



Service user involvement in MHRN adopted projects. Report of a survey conducted in 2006.

Introduction

The aim of this exercise was to obtain a detailed picture of service user involvement in projects adopted by the MHRN. The level of actual service user involvement found in the projects was compared with the plans for service user involvement included in the projects' applications for adoption.

Methods

The work began in January 2006, at which time there were 35 projects running on the network, and these formed the sample¹.

Statements regarding planned service user involvement were obtained from the adoption applications made by the projects and from the minutes of the relevant Adoptions Committee meetings.

Hub coordinators were asked to identify a suitable initial contact for each project, and contact was made by email requesting information or referral to a more appropriate contact. These contacts were also asked to pass on a request for information to service users involved in the projects (if any), who could choose to provide information anonymously or to contact SURGE directly. Non-responders were prompted on at least two further occasions.

Only involvement of service users in the implementation of the projects was considered, and involvement of service users in the planning stages of projects (commonly referred to on applications for adoption) was not recorded.

Results

Service user involvement in projects

29 projects were contacted by SURGE directly, and information on the remaining 6 was obtained via a service user development worker at one hub. Information was obtained from 25 projects (71%).

In 16 studies (64% of those that responded) there was no current service user involvement. However, future involvement of service users was planned in 5 of these studies, and in 2 of these the survey resulted in a request for advice from SURGE, which was given.

In 9 studies (36% of those that responded) there was evidence of service user involvement. In 2 of these projects service user involvement was in the form of

¹ 3 further projects adopted but not started at the time of the survey were excluded

participant feedback to researchers, in one project the service user was a volunteer in the research institution with limited contribution to an MHRN project, and in one project the role of service users could not be clarified. The other 5 projects (20% of those that responded) involved service users as employed research workers or steering committee members.

Interview findings

Interviews were conducted with six service users involved in MHRN projects. Of the six people interviewed, five were employed as research workers, typically concerned with data collection and entry, and interpretation of qualitative data. One interviewee had the remit of providing information to doctors and participants, students, etc. and promoting the study on a voluntary basis.

The five employed research workers all had a contract, a written role description (though not all regarded this as adequate or accurate), and received payment. All were involved in the actual research process of the study, and one had also been responsible for setting up a part of the study. This person described a high and satisfying level of control over the study. All other research workers felt they had only limited control over their work and were not involved in the making of important decisions concerning the project.

They were all doing qualitative interviews and some of them were also recruiting participants, an aspect of the role which was felt to be a source of considerable pressure. It was suggested that two main difficulties arose for researchers related specifically to their service user background: First, feeling pressure to recruit patients into the study while at the same time doubting the ability of some potential recruits to give informed consent. Secondly, personal emotional involvement with interviewees was sometimes inevitable, given their own experience.

Several interviewees mentioned the tension arising through having a service user background and working in a highly competitive, institutionalised, academic environment. Their personal desire to improve service users' experiences with services could appear incompatible with the actual work they had to do. Some felt lost and alienated in the academic environment.

The most prominently expressed wish was to have more supervision, formal and personal support, and more open and frank communication in general. It was thought desirable to have clear arrangements about who to talk to and where to turn in case of personal problems; there should be time and space for this away from the usual workplace. At the work place, there should also be open discussion about the possibility of the service user researcher falling ill. It was felt additional stress was generated by "suspicion" and "worries that the service user researcher may get ill" on the part of non-service user researchers.

The plans and the realities of service user involvement in the MHRN

The original goal of making detailed comparisons between the plans for service user involvement outlined in the adoptions application and the actual service user involvement was modified as it became apparent at an early stage that in many cases there was no relation between what was outlined and what actually happened. One reason for this may be that the ideas of how to involve service users, and in which roles they may be involved in the project were to some extent ambiguous in the adoptions applications; clear statements often missing. This may have contributed to plans for service user involvement being lost in the project setup and execution.

Also, in many projects the only service user involvement mentioned in the adoptions form was involvement in the development of the protocol and no further involvement seemed to have been planned. Hence no plans could be compared to actions.

Surprisingly, the most thorough and extensive service user involvement was found in projects that stated very little about their plans for service user involvement in the adoptions form.

Conclusions and Recommendations

This survey establishes a baseline for service user involvement in the initial group of projects adopted by the MHRN. It shows that despite the requirement to demonstrate plans for service user involvement at the point of adoption, such plans are often not carried through. Only just over a third of projects could demonstrate service user involvement during their implementation phase. One fifth of responding projects demonstrated a significant level of user involvement and a further 16% involved people to a lesser degree, for example through participant feedback. The survey will be repeated in two years time to establish whether progress has been made.

Service users employed as researchers in projects face a number of challenges which are common to all researchers in academic environments, but may experience additional tensions and stresses, for which they require appropriate support.

The Good Practice Guidelines (GPG) already published by SURGE make detailed recommendations for developing appropriate plans for service user involvement, for implementing those plans after adoption and for supporting service user researchers.

SURGE recommends:

1. The GPG should be widely disseminated by the MHRN and made available to projects at the earliest possible stage in their development².
2. MHRN should encourage funding organisations to provide budget lines for appropriate service user involvement.
3. MHRN should, through the adoptions process, encourage the development of clear plans for service user involvement at the earliest possible stage. The adoptions committee should assess these plans to ensure they are clear and feasible, and include details, with budgeting, for the involvement of service users at different stages of the project.
4. MHRN should utilise its knowledge and support structures to facilitate user involvement and, through hubs, encourage projects to seek advice from SURGE at an early stage in their projects.

² Please note: Good Practice Guidelines (GPG) available to download from 'Service User Involvement' section of MHRN website (www.ukmhrn.info).