



Executive Summary

User involvement in efforts to improve the quality of drug misuse services: factors that promote and hinder successful working

Research report submitted to the Department of Health March 2007

Department of Psychological Medicine, Imperial College London

Sue Patterson, Mike Crawford, Tim Weaver, Deborah Rutter, Kostas Agath, Eliot Albert, Andrea Hunt and Vanessa Jones

BARRIERS TO THE EFFECTIVE TREATMENT OF INJECTING DRUG USERS

EXECUTIVE SUMMARY

BACKGROUND →

This report describes a study that explored the involvement of people who use drugs in planning, commissioning and delivery of drug treatment services. User Involvement (UI) has been progressively embodied in public policy for over 30 years and has been made a central feature of the modernisation of the NHS. Since January 2003 all providers of state funded health and social care services have had a statutory requirement to involve users in their activities. While UI has been promoted as a means to improve service quality, formal evaluative studies have rarely been conducted. Evidence from the mental health sector supports the notion that UI can contribute to service development and highlights factors that promote successful involvement. Support for UI is qualified however by some commentators who note the impact of inherent imbalances in power between service users and providers.

There is a long history of people who use drugs utilising self-help models and reports from overseas highlight the role that current and past drug users have played in delivery of interventions and establishment of harm minimisation services. However, commentators suggest that drug treatment services in the UK have been slow to involve users.

Efforts to respond to the major public health issues surrounding problematic drug use are guided by the Updated Drug Strategy 2002, that aims to increase the number of people accessing treatment services. As evidence is clear that retention in treatment impacts on outcomes, efforts to improve the users' experience of services may be an important mechanism through which to meet this aim.

STUDY AIMS →

Against this background the research aimed to:

- quantify the level of UI in efforts to improve the quality of drug misuse services
- examine the range of different methods used
- explore the views of users, providers and commissioners of services about how successful these different methods are
- investigate factors that facilitate and hinder successful involvement.

METHOD →

To achieve these aims we conducted a multi-method study combining quantitative and qualitative research methods. We surveyed service commissioners, providers and users in a representative 50 of the 149 English Drug Action Teams (DAT) and conducted in-depth case studies in six DAT areas. Surveys contained a mix of open and closed questions addressing study aims. Our case study sites were purposively selected to reflect a range of geographic and demographic factors potentially impacting UI and self reported stage of development of UI. In each case study site document review was followed by interviews and focus groups which explored participants' experiences of user involvement in the development of drug treatment services.

The project was guided throughout by a project advisory group (PAG), comprising members of the study team, service managers, clinicians, service user representatives and senior staff from the NTA and DH. The PAG advised on study site selection, development of questionnaires and topic guides and provided direction in relation to the final report.

FINDINGS →

We received completed surveys from 45 (90%) commissioners, 21 (42%) NHS Trusts, and 32 (64%) voluntary sector providers. 139 participants from all stakeholder groups took part via interview and focus groups. Data from the survey and case studies provide complementary evidence in relation to UI in the drug treatment field.

a. Implementation of UI in efforts to improve the quality of drug misuse services

We found wide variation in the degree to which UI systems and structures have been established. Our findings highlight the disparity between and within DATs in terms of models and mechanisms used and the degree to which UI is integrated in planning, commissioning and development of services. While 82% of DATs reported some engagement with user groups or individuals, fewer than half (47%) had formal user representation at commissioning level. UI workers were employed in 10 DATs (22%) and identified as central to coordination and facilitation of UI in these areas. Our findings indicate a lack of strategic UI planning in many DATs. While various mechanisms are being utilised, processes to enable user input to contribute systematically to commissioning and service level development are often not well defined. A significant minority of DATs (n=16; 36%) evidenced no user involvement at strategic levels with fragmented and inconsistent UI within services. However we found well established centralised models supporting engagement in a small number of DATs. These models appeared to provide frameworks to enable meaningful input and feedback mechanisms to operate between users, services and the DAT.

b. Methods for involving service users

We identified a range of mechanisms being utilised to enable user input at commissioning and service levels. Surveys across stakeholder groups and case studies evidenced broad consistency in methods of UI reported. In the main these were ad hoc and disconnected rather than elements of a strategic approach. However we were able to identify various structured models that potentially might enable ongoing DAT wide UI.

Structured UI models, established in a minority of DAT areas, included representative and advocacy models. Representative models included a unionised structure with service based user groups contributing delegates to advisory groups at DAT level, a volunteer program in which trained volunteers worked as team members at service level, promoting engagement with users and facilitating communication between DAT, services and users; and a user group led model with the user group having representation at DAT level and regular meetings with service managers. The advocacy model centred on a UI worker employed by the DAT participating in DAT committees and intervening at service level on behalf of users.

We found similar UI mechanisms being used in both NHS and voluntary sector services. However differences in approach were apparent with a strong philosophical commitment to partnership with users evident in voluntary agencies and structured engagement more likely in NHS services.

While engagement with groups was commonly reported by DATs and services in the survey, responses to open questions and our case studies highlight the wide variation in structure, form and purpose of groups. Commonly the role of groups in relation to formal processes was ill-defined and inconsistent. User groups that responded to our surveys all sought involvement in UI and told us that they had representation on DAT committees.

Apart from committee representation, various consultative mechanisms were the predominant form of UI found in services and DATs. These were characterised as 'formal' where data were gathered in a systematic manner for a specific purpose, or 'informal' where anecdotal feedback was obtained but mechanisms for influencing service development were not defined. Consultative meetings and open events were frequently reported as mechanisms of involvement by commissioners and service providers. These forums were generally convened to address planning issues or to provide an avenue for information-sharing. The majority of services reported infrequent use of purposive surveys to determine user views about specific issues. Often these related to service-originated development ideas and were generally 'one off' rather than part of systematic engagement. Informal UI mechanisms included 'open door policies', use of various means to engage users in conversation and seek their views (including managers taking a role in front line service delivery) and suggestion boxes. Our case studies highlighted the important role of needle exchange and key workers in communication between users and services, although mechanisms for utilising information gathered in this manner were often unclear.

Involvement of users in human resource (HR) management, principally through recruitment was reported by 30% of NHS and Voluntary sector service providers. However we found minimal evidence of participation of users in HR in case study sites. While formal complaints mechanisms exist in all services, they are seldom used in drug treatment services and are not seen as a mechanism for user involvement. Our case studies demonstrated that formal complaints were seen as a last resort and users were often unaware of processes open to them.

c. Rationale and value of UI

We found wide ranging views about the rationale for UI and its objectives. Respondents expressed varying opinions regarding the effectiveness of various methods of involvement and their potential to contribute to service development.

In the main, we found an attitude of acceptance surrounding UI and acknowledgement that people who use drugs and services had a contribution to make in relation to service development. We also identified strong supporters of UI for whom the users' experience was central to efforts to improve services. Although some case study respondents reported ambivalence about UI and viewed it as extra work, all acknowledged that UI was here to stay. Generally UI was seen as having potential to enhance service development and increase efficiency and cost effectiveness.

While some respondents were frustrated and expressed a sense of futility, the overall sense was one of enthusiasm and hopefulness regarding the potential for UI to make a real difference.

d. Factors that facilitate and hinder successful involvement

We found multiple interconnected cultural, organisational, and individual variables influencing UI with case studies adding depth to factors identified through survey.

Key factors hindering UI included:

- Central policy does not link UI to other specific strategic objectives. This resulted in the perception that UI is 'extra work' rather than a core component of all service development activity
- Complex and non-coterminous organisational structures and unclear responsibility for implementation of UI
- Lack of dedicated resources
- Lack of strategic UI planning at DAT and service levels
- Limited awareness about UI among service users
- Limited numbers of users seeking to participate formally in existing UI structures.

These factors, against a socio-political background characterised by power imbalances in which drug use is illegal and people who use drugs experience stigma and prejudice, combine to challenge integration of users with service commissioning and management systems and processes. Our findings suggest that this has contributed to the varied UI we found, making it difficult to evaluate and identify outcomes. Consequently feedback into policy and strategy development is limited and progress with UI is inhibited.

Conversely, UI was seen to be promoted by:

- Strong policy with clear objectives supported by guidelines providing a robust yet flexible framework for participation
- Open organisational cultures in which the user experience of receiving services was recognised as valuable to service development
- Leadership of UI at all levels supported by commitment and dedicated resources
- Use of multiple mechanisms for UI as part of a strategic approach with clearly defined objectives
- Matching methods of UI to goals and the capacity of users, both individually and collectively, for involvement
- Motivated users who were enabled to meet their goals for involvement, including giving back to society, improving services for others and self development
- Promotion of UI as a right and opportunities for participation.

Our findings highlight the need to openly address power issues and challenge stereotypes as underpinning development of collaborative UI.

e. Outcomes of user involvement

Although it is difficult to isolate the effects of UI from other factors that influence organisational change, service users and providers described a number of occasions when UI had led to or hastened changes in service organisation and delivery. The role of users in identifying service gaps was also highlighted. Service users and commissioners provided details of instances where the role of UI had been instrumental in changing aspects of service provision, ranging from decisions about where new services should be located, to changes to opening times and to alterations to injecting paraphernalia services provide. Service providers also highlighted the positive effect that UI had had on changing attitudes to the role of users in efforts to improve service quality. Given our finding that multiple interconnected cultural, organisational and individual factors surrounding the drug treatment field contribute to difficulties embedding UI, it is encouraging therefore to note the potential for formal UI, currently in its infancy, to be self-nurturing.

DISCUSSIONS AND CONCLUSIONS

Our findings provide the most detailed picture to date of the extent and nature of UI in drug treatment services in England. Although this picture is variable across DATs, there is evidence that the experience of users is increasingly recognised as complementary to technical expertise.

We have identified a number of factors that promote and hinder involvement and emphasise the need for robust policy to underpin further development. It is apparent that embedding UI within policy and planning is fundamental to its integration in public drug treatment services and achievement of specific policy objectives.

We have not been able to identify a single 'best practice' model but have provided evidence regarding the range of mechanisms used and their utility. Our findings highlight the multi-faceted nature of involvement, the difficulty that stakeholders have defining it and a lack of clarity around appropriate levels of influence. It seems too that while UI is perceived as expedient, stakeholders are generally unsure how to measure success. Commitment, leadership and dedicated resources at DAT and service level are vital to success.

While it has been difficult to isolate the effect of UI in service developments in terms of direct outcomes, it is apparent that user expertise is encouraging quality improvements. The need for further research to explore outcomes of user involvement both at service level and for individuals is critical in building an evidence base that can inform policy and practice. Given our finding that a primary outcome of involvement has been further involvement, it is clear that user involvement can build on itself. It will be critical that processes formalising and evaluating involvement do not constrain maturation of UI.

DISCLAIMER

The research on which this study was based was supported by a grant from the Department of Health (Policy Research Programme) under its DMRI-ROUTES initiative. The views expressed in this report are those of the research team and not necessarily those of the Department of Health.

CONTACTS

Dr Mike Crawford
Reader in Mental Health Services Research
Department of Psychological Medicine
Imperial College London
Claybrook Centre
37 Claybrook Road
London W6 8LN
m.crawford@imperial.ac.uk

DMRI/ROUTES Programme
Professor Susanne MacGregor
Susanne.MacGregor@lshstm.ac.uk