

August 2003

Doing it for real: a guide to setting up and undertaking a User Focused Monitoring project

The first User Focused Monitoring (UFM) project based on the model developed by the Sainsbury Centre for Mental Health (SCMH) was carried out in Kensington Chelsea and Westminster as a pilot project in 1996 by Dr Diana Rose.

Since then, many projects have developed around the country that use the term UFM to describe their work.

SCMH now supports such projects in the form of a network of service user led monitoring projects, which includes projects that have had little or no previous link with the Sainsbury Centre UFM model.

The network was formed in 2002 and consists of co-ordinators and service user researchers from 12 projects. It meets every 2/3 months and aims to provide a space for support, reflection and challenge for both co-ordinators and service user researchers.

One of the first pieces of work that the network set itself was to document some of the core criteria necessary to undertake a UFM project and the results appear on page 2. The groups within the network recognise that UFM can and indeed, should take different forms and the membership reflects this rich mix of styles and shapes. However, this diversity meant that we felt it was important to define what we 'stand' for as a network, as we hope our membership will widen to include others.

We are aware of some projects using the term UFM to describe themselves that have not adhered to some of the basic criteria in running projects. This has often resulted in a range of problems: co-ordinators feeling unsupported and isolated, service user researchers left unclear about the extent of their participation, lack of follow through on reports and projects overrunning due to unreasonable initial expectations.

What we have collectively tried to do in the document is to indicate what we think defines the essence of UFM, drawing on the wealth of experience in the group. As such, we have set out those criteria that we regard as essential and desirable for the successful completion of a UFM project. We nevertheless recognise that UFM should be a locally owned affair and that many operational matters will need to be decided within each local setting.

We hope this document will be of use to service users, community organisations and statutory bodies who are contemplating or currently undertaking or commissioning UFM.

Members of the network currently include service user researchers and/or co-ordinators from projects in Derby, Bristol, Northampton, Nottingham, London and Weymouth and their contact details are set out below.

We will be revising this guidance in approximately 9 months (May 2004) and welcome constructive feedback and comment. For information about the UFM network contact Nutan Kotecha on n.kotecha@scmh.org.uk or tel 0207 827 8344.

UFM network members contact details

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Criteria that we regard as essential and highly desirable for the successful completion of a UFM project

Issue	Essential	Highly Desirable
A. The aims of the research	<p>these are to:</p> <ul style="list-style-type: none"> • evaluate existing services for people with mental health problems <i>and to</i> • make positive changes in mental health services and generate creative alternatives to existing services. 	
B. Active participation	<ul style="list-style-type: none"> • Projects should actively aim to secure the participation, (as researchers, interviewees 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.¹ • The project will provide opportunities for individual service users to participate in a range of ways and at different levels in the research process; eg question development, data input/analysis. 	
C. Independence	<p>is a core principle that in practical terms would mean the following:</p> <ul style="list-style-type: none"> • Service user research group has the freedom to write and publish their findings without interference. • Co-ordinators and the service user research group have control over key decision making areas such as time scales for projects. • Co-ordinators to have control over budgets <p>Projects must have <u>secure and adequate funding</u>.</p>	

Issue	Essential	Highly Desirable
D. Secure and adequate funding	<p>is needed to ensure:</p> <ul style="list-style-type: none"> • That all service users (including interviewees) are appropriately paid.² <p><u>Note:</u> Given that benefits legislation is a complex and fast changing area and that practice of benefits agencies varies widely from area to area, each service user must be supported in obtaining independent benefits advice about how payment for participation in the project will affect their benefit status.</p> <ul style="list-style-type: none"> • That each project has a co-ordinator who is paid and who is employed for a sufficient amount of time to support the work to completion. • The independence of the research is in no way undermined by the possibility that funding could be reduced or withdrawn as a result of the research findings or recommendations made. 	<ul style="list-style-type: none"> • The long term sustainability of the project. Projects should ideally be funded for a minimum 3 years³ to ensure that a full 'evaluate/ implement/ re-evaluate' cycle is completed. • That service users involved in the project can participate in the post-report process of implementation. • The funding is provided by a body that is not directly involved in the delivery of the services to be evaluated.
E. Group process	<ul style="list-style-type: none"> • Projects should draw the service users⁴ involved into as many of the key decisions as is practically possible. • The co-ordinator should be <u>responsible and accountable</u> to the research group. They should view themselves essentially as facilitators, although the co-ordinator also needs to be able to lead where necessary to ensure that the project follows the UFM values (including adhering to equalities issues). 	
F. Supervision, support and training	<p>Supervision, support and training, e.g. computer skills/data analysis, need to be made available for the co-ordinator and service users involved throughout.</p>	
G. Control and management of the project	<p>This should lie primarily with service users as follows:</p> <ul style="list-style-type: none"> • People carrying out the interviews are service users. • Co-ordinators have a demonstrable understanding of and commitment to service user led projects. • Interview questions are developed by the service user research group, with reference to and with major input from a range of people using the service under evaluation. • Service users lead the management of the project i.e. are in a majority in any management structure. • Service users are actively involved in analysing the findings, writing the report, drawing up recommendations for change and feeding back findings to local service users. • Service users participate in the planning and monitoring of any implementation plan. 	<ul style="list-style-type: none"> • Co-ordinators are service users. • The topic investigated is chosen based on the concerns expressed by service users locally. • Active outreach work by the project team to achieve true participation of a range of people using the service(s) under evaluation.

Issue	Essential	Highly Desirable
H. Commitment to implementation	Mechanisms to consider recommendations emerging from the research findings and to implement change should be planned for in the early stages of the project. This should include proposals for how service users will be involved in this process.	A draft implementation plan is drawn up when the topic to be investigated has been identified. This implementation programme should be revisited when findings from the research are emerging.
I. High Standards of research	High standards of research/evaluation methodology should be maintained ⁵ and access to support and expertise should be made available at the outset to ensure this.	
J. Flexible Training approach	Adequate, flexible and thorough training is provided that caters for service users of different strengths and levels of experience. (<i>training outline to be developed</i>)	

Footnotes

¹ For example people who have been threatened with or experienced compulsory admission and treatment, people who are perceived as difficult to manage, too ill or too dangerous to be interviewed, and people who have complained about or who have disengaged from mental health services as well as black, (using this word in its wider political sense) and Irish communities. Other communities important to reach out to include people who would not regard themselves as having a mental health problem, homeless people, refugees and asylum seekers, travellers, people with disabilities, including those with multiple or invisible disabilities. Also women with children, lesbian, gay or bisexual men and women, different age groups, and those who have experienced drug and alcohol problems.

² For some general information and guidance on the subject of payments to service users, see

- NIMHE West Midlands, Mental Health Development Centre. (2003) *NIMHE West Midlands Guidance Paper - Payment of Service Users and Carers*.
- Ryan, T and Bamber, C. (2002) *Pricing participation: a survey of organisational payment practices to users and carers for expenses*, North West Mental Health Development Centre, soon to be available online at www.nimhenorthwest.org.uk
- Hanley, B., Bradburn, J., Gorin, S., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S. and Wallcraft, J. (2000) *Involving consumers in research and development in the NHS, Briefing note for researchers*, Consumers in the NHS Support Unit: London.

³ UFM is designed as a programme of ongoing evaluation and re-evaluation that provides an opportunity to monitor whether changes are taking place in the quality of service users experience of mental health services. Each 'round' of evaluation takes approximately 12 months.

⁴ Service users are people who have used or are currently using mental health services.

⁵ The groups within the network hope to prepare some further guidance on this. In the interim, see *User's Voices, The Perspectives of mental health service users on community and hospital care* (2001) by Dr Diana Rose, published by The Sainsbury Centre for Mental Health and the *DIY Guide to Survivor Research* (1999) published by the Strategies for Living Team at the Mental Health Foundation.