



## Service User Participant Information Sheet (v.4 2.6.09)

### Rehabilitation Effectiveness and Activities for Life

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You are being invited to take part in a research study. Before you decide whether or not to take part 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 sheet carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information (our contact details are at the end of this leaflet). Take time to decide whether or not you wish to take part in the study.

#### What is the purpose of the study?

The study aims to assess the services and quality of care delivered to people in every inpatient rehabilitation unit in England. The study will take place over five years.

#### Why have I been chosen?

We are hoping to involve as many users of inpatient rehabilitation services as possible from across England. We are asking you if you would be willing to help because you are receiving inpatient rehabilitation.

#### Do I have to take part?

No, you are free to choose to take part or not. If you decide that you do not want to take part in this study, it will not affect the treatment you receive in any way. If you agree to take part but later change your mind, you can leave the study at any time. Again, this will have no effect on the care that you receive.

#### What will happen to me if I take part?

In the first part of the study we will survey all inpatient rehabilitation services in England. As well as collecting information from the unit manager about their service, we want to talk to users of services about their experiences of the unit and the kinds of things they do with their time. This will take no more than about 30 minutes and will help us work out how well the unit is helping the people who live there to get on with their lives. We would also like your permission to collect some information from your hospital records about the care you have received from services. We would also like to interview 2-3 service users from 10-15 services in more depth.

In later stages of the study we will do two things:

First, we will develop and test a staff training programme to help service users with their activities on and off the unit. About half the rehabilitation services will be involved with this part of the study. If you are a user of one of these services we would like to interview you twice, once before the staff training and once 12 months later. These interviews will take no more than 15 minutes and we will ask you about the activities that you have taken part in over the previous week, your quality of life and your views on the service. We would also like to interview 2-3 service users from around 10 of these services in more-depth and record these interviews. This will help us to understand which aspects of the staff training were helpful and which were not. These interviews will take no more than 30 minutes. We will also ask your permission to collect information about your care from your hospital records and for a staff member to complete a questionnaire about your abilities and about any specific difficulties you may have.

Second, we will also investigate what things help service users most to get discharged from hospital and get on with their lives. About half the rehabilitation services will be involved with this second part of the study. If you are a user of one of these services we will ask you for permission to collect information about your care

from your hospital records and for a staff member to complete a questionnaire about your abilities and any specific difficulties you may have. These questionnaires will be completed twice, 12 months apart. You will not be asked to take part in an interview.

In all phases of the study, the researcher (*Nick Green or Isobel Harrison*) will come to visit you so that you don't have to travel to meet with them.

Both your case note information and any recordings of your research interviews will be anonymised so that you cannot be identified from them.

### **What do I have to do?**

If you are willing to take part the researcher (*Nick Green or Isobel Harrison*) will arrange to meet with you to answer any questions you may have. If you are happy to take part, they will ask you to sign a consent form. They will specifically ask you whether you are willing for the researchers to gather information about you from staff and your case record and whether you would be willing for this to happen if you later become unwell and cannot give your consent for this at the time. They will then go through the initial research interview with you.

### **What are the possible disadvantages of taking part?**

Other than giving up some of your time to do the interview, there are no disadvantages to taking part. The research interviews will take 15-30 minutes. You will continue to have access to your usual range of services. Taking part in the study will not interrupt or change the care you usually receive in any way.

### **What are the possible benefits of taking part?**

We hope that the information you share with us in the interview will allow us to assess how well the care that the unit gives matches up to the experiences of those who live there. We hope that the information we get from this study will help us to assess and review the care that inpatient rehabilitation units give people who experience mental health problems in the future. We will also offer all those people who complete the research interviews £10 per interview in recognition of the time they have given to be involved in the study.

### **What if there is a problem?**

Any complaint you have about the way you have been dealt with in the study will be addressed.

#### *Complaints:*

If you have a question or concern about any aspect of this study, you should ask to speak the main researcher Dr Helen Killaspy (Tel: 0207 794 0500 x 33950) who will do their best to help. If you remain unhappy and wish to complain formally, you can do this through your local Mental Health or Primary Care Trust's Complaints Procedure. Details of how to do this can be obtained from the Trust's website or from your care co-ordinator or keyworker. Alternatively, you may contact the Research Governance Sponsor of this study, University College London (UCL). Please write to the Joint UCLH/UCL Biomedical Research Unit, R&D Directorate, Rosenheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting reference 09/0003.

#### *Harm:*

Every care will be taken to ensure your safety during the course of the study. UCL has indemnity (insurance) arrangements in place for non-negligent harm, in the event that something goes wrong and you are harmed as a result of taking part in the research study. If you are harmed and this is due to someone's negligence then you may have grounds for legal action for compensation but you may have to pay your legal costs.

### **Will my taking part in the study be kept confidential?**

All the information you provide to the researcher (*Nick Green or Isobel Harrison*) will be stored in an anonymous fashion. That is, you will be given a unique research number and only this number will appear in the information stored. Stored information will be controlled by the researchers (*Nick Green or Isobel Harrison*) and only they and other members of the research team will have access to this information. The information will be kept in locked cabinets in a locked office. The information you provide will be destroyed after 20 years.

All information related to the study you give during treatment is confidential. Under some circumstances, for instance if you told the researcher that you were feeling desperate, wanted to harm yourself or someone else, this information may need to be passed on to your key-worker or your doctor.

### **What will happen to the results of the research study?**

Once the study is completed we will produce reports that will describe the findings of the study. We will produce a summary of our findings which we will send to all those people who take part in the study who

would like a copy. If you would like a copy we will send you one. You will not be identified in any report or publication. The reports we write will not include personal details of the people who take part, it will only describe the results of the study as a whole

**Contacts for further information**

If you have any further questions about the study, please contact Helen Killaspy on **0207 794 0500 x 33950** or by email: [h.killaspy@medsch.ucl.ac.uk](mailto:h.killaspy@medsch.ucl.ac.uk). Otherwise, the researcher (*Nick Green or Isobel Harrison*) will contact you in the next few days to see if you would like to arrange an appointment to meet.

The other members of the research team are Professor Michael King (University College London), Dr Frank Holloway (South London and Maudsley NHS Trust), Professor Tom Craig (Institute of Psychiatry). Dr Paul McCrone (Institute of Psychiatry), Ms Sarah Cook (Sheffield Hallam University), Dr Cathy Hill (Sheffield Hallam University), Gerry Leavey (University College London).

**THANK YOU VERY MUCH FOR YOUR TIME AND HELP WITH THIS STUDY**