

INFORMATION ABOUT A RESEARCH STUDY IN WHICH YOU ARE INVITED TO TAKE PART
Participant Information Sheet (questionnaires): Version 2.0 - 27/07/2011

Study title: Service users' experiences of recovery under the 2008 Care Programme Approach

We are inviting you to take part in this study, if you would like to do that. To help you decide, we are providing you with details about the study in this information sheet. Please take time to read the information carefully before you make up your mind. Please also feel free to talk with someone else before you make your decision.

What is the study about?

The study will explore what role service users think the 2008 Care Programme Approach can have in promoting recovery as they understand it.

Why is the study happening?

In the 1980s and 1990s, service users came up with their own ideas about recovery from mental health problems. They said that recovery need not mean that you are free from difficulties; what is important is whether you can recreate a sense of yourself and build a meaningful life, regardless of problems. They emphasised the importance of things such as hope, personal choice, control over what happens to you, social networks and the use of a wide range of resources, rather than purely medical ones. Since then, professionals have put an increasing emphasis on recovery-based approaches. A number of service users have expressed concerns about professional approaches to recovery, however; they think that professional definitions of recovery are different from their own definitions. Service users have also questioned whether the revised Care Programme Approach introduced in 2008 does promote recovery as they mean it. For example, they are unhappy that the Care Programme Approach is linked with sectioning and community treatment orders. It seems important therefore to explore further how well service users think the 2008 Care Programme Approach can support them with their own idea of recovery.

Who is responsible for the study?

A research team based at the Mental Health Foundation, a leading UK charity based in south London. As part of its role, the Mental Health Foundation carries out research into issues and helpful resources for people with mental health problems. Dr. Dan Robotham is in charge of the research team. The two research team members are Dorothy Gould, who will lead the day-to-day process, and Sarah Yiannoullou. Dorothy and Sarah are both people

who have used mental health services themselves. Sarah is also the manager of the National Survivor User Network (NSUN), a national resource for user-led mental health organisations and for individuals with experience of mental distress; NSUN is a partner for the study. The study has been funded by the London Development Centre/National Mental Health Development Unit.

Why have I been invited to take part in the study?

You have been approached because you have had experience of the Care Programme Approach since October 2008 and so are in a good position to comment on it. The Trust whose services you use is also London-based, which fits the requirements of the funders.

Do I have to take part?

No. It is entirely up to you. The care which you receive will not be affected in any way by your decision. If you do choose to join in the study, you can also withdraw at any point without giving a reason and again without your care being affected at all. We will then destroy any information which we have from you.

What will be involved if I decide to take part?

The first step will be for you to contact the research team, using the details at the end of this information sheet. A research team member will then talk more with you about the research, give you the chance to ask questions and check that the information about the research is clear to you. If you then make a definite decision to take part in the research study, the researcher will send you a consent form to complete and sign. You will also receive a questionnaire to fill in, together with a letter which explains the questionnaire.

The questionnaire will be about your experiences of recovery under the 2008 Care Programme Approach. The questionnaire has two parts. In Part A you will be asked for some brief information about yourself, e.g. your gender, your approximate age and your ethnic origin. That is because people can have different experiences of services, depending on their background, and it is helpful to know how diverse participants are. Part B of the questionnaire has questions about recovery: how you see it, what support you want from mental health staff and whether you receive this from staff involved in your care, what impact sectioning, or a community treatment order has had on your recovery (if you have experienced either of these) and what recommendations you have about recovering under the 2008 Care Programme Approach.

You can answer most of the questions by ticking a box and in a few places, you are asked to write in a response. Everyone is different, but on average we would not expect the questionnaire to take more than 20-30 minutes to complete. If there are any questions which would make you feel uncomfortable to answer, you can just go past these and move on to the next question. You are under no obligation to reply to all the questions if there are some which you would prefer not to answer.

How long will I have to complete the questionnaire?

You will have up to a fortnight to do that.

Who will see my answers?

All the information which you provide will be treated in strict confidence. Only research team members and their administrative staff will have access to it, unless you mention anything which indicates that you, or someone else is at risk of serious harm, or make a criminal disclosure; in that case we would contact your care co-ordinator, letting you know that we need to do so. Information from you will be stored securely in locked cabinets and computer records which only research team members can access; Dr Dan Robotham, the research team leader, will have responsibility for that. If you take part in the research, we will ask you for contact details, but only so that we can communicate with you about the research. Your answers will also have your name and address removed and replaced with a numerical code, so that you cannot be identified. We will also shred any information from you within six months of the end of the research.

How will my answers be used?

The information which you provide will be included in a report and recommendations about the part which the 2008 Care Programme Approach can play in promoting recovery and in a check list of good practice. These will take about 6 months to produce. Your name and any details which might identify you, or your social networks will be omitted from these documents. We then plan to publish the documents on the Mental Health Foundation, National Survivor User Network and Department of Health websites, with links to other relevant websites, and to circulate them to mental health organisations and to study participants.

What are possible benefits of taking part?

The study will give you a chance to say how effective the 2008 Care Programme Approach has been in helping you to recover and what recommendations you have about it.

What will I receive in return?

You will have the opportunity to be entered into a prize draw. There are five £10 vouchers to be won and you will have a one in twelve chance of receiving one of these. You will be offered a summary of the research findings once the study is complete. The full report will also be available on request.

What are possible disadvantages of taking part?

There are no major disadvantages. The questions will, however, be about your experiences of mental distress and of drawing on mental health services. Because of this, it is possible that a question might bring up a difficult memory for you. We have therefore asked your organisation to name support which can be made available to study participants, if

necessary, and we will pass this information on to you. If you should become upset, you are completely free, too, to stop answering the questionnaire.

What if I have a complaint about the study?

The researchers will do everything they can to make sure that things go well. If you are not happy, however, please let us know so that every effort can be made to put things right for you and to prevent such errors in the future. You will also be able to talk with Eva Cyhlarova, the Mental Health Foundation's Head of Research (tel: 020 7803 1113), if you want, and she will try to resolve the issue. If a problem is not sorted out within a reasonable amount of time, the issue will automatically be passed on to the Mental Health Foundation's Chief Executive, Dr. Andrew McCulloch, and he will take action about it. If you remain dissatisfied, you should write to the Mental Health Foundation's Trustees. Staff at the Mental Health Foundation will be available to advise and help you through this process.

Who has reviewed the study and made sure that it is of good quality?

The study has been reviewed and checked by Dr Jayasree Kalathil, an experienced service user researcher who holds a PhD, and by a NHS Research Ethics Committee, an independent group of people who are responsible for ensuring that research has been set up safely and well and that participants' interests are safeguarded.

How do I make contact with the researchers if I want to take part in the study?

Either Dorothy Gould, or Sarah Yiannoullou will be available to talk with you, if you are interested in the study. You can phone Dorothy to let her know (on 020 8340 3029) or email her at gould.dorothy@gmail.com. Alternatively, you can contact Sarah Yiannoullou at the National Survivor User Network. Her phone number is 020 7820 8982/ 07778 659390 and her email address is sarah.yiannoullou@nsun.org.uk. Please also feel free to use a supporter to help you make contact if you want.

And thank you for taking the time to consider taking part in this research study