

Feedback from trusts to proposals for a national survey of mental health service users

Introduction

This note addresses the main concerns and questions raised by trusts about proposals for a national survey of mental health service users. The feedback from trusts will be used to inform the further development of the survey methods and guidance for trusts.

What are the benefits of taking part in another survey, particularly when many providers are already conducting in-house service user consultation?

Obtaining feedback from service users and taking account of their views and priorities is vital for bringing about improvements in the quality of care, and placing the service user at the centre of mental health services.

A centrally coordinated national survey of mental health service users will allow organisations to benchmark their results with other similar trusts, and the national picture. The survey will identify organisations where service users give a positive response to the survey, so that best practice can be shared.

We recognise that many organisations are already active in consulting users and getting feedback. In many cases this work is already complimentary to the national survey. Given greater notice about national survey initiatives in the future, we hope that trusts will be able to plan work to obtain patient feedback to make the best use of local and national initiatives.

Why don't the topics of the survey cover all of a mental health trust's services, the full variety of service users and more locally specific issues?

Developing a survey for service users of mental health services has been very complex, for all the reasons raised by

trusts. It has become clear during the development of the survey that it would not be possible to develop one survey which was relevant to different groups of service users, for example older people, children and adolescents, or people with learning difficulties. Consequently, in order to make a start with this important programme of work, the decision has been taken to focus the first survey on adults (aged 18-65) on CPA registers. Once evaluation of the survey has taken place, future surveys may be developed, or this survey adapted to cover other groups.

This initial survey has been developed with a high degree of input from service users to address the issues that are most important to them. It has been designed to work across a range of settings (eg community, outpatient) and so specific questions about a particular service or environment are not possible. We are aware of the important issues about quality of the care environment for inpatient service users in particular, and hope that these can be addressed in a later survey.

The timetable for this survey would not allow local flexibility in the questionnaire: we plan that future surveys will be divided into core questions and optional questions, to allow local flexibility, following the approach taken for the acute surveys.

Will it be possible to breakdown the survey results into different areas of an organisation's services?

A number of trusts have pointed out that they are organised on a locality basis, often to enable close working with partner organisations, or as a results of recent mergers.

In order to produce a breakdown of results within the trust, trusts could increase the number of service users they include in the survey, and seek advice from their approved survey contractor about how to produce an analysis of results on this basis.

Have service users been involved in developing the survey?

We have involved service users to develop the surveys. Examples of the research and consultation with service users includes:

- a review of existing research with service users.
- focus groups with service users to identify issues which are most critical to them about services.

- drafting of the questionnaire to reflect the concerns of service users.
 - further testing of the questionnaire with service users on a one to one basis, to ensure questions make sense.
- We have also held interviews with a range of people working in the mental health sector, and with representatives of service user organisations.

Further information about each of these stages is given in the appendix.

We are now ready to pilot the survey, by posting the questionnaires to a sample of service users. This will go ahead once ethics committee approval for the survey has been obtained.

Will a survey have difficulties in gaining a sufficient number of responses in the mental health service arena, particularly a postal one?

During the development of the survey, a review of the literature was undertaken to assess the options for undertaking the survey. The postal method was chosen to make it feasible to reach enough service users across all trusts, to provide comparable results at trust level.

Although there is some evidence for low response rates for postal surveys of mental health service users, many of these surveys have not adopted current best practice for postal surveys (such as using two reminders). We will be piloting the surveys, and this will provide us with information about expected response rates for this survey.

A number of steps have been taken or are planned to ensure the best possible response:

- short, salient questionnaire: the questionnaire will be 8 pages long and focus on issues of greatest concern to users. (See above re development of questionnaire.)
- 2 reminders will be used.
- publicity for the survey: the guidance will include advice on engaging trust staff and on how to generate positive publicity about the survey.
- support for completing the questionnaire: the scope for a dedicated helpline for the survey is being explored.

How has the sample size been determined, and should this vary between trusts of different sizes?

The aim for at least 500 completed questionnaires (from a sample of 850 users) is to enable comparisons to be made between trusts and the national benchmark. This sample does not need to be increased for larger trusts, since it is the number of responses, not the proportion of the total population which affects the precision of the results.

The guidance will provide detailed instructions for who is eligible for the survey, and how to draw the sample. The guidance will also provide advice to small providers who may have fewer than 850 service users on the CPA register.

Has there been sufficient consideration of service user consent and other ethical issues?

Approval is being sought from the Multi-centre Research Ethics Committee (MREC). Guidance is being developed to addresses ethical issues relating to this survey. The guidance explains how confidentiality of responses can be maintained.

What logistical aspects will need to be considered in order to carry out the survey in the most efficient and timely manner?

A guidance manual will be provided to detail the requirements and procedures for conducting the survey, and the deadlines given will allow the tasks to be achieved in a time to produce the required results.

The guidance will cover issues such as the practicalities of using a contractor or working in-house, how to compile a survey sample, maximising the patient's receptiveness to the survey process, data-protection, collecting responses from non-English speakers, making sense of the data, etc.

Examples of survey guidance manuals (for the forthcoming acute outpatient and A&E surveys) can be downloaded from the NHS Surveys website:

<http://www.nhssurveys.org/categories.asp>

The guidance is likely to be available at the beginning of February 2003.

Will there be any funding to help carry out the survey?

No additional funding will be available as it is an existing requirement of NHS organisations to collect feedback from

service users in a systematic way. We appreciate that trusts have received relatively little notice about the survey, and we plan to address this in the future.

Sarah Scobie
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Appendix: development of mental health survey

INTERVIEWS

- Telephone and face-to-face interviews were conducted with a range of individuals working in the mental health voluntary sectors. These included representatives from MIND, Rethink, Mental Health Matters and the UK Advocacy Network.
- Face-to-face interviews were also conducted with local mental health professionals in Oxfordshire.

LITERATURE REVIEW

- A literature review was conducted to identify mental health surveys carried out in the UK in recent years.
- Some of the questions in the questionnaires identified in this review helped to inform the topics that should be covered.

FOCUS GROUPS

- Five focus groups were conducted in Maidstone, Guildford, Oxford, London and Leicester.
- A topic guide was drawn up in consultation with members of the DH Mental Health Team.
- Participants were recruited from user groups, MIND and an advocacy group for ethnic minorities. One group consisted of ex service users who were now acting as patient representatives. In total, 11 females and 18 males took part and ages ranged from 20 to 70.

DRAFT QUESTIONNAIRE

- Drawing on all the above, a draft questionnaire was compiled and circulated to members of the DH Mental Health Team, the steering group and CHI. The DH mental health team circulated the draft questionnaire to the NIMHE User and Carer group.
- Comments from the above were used to amend the questionnaire where it was considered appropriate.

COGNITIVE INTERVIEWS

- Individual cognitive interviews were conducted with 5 females and 2 males on standard and enhanced CPAs. They were recruited via MIND, Mental Health Matters and the Mental Health Shop in Leicester.
- As issues were raised in the completion of the questionnaire, it was revised and amended accordingly and new drafts tested in subsequent interviews.

- The cognitive interview demonstrated that the questionnaire had to be short and simple if respondents are to be encouraged to complete it.
- None of the cognitive interviewees raised any objections to the questions asked and there were very few recommendations for additional questions.
- Interviewees were further probed about the potential for offence to be caused by sensitive questions, such as those that refer to alcohol and drug abuse, but none of them found these questions offensive.