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**Quality assurance/monitoring of mental health  
services by service users and carers**

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"Empowerment is not a destination, but a journey."

From: *User Empowerment in Mental Health: a statement by the WHO Regional Office for Europe* (WHO & EC, 2010)

"It's common sense, really. Involve the customers in the decision-making and you're going to get a better product."

Dr Richard Bentall in an interview for the *New York Times* on 30 November 2009.

"If the evaluation of services [is] genuinely to reflect the concerns and views of the people who use them rather than those of providers, then users should lead the process at every stage: from the questions asked, through the collection, analysis and interpretation of data to the final reporting of the results and development of recommendations for change."

From: *A guide to user-focused monitoring* (Sainsbury Centre for Mental Health, 2007).

## Statement of topic

This paper summarizes what is currently known about the empowerment of people with mental health problems and their families/carers in relation to the quality assurance and monitoring of mental health services. It includes evidence from the literature about what works, as well as implications and options for policy-makers. It concludes with a number of practical recommendations for policy-makers, service providers and others.

## Background to the issue

The empowerment of mental health service users and carers is one of four key priorities for the WHO Regional Office for Europe. A recent WHO statement defines empowerment as: "the level of choice, influence and control that users of mental health services can exercise over events in their lives" (WHO, 2010).

Throughout Europe, mental health service users face social exclusion and discrimination, often lacking information, choice and control when in contact with mental health services. Their friends and families are also often excluded from decision-making in mental health.

WHO (2008) collected baseline data in 42 countries in the European Region, finding little evidence of systematic, meaningful service user or carer involvement in quality assuring services. During the "Lille seminar on User Empowerment" (WHO Collaborating Centre, Lille, France, 2008), Matt Muijen commented:

A particularly important indicator of empowerment is for us whether users and carers are involved as full members in the external inspection of services. Remarkably few countries confirm that they do so, despite positive experiences in places who have tried this.

Yet, such involvement leads to evaluations, which are more relevant to people's needs and concerns. Further benefits include developing more relevant outcome indicators, improving the quality of information obtained from service recipients (who often speak more freely to peer interviewers) and suggesting practical change strategies to improve services (Davidson et al., 2009). There is evidence that involvement in quality assurance enhances people's skills, confidence and sense of worth (Kotecha et al., 2007).

WHO is currently producing guidance standards (indicators) for European countries for the empowerment of service users and carers. These include standards for service user and carer involvement in inspecting and monitoring services, and will seek to ensure, for example:

- the engagement of service users and carers in the development and implementation of relevant national policy and in related research, training, monitoring and inspection;
- statutory rights for service users regarding their involvement in the implementation and monitoring of services at local level;
- that service users are given the chance to be involved (possibly as partners) in all stages and at all levels of planning, delivering, running and evaluating the services.

## **Policy implications and policy options**

### **Creating a national policy strategy to sustain involvement**

Currently, only the Netherlands and the United Kingdom have legislative requirements for engaging patients and the public in health care policy. Other European countries use local, democratic mechanisms, plus patients' rights and complaint systems. Effective involvement needs a strategy that goes beyond simply electing lay representatives to boards and committees since many people with health problems feel unable to stand for election or may drop out of regular participation once elected (Tritter & McCallum, 2006).

### **Thinking about involvement**

Concepts of involvement have been much influenced by Arnstein's ladder of citizen participation (1969). However, this may no longer fit the complexity of real-life situations in differing political and social cultures:

A linear, hierarchical model of involvement – Arnstein's ladder – fails to capture the dynamic and evolutionary nature of user involvement....user involvement requires that the structure and process be dynamic and negotiated by users themselves (Tritter & McCallum, 2006 p.166).

Policy-makers need to work with diverse individuals and groups at local, organizational and national levels in ways, which fit the situation in their countries, as well as to take on board essential principles and values of empowerment. Involvement systems should be flexible enough to evolve towards equal partnership with stakeholders where this is not yet happening.

## **Methods of involvement**

Several European countries have developed methods, which have been used locally and nationally to engage service users and carers in the quality assurance and monitoring of services. These range from consultation exercises and surveys, to the participation of service users and carers as full members of service inspection teams, to service-user-led evaluation and monitoring of services (Annex 1).

### **Consultation and survey methods**

Surveys, focus groups and other kinds of consultation can provide an opportunity for large numbers of service users and family members to give their views. If the same exercise is repeated, changes over time can be monitored. This method works best when service users and family members are actively involved in developing and carrying out the consultations as this ensures relevance of the questions asked.

### **Involvement as partners in service inspection teams**

Service users and family members can be invited and trained to take part in existing service inspection teams, with the same status as other inspectors. This can work well and may not require additional funding. One disadvantage may be that working with a standard inspection system does not give lay inspectors an opportunity to represent their own views or those of their peers.

Other methods include "mystery shopping", which is a form of market research. The principles have been adapted for quality assurance of mental health services. Service users may be asked to give anonymous feedback about services they use (Heingartner, 2009).

### **User-focused monitoring**

In this method, service users are trained to conduct interviews, focus groups and surveys with other service users on their experiences and views of mental health services. The researchers are typically drawn from the service being evaluated and help to generate relevant questions for their peer group. The service providers and service user representatives then meet to discuss ways of strengthening and improving service delivery. This method draws on the experiences and perspectives of the service users and builds their confidence and capacity. As with conventional surveys, repeated cycles of research and feedback lead to service improvements (User Interviewing User, 2006; Kotecha et al., 2007).

## Conclusions and recommendations for action

European Member States have different legislative frameworks for lay involvement and they are at different stages in this work. We recommend that countries develop a strategy to fit their starting point. This could mean beginning with consultative approaches and building towards partnership models and service-user-focused monitoring. The countries that have already undertaken some service-user-led work could further develop it.

We believe that the following recommendations constitute the basic essentials for effective service user and carer involvement in quality assurance and monitoring.

### **Work towards national frameworks to support involvement**

Service users cannot do everything for themselves and national policy-makers have an important role to play in providing a framework to support involvement. Involvement in quality assurance and monitoring works best when supported by a coordinated and funded national policy structure backed by legislation (Tritter & McCallum, 2006). Where this does not exist, service users, carers and service providers need to lobby for change.

### **Ensure quality assurance and monitoring leads to service improvement**

Ideally, there should be continuous cycles of monitoring, evaluation and development of services. This helps people at all levels to see the benefit of involvement: service providers and service users see better services; those who become involved see the fruits of their involvement and are more likely to continue to be involved in the future.

### **Conduct quality assurance from service user and carer perspectives**

Assessments that involve service users and carers should address the factors that are important from their perspectives (Campbell, 2009). Evidence-based practice is only as good as the evidence on which it is based: the more that quality assurance is based on service-user-defined outcomes, the more relevant the evidence base becomes to them.

### **Apply good practice principles**

There are numerous examples of good practice principles for user involvement that apply equally to involvement in monitoring services (see, for example, Schrank & Wallcraft, 2009). Such principles include:

- ensuring adequate funding for involvement;
- providing training and support for all stakeholders;
- ensuring clarity and transparency regarding the purpose of evaluations.

### **Understand and adopt core principles**

For service user/carer involvement in evaluation to work, there are a number of core principles that all stakeholders (policy-makers, service providers, service users and carers) must understand and commit to. These include that:

- only service users can represent service users and only carers can represent carers.;
- service users and their families are the best people to comment on service quality;
- the views and experiences of service users and carers must be valued and seen as valid and credible;
- the views of service users and carers should not be invalidated as being "unrepresentative";

- service user/carer involvement in evaluations must not lead to reprisals.

### **Build capacity in service user and carer organizations across Europe**

To achieve all this effectively, it is important not to expect too much of too few people. Service user and carer movements have developed at different rates across Europe. There is always a need for investment in the infrastructure and capabilities of service user and carer groups and in their networking opportunities for doing this work. The greater the number and diversity of people involved in the work, the more effective it will be.

### **Win hearts and minds**

For involvement to be effective everyone needs to believe in its value and trust should be built between healthcare workers and service user and carer organizations. Involvement works best if there is someone to champion it, preferably at a high level in the relevant statutory body.

### **Evaluate the involvement of service users and carers**

The systems and methods chosen for service user/carer involvement in evaluations themselves need monitoring in order to develop best practice and improve effectiveness. Throughout this, it is important to be clear about the purpose of every initiative and to critically evaluate its effectiveness in achieving its aim. This is equally important for initiatives that are successful and those that are less so. They should all contribute to our learning.

### **Be innovative**

Although we recommend the above as essential actions, we also believe that stakeholders must be flexible and innovative in thinking about user and carer evaluations of services and ensure that any evaluations are sensitive to the local context.

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## Annex 1

### Methods of service user and carer involvement in quality assuring services

<b>Evaluation</b>	<b>Description</b>	<b>What works</b>	<b>Drawbacks</b>	<b>Requirements</b>	<b>Examples</b>
<b>Surveys of mental health service users and their families and carers</b>	Local, regional and national level surveys of people's experiences.	Sample sizes are large so most people can give their views; surveys are anonymous and confidential; repetition means services can be monitored over time; often cost-effective; surveys can be simple; a good option where strong service user/carer involvement structures do not exist.	Service users may be sceptical and so the number of responses can be disappointing; surveys can be superficial; the questions may not be relevant and important to service users/carers; service user/carer involvement in monitoring services is at a minimal level.	Surveys need to be a duty of statutory bodies to ensure comprehensive coverage; service users and carers should be involved in setting the questions; systems are needed to administer, analyse and feedback results; funding is required.	The National Centre for Social Research in the United Kingdom conducts large-scale surveys with people detained under the Mental Health Act and people using community mental health services. See: <a href="http://www.nhssurveys.org/survey/696">http://www.nhssurveys.org/survey/696</a>
<b>Involvement in statutory bodies carrying out inspections</b>	Service users can be trained to join existing inspecting teams where these already exist.	This can be a simple way of involving users in monitoring; little funding is required as service users join existing teams and structures; service users have the same status as all other inspectors; inspections carry authority and credibility with stakeholders; inspections should lead directly to service improvements.	Services are not monitored solely from a service user perspective – instead the focus is on the legality of involuntary detention.	Existing structures for inspecting mental health services; appropriate training and support.	In the United Kingdom, the Care Quality Commission monitors the use of the Mental Health Act for people detained in psychiatric units involuntarily. Service users have been trained as Commissioners, giving them the power to inspect such facilities. See: <a href="http://www.cqc.org.uk/guidanceforprofessionals/mentalhealth/workingwithpeoplewhoserightsarerestricted/ormonitoringoftheuseofthementalhealthact.cfm">http://www.cqc.org.uk/guidanceforprofessionals/mentalhealth/workingwithpeoplewhoserightsarerestricted/ormonitoringoftheuseofthementalhealthact.cfm</a>

Evaluation	Description	What works	Drawbacks	Requirements	Examples
<b>Mystery shopping</b>	Existing service users and carers are recruited to give regular feedback on their contacts with services. Alternatively, pseudo service users/carers are trained to access services and report their experiences. In both instances, anonymous feedback is then given to staff to help them improve the service they provide.	Mystery shopping is anonymous and confidential; staff may routinely improve their practice; if real service users/carers are used, the service gains direct feedback on genuine encounters; unique information can be generated; information can be gathered over time to monitor improvements.	This is costly where pseudo patients are used (e.g. planning, time, money, training etc); there is debate regarding the ethics of pseudo patients; other methods may get similar results e.g. interviewing service users/carers about their experiences.	Careful thought and planning (which must involve service users and carers); appropriate structures including feedback mechanisms; funding; ethics approval may be required.	Examples can be found in the Netherlands, the United Kingdom and the United States. For more information on mystery shopping see:  1. <a href="http://psychservices.psychiatryonline.org/cgi/content/full/60/7/972">http://psychservices.psychiatryonline.org/cgi/content/full/60/7/972</a>  2. <a href="http://pb.rcpsych.org/cgi/content/abstract/34/4/121">http://pb.rcpsych.org/cgi/content/abstract/34/4/121</a>
<b>User focussed monitoring (UFM) or surveys of users' views carried out by service users</b>	Service users are trained to conduct interviews, focus groups or surveys with other service users about their experiences of and views on mental health services. Trained service users come from the service being evaluated and so understand the service. Conferences are then held between service providers and service user representatives to discuss ways of strengthening and improving service delivery.	This approach is: in-depth; meaningful; draws fully on users' experiences and perspectives; builds on service users' capacity; is action-orientated; has credibility with service users; responses are anonymous and confidential; regular monitoring means a cycle of improvement can be established. The approach could also be used with carers.	This approach is time-consuming and must be set up thoughtfully; adequate funding is needed; staff may need training to be convinced of the value of service user controlled evaluations.	Enough time and funding to establish the programme; training for both service users and staff; strong service user groups and networks; the approach must be led by service users. Mentoring by experienced service users from different regions/countries could be helpful.	, for example: <b>Germany:</b> Russo J et al. (2007). <i>Aus eigener Sicht. Erfahrungen von Nutzer/innen mit der Hilfe</i> <b>Norway:</b> User Interviewing User (2006). <i>Rapport fra BSB-undersøkelse: Tjenester for mennesker med psykisk helseproblematikk</i> Stange kommune <b>United Kingdom:</b> Rose (2001). <i>Users' voices: the perspectives of mental health service users on community and hospital care.</i> Sainsbury Centre for Mental Health