

A Guide to User-Focused Monitoring

Setting up and running a project

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This publication is essential reading for all mental health staff and service user groups who wish to ensure that the user's voice is heard in evaluations of mental health services. It provides a step-by-step guide to setting up and running a user-focused monitoring project where teams of service users are trained to interview other users about their experiences. It covers all stages of the project from recruiting the co-ordinator and interviewers, to training the team, developing research tools, analysing the findings and disseminating the final report.

The following is an extract from this publication which includes:

- ❖ List of contents
- ❖ Foreword
- ❖ Introduction – What is User-Focused Monitoring
- ❖ Essential Criteria for UFM Projects

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Contents

Acknowledgements	4
Foreword	5
Introduction	7
1 Diversity, inequalities and power imbalances	13
2 Getting started	17
3 The UFM co-ordinator	25
4 The research group	28
5 Training	35
6 Payments	41
7 Criminal Records Bureau checks and honorary contracts	43
8 Research design/methods	46
9 Developing tools for the research	52
10 Sampling and carrying out interviews	57
11 Objectivity, bias and reflexivity	63
12 Analysing data	65
13 The final report	68
14 Dissemination, implementation and outcomes	70
15 Future directions	75
Glossary	79
Abbreviations	83
References	85
Appendices	
1 Guidelines	88
❖ Carrying out interviews	88
❖ Roles and responsibilities of an interviewer	90
❖ Safety	90
❖ Confidentiality	91
❖ Setting up advisory/steering groups	92
2 Example of site visit questions and sample page of workbook	94
3 Resources	95

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This publication is dedicated to all those people who identify as service users or survivors of mental health services.

Foreword

Mental health services look very different according to one's position in relation to them: the perspective of those who provide them is poles apart from that of people who are on the receiving end of their ministrations, and differs again from the perspective of their relatives and friends. Historically the views of service providers have been the primary, and often the only, consideration. Service recipients were typically deemed incapable of expressing a cogent or meaningful perspective. 'Lack of insight' was deemed to be part and parcel of their illness, so their opinions were dismissed as nothing more than a reflection of their underlying pathology.

But over the last 30 years things have been changing. The demands of an increasingly vociferous and influential user/survivor movement in the 1980s have led to ever-greater attention being paid to the experience of using mental health services. The vision for the 'modernisation' of services presented in the *NHS Plan* (DH, 2000) and in the *National Service Framework for Mental Health* (DH, 1999), and reflected in all subsequent policy guidance, has at its core the requirement that services be tailored around the wishes, preferences and needs of those who use them, to create a patient-led NHS (DH, 2005a) that people have a positive experience of using.

Although we are clearly a long way from achieving this vision, obtaining the views of those who use the services is an increasingly important way of evaluating that quality. At a national level, the Healthcare Commission has conducted annual surveys of the views of those who use community services, and in 2007 it will also carry out an inpatient survey. At a local level, numerous attempts of varying quality have been made to provide individual teams and facilities with feedback about what they ought to do differently.

Service users have always been 'involved' in these surveys but traditionally only as respondents to the enquiries of clinicians and researchers. It remains the norm for clinicians and researchers to design questionnaires, interviews and inventories that reflect their own interests and concerns, which may or may not reflect the priorities of service users. Many service users remain reluctant to be open about their opinions for fear that this might have a negative impact on the support they receive, and all data obtained in the surveys is analysed and reported from within the parameters determined by the service provider.

The development of user-focused monitoring (UFM) at the Sainsbury Centre for Mental Health represents a radical departure from this tradition. The team responsible for this initiative was led by Dr Diana Rose, herself both a qualified researcher and a long-term user of both inpatient and community mental health services. It started from the premise that if the evaluation of services was 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.

UFM offers two types of information: the qualitative information necessary to inform providers about the types of changes that are needed, and the quantitative information necessary to evaluate the

impact on the experience of using an individual service of any changes that have been made. Therefore, by repeating the process at regular intervals a team or service can progressively implement user-focused practice and service developments, and evaluate the impact of these on user experience in a continuing cycle of improvement.

We sincerely hope that this guide is widely used by service providers, commissioners, clinicians, researchers and service users to improve the quality of services. The people who use mental health services are the most important people in them (DH, 2000). It is only through this type of process that we can ever hope to achieve the vision of genuinely user-centred services tailored to the needs and preferences of those who use them.

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Introduction

“Evaluation is exciting work that can really make you think about what you are doing and why.”
(Mckie et al., 2002)

About this guide

This book is essential reading for all those who wish to ensure that the service user's voice is heard in evaluations of mental health services. It provides a guide to setting up and running a user-focused monitoring (UFM) project where teams of service users are trained to interview other users about their experiences.

It has been written by people who have been involved in the development and delivery of UFM. They describe the practical challenges they have faced and how these were resolved. A list of essential criteria for UFM projects has been developed as a result of their experiences (see page 10) and this guide shows how these can be put into practice.

The guide is aimed at service users and mental health staff, including practitioners, managers and commissioners, who wish to set up a UFM project or find out more about the process. It will also be of interest to voluntary sector organisations that wish to support or develop a UFM project.

What is UFM?

UFM is a way of carrying out research in which the people who use mental health services evaluate the experiences of other mental health service users. It can be used both in the community and in hospital. It aims to put service users at the heart of the process and to improve the quality of mental health service delivery. It may also be a useful way of generating creative alternatives to the services that exist now.

The idea of service user involvement in mental health service development and practice is now firmly established. However, there are still serious questions as to its consistency and effectiveness (Trivedi, 2001; Trivedi *et al.*, 2002; Oliver, 1992), and there are few examples of involvement moving beyond consultation to control. A greater understanding of the complexity of user involvement together with what needs to be put in place to support it properly (HASCAS, 2005) may now be emerging.

All UFM interviewees and interviewers are service users (many with severe mental health problems). Service users lead each stage of the UFM evaluation process (see Figure 1). UFM enables a wide range of service users whose voices are rarely sought to contribute their views, experiences and ideas to the evaluation process. This means reaching out to, among others, Black and minority ethnic (BME) people, those from refugee, gay and lesbian or homeless communities, individuals with physical or multiple disabilities and those who are economically and socially deprived.

“We know from our experience that engaging patients and members of the public leads to research that is more relevant to people’s needs and concerns, more reliable and more likely to be put into practice.”

(DH, 2006a)

Powerful systems of exclusion particularly affect marginalised groups and explain why these tend to be present in the poorest (in terms of quality) parts of the mental health system. This creates ever-deepening exclusion and isolation and can lead to coercion and abuse within services (SCMH, 2002; Fernando, 2003; Williams & Keating, 2005).

People with mental health problems have also traditionally fared particularly badly in mainstream mental health research, which has been dominated by medical issues such as diagnosis and drug-based interventions. In this research, people who have mental health problems are ‘subjects’ who are researched and assessed in terms of their propensity to ‘mental illness’, with little regard to how they are affected by social and economic deprivation.

Service users and survivors have come up with a range of responses to being treated in this way (Pilgrim, 2005). UFM is one of these responses.

In traditional, professionally run evaluation interviews, service users are hesitant to be too open about their experiences. UFM has clearly shown (Rose, 2001) that if research is designed and conducted by service users it provides information that seldom emerges from more traditional research. Such information is essential if services are to become truly user-centred and driven by the needs, vision and creativity of those who most frequently use them.

“My worst nightmare for UFM is that it is seen like a pretty butterfly that does nothing, a nice ornament. It’s about people who have used mental health services, and often had a bad time of it, coming together to produce something that’s useful, and that produces change.”

UFM group member

Benefits of UFM

Over the last ten years, UFM has been developed at many sites in the UK. It has been shown to:

- ❖ provide an opportunity for people to lead and carry out an evaluation of a mental health service (drawing on their personal experience of services);
- ❖ enable the voices of marginalised service users to be heard and to influence service development;
- ❖ provide new perspectives and information to service providers;
- ❖ provide a crucial ‘tool’ for clinical governance;
- ❖ actively enable the development of equitable and constructive working partnerships between people who use services, service providers and commissioners and wider communities within a locality.

“My self-confidence and self-esteem, absolutely at nil when I first became involved with UFM, have had a tremendous boost and I have found that I have used organising skills I didn’t know I had. I have made great friends within the team and have had many laughs. I appreciate the help and support everyone offers, not just to me, but also to each other. It has also been good to see other members of the team using their old and new skills.”

UFM group member

Where UFM is carried out in accordance with the principles set out in this guide, it also brings direct benefits to service users involved in UFM groups, by:

- ❖ providing an opportunity to do something that values personal experiences;
- ❖ reducing isolation and providing an opportunity to make new friends;
- ❖ participating in an activity that is not about being helped but helping others;
- ❖ earning money;
- ❖ developing skills and confidence.

How it all began

The idea of UFM was developed at the Sainsbury Centre for Mental Health (SCMH) in 1996 and, originally, UFM projects were co-ordinated directly by members of the UFM team based there. Findings from these early reports are presented in an earlier publication, *Users' Voices* (Rose, 2001).

From 2002, as new UFM projects were set up, co-ordinators were recruited locally, with 'arm's length' support available from the UFM co-ordinator at SCMH. Soon after, a national UFM Network was set up specifically to support local UFM projects and to enable UFM co-ordinators and group members to network and share experiences and progressively refine the process of UFM. During this time, both the co-ordinator at SCMH and the UFM Network received many requests for information and advice about UFM, not only from individual service users and service users' groups but also from NHS managers, clinicians and commissioners of services. It also became apparent that some projects identifying themselves as UFM projects were being undertaken in less than desirable ways and not in accordance with the principles that had been developed and then set out in *Users' Voices*. In response to this it was decided to produce an accessible and comprehensive guide setting out the practice, achievements and challenges of UFM.

The UFM approach is part of a much broader development, in which people who identify themselves as survivors and/or service users carry out research within mental health services, covering issues that range much wider than services themselves, such as employment, self-definitions of distress, coping strategies and alternatives to medical treatment.

We want to acknowledge the fact that many of the ideas developed for UFM and set out in this guide have their roots in the ground-breaking research emerging from the emancipation and disability movements of the 1960s and 1970s (Turner & Beresford, 2005). This work provided the foundation for the development of service user research. It is important to remember that UFM is only one approach to service user-led research; it does not claim to be the only or the right way.

At the same time, whatever the nature of service provision in years to come, the need for services to be evaluated from the standpoint of people who use them has never been greater. This is a political issue. There remains a huge chasm between the political imperatives of managing risk and the imperatives of creating services that are enabling and provide real support, sanctuary and safety. Establishing and sustaining UFM projects has involved great struggle which will continue just as struggles continue in user involvement generally and in user-led research.

Essential criteria for UFM projects

A list of essential criteria for UFM projects has been developed by the UFM Network, based on their experiences in setting up and running projects. These are derived from a list first published in *Doing it for Real* (UFM Network, 2003).

1. Projects should be led and controlled by service users. This means, for example, that:
 - ❖ the research topic is chosen on the basis of the concerns of local service users;
 - ❖ the questions are created by service users with reference to and input from a range of people using the services under evaluation (e.g. people outside the UFM group itself);
 - ❖ service users form at least one-half (plus one person) of any management structure, e.g. steering group;
 - ❖ service users are actively encouraged and supported to take part at all stages of the project.

In circumstances where it has not been immediately possible to recruit a co-ordinator with personal experience of using services or mental health difficulties, UFM co-ordinators must have a demonstrable understanding of and commitment to service user research and involvement, and a commitment to working towards UFM becoming a fully service user-controlled project.

2. There should be a clear focus on the development and improvement of those services that are most frequently used by service users, particularly those from marginalised groups.
3. There should be an active commitment to secure the participation (as UFM group members/ researchers and wider contributors) of (a large proportion of) service users who have used the services under evaluation, including those people whose voices are rarely heard.

The project should provide opportunities for individual service users to be involved in a variety of ways and at different levels in the research process, for instance, question development, data input, analysis, writing the report and recommendations for change, dissemination and implementation process. All service users (including interviewees) should be appropriately paid for their input and have their reasonable expenses reimbursed.

Service providers and others involved in the project (e.g. steering or advisory group members) should be active in promoting UFM within services and be proactive in supporting it to achieve and maintain its principles, particularly in relation to following through recommendations to achieve positive change.

4. There should be an aim to disseminate findings as widely as possible, including ensuring that all interviewees receive feedback on the findings of the evaluation and are invited to give their views on the process and outcomes. Allies within mental health services and funders should provide support for this.
5. There should be a commitment to addressing equalities issues, e.g. by ensuring that the views and opinions of those people whose voices are rarely heard are included, as members of the UFM group and as participants (i.e. those being interviewed). These may include:
 - ❖ people who have been threatened with or have experienced compulsory treatment;
 - ❖ people who are perceived as 'difficult to manage', too ill or too 'dangerous';
 - ❖ people with disabilities, including those with multiple or invisible disabilities;

- ❖ Black and minority ethnic (BME) and Irish communities;
 - ❖ people who have complained about or who have disengaged from mental health services;
- as well as many other excluded groups (UFM Network, 2003).

It is important to remember that there is a distinction between those people who identify as service users who are involved in creating and shaping the UFM process (e.g. as members of the group and interviewers) and those who are participants in the evaluation itself (i.e. those who are interviewed). Both groups will include people who have had significant mental health problems.

UFM works as an enabling group process, designed to ensure that UFM principles (including those of equality and open access for all) are upheld and that the focus of the project is maintained. The co-ordinator is accountable to the UFM group and is fundamentally a facilitator, although responsible, together with any steering or advisory group, for ensuring that UFM principles are adhered to. There should be regular opportunities for new people to join the group.

6. There should be independence, with the UFM group and co-ordinator having control over key decision-making areas such as timescales for projects and budgets, with the freedom to write and publish their findings without interference. True independence cannot be achieved without secure and adequate funding, e.g. to employ the UFM co-ordinator, to pay service user project workers and other costs, and to allow sufficient time to take the project to completion.
7. The UFM group should develop and follow good standards of research methodology (see Chapter 8).
8. The co-ordinator and project group should receive supervision and support, with access to appropriate expertise, throughout the UFM project. This should be flexible to allow for differing levels of experience, strengths and skills.
9. Accessible, flexible and comprehensive training should be available for the whole project team, including the co-ordinator, catering for the different needs of the service users involved.
10. There should be a commitment to implementing the recommendations from commissioners and service providers. This should be demonstrated by planning the process for implementation as early as possible and making resources available for it, including for the involvement of service users.

