



Mental Health  
Research Network



**NHS**

**National Institute for  
Health Research**

## INVOLVING SERVICE USERS IN MHRN-SUPPORTED RESEARCH CASE STUDY

The National Institute for Health Research Mental Health Research Network (NIHR MHRN) helps make research about mental health happen in the NHS in England. We work through eight regional offices (called hubs) and currently support more than 300 multi-centre studies and clinical trials. We offer very practical support to research teams, helping them set up and recruit through services run by more than 60 mental health trusts.

The MHRN supports studies that involve people with mental health experience, and, if pertinent, their family members. There are different ways in which research teams can involve the people who ultimately benefit from their studies and trials, and we can offer advice about the best way to do this.

Our hub teams support – and can introduce researchers to – service users who are willing to act as consultants, advisors, steering group members or researchers. Our centrally-based Service Users in Research supports involvement activities throughout the MHRN and commissions people with experience of mental health problems to produce guidance and resources for researchers.

**This is one of a series of case studies commissioned by the NIHR MHRN to illustrate and share examples of good practice.**

For more information about service user involvement in the Mental Health Research Network and the work of Service Users in Research, visit

[www.mhrn.info/serviceusers](http://www.mhrn.info/serviceusers)

## Cost of Stigma Inventory (COSI) study

■ This case study was compiled in 2010 by Harminder Kaur.

It was commissioned by the MHRN via the North East Hub and produced in this format in June 2011.

## Information about the study

The COSI study was concerned to develop a Cost of Stigma Inventory (COSI) questionnaire, to be used to determine the economic costs arising from the stigma borne by people who have mental health problems. Relating as it did so directly to the experiences of people with mental health problems, the input of service users was a needed and valuable component in the research. Indeed, the input of service users was to some extent a formative element in the study, as two members of the research team had themselves experienced mental health problems.

When the Cost of Stigma Inventory questionnaire has been developed and refined, it will be used to measure the financial costs of stigma experienced by participants in a larger study (MIRIAD – Mental Illness-Related Investigations on Discrimination). People participating in this study will complete a measure of stigma they have experienced (DISC – Discrimination and Stigma Scale) and this will be compared with costs identified in the Cost of Stigma Inventory.

## Focus group

The researchers considered that the best way to formally involve service users in the COSI study would be through participation in a focus group. The remit of this group was to examine a draft of the COSI questionnaire and to supply feedback, so that the questionnaire could be amended in the light of the participants' experience and knowledge of stigma and discrimination.

Service users were recruited through the MHRN and the group met at the Institute of Psychiatry, a school of King's College London. The chief investigator, Dr Paul McCrone (now Professor), chaired the meeting, which was attended by seven service users and one carer, and which lasted for approximately two hours. Participants were paid £15 for their time and their expenses were reimbursed.

## Feedback from service users

One service user who was present at the focus group meeting has reported that all the service user participants had experienced stigma and discrimination. The general feeling of the group, as reported by this participant, was that the COSI questionnaire would be a valuable tool. However, it was also felt that the magnitude and full costs of the impact of stigma and discrimination were not fully captured by the questionnaire.

This service user participant's overall view of the meeting is positive. It appeared to him that the participants were very engaged, and that Dr McCrone was very attentive to the discussion. However, he also thinks that the discussion related a little too much to personal experience at the expense of a detailed examination of the COSI questionnaire. In addition, he thinks that the perspectives of carers were not adequately taken into account, in part due to there being only one carer present, and that a small number of voices were too dominant in the discussion.

Another service user who attended the meeting has reported that it was well supervised, and that the atmosphere was supportive. The atmosphere of the meeting was important to him because he found it difficult to discuss experiences of stigma and discrimination with unknown people in an unfamiliar environment. In his view, the discussion of the COSI questionnaire was productive, with quite substantial changes to the content, wording and layout being proposed. He also felt that Dr McCrone listened attentively, and that participants had an adequate opportunity to share their thoughts, despite the tendency of one person to speak too much.

## Feedback from the researcher

Dr McCrone has reported that the focus group was a very useful component of the COSI study, and, following the meeting, significant changes were made to the questionnaire.

A question that had simply asked whether a person was employed or unemployed was substantially changed so as to more adequately correspond to the diverse range of occupational statuses which service users might occupy, with the new question allowing for nine possible responses. The occupational categories recognised in the amended question were as follows: paid or self employment; voluntary work; sheltered employment; unemployment; study; occupational training or apprenticeship; being a housewife or househusband; being retired; and other.

In addition, two further questions relating to employment/occupation were added to the questionnaire. These addressed stigmatisation and unfair treatment by co-workers, and the provision or non-provision of adaptations or allowances for mental health problems under the Disability Discrimination Act.

The COSI questionnaire was further modified by the addition of a completely new section relating to discrimination by financial institutions and in connection with housing provision. Among the questions asked in this section were questions concerning applications for a mortgage, for insurance, and for a driving licence. In addition, changes were made to a section of the questionnaire relating to receipt or avoidance of services due to stigma or discrimination. Among these changes were the addition of dentists and specialist doctors under the category of health care services.

## Summary

- 1) Consultation with service users concerning the COSI questionnaire was a central component of the COSI study.
- 2) This consultation took the form of a focus group, which service user participants report was a positive and useful exercise.
- 3) The chief investigator considered consultation with the members of the focus group to have been of significant assistance in developing the COSI questionnaire.
- 4) The COSI questionnaire was substantially revised following the focus group, so as to better capture the costs of stigma and discrimination experienced by people with mental health problems.



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**Service Users in Research**  
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