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Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative

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Abstract

Objectives: to explore the involvement of mental health service users in the redesign of in-patient mental health services in six Trusts participating in a multi-regional NHS modernisation programme. *Design:* semi-structured interviews and observation of team meetings undertaken as part of an action research study. *Participants and setting:* users, clinical, medical and managerial staff from six mental health trusts which participated in the Northern & Yorkshire and Trent regions' Mental Health Collaborative (MHC).

Results and conclusions: whilst there were some problems, user involvement was undoubtedly a strength of the MHC in comparison to other modernisation programmes within the NHS we have studied. However, the particular challenges posed by the specific context of acute mental health services should not be overlooked. The initial approach taken in each of the sites was to simply invite a user or user representative to join the local project team. In the course of events, various changes were made to this initial mechanism for involving users in the ongoing work of the teams. These changes - and setbacks in some sites - make drawing firm conclusions as to the effectiveness of the various strategies employed problematic. However, our qualitative data suggest a number of broad lessons which will assist both those leading and participating in other redesign initiatives to maximise the benefits to be gained from service user involvement.

Keywords: user involvement, mental health services, qualitative research, action research, quality improvement

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Introduction

This paper reports findings from an independent evaluation of the Mental Health Collaborative (MHC) in the Northern & Yorkshire and Trent regions of the English National Health Service (NHS), with particular reference to its approach to user involvement. The Northern Centre for Mental Health (NCMH) proposed the MHC as it had identified acute in-patient care as a serious cause for concern across all the Trusts in Northern and Yorkshire region. A consortium of NCMH, Trent and Northern & Yorkshire regional offices delivered the MHC with expert advice on collaborative methods from the Leicester Centre for Best Practice.

Background to Collaboratives

Collaboratives are a quality improvement approach based broadly on the principles of continuous quality improvement (CQI) and service redesign and involve a network of organisations working together for a fixed time period on a specific clinical area¹. Collaboratives are part of the Labour Government's modernisation agenda as outlined in the NHS Plan². The Secretary of State's diagnosis is that 'the NHS is a 1940s system operating in a twenty-first century world', in which:

'old-fashioned demarcations between staff, restricted opening and operating times, outdated systems, unnecessarily complex procedures.....combine to create

*a culture where the convenience of the patient can come a poor second to the convenience of the system.*²

The NHS Plan seeks to tackle this by redesigning services so that they are responsive to the needs and convenience of patients, not the organisation. Collaboratives - which originate from the work of the Institute for Healthcare Improvement (IHI) in the United States (US)^{3,4,5} - are one vehicle for implementing this vision. The IHI's work is firmly grounded in CQI theory but - unlike many other approaches to quality improvement in the NHS - has always been explicitly focused on clinical activity and improving the quality of clinical care for the patient; administrative and other processes can support this but are not the primary concern. An important principle in the IHI's approach is that mistakes, duplication and delays in care are rarely the fault of individual professionals; instead the blame lies collectively with the systems and processes which have grown up unchallenged over the years. It is argued that frontline clinical teams are best placed to understand and critique these systems and processes and can begin to redesign them using a variety of different models, with a consistent emphasis on careful analysis and a spirit of open inquiry rather than fault-finding and blame.

A collaborative brings together groups of 20-40 health care organisations into a mutual support and learning network which works together for approximately a year on improving a specific clinical or operational area. Participants are given a series of targets to work on which will improve the patient experience. All the project teams from the different organisations meet together every two to three months for a 'Learning Session'

at which they exchange ideas and report on progress, and receive support and guidance from an expert panel.

Collaboratives use an accelerated model for quality improvement developed initially by Langley and colleagues⁶ and adapted for use in healthcare. The model has two parts. Firstly, it poses three fundamental questions: what are we trying to accomplish? How will we know that a change is an improvement? And what changes can we make that will result in improvement? Secondly, the ‘Plan-Do-Study-Act’ (PDSA) cycle, which is in effect a quality improvement cycle. The aim is that ideas for change can be tested quickly on a small scale, by frontline clinical teams, with the results informing further work. It is assumed that such small changes build to larger improvements through successive PDSA cycles.

The rapid spread of Collaboratives in the NHS is attested by the fact that where there were none prior to 2000, numerous national or multi-regional Collaboratives are now underway or have been completed⁷, involving thousands of improvement teams and hundreds of Trusts, and said to be affecting millions of patients⁸.

The Mental Health Collaborative

Thirty-seven organisations across the two former NHS regions of Northern & Yorkshire and Trent took part in the MHC which began in October 2000 and ended in November 2001. Some were specialist mental health organisations, whilst others combined mental health provision with community and/or general acute hospital services. Sites were given some limited central funding to provide project management support. In some cases, the

central funding was supplemented locally to increase the amount of dedicated project management time and provide some cover for clinical staff working on the collaborative.

The focus of the MHC was on in-patient mental health services, but project teams also included community health and social care staff to ensure the whole patient care pathway was considered. At the outset, twenty-four quality standards were identified by an expert reference panel, divided into three phases of the user experience: admission, stay and discharge. Alongside each standard was a suggested target: each participating team was able to choose which standards to work depending on which they deemed most applicable to their local circumstances as well as to set their own targets. The targets were intended to be challenging and all data was to be collected in a standardised form across the collaborative. Examples from the three phases include:

- *Admission*: On admission, patients should be told what to expect during their stay and should be given written information. This should be documented in the notes
- *Stay*: The patient and named nurse will work out together and agree a care plan within seven days of admission
- *Discharge*: Patients will know the name of their care co-ordinator prior to discharge and will have met him or her

All sites used PDSA cycles to improve their achievement of these standards. Monitoring combined audits of patient records and interviews with service users (using a structured questionnaire), to examine the match between users' perceptions of their experience with

what was formally recorded. Direct user involvement in the monitoring process was a key principle of the MHC.

Collaboratives and the user perspective

As noted, collaboratives are seen by the government as a method for redesigning services so that they are responsive to the needs and convenience of patients. Collaborative participants are encouraged to think themselves into the position of service users and see current processes and systems as if through their eyes. From this user perspective, they are asked to challenge ‘taken-for-granted’ assumptions about the way things are done, where they are done, why and by whom.

One way to help staff achieve this fresh perspective is by asking users themselves to become involved and offer their own critique of current processes and systems. In fact, collaboratives in different clinical areas have taken varying approaches to the direct involvement of users, and in some cases have quickly reverted to using professional views as a proxy for the user perspective⁷. In contrast, the MHC steering group insisted that direct service user input to the improvement process was essential. Each participating site was required to include at least one service user on the local project team and the routine project monitoring process included a user questionnaire: a distinctive feature of this collaborative.

The need to involve service users in decisions about their own care and about services more generally has gradually been gaining greater recognition within UK welfare

services over the last two decades. Fuelled by the consumerist ideology of the previous Conservative government and by the growth of a series of user movements campaigning for changes within service provision, there is a growing acceptance that many service users want a greater say in how their care is provided and have a right to be consulted about the nature and type of services they receive^{9,10,11}. While progress has undoubtedly been made, there is clear evidence to suggest that much involvement can be tokenistic, failing to move beyond the level of rhetoric to reality and failing to alter the balance of power between users and professionals/managers. Within mental health, for example, a recent review of adult mental health services has highlighted a series of benefits associated with user involvement, but also a series of barriers which need to be overcome if meaningful involvement is to take place (see Box 1).

[INSERT BOX 1]

The emphasis on user involvement at the heart of the MHC represents an important opportunity to learn from the experience of those who took part.

Evaluation aims and methods

The evaluation lasted six months and one of its aims - reported on here - was to identify what lessons could be learnt about the involvement of service users in the context of service redesign. A final evaluation report is available¹². There were five elements to the research.

Case study based

Six case study sites (three from each region) were randomly selected from the 37 clinical teams participating in the Mental Health Collaborative. This reflected a deliberate choice on behalf of the Steering Group and research team to conduct an in-depth analysis of a relatively small number of teams rather than a broader, hence more superficial, analysis of a larger number.

Interviews and direct observation

Over the six months of the research, each of the six case study sites was visited at least twice and 65 semi-structured exploratory interviews undertaken with project managers, team members, user representatives and other key informants and stakeholders. During these visits nine local project team meetings were observed and analysed and the views of other members of staff not participating directly in the Collaborative were elicited more informally.

The researchers employed both face-to-face and telephone interviews, the tone of which were naturalistic and conversational. The focus of these interviews was the nature of the 'receptive context' for the Collaborative within the study sites¹³. This included identifying key success factors as well as supports and barriers to the successful implementation of the 'Breakthrough' method. The interview schedules were adapted from tools already used by the team in their previous evaluations of other NHS Collaboratives⁷. Interviews were tape-recorded, subject to the approval of those being taped, and summary transcripts were made in order to enable researchers to supplement and validate their hand written notes.

Formal measurement instruments

The research team investigated a number of formal instruments for possible use in the study. In the event, the Organisational Change Manager (OCM), developed by Professor David Gustafson of the University of Toronto and Madison Healthcare Improvement Ltd, Wisconsin, was used. The OCM seeks to identify the primary strengths and weaknesses (danger signals) of a change/improvement project, and offer a predictor of the chances of successful implementation. The tool is for use at the start of a project, while a project is underway and/or after it concludes, and is suited for use by teams themselves to monitor their own progress and decide where corrective steps need to be taken - 'internal' action research, as it were. Since 1990, the OCM has been used by more than 400 organisations across the US, Canada and Europe to evaluate their change efforts. This was the first time the OCM had been used in the UK.

The OCM was sent to the 66 project team members in the six case study sites and 49 completed questionnaires were returned: a response rate of 74%. The results are reported elsewhere¹².

Analysis of data

The qualitative data gathered from the semi-structured interviews and observation of team meetings were subject to content analysis, that is indexing by theme and subsequent analysis. The themes were developed on an ongoing basis as the data were collected by the researchers and each researcher read, shared and cross-checked the analysis of the interview notes. The data was then triangulated with the results of the questionnaire and quantitative data on performance for each of the sites (as provided by the Steering Group) to provide the basis for our findings and recommendations.

Action research

Action research is a way of 'recycling' interim data analyses during the research period itself (as opposed to just at the end), in order to create an ongoing and 'intelligent' dialogue between researchers and practitioners, thereby shaping the thinking around and direction and development of the change initiative itself¹⁴. Feedback to the MHC Steering Group took place at scheduled meetings prior to two Learning Sessions. The feedback took the form of members of the research team sharing their data with the Steering Group and exploring particular themes or findings which had arisen to that point in time.

Findings relating to user involvement

User involvement in process mapping

Process mapping is a technique borrowed from industrial approaches to quality improvement, such as re-engineering¹⁵. The purpose is to analyse the detail of what happens to the patient as they pass through a healthcare system (see Box 2).

[INSERT BOX 2]

Mapping the patients' journey had made a big impression on many local project team members and shed new light on the 'taken-for-granted' routines and practices mentioned above. Having users on the local project teams meant they could be directly involved in process mapping and challenge staff's sometimes incomplete account of patients' experience. In most cases, this was felt to be extremely valuable and a powerful mechanism for convincing staff that change was needed.

'By far the most important piece of work we did at any stage was mapping the patient's journey and getting an understanding of how they feel going through the process. Had we not done that we'd have been assuming all sorts of things.' (Project manager)

One site identified the following key issues in their baseline mapping of the patient's journey:

- There were too many routes to admission
- There were too many steps for the patient from admission to discharge
- Patients have to 'tell their story' at least four times and to different professionals
- There were a number of possible blockages to keeping the process of care fluid: a) too many unnecessary administration tasks which might be more appropriately carried out by the ward clerk, b) insufficient staffing levels when too many patients are on close observation, and c) the appropriateness of some tasks to the nurse's role e.g. at meal times.

From this baseline assessment the project team identified seven projects around which they based their initial PDSA cycles (for example, to identify exactly what information is needed from patients on admission to prevent duplication).

However, not all sites found involving service users in process mapping to be altogether productive. In one site, the project team found that trying to map a typical patient process did not 'fit' the chaotic variability of mental health processes. Their concern was that in trying to represent everyone's experience through one process map, one might in fact end up with a bland artificial account, representing no single user's experience accurately.

Instead, they developed a different approach of gathering individual ‘patient stories’ by means of the project manager and a user representative interviewing individual patients about their experiences of in-patient care. These were in effect individual process maps, but the team felt that they were more compelling evidence because they were ‘genuine’. However, staff used to seeing themselves as the defenders of patients’ best interests may find it uncomfortable to realise how the care they provided was perceived.

Obtaining service users’ views via a questionnaire

Part of the MHC approach to monitoring teams’ progress in meeting the standards was to ask service users who had recent experience of in-patient care to complete a questionnaire. Ten completed questionnaires were required every quarter during the collaborative.

The idea of the user questionnaire was viewed by participants as good in theory, but the local project teams found it difficult to administer in practice. There were several reasons for this. Firstly, there were reservations about the design and format of the questionnaire. Project team members in one site commented that ‘there was no information relating to the needs of the client’ and ‘there were not enough questions on the questionnaire to allow you to hear the patient’s perspective’. This particular team decided to develop their own questionnaire locally. Secondly, interviewees themselves were generally critical of the user questionnaire as a way of assessing progress. They were unsure how clear and intelligible the questions would be to an average service user. They were also concerned

that the nature of mental illness could make it difficult for people to answer questions about a time when they were very ill, such as an episode as an in-patient.

'Answering questions about admission when you were very ill is problematic. They're good things to be asked but people simply don't remember.' (Service user)

The professionals in the project teams also had reservations about how valid the data from the user questionnaires could be:

'When you're ill, you don't remember. The information that comes back doesn't necessarily reflect what's been going on, but nevertheless it's taken as if it is.' (Ward manager)

Specific concerns among staff were that the custodial aspect of the nurse's role in acute mental health care could skew service users' perspectives on how patient-centred staff were. Thirdly, there were practical problems associated with administering the questionnaire and obtaining the required amount of data. In one site, the project team had failed to convince any service users to take any part in the questionnaire interview, even after involving the project team's user representative and the patient advocacy service. As a result, they intended to administer a postal questionnaire instead. In another team, one service user suggested that the questionnaire could be administered by Community Psychiatric Nurses (CPNs) once users had been discharged home. Such an approach would need coordination, but in theory could offer a way forward as service users may be

more likely to participate if supported by a professional they know. However, the site which tested this approach found it problematic as the process relied on CPN and social work colleagues finding the extra time to go and conduct the interviews - time which was not always available.

A final issue pertaining to the user questionnaires suggested that as well as problems with the instrument itself, there were deeper cultural issues influencing its value. One manager wondered whether the local organisational culture was sufficiently developed to enable the full benefit of the user questionnaire to be realised:

'I wouldn't want you to think we don't value service users - but this [questionnaire] would be quite a new thing, and there's always an element of scepticism. Perhaps if we had more of a culture of involving users they'd be more willing to come forward....and staff might be more willing to try to make it work. It's about getting the culture and strategy in place that whatever we do, we involve users. But we're not there yet.'

(Director of Mental Health)

The way the questionnaire results were used in monitoring progress in the MHC meant that they provided 'direct' evidence of the extent to which standards had been met. Given the issues and reservations related to the user questionnaire outlined here, further careful consideration is needed in using such an approach and to ensure that a user questionnaire is designed, administered and interpreted appropriately.

Involving service users in project teams

The approach endorsed by the MHC was to invite a service user or user representative to join the project team as a member, to attend the Learning Sessions and to be closely involved with all aspects of the work related to the collaborative. Across all six sites, responses to this approach were generally positive both from service users and professionals in the project teams:

'They always discuss things with me to get my point of view as well. I suppose it's just nice to be there in case I do have something to say on a matter, to represent patients.'
(Service user)

'I have been bowled over at how some really not very well people have talked, and the level of debate and the responsibility in tackling what were very personal and painful issues, but really trying to look at the bigger picture.....That was a really good experience.' (Approved Social Worker (ASW))

Coupled with the enthusiasm and positive reactions to involving service users in project teams, our data also highlighted some issues requiring careful consideration so as to optimise the value and benefit of this approach.

One such issue was the complexity of creating an environment where service users and professionals could work together as equals in the project team:

'It can be difficult for service users to feel safe in giving their views and it is important to do what we can to enable them to feel they can be honest.' (ASW)

'I was very nervous. Because I've been on the ward myself, there were two nurses that I knew of in the team. When you're there as a patient, they're your boss sort of thing, and you feel a bit inadequate. But they really made me feel at ease and they listened to me and that built my confidence up.' (Service user)

Thus, both service users and professionals found that working jointly in project teams held both challenges and rewards for those involved. For some interviewees, however, relationships were complicated by the nature of providing acute mental health care and the tension between caring and custody:

'the custodial bit - you could be working really well in the team and then the service user member of the team needs to be sectioned. Where does that leave you in the relationship? It can be handled - I'm not saying it's impossible - I think it's about being up front about it in the first place.' (Director of Mental Health)

Another factor which made it difficult to develop the user perspective in the teams was that they were only required to have one service user as a member. Most interviewees felt in retrospect that more service users on the project team would have increased the confidence of service users by providing mutual support:

'We think it would be better if we could have two service users in a team - you feel a bit isolated as the only one not in a professional position.' (Service User Representative)

'I suppose I would have always liked more service users: we've really got ones and twos. And to be honest, I would have preferred half and half. So that was a concern.' (CPN)

From the service users' perspective, an emergent theme was feeling a lack of confidence and lack of preparation for working in the project team:

'A lot of it does go over my head because I'm not familiar with everything they're talking about. I was a patient, and I've never heard about this side of things. There are a lot of things I don't really understand. It can be a bit confusing at times.' (Service user)

And in some cases, this led to a reluctance to be involved:

'Of all the service users we approached, they all wanted a low key position – they weren't very happy about being part of meetings and talking in front of so many people.' (CPN)

Careful thought and effort was needed to ensure that service users felt able to contribute as fully as they wanted to the project team. This included varying types of support. One team had provided 'payment in kind' in the form of training in communications and computing skills. Other forms of support provided to users were also considered:

'We gave a great deal of thought to how to involve service users. One thing we thought about was that a service user might have to have a link with a professional in order to have supervision or support outside the meeting. It would be useful for the user to get support from the advocacy service because they know about service users and needs. It is important that they have their support around them.' (Project manager)

In at least one site, the use of patient advocates to facilitate and support user involvement in the project team had been found to be useful:

'The patient advocate has been really excellent. S/he has helped to get the wording, language and understanding right with the patient questionnaire. S/he is really good with the feedback as well from the wards – s/he does the questionnaire on the wards and feeds back lots of other things as well, and s/he feels much more engaged with the ward as well so that has been a change for them.' (Project manager)

As well as raising issues about how service users could be supported to take an active role, the data highlight how user involvement of this type can be perceived as being unrepresentative:

'There wasn't really a mechanism for somebody to have a representative function, rather than just an individual patient function.' (Consultant)

'What I hope is most important is getting a wide range of views from people who are using the service as well as from a relatively small number of people who are willing to be involved in planning.' (Locality Director)

Although the question of representation by service users was raised by many interviewees, the data did not contain many specific suggestions as to how this issue could be positively addressed. Similarly, some interviewees - whilst agreeing user involvement was very helpful - suggested that having users on the project team did not work well in practice. Rather, teams had found other ways to access user opinions in what was perceived as a less threatening environment. For example, ward community meetings and focus groups were being used as alternative ways of eliciting user views. Another site had formed a standing service user committee, facilitated by one of the MHC team members, and to which anyone could contribute.

Improvements made through service user involvement

All six case study sites made progress - to varying degrees - in involving service users . Changes made have been primarily focused on detailed process issues, such as improving documentation (for example, discharge leaflets and contact cards) and enhancing patient-orientation on the pilot wards (for example, ward maps, photo boards and ward booklets). Some other improvements were specific to the extent to which users are involved in the MHC itself, and the mechanisms by which such involvement was facilitated. To illustrate, table 1 presents the changes in one of the case study sites made as a result of user involvement in the MHC.

[INSERT TABLE 1]

Some of the improvements suggested by service users were not the changes that staff themselves would have prioritised, but they did appear to have made a greater impact than staff would have anticipated. This led to observations that:

'we need to setting our expectations at the user and carer level not at the professional level'(Service Manager)

'I think sometimes as health professionals, you get tied into organisational things, complicated bits of treatment, and the service users are saying well what's really important is when the tea room opens, not whether I spend half an hour with my key worker every day.' (Occupational Therapist)

Many participants commented that user involvement had challenged their assumptions and led to new insights:

'Service users have a stronger voice - it's dead easy for me to say what is wrong with the ward but a patient there may have a completely different view.' (CPN)

'You have to remember that we are bound by loads of structures and red tape and service users aren't. We get worried about all these things but service users will say 'that doesn't bother me, I want to do it this way or however I like'.' (Project Manager)

Discussion

Despite some criticism of the design of the initial tools used to facilitate user involvement, the involvement ethos has been a particular strength of the MHC compared with other NHS Collaboratives and previous quality improvement initiatives.

Prompted by the requirements and expectations of the MHC, the local project teams had made significant progress in improving not only levels of user involvement but also the nature of that involvement. When considering just how much progress had been made, it is important to bear in mind the relatively low priority given to engagement with users in some of the sites prior to the MHC. Several participants acknowledged that the approaches to user involvement in the past had been little more than tokenism, and that a different attitude and approach had been needed:

'In this area, we are starting from a low level of user involvement. We have service users on various things but it has been very tame and selective up to now. This feels like the first time professionals have seen user involvement positively rather than just as them making complaints.' (Voluntary sector representative)

'It's wonderful that it's happened at all, frankly. There's been an appalling history of no, or completely token and patronising, user involvement. But people are so shy of it. In health, much more than social services, people are so twitchy around confidentiality that that gets in the way.' (ASW)

Whilst greater levels of direct user involvement are likely to show benefits particularly in the longer term, sites were already considering the impact of this shift in emphasis and where they should go from here:

'I think it has shifted certain people within the collaborative, and that will ripple out. It's cut down the them-and-us feeling. You hear people saying in passing that 'it was interesting what [a service user] was saying the other day'. (ASW)

'I think it'll stop rippling unless there's a constant push. It certainly needs to be someone's job. The ideal would be practitioner and user involvement built routinely into practice improvement but we're a long way off that. So the second choice is to have it in this add-on way: it hasn't got its own momentum yet.' (ASW)

Conclusions

A key objective of the research was to draw lessons from the experiences of the six sites regarding user involvement. Whilst there were some problems, user involvement was undoubtedly a strength of the MHC. The MHC has in turn helped to facilitate progress in involving users locally.

Some of the methods initially employed to facilitate user involvement were relatively unimaginative (for example, having a single user on the project team) and none of our

case study sites sought to employ and train users as a means of developing totally user-defined targets.

However, the particular challenges posed by the specific context of acute mental health services should not be overlooked. Users' perception of their experience, and the feedback and input they give to a project team, may be coloured by the ambivalent nature of their relationship with staff; equally staff may feel that meeting all users' requests would be incompatible with safe and appropriate care.

As noted above, the initial approach taken in each of the sites was to simply invite a user or user representative to join the local project team. As we have described, in the course of events, various changes were made to this initial mechanism for involving users in the ongoing work of the teams. These changes - and setbacks in some sites - make drawing firm conclusions as to the effectiveness of the various strategies employed problematic. However, our qualitative data suggest that broad lessons include:

- ◆ Involving service users in mapping the patient journey can be valuable in building insight into the impact of 'taken-for-granted' routines. However, care needs to be taken to ensure that this approach does not neutralise the variability of the patient experience, to the point of making the results meaningless.
- ◆ In involving service users in process mapping work, it is important to view the activity as a means to an end, rather than as an end in itself. While it is important that the final 'mapped process' is credible and seems representative, it is within the

discussion and sharing of perceptions between users and professionals where the real learning and potential for service improvement lies.

- ◆ If questionnaires are to be used to obtain service users' views, the users themselves need to be involved in the design and formatting.
- ◆ Issues of data validity need to be carefully considered when introducing user questionnaires. In particular, the nature of acute mental illness and the carer-user relationship need to be taken into consideration when employing such tools to assess progress against agreed measures.
- ◆ It is important to anticipate potential practical and cultural barriers which may mean service users are reluctant to respond to user questionnaires, or to other forms of user involvement.
- ◆ If service users are to be members of a project team, there should always be more than one user or user representative to provide mutual support and enhance confidence.
- ◆ The work needed to create an environment where professionals and service users can work together in a project team as equal contributors should not be under-estimated
- ◆ Practical and symbolic barriers to the participation of service users, such as lack of recognition (whether formally through payment or informally through training), need to be addressed.
- ◆ Direct support to enable service users to contribute fully to the project team needs to be offered - for example, through patient advocacy services - by means of an ongoing link with a professional member of the team, or by providing training to develop skills and confidence.

- ◆ Ways need to be found of ensuring that views fed into projects by service users are representative as far as possible.
- ◆ Ward community meetings and focus groups can be used as an alternative to having a single user or users serving as members of a project team.
- ◆ Staff also need support to deal with the challenges and implications of genuine engagement and partnership with service users.

Above all, attempts to involve service users in the MHC must be seen as a starting point. From a relatively low base, the case study sites have begun to involve users in service improvement and to appreciate the benefits that user involvement can bring. In the process, however, they have encountered a series of challenges and barriers which have to be overcome if users' experiences and priorities are really to help shape mental health services. What matters now is how the case study sites and other service providers seek to build on this initial learning in order to ensure that meaningful user involvement becomes a mainstream feature of their work.

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BOX 1 User Involvement and Mental Health¹⁶

Benefits:

- Service users are experts, with an in-depth knowledge of mental health services and of living with a mental health problem. These experiences are an important resource that can help to improve individual packages of care as well as services more generally.
- As a result of their experience of mental illness, service users have developed a range of coping mechanisms and survival strategies that help them to manage their mental health problems and go about their daily lives as best they can. If mental health practitioners do not tap into this expertise, they make their own jobs much harder by focusing on users' weaknesses rather than building on their strengths.
- Service users and mental health workers often have very different perspectives. As a result, involving users can provide extremely rich data which prompts practitioners to re-evaluate their work, challenges traditional assumptions and highlights key priorities which users would like to see addressed.
- Users have been able to develop alternative approaches to mental health that might help to complement existing services or suggest new ways of thinking about mental health.
- User involvement can be therapeutic, enabling people to feel that they are being listened to and that their contribution is being valued. Helping to shape services – particular when users work together collectively - can also help people to increase their confidence, raise self-esteem and develop new skills.

Barriers:

- There is a lack of accessible information.
- User involvement, if done properly, can be expensive and time consuming.
- Existing mechanisms for involving service users in their own care may be limited in terms of their effectiveness (for example, care planning or formal complaints processes).
- Professionals wishing to promote user involvement frequently express concerns about the 'representativeness' of individual service users, sometimes suggesting that particular users may be "too well", "too articulate" or "too vocal" to represent the views of users more generally. While it is important that all users with views to contribute feel able to become more involved, a number of commentators emphasise the danger that the concept of 'representativeness' can be used as a sub-conscious

method of resisting user involvement¹⁷ (see Lindow, 1999 for a response to this issue).

- Many mental health services may not be conducive to user involvement. For some people, mental health services can be experienced as extremely disempowering, with users being compulsorily admitted to hospital and medicated against their will. Users' contributions may also be discounted as a result of their illness or of public attitudes about risk and dangerousness
- User groups seeking to campaign for more responsive services often face a range of practical difficulties, such as financial insecurity and a lack of training.
- Some workers may find it difficult to view service users as experts and resist moves towards greater user involvement.

BOX 2 Process mapping

- identify a process – where does it start? Where does it end? (E.g. the process of coming for an out-patient appointment, from the moment the patient walks through the door of the hospital to the moment they leave)
- identify all the steps in the patient’s journey through the system, from the patient’s perspective (including times when they are waiting, or moving from one department to another) and which members of staff are involved at which points
- understand where there are delays, duplication or potential for errors – for example, where responsibility for a patient passes from one member of staff to another (sometimes known as a ‘hand-off’) the risk of mistakes or lost information increases
- analyse which steps in the process add value to the patient and which do not, always coming back to the questions ‘Why do we do this? What does it add for the patient?’

TABLE 1 Catalogue of changes made during the MHC in one case study site on issues relating to service user involvement

Before	After
Service users were not routinely involved in the organisation of their care.	A patient-held record is now being developed to support patients in making their own records about care they receive.
Patients were not routinely asked to become involved in the design of their care plans, or to sign them.	Patient signatures now required on care plans, and a record made of their involvement/understanding.
Changes to organisation of therapeutic activity requires information from service users.	Questionnaire sent to recently discharged service users asking for their views regarding the activities that would be most helpful to them. Responses aid the reorganisation process.
Patients requested more regular discussion regarding ward issues, with the nursing team.	Regular community meetings are now held on the ward. All patients invited to attend. Patients decide agenda for each meeting.
Difficulty assessing patient's experiences relating to the collaborative improvement measures.	All patients now invited to complete questionnaire relating to MHC improvement measures. Opportunity made for postal returns. Responses demonstrated service user satisfaction with the changes.
Difficulty effectively communicating with patients regarding the aims of the project, changes made and current plans.	MHC newsletter now given to all patients to explain project, detail changes made and provide overview of planned changes.

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