



National Treatment Agency for Substance Misuse

NTA Guidance for local partnerships on user and carer involvement

1 What user and carer involvement means

The NTA believes that service users should be involved in all key aspects of decision-making in relation to their care and that carers should be involved as fully as is agreeable to the user. Involvement will occur at a regional and partnership level and in reviewing the Treatment Plans; the 2006/07 Treatment Plans require evidence of effective user and carer involvement.

This guidance document identifies the principles behind user and carer involvement. A further document provides an audit tool by which users and carers, local partnerships and the NTA regional teams can assess the influence and impact user and carer involvement has in a partnership area. This will follow shortly.

1.1 The need for user and carer involvement

Section 11 of the Health and Social Care Act 2001 places a duty on NHS organisations to make arrangements to involve and consult patients and the public in:

- planning services that they are responsible for
- developing and considering proposals for changes in the way those services are provided
- decisions to be made that affect how those services operate.

Involving users and carers is not an end in itself but a way of achieving three fundamental objectives:

- strengthened accountability to all stakeholders
- services that genuinely respond to the needs of users and carers
- a sense of ownership and trust.

Therefore, at national, regional, commissioning and service provider level, users and carers should be actively involved in planning, delivering and evaluating service provision.

The overall aim of Section 11 is to increase patient-centred care and improve the users and carers experience by ensuring they are involved at the beginning of any process to develop or change services.

Section 11 applies to all NHS organisations, including national agencies, strategic health authorities, and local trusts. It can also apply to non-NHS service providers, who provide services to patients through contracts and service level agreements, or a commissioning partnership where the NHS is one of the partners.

1.2 When and where to Involve

Section 11 places a duty to involve and consult users and carers;

- not just when a major change is proposed, but in the ongoing planning of services
- not just when considering a proposal but in developing that proposal
- in decisions that may affect the operation of services.

'Involving and consulting' has a particular meaning in the context of Section 11. It means discussing with users and carers their ideas, your plans, and their experiences of using services and why services need to change. Also, what they want from services, how to make the best use of resources and so on.

What is important is that involvement and consultation is adequate both in terms of time and content and that it is appropriate to the scale of the issue being considered. Part of the involvement process may be to discuss with stakeholders the most appropriate arrangements for any further involvement.

User and carer involvement is central to developing any organisation or service. The substance misuse treatment system must recognise and value the benefit of listening and responding to users and carers and recognise that the users experience is often the catalyst for improving the way services are delivered.

1.3 Understanding the user's perspective

Real user and carer involvement is not about ticking boxes, it is about the treatment system developing constructive relationships, building strong partnerships and communicating effectively. For user's experience of services to improve, staff and management will need to have ongoing and meaningful dialogue with them, their carers and other stakeholders about improving and developing services. Through this approach organisations will;

- learn more about the users and carers experiences of the treatment providers
- tap into the enthusiasm and energy of their users and carers to make long-term improvements
- develop and encourage closer relationships between staff and users and carers
- improve the quality of the care they are providing
- identify ways of meeting users and carers needs more appropriately
- be able to use information provided by users and carers to help them make improvements
- make sure changes make sense to those that are affected by them.

The duty to involve is the continuation of a process that aims to strengthen accountability to users and carers and the local communities and make sure there is transparency and openness in decision-making procedures. Partnerships and treatment services must develop and adapt around

the needs of the users in order to build trust and confidence between this groups of service users and the planners and deliverers of services.

1.4 Planning in partnership

Whatever the starting point, users and carers perform a central role as partners within the treatment system, working with all other partners to find the right solution for identified local needs. The principles behind this are:

- Designing services with local populations, not for them;
- Solutions developed for health communities rather than individual services or organisations; (in this instance drug users, service users and ex-users are the health community)
- Using recognised service improvement techniques to make improvements.

1.5 Consequences of partnership planning

These changes will alter the way that services are planned. The treatment system needs to understand and be connected with people by asking what they want and need. Information about current services and the problems they face needs to be shared openly so people can get involved in a meaningful discussion. We should encourage modernisation – including redesigning services, adopting new technology and techniques and changing workforce patterns – to make sure that options for the future are long-term and meet the needs and wishes of the people using the services.

The main emphasis of the duty to involve and consult is that open discussions with users and carers and staff, should start at the beginning – before minds have been made up about how services could or should change. In addition, this discussion needs to continue throughout the process. All stakeholders need to feel that they have had the opportunity to influence the debate at important stages, and that they have been kept properly informed throughout.

2 A framework for involvement

In order to have meaningful user and carer involvement throughout the substance misuse treatment system we must have a system that links the variety of partnerships, providers, users and carers with each other at all levels.

The aims of the framework are to enable all those involved to improve the quality of care by being informed about the experiences of users and carers, ensuring that services are able to respond to need, including users and carers through partnerships and ensuring that any changes that occur make sense.

In order to achieve these aims it will be necessary to work in six areas. Each local partnership and service provider must have sufficient activity within each of these areas to ensure that involvement within that area is meaningful and the achievements lead to sustained benefits.

	Information	Feedback	Influence
Individual	Information to service users and carers about treatments and services	Service users can feed back on their own care and treatment, and raise issues of concern	Shared decision making between service users, carers and professionals
Collective	Information to the wider public about how well the organisation is doing	Trends in complaints, PALS issues, etc Feedback on service user experience	Involvement in policy and planning

Table 1

Information

Partnerships have a key role in ensuring that service users have enough correct information to be involved at an individual level in decisions about the care and treatment they receive. The direct provision of information is concerned with treatment decisions, care planning and goals and, of progress in treatment.

Information at the collective level encompasses a wide range of information, including, what the role of the DAT is and the range of services that are available in each area. This information is intended to assist those who have identified a need for treatment make an active choice about which service to approach or for those in treatment to choose another treatment or provider. Information should also be for wider stakeholders about how well the organisation is doing in involving people.

Feedback

Each local partnership and the services in an area have a role in seeking the views of individual service users and should draw up a strategy for gaining feedback. Within NHS organisations, this includes but is not limited to, the use of PALS services and the complaints process as routes of feedback. PALS and complaints services should provide the local partnership with information on

trends in issues raised with them, any activity they undertake on behalf of service users and the number of complaints received. In non-NHS providers, similar processes should be put in place.

Services should also provide information to service users about local service user groups, advocacy services and regional users' forums. Partnerships and services should facilitate the engagement of local users/carers with regional involvement opportunities.

Feedback can also be gained through the national NTA annual service user satisfaction survey.

Service user groups and carer groups are also useful in providing feedback to the partnership about strategic issues and to services on operational issues. It should be remembered that not all service users or carers choose to be part of such groups so this collective approach does not include all service users or carers and efforts should be made to reach beyond the groups, although local user groups and carer groups should be encouraged and supported to consult widely.

Influence

At an individual level, influence is having the ability to make shared decisions between users and providers and, where appropriate, carers. This is about the user having influence over what treatment they receive and how it is delivered and not having decisions made for them. Including users in treatment decisions is an essential part of care planning.

The partnership has a key role in supporting service user groups and carer groups and their representatives to participate in their work throughout the planning and delivery processes. This includes supporting and facilitating them to participate in a range of activities. Partnerships may have to be willing to change their approach to some aspects of their work in order to be more inclusive.

Users and carer involvement should increase from providing information, through participation in dialogue at a partnership level, to producing guidance at national level. However, such influence will not necessarily be sequential. All three dimensions e.g. information, feedback and Influence will need ongoing development work to ensure there are connections between them.

Partnerships should measure not just what is happening within each of the six areas but be clear what outcomes have resulted from these actions.

3 Local action

The following describes what such a framework would look like, from a local perspective.

3.1 Strategy and Planning

In order to ensure that user and carer involvement is applied equitably across a local drug treatment system the local partnership must commit itself to a strategic and planned approach to the design and implementation of a user/carers involvement strategy.

User and carer involvement should be built into the annual planning cycle and should start with a thorough baseline assessment from which the strategy and annual action plans should be developed. The strategy and action plan should be developed with the involvement of users and carers and other stakeholders.

The involvement strategy should have a clear vision, rationale, purpose and agreed objectives. These objectives should be carried out across the dimensions and levels of involvement (See Table 1) so that involvement of users and carers develops across the system at an appropriate rate and does not over populate any one section. These processes must transfer into practice and be integrated into operational activities, ways of working and governance arrangements.

The partnership must be clear how it is to be held accountable for involvement performance and its delivery. The annual plans and the mechanism for accountability must be communicated within the partnership, to the services it commissions and to users and carers.

3.2 Resourcing

The partnership should recognise the need to resource involvement work appropriately and a realistic budget committed to ensure that the variety of aims and objectives set out in the strategy and action plan are achieved. The partnership should ensure that an assessment of existing resources and activities is undertaken and that these, as well as new resources, are identified within the Treatment Plan. An identified lead within each partnership should manage the delivery of the action plan and ensure that appropriate resources are in place to deliver it.

The partnership should ensure that individuals with specific roles and responsibilities for involvement work are identified within each partner agency or commissioned organisation. Resources should be allocated for joint initiatives with other organisations in involvement and for community development work.

A review process should be in place to determine that resources are used appropriately to achieve the identified objectives and that measurable increases in involvement investment and activities are in line with the strategy. Users and carers must be involved in this review process.

Resources for staff development and user and carer development must be clearly identified within the overall resources allocated to involvement.

3.3 Training, support and development

Within the strategy, there must be recognition of the need for training and development for all those involved and appropriate resources must be made available to support this. As part of the strategy

and action plan a training needs analysis should be undertaken to identify the skills and competencies required. Once identified, these skills and competencies should be integrated into job descriptions and accountabilities for individuals. Training and development needs should be regularly reviewed and updated as a regular on-going activity and a delivery plan developed. The reviews of training and development should identify the level of awareness and understanding of involvement amongst those participating.

Training and development should be provided to existing staff to raise awareness and understanding about involvement and to address particular skills gaps or behaviours. Staff with specific roles and responsibilities for involvement should be provided with access to training programmes aimed at developing competencies on involvement work.

Good practice should be widely reflected in the design and content of training and development programmes, including the involvement of users and carers, external partners and other key stakeholders in the delivery of such training. Training and development should be provided on a shared basis to users and carers and other stakeholders

3.4 Engagement and inclusion

The partnership should have knowledge of existing user/carer networks and involvement activities by others seeking to involve these groups. The partnership should develop sufficient working relationships with these existing networks to facilitate on-going access to their expertise.

The involvement strategy should identify who needs to be informed and involved in different aspects of the partnerships involvement work. It is good practice to ensure that users of information are involved in how information is developed and in what forms it is provided. User/carer views should be used to help to evaluate and shape the content and style of information provided to them from the partnership. Training and development opportunities must be provided for user and carer networks and representatives taking part in the involvement structures and processes – ideally jointly with staff, checking with them what would be most useful. Any involvement events should be held at convenient times and in appropriate venues – these need to be properly identified and publicised.

Information about user and carer structures and networks and community development and involvement initiatives should be routinely shared with other organisations and information provided in easily accessible and understandable forms and in appropriate languages.

The users/carers should be clear about why the partnership or provider is seeking to inform or involve them and have sufficient opportunities to get involved – offer feedback, make a complaint, influence relevant matters.

3.5 Collaboration and partnership

The partnership should have knowledge of the key partners who should be part of collaboration or joint initiatives. All these partners should have a common understanding and a shared vision of involvement and be willing to co-operate and collaborate. It is appropriate to share staff expertise and financial resources between different organisations and other stakeholders in the partnership.

Joint involvement strategies, structures and processes should be in place and used as a key part of involvement. Any joint involvement plans and initiatives between different organisations should be clearly communicated to users/carers.

Information about outcomes from involvement initiatives and good practice on involvement should be routinely shared between different organisations.

It should be clear to users and carers that organisations are working collaboratively on initiatives, keeping them informed and involved.

3.6 Results and impact

The partnership must monitor and evaluate the impact of its involvement work. The partnership should be clear about what information it needs, what it will do with the information, and be sure that the criteria for assessing the impact of involvement initiatives are clear. This information must be reviewed in collaboration with users/carers.

The partnership must report back on the impact of involvement initiatives with users/carers to all partners and use the outcomes to input into governance processes, performance management and future plans and initiatives.

The partnership must have a clear appreciation of the needs and expectations of different groups of users/carers – as a basis for priority setting, strategy development and service innovation.

3.7 Treatment Plans

Although there are specific sections within the annual treatment plan for users and carers, involvement should be regarded as cross-cutting and evident throughout the treatment plan. The users' grid and the carers' grid should each reference these aspects and contain any initiatives and plans not covered elsewhere in the treatment plan, such as the user and carer involvement strategy.

4 Further Reading

The above information is drawn from the following documents:

Strengthening Accountability – involving patients and the public – policy guidance
(http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4008005&chk=rVmyFE)

Strengthening Accountability – involving patients and the public – practice
(http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4074289&chk=2mwdZZ)

Patient and public involvement in health: The evidence for policy implementation

(http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4074289&chk=2mwdZZ)

Getting over the wall: How the NHS is improving the patient's experience

(http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4090841&chk=hvIEoY)

Patient Experience Definition

(http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/InvolvingPatientsPublicHealthcare/InvolvingPatientsPublicHealthcareArticle/fs/en?CONTENT_ID=4076096&chk=DJvxJk)

Other Useful resources include:

Signposts – a practical guide to patient and public involvement in Wales

(<http://www.wales.nhs.uk/sites/page.cfm?orgid=420&pid=2459>)

Signposts 2 – developing patient and public involvement practice

(<http://www.wales.nhs.uk/sites/page.cfm?orgid=420&pid=2798>)

User Power: the participation of users in public services

(<http://www.ncc.org.uk/publicservices/publications.htm>)

Improvement Leaders Guide – involving patients and carers

(<http://www.wise.nhs.uk/cmsWISE/Tools+and+Techniques/ILG/improvementskills/improvementskills.htm>)

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