



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)

# Is there a pathway to recovery through care coordination? Emancipatory action research with mental health service users, carers and professionals within Northumberland, Tyne and Wear

■ This case study was written by Tony Jones, service user and carer involvement in research coordinator for Tees, Esk and Wear Valleys NHS Foundation Trust and Kate Hughes, clinical studies officer at the MHRN North East Hub. The case study is based on interviews with the chief investigator, Dr Toby Brandon, and two service user researchers

who have been involved in the study. This project was given the Gold Award for the best service user involvement plan on a MHRN-supported study in 2010.

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

## Study summary

This research is funded by the National Institute for Health Research *Research for Patient Benefit* stream and is located within the Community Health and Education Studies Research Centre (CHES) at Northumbria University.

Government policy over the last 10 years has attempted to tackle professional and public concerns around effective services for people with mental health needs and their carers – by, for example, the introduction of the Care Programme Approach (CPA), which advocates care coordination through the allocation of a key worker system, co-signed care plans and the considered arrangement of sometimes complex packages of care.

However the quality and delivery of care coordination has been patchy and it is still unclear to many what good practice means. To make a real change for mental health service users and their carers, this research is being led by both service user and carer organisations. They have designed the study, will be conducting the interviews and analysing the data.

The project is organised around three distinct phases, the first of which is a Delphi study. This involves sending out a series of questionnaires to informed respondents in order to develop a clear agreed view of what good care coordination actually is in practice. Questionnaires (tools) will also be independently developed and used by service user and carer researchers.

The second phase will involve trained mental health service users and carers interviewing other service users and carers about their stories of care coordination and recovery journeys. In addition, professionals will be interviewed and all the responses will be used to develop a good practice 'toolkit' relating to care coordination. This will include the agreed opinions from the Delphi, the questionnaires developed in the project, and the stories and other material gained from the interviews. It is intended that the different findings and developed toolkit will be used to improve care coordination both locally and nationally.

## How were service users identified and recruited to take part in the study?

The chief investigator (CI) of this study is Dr Toby Brandon from Northumbria University. Dr Brandon has always had an interest in working alongside service users. This interest has been influenced by a number of factors, including previous work about mental health at Durham University, and personal experience of a family member accessing mental health services. Prior to this study development, he was keen to build on previous links with a service user coordinator with whom he had worked when this individual was accessing mental health services. This service user coordinator and a service user group called the User Centre Advice Network (UCAN) were approached with the purpose of setting up a service user steering group. The aim of the steering group was to empower service users to shape and develop a relevant research question and proposal. UCAN was based in North Tyneside and was established in 1994 by a group of mental health service users in response to the closure of the local NHS day hospital. The aim of UCAN was to provide support, information, activities and opportunities for involvement in a wide range of service improvements. Unfortunately, it closed at the beginning of 2010.

The CI regularly met with a group of six to seven service users from UCAN. This steering group initially formed a list of prioritised areas that they believed required researching. As a group, they identified that the process and delivery of care coordination and its relationship to recovery, was an important area requiring further research. Additional service user groups were consulted via service user and carer networks within the north east of England.

## What involvement has there been?

Service users have been involved from the outset. Not only have service users identified the research question, they have also been involved in designing the study and obtaining approvals. Both the CI and service user researchers who were interviewed report that this project has been an equal partnership to date. One service user researcher described this as 'an equal partnership in the true sense' in that all decisions have been made in partnership from the outset. They felt this was a contrast to their previous experiences, where the term 'user-led' may have been used but did not involve a true equal partnership. The future plan for this study is to train and support service users to interview, collect data, analyse and report on the data.

## Challenges relating to user involvement

The CI identified that the requirements for academic funding differ from how service users communicate their research ideas and proposals. The challenge for him lay in taking the steering group's ideas and formulating a research proposal that met academic requirements for funding but did not take away from the spirit of what service users wanted to be addressed. He did not want to control the study and therefore had to balance his guidance appropriately.

The CI also identified information-sharing as a challenge in terms of appropriate filtering of information such as emails. Within this, he recognised that he did not want to swamp service users with more trivial information but also wanted to avoid service users feeling that they were being kept out of any aspect of the process.

The service users interviewed clearly reported that they have not encountered any challenges in relation to working together as a group and in working alongside the academics. The only difficulty they reported was in relation to the ethical approval process and attendance at the local ethics committee meeting. One service user researcher interviewed had attended the first ethics committee meeting and clearly reported that this was a negative experience from her perspective. This user expressed concern that the ethics committee

did not understand service user participation/ involvement in mental health research. Both the CI and service users identified that there appeared to be a lack of understanding/confusion within the ethics committee in relation to mental capacity, permission to consent and the consent process.

Both interviews conducted have also highlighted that the ethics committee had concerns regarding the concept of service users interviewing other service users and carers in relation to managing stress/distress of participants and service user researchers. The primary concern highlighted by the research ethics committee in the first submission was one around the 'protection' of mental health service user respondents, in particular the awareness, training and use of the Mental Capacity Act by the proposed service user researchers. In addition, and connected to this, clarification around potential clinicians' involvement in the selection process was also sought. Confidentiality was not a major issue raised.

Both the CI and service user researchers recommended that consideration needs to be given to a service user taking up a lay position on ethics committees. The CI has identified that in future, he would offer more robust preparation for service users in relation to, and before service users attended, such meetings.

Both the CI and service users identified that the length of time between receiving funding and gaining approval was a challenge in relation to maintaining the motivation and involvement of service users. From the perspective of service users, they identified that it is difficult for service user volunteers to maintain motivation and engagement throughout the complex and challenging approval process. As ethical approval took six months for only stage 1, and has not yet been given for stage 2 of the study, service users reported disappointment. Although this was a challenge echoed by the CI, he also acknowledged that this time could, and had, been used beneficially in terms of addressing service user researcher training needs, and preparing more robustly for the next stages of the study. The issues raised within ethics have been used proactively, and have led to the development of a training module in research, which will be available for service users and carers interested in research.

The CI also reports that with hindsight, he would have bid for monies to allow him to support service users to attend more research-related conferences. He now believes this would have helped to connect the service users involved with the wider research networking community.

## What have been the benefits/impact of user involvement on this study?

Service users report that they have benefited from feeling valued as equal members in the eyes of the academics working on the study, and being involved in something 'important'. They report that it will provide opportunities for service users to receive research training, and to learn from others who already have research experience.

The CI reported that without this involvement, he would not have been reassured that he would have been conducting a piece of mental health research of any relevance to practice. He reported that service users have brought direction, guidance, clarity and focus to this study, at both a micro and macro level.

Both service users and the CI believe that this study has huge potential in developing the role of service users in research. They are keen for this to provide a platform for sustainability in the area of user involvement in research in the north east of England.



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*Service Users in Research*  
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