take part in an interview, it may be possible to recognise some of the things that you have said as I will need to record this information verbatim. However, there will be no identifying features of your information available for anyone else to recognise you by.

What happens if the research causes me distress?

It is understandable that some people may find the reminder of their illness to be traumatic. The researcher will make every effort to support you throughout the questionnaires should you wish. If you should become distressed, either during or after completion of the questionnaires, then you can speak to your GP or contact the researcher who will provide contact details of a support service in your area.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

NHS bodies are liable for clinical negligence and other negligent harm to individuals covered by their duty of care. NHS Institutions employing researchers are liable for negligent harm caused by the design of studies they initiate. The provision of such indemnity for negligent harm is provided by Leicestershire NHS Partnership Trust.

In the event that you do become distressed or harmed during this study and this is due to someone's negligence then you may have grounds for a legal action for compensation against (Leicestershire NHS Partnership Trust) but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Who has reviewed this study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the Nottingham 2 Research Ethics Committee.

Thank you for reading this, if you would like any further information or there is anything you do not understand please contact Catherine Harrison:

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Many thanks for your time.