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Substance Misuse Treatment Framework (SMTF)
Service User Involvement

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1. Introduction

1.1 Purpose

This guidance document is a component of the Welsh Government's Substance Misuse Treatment Framework. It is intended to provide guidance on the involvement of service users to Area Planning Boards (APBs), service commissioners, planners and providers and to service users, their families and carers.

This document replaces the 'Service User Involvement Framework' published in 2008. Although the background to and principles of service user involvement remain unchanged, the original document has been revised to provide a clearer statement on how the service user involvement agenda should be taken forward.

This revised 'Service User Involvement Framework':

- includes further guidance on how the principles of service user involvement should be implemented;
- sets minimum criteria for effective service user involvement to ensure that a consistent approach can be implemented by service commissioners and providers;
- offers suggestions on how service users can be engaged with in a variety of more meaningful ways over and above current practices;
- includes a section on best practice of service user involvement, including case studies from a range of policy areas.

This document has been produced utilising the principles of co-production, recognising the resources that citizens already have, and delivering services with, rather than for service users. A collaborative approach was applied when revising the original document. Service user networks were utilised through the All Wales Service User Movement group ('AWSUM') to ensure that the views of those who access services in Wales were able to shape the revised framework. APBs have also been contacted to inform the initial draft of this document and it has subsequently undergone a formal consultation process.

An Easy Read version of this framework is also available.

1.2 Context

There has been and continues to be considerable discussion about service user involvement and participation in the substance misuse field. However, a lack of clarity remains on exactly what is meant by the terms 'involvement' and 'participation'. The definition of key terms used in this document can be found in Annex 1.

Section 183 of the National Health Service (Wales) Act 2006 states that:

> *"Each Local Health Board must make arrangements with a view to securing, as respects health services for which it is responsible, that persons to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on—*

(a) the planning of the provision of those services,

(b) the development and consideration of proposals for changes in the way those services are provided, and

(c) decisions to be made by the Local Health Board affecting the operation of those services."

There is therefore a statutory duty on Local Health Boards to make arrangements with the aim of involving patients and the public in the planning and decision making processes of services.

In addition to this statutory duty, Standard 8 of 'the National Core Standards for Substance Misuse Services in Wales' (May 2010) provides that *"the views of service users, carers, relatives and the public should be taken into account in the design, planning, delivery and review of all substance misuse services, including general advice and information"*.

The Welsh Government remains committed to ensuring that service users are involved in the planning, design and delivery of substance misuse services in Wales and that we continuously improve in this area. This guidance is intended to reiterate the importance of involving service users in the development and delivery of all outcome based commissioning strategies to all substance misuse service commissioners and providers, including Local Area Planning Boards.

In England, the National Treatment Agency has developed similar guidance for the involvement of substance misuse service users and family members, alongside such groups as the Alliance (an advocacy group) and the Drug Users Forum.

1.3 Background of Service User Involvement

Historically people who misused substances, or were at risk of substance misuse, were rarely involved in helping to develop the health and welfare services that they accessed. There was a perception that substance misusers did not recognise that they had anything to offer to the development of substance misuse policy and practice at any level. Indeed there has been a perception that people who misuse substances have very little to offer governments, services and the community. In reality nothing could be further from the truth.

During the past twenty years, people who misuse substances or who use substance misuse services are increasingly being recognised as crucial components in the development of effective services.

Early examples of service user involvement groups were founded in the Netherlands through an organisation called 'Junky Bond' which has since been amalgamated with an Amsterdam service called Belangenvereniging Druggebruikers MDHG, and the USA (the National Association of Methadone Advocates 1973). More recently active service user and drug user groups have been developed in Germany, Australia, Canada and Switzerland.

The development of patients' power within the UK health fields and especially in the learning disability sector and mental health sector showed successful involvement in similarly stigmatised patients. In the mid 1980s the HIV/AIDS epidemic gave added impetus to the need to improve services for people who

misuse drugs and were at risk from blood borne viruses. The involvement of people with HIV was an essential component in addressing drug related harms.

The importance of service user involvement is increasingly being recognised within the public sector, whilst concepts such as co-production, discussed later, are also gaining ground. Case studies of good practice of service user involvement can now be found in both the health sector and in wider public services. Examples of these case studies can be found in Part 2 of this document.

Since the original 'Service User Involvement Framework' was published, the 'Recovery' agenda has developed greater momentum in Wales and other components of the Substance Misuse Treatment Framework have re-enforced the importance of service user involvement. The Recovery Substance Misuse Treatment Framework provides guidance on how providers can offer services and interventions to maximise the opportunity for service users to engage in appropriate support and treatment, thereby enabling them to make changes in their behaviour to improve their overall chances of sustainable recovery.

Part 1: Service User Involvement Framework

Key Guidance and Criteria for Service User Involvement

2.1 Introduction

This document seeks to promote the benefits of involving service users in the development of policy, and in the design, planning, delivery and evaluation of substance misuse services, at all levels. It is aimed at substance misuse service users, providers and commissioners within the statutory, voluntary and independent sectors and within the Criminal Justice System where appropriate.

Key definitions relating to service user involvement can be found in Annex 1 of this document.

2.2 Principles of Service User Involvement

Service user involvement builds on the principle that whilst professionals provide expert advice, the people who use the service are experts on both their own treatment needs and on how services can be improved in the future.

Allowing people to contribute in different ways, means that they become valued as assets rather than recipients of services and that provision can move away from a culture of dependency towards a culture of joint decision making and responsibility.

Service users have unique experiences, skills and abilities that enable them to provide 'expert advice' in this field; therefore substance misuse strategies and services are likely to be more effective if they are developed and delivered with the direct involvement of the people who use them.

2.3 Service User Involvement – responsibility and accountability

At National Level

Ultimately, it is the Welsh Ministers who are legally responsible for the provision of health care, including substance misuse treatments, in Wales under sections 1 and 2 of the National Health Service (Wales) Act 2006.

However, substance misuse service users should be involved at every level of the development, delivery, and review of substance misuse services in order to:

- comply with Section 183 of the National Health Service (Wales) Act 2006 and the statutory duty placed on Local Health Boards to involve patients in planning and decision making processes
- ensure that substance misuse services are developed to meet the needs of service users
- ensure that substance misuse services provided are of good quality
- ensure the delivery of positive treatment outcomes for the individuals.

It is therefore essential for service providers and commissioners to adopt a genuine partnership approach, where substance misuse service users have the right to be involved in the design, commissioning and delivery of services.

The Welsh Government requires service commissioners, providers and planners to actively ensure that service users are genuinely, meaningfully and constructively involved in all aspects of substance misuse services. This involvement should not be seen as a one-off intervention or 'tick-in-the-box' exercise, but should become embedded in the process of substance misuse service provision across Wales.

Although this framework strongly advocates the involvement of service users in the commissioning cycle, service users are not ultimately responsible for the delivery or failure of a service.

At Local Level

The Crime and Disorder Act 1998 requires responsible authorities in Wales to formulate and implement, in addition to a strategy for the reduction of crime and disorder, a strategy for combatting the misuse of drugs, alcohol and other substances in the area.

Responsible authorities are currently defined as the Local Authorities, the Chief Officer of Police for the area, Fire and Rescue Authorities, the Local Health Board and the provider of Probation services in that area

Responsibility for planning and delivering services to tackle substance misuse at a local level lies with the responsible authorities and their partners within the 22 Community Safety Partnerships ("CSPs").

CSPs are charged with formulating and implementing a strategy for their respective Local Authority areas in combatting the misuse of drugs, alcohol and other substances. CSPs are therefore accountable for the delivery, and consequently any failure, of the local substance misuse service.

APBs were established in 2010 as part of the new arrangements to deliver the Welsh Government Substance Misuse Strategy 'Working Together to Reduce Harm'. The APBs provide a regional framework to:

- strengthen partnership working and strategic leadership in the delivery of the substance misuse strategy; and,
- enhance and improve the key functions of planning, commissioning and performance management.

The membership of the APBs includes representatives from the responsible authorities involved in the CSPs to ensure a link between their substance misuse responsibilities. The APB is a mechanism which allows the responsible authorities to come together at a regional level to enable their statutory responsibilities to be discharged.

To assist APBs, Substance Misuse Advisory Regional Teams ("SMARTS") have been established by the Welsh Government. Their main role is to provide strategic support to the APBs and to assist with the delivery of the Welsh substance misuse strategy and local substance misuse action plans on the ground.

National Principles for Public Engagement in Wales

The National Principles for Public Engagement in Wales (2011) provide 10 core principles that are needed for meaningful public engagement. These are attached in Annex 2.

In addition to the responsibilities that service commissioners and providers have to ensure that service users are involved in the provision of substance misuse services, service users are also responsible for a number of elements when working together with service commissioners and providers. This includes:

- where possible service user groups should make themselves known to service commissioners and providers
- service users should be honest about their experiences of services
- service users should actively input their views when working with service commissioners and providers
- service users should attempt to keep to commitments where possible.

2.4 Benefits of Service User Involvement

The meaningful involvement of service users offers benefits to service providers, service commissioners, individuals and the community at a strategic level.

At a commissioning level, service user involvement in the design and review of services can:

- ensure that services are relevant to local needs
- ensure that services are accountable to service users
- enable service users to voice their opinion on services and identify good practice and areas of concern
- provide a vehicle through which consultation on future action plans can be undertaken.

Working in partnership with service users can benefit substance misuse service providers through:

- creating more opportunities for people who use or want to use services to get involved
- encouraging a sense of ownership of services for service users
- empowering service users to become engaged in the provision of services
- aiding the recovery of service users through empowerment and involvement
- assisting in the dissemination of information and education
- encouraging more people into treatment and to remain in treatment until a successful outcome
- assisting in developing a skilled and responsive workforce
- developing innovative ways of working that improve service quality
- ensuring that services meet clients needs

- providing service users with an opportunity to be valued and develop new skills that enhance treatment outcomes
- potentially increasing capacity through development of peer support and/or mentoring schemes.

There is a relationship between service user involvement, peer support activities and recovery. More information on the principles of 'recovery' is available in the Substance Misuse Treatment Framework: Recovery Oriented Integrated Systems of Care.

The active involvement of service users in the shaping and delivery of substance misuse services benefits individuals and the broader substance misusing community through:

- providing service users opportunities to be valued and heard
- enabling users to develop a sense of empowerment
- providing opportunities to share and allow others to benefit from their unique experience and expertise
- providing opportunities for the acquisition of new skills and interests
- providing opportunities to develop mutual support networks
- ensuring that services received are relevant to service users needs
- providing opportunities for individuals to become "health activists" for other substance misusers
- addressing the stigma issues that effect substance misusers by providing an opportunity for service users to add value and contribute to service provision.

2.5 Models of Service User Involvement: 'The Ladder of Participation'

Service users should have the freedom and choice to participate in the design, delivery and review of substance misuse services in a range of ways, fluctuating between them as they choose.

Historically, a ladder of participation has been used to describe the ways in which a service user may wish to become involved.

Rung 7	**Initiating** Service users generate ideas for action and make all the major decisions. Staff are available for consultation but do not take charge. For example a service user group making commissioning decisions.
Rung 6	**Implementing** Service users are given responsibility for a project and its outcomes. An example of this could be service users operating a needle exchange service.
Rung 5	**Decision Sharing** Service users share responsibility for decision making with staff or commissioners. This could include being involved in the recruitment of staff members within a project.
Rung 4	**Representation** Service users represent the views of their peers on specific items, this might be through service users forums or message boards.
Rung 3	**Consultation** Staff or commissioners generate ideas and make key decisions, but consult service users. Staff or commissioners take service users views into account and give feedback on decisions and action. For example, consulting on proposed changes to opening hours within a service, or the development of a new service.
Rung 2	**Positive Contributions** Service users are asked for their views on something but don't have any say about how these questions are asked or what happens to any of the information they gave. An example of this could be an annual service user satisfaction survey carried out within agencies or commissioners, where the questionnaire is developed by staff.
Rung 1	**Information** Service users are given information by staff. They may passively consume this (poster, leaflets) or actively (meetings that give information). Staff have control of the information, deciding what, when and how it is shared with service users.

Susan Lawrence
(Adapted from Hear by Right/Roger Hart/Arnstein)

Service users may choose to be involved at one level over another due to their personal strengths, circumstances or the nature or organisation that they are in contact with. The level at which service users are engaged at should be appropriate to the situation involved. For example in-patient detoxification services may offer different opportunities for involvement compared to open-access drop-in services.

At all rungs of the ladder, the level of service user involvement is the decision of the service user themselves. This is particularly true at higher rungs of the ladder, which in some cases are only achievable where service users are happy to volunteer their time.

However, commissioners and providers should provide opportunities for involvement at all seven levels of the ladder wherever possible.

Case studies of service user involvement that involve different levels on the ladder of participation are located in Part 2 of this document.

2.6 Service User Involvement and 'Co-production'

The need for the public sector to embed co-production into service provision is becoming increasingly apparent. NESTA[1] (National Endowment for Science, Technology and the Arts) describe co-production as 'delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours'.

Co-production aligns to the highest level of service user involvement (see the 'ladder of participation' above). It allows those service users who wish to be involved to co-commission, co-design, co-delivery and co-evaluate services. Over time it is ultimately this level of service user involvement which should be aspired to in the provision of all substance misuse services across Wales.

In order for this framework to be fully and effectively implemented and to deliver on the Welsh Government's stated support for co-production wider cultural and behavioural changes are needed in how service users are viewed.

It is therefore vital that all parties involved, whether service commissioners or providers, fully understand the benefits and importance of service user involvement. In many cases it may be necessary for staff to undergo training on what constitutes service user involvement, how it can be achieved and the importance of diversity and respect.

Organisations must embed service users involvement into wider planning and workforce development strategies in order to ensure that service users are involved at appropriate times and that staff have the relevant expertise to facilitate this involvement.

Whilst service user involvement must play a substantial role in the provision of all substance misuse services, the concept of co-production should also be considered by service commissioners, providers and users.

[1] NESTA is the National Endowment for Science, Technology and the Arts – an independent body with a mission to make the UK more innovative

2.7 Key Criteria for Service User Involvement

It is important that both service commissioners and providers implement a number of measures to allow meaningful service user involvement in the provision of substance misuse services across Wales.

A service user involvement checklist has been provided in Annex 2 of this document. The table lists a number of criteria that should be fulfilled to enable effective service user engagement. The checklist can be used to evaluate current levels of service user involvement and consider what further steps need to be taken. The list is not comprehensive but aims to trigger further consideration of, and innovation surrounding, how to involve and consult with service users. More details on good practice of service user involvement can be found in Part 2 of this document.

It should be remembered that service user involvement is a dynamic process and innovative methods of engaging with service users should be sought on an on-going basis.

Part 2: Service User Involvement Framework

Implementation and Case Studies

3.1 Putting Principles into Practice: Key Points to consider

This part of the document includes guidance on how the principles of service user involvement can be taken forward and case studies of successful service user involvement. These case studies are taken from different policy areas and are intended to act as examples of good practice and illustrate how service users can be involved at multiple points in the commissioning cycle.

When taking forward the service user involvement agenda it will be necessary for service commissioners and providers to consider the following:

- Service users may require additional support to become involved. Increasingly new forms of technology and social media, such as online forums or skype, may be used in order to engage with service users more easily.
- Consideration should be given to using a wide range of engagement tools as possible to ensure that as many service users views are received as possible. Methods of engagement should be expanded to engage with a wider range of service users where possible.
- Social media can be used in a variety of ways to engage with service users. For instance, services could use existing websites or other forms of smart technology to capture the views of service users.
- Consideration should be given to training of all participants. This includes the training needs and up skilling of service users to become service user representatives. In addition, participation training for facilitators or leaders of meetings and events and training on the benefits of service user involvement and how it can be achieved may be required for members of staff. Where necessary diversity and respect training should also be considered.
- Support should be offered and given to service users where needed, in order to ensure that all service users are comfortable with engaging with service providers and commissioners.
- Consideration should be given to funding and supporting the development of local Service User Groups.
- Clear procedures should be set out for all attendees of a group, meeting or committee.
- Clear aims should be laid out from the outset so that service users are aware of the overall outcome sought and role that they play in achieving it.
- Regular breaks should be incorporated and flexibility should be considered with regards to timings, locations and length of meetings.
- Service users should be involved at the earliest stage possible and their involvement should be consistent throughout the process.

- Consideration should be given to contingency plans, in respect of all those involved, such as back-up or support representatives to attend meetings.

3.2 Accountability and Governance

In order to ensure that effective service user involvement is possible it is necessary for all organisations who engage with service users to have in place robust accountability and governance arrangements.

These arrangements should ensure that all service user involvement takes place at an appropriate level and that there are individuals responsible for supporting service users who are involved with the organisation.

Governance arrangements should be put in place to ensure that service users are fully aware of the complaint procedures that are in place and that any complaints received are appropriately dealt with and escalated if required.

3.3 Expenses

Consideration must be given to the payment of service users and the re-imbursement of any expenses. Expenses should be offered, rather than sought by service users and payments should be made on the day of the event or, if possible, in advance.

The Welsh Government recognises the importance of national forums, such as the All Wales Service User Involvement Movement, and will reimburse any expenses incurred by service users who are involved in contributing to substance misuse strategy at a national level. This includes their participation and involvement on the Substance Misuse National Partnership Board which meets three times a year. The same commitment is expected at regional and local levels by the relevant authorities when engaging with service users.

3.4 Engaging Service Users with Diverse Needs

Organisations in Wales have had mixed success in engaging substance misusers from special needs and hard to reach groups. However, appropriate training, support and planning will help to improve and encourage the engagement of these services users:

- There is a legal duty under the Equality Act 2010 to ensure that reasonable adjustments are made to deliver equality of access for all protected characteristics. This duty is anticipatory and requires public bodies to be proactive in making adjustments to ensure all access and communication needs are met.
- Whilst all information should be in a clear jargon free language, some service users may need information in other ways – e.g. Welsh and other languages (both written and verbal), easy read, Braille etc. See 3.5 below.
- For some cultures and groups limiting the meetings to members of that group only may make it more comfortable for them to participate (e.g. women, young people, older people, and abstinent service users). This may also be the case where service users' personal histories or circumstances mean that it would be uncomfortable for them to attend certain group meetings.

- It is important not to assume that because someone has a special need that they would necessarily only need or want a different service.
- Thought should be given on how to engage with and collect views from those with learning disabilities. This could include the collection of 'social stories' rather than formalised questionnaires or focus groups, in order to gather feedback.
- Although it may not be appropriate for children or younger people to attend service user groups with adults, in many cases direct engagement with youth services is appropriate. This is particularly relevant when developing substance misuse educational services. See 3.6 below.
- Be aware of service users special holidays, events or activities (holy days, school times, chemist pick up times etc). Be aware of times of day, places, safety and transport. There are many different special need groups and communities, service user involvement is a key way of ensuring our strategies and services are accessible to all.
- There is a high prevalence of people with a co-occurring substance misuse and mental health problem and therefore special consideration is needed with engaging with service users who may also suffer from mental health problems.

3.5 Languages

The Welsh Language Act 1993 obliges all organisations in the public sector that provide services to the public in Wales to treat Welsh and English on an equal basis. 'More than just words' is the Strategic Framework for Welsh Language Services in Health, Social Services and Social Care. The framework emphasises the need for people working in health, social services and social care to recognise that many people can only communicate their care needs effectively through the medium of Welsh. Therefore, when required, service users should be able to access service user groups or become involved in the provision of services in either English or Welsh. In some geographical areas, the ability to access services or provide feedback in Welsh is vital.

Equally it may be necessary to consider whether some service user involvement techniques should be available in different languages and formats to enable maximum engagement (i.e Braille/hearing loops etc.). This is particularly important for methods that allow service users to feedback on a service. This may be more relevant to some areas than others.

3.6 Engaging Children and Young People

It is particularly important to engage with children and young people on issues regarding substance misuse for a number of reasons.

Firstly, substance misuse in children presents particular issues requiring consideration and a tailored response. Although adolescence is typically an age of experimentation and risk taking into which substance misuse may present as a short experimentation, this is occurring in younger children over time. Where more chronic, entrenched substance misuse occurs in adolescence it is invariably associated with, if not precipitated by considerable, complex additional

difficulties necessitating a coordinated multiagency response from education, local authority children services, 3rd sector, health professionals (e.g CAMHS, Sexual health, school nursing & GP etc.) and occasionally youth justice professionals. Therefore engaging with young people who are directly involved with substance misuse services is vital to ensure that these services are appropriate to local need.

Secondly, engagement with children and young people can have preventative benefits for the young people, those close to them and their community. Engaging with children and young people at the time when they are most vulnerable to the effects of substance misuse can be in an important tool in preventing many of the harms caused.

Lastly, substance misuse impacts on children and young people who have a family member or carer with a substance misuse problem. These children are at risk from further negative consequences in the future. Support groups are an important means of engaging with this group (see 3.8).

3.7 Involving Expectant Mothers

A healthy pregnancy maximises the chance of having a healthy child. Expectant mothers and their unborn children are particularly at risk from the harms caused by substance misuse. The appropriate and effective intervention of substance misuse services is vital to ensuring that these risks are minimised. Wherever possible substance misuse services should engage with expectant mothers to ensure they receive the treatment needed and that local services are as accessible and effective as possible for this group.

3.8 Families and Carers

Whilst this framework primarily relates to engaging with service users themselves, it is also important to take on board the views and feelings of carers and family members who often believe their concerns are ignored.

The Carers Strategies (Wales) Measure 2010 places a requirement on the NHS and Local Authorities in Wales to work in partnership to prepare, publish and implement a joint strategy in relation to carers.

Carers and families should have appropriate information made available to them and further learning opportunities to develop skills for dealing with substance misuse problems.

Families and carers groups play a vital role in supporting family members and carers of those with a substance misuse problem, enabling group members to provide support for service users themselves.

3.9 Methods of Involvement

The involvement of service users will require planned input of resources – both worker time and money (for example it may take longer to achieve some outcomes, where consultation with service users takes place, it may be more expensive to ensure documents are in a jargon free form).

A number of APBs and provider services already employ service user development officers to support a range of involvement activities. Whilst all staff need to be involving service users in their work, it is sometimes helpful to establish a lead worker (See Annex 3).

Ensuring that service users, providers and commissioners are able to access up-to-date training on service user involvement will be an important feature implementing this framework. Planning for meaningful and on-going service user involvement should ensure that issues of sustainability and succession planning are taken into account. Service users may move on and wish to be less involved in consultation and new service users may wish to become involved over time.

As with any forms of engagement, it is the service user's decision to be involved or to take part in certain involvement activities.

The following activities can be supported by such roles or conducted independently:

Service User led initiatives

- **Volunteering, advocacy, mentoring and peer support**

Involving people who are in a position to reflect on their own experiences of treatment services and who wish to provide support to others.

- **Peer education**

This includes the dissemination of harm reduction advice using peer educators and can be an effective way of providing information to groups that we have more difficulty engaging.

- **Service user forum**

This could be in the form of a self-help group, peer support, lobbying, campaigning or information sharing group. Speakers and trainers may be invited to speak on topics selected by the membership. Providers and commissioners may also seek the views of these groups. Social media and on-line message boards can offer opportunities for service users to contact one another on a national or even global basis to share views and experiences.

Provider/commissioner led initiatives

- **Surgeries/face to face interviews**

Some service users may feel more comfortable sharing their views in person. Managers and commissioners may choose to conduct open surgeries within agencies, forums, GP clinics and on an outreach basis to gather the views of service users.

- **Stand alone events**

These might be generic or single issue events to consult on specific issues or to gather information on need.

- **Service user representation on planning teams**

Service users should be represented on APBs, the Substance Misuse National Partnership Board and other planning groups. Within organisations there may be opportunities for service users to be involved in team meetings or planning events. However the decision to attend meetings lies with the service user.

- **Regular surveys, questionnaires and suggestion boxes**

Many agencies conduct annual surveys or exit questionnaires. This information can highlight areas for immediate service improvement and change.

- **Development and operation of services**

An example of this work is needle exchanges and information services and production of magazines.

- **Advisory or reference groups**

Commissioners and providers may wish to support service user reference groups in recognition of the expertise that service users have in the field. These groups will be consulted on specific issues, for example when services are commissioned or redesigned.

3.10 Community Health Councils

In addition to actively involving service users in service provision, Community Health Councils play a role in representing service user interests. One of the key roles of Community Health Councils is to represent the interest of patients and the public in the NHS through: providing information and support for patients and the public to access appropriate health services; eliciting the patients/public views of services; encouraging engagement of local people in the planning and delivery of health services and providing an independent complaints advocacy service. For more information on Community Health Councils, a web-link has been provided in Appendix 1.

3.11 Case Studies of Good practice

The following case studies provide examples of good practice of service user involvement at different points in the commissioning cycle across different policy areas, including health and social care.

Service user involvement in planning services: The South Wales Cancer Network

The South Wales Cancer Networks' Patient Forum is made up of cancer patients and carers from all over South Wales. The group has evolved from a project set up in 2005 between Macmillan Cancer Support and the then three Cancer Networks in Wales.

The Cancer Networks (South Wales Cancer Network and North Wales Cancer Network) play a role in co-coordinating the planning, organisation and delivery of cancer services in partnership with Health Boards, Trusts, Community Health Councils, Voluntary Organisations and Public Health Wales in Wales.

The Patient Forum was initially set up using a face-to-face format but is now transitioning into a Virtual Patient Forum that works on a task and finish basis. This Forum allows patients to become involved in various activities including focus groups; surveys and an annual conference. Patients are invited to act as representatives on committees, boards and steering groups where service planning occurs. The forum members are also encouraged to be actively involved in the process at a local level as well – within their own Local Health Board or in support of local Third Sector organisations.

The aim of patient involvement is to build up the relationships between patients, carers and the health professionals so that patients can become involved at the decision making process from the outset rather than just as a cursory "tick in the box". It gives patients a voice in the development of services and the opportunity for Health Boards and Organisations to listen actively to this voice.

Service user involvement in procuring services: The Children's Commissioning Consortium Cymru, Rhondda Cynon Taff

The Children's Commissioning Consortium Cymru, a partnership of 15 Welsh local authorities has been commended by the Children's Commissioner for Wales for its efforts in actively involving young people in the commissioning and procurement of its fostering services.

When developing its Foster Care Framework Agreement it applied a 'speed dating' approach in order to allow young people with experience of being in care to become involved in the evaluation of potential placement providers. Using an outcomes framework young people explored what was important to them about care placements and decided on questions to ask potential providers. These providers were then given 90 seconds per question to answer 8 questions during a specially designed session. The responses given were then evaluated by young people and formed part of the tender evaluation.

As well as specific events young people continue to be actively involved in framework management development through other means. For instance young people have rebranded desired outcomes with friendlier language and developed an online outcomes survey. This forms part of a 360 degree outcomes capture to identify whether outcomes are being achieved by framework providers from the perspective of young person, carers and social workers. The results received are used as part of the annual performance review of Framework providers and the review method has been implemented with a high response rate from young people.

Service user involvement in maintaining servicing: Taff Housing Association, Cardiff

Taff Housing Association is a community-based housing association, which operates in partnership with the Welsh Government (WG), Cardiff Council, the Vale of Glamorgan Council, Newport Council and local RSL's. Taff Housing Association provides over a thousand affordable homes in Cardiff as well as specialist, supported housing projects for young women, mothers and babies and male refugees.

Taff Housing Association initially worked closely with the social enterprise Spice to develop a comprehensive model for tenant participation. This has involved introducing a 'Timebank' Scheme – using time credits to provide opportunities for not only Taff Housing Association Tenants but also supported clients to become more active in the community.

One Timebank credit can be earned for each hour that participants give to Taff Housing Association, their community or their supported housing project (e.g. gardening, organising events, giving feedback on services, attending Board meetings, interviewing staff etc.) Participants can use their credits to access local

amenities and entertainment, such as access to a local cinema and art centre, entry to Cardiff Castle or Techniquest and fresh food at local cafés and co-operatives.

The aim of the Scheme is to maximise opportunities for participants and to encourage greater involvement in their communities, as well as challenging the dependency culture that can quickly develop, undermining their confidence and capacity.

Service user involvement in evaluating services: Taff Ely and Rhondda Local Diabetes Planning and Delivery Group

Pontypridd and Rhondda NHS Trust, in conjunction with Rhondda Cynon Taff Local Health Board, have a well-established Local Diabetes Planning and Delivery group. The group was established in 2004 and actively recognises the value of personal contributions from service users to enhance the insight of professionals in diabetes services.

A Patient Reference Group acts as the local point of consultation for users to feed into and back from the Planning and Delivery group. The Reference Group meets to discuss local diabetes services and consider proposals for developments. Their aim is to:

- ensure that people living with diabetes have an opportunity to express their views
- agree and produce reports on service user issues
- support and encourage the work of the Planning and Delivery group
- act as a 'critical friend' to the service, offering an alternative perspective, and challenging the assumptions of healthcare professionals and managers
- suggest ways that other service users might be involved and engaged in planning services
- engage positively with professionals and NHS organisations
- feed the range of views of people with diabetes into the discussions at Planning and Delivery group meetings.

The group acts as the local source of user representatives and is open to those with diabetes and their carers. Training has also been available for members of the group. After every meeting the Reference Group elects one or two people from the group to attend the planning and delivery group and to present issues raised during the reference group meeting.

Together the Planning and Delivery group and Patient Reference Group allow those living with diabetes to have their voices heard and to play an active role in shaping the services available to them.

Service User involvement in reviewing services: Substance Misuse services in Wrexham

The 'Perfect Engagement' event was hosted in February 2013 by WASUP (Wrexham Alliance Service User Partnership on behalf of AVOW), who engaged with substance misuse service users in Wrexham County Borough.

The event had two aims. The first was to give people who use Substance Misuse Services in Wrexham an opportunity to talk about their experience of using these services, exploring barriers and any potential solutions. The second was to feedback the outcome of these discussions to providers and commissioners on the same day.

The session was structured around 3 main questions, which service users then discussed in small groups during the morning. Feedback from the morning discussion groups followed lunch and the event closed with a general discussion session.

The day was perceived by service users, providers and commissioners to be a particularly valuable experience in bringing people together. It enabled an open and honest dialogue to take place in an attempt to break down barriers whilst also seeking a collective agreement to be more proactive in future recognising the contribution that service users can make to the development of services.

Service User Involvement: Engaging Children and Young People

Flintshire Sorted is a needs led organisation driven towards minimising the impact of alcohol and substance misuse on young people (YP), their families and the community. In order to ensure the organisation is 'child centred', Flintshire Sorted actively engage YP in processes to ensure they provide a service that is "Led by YP for YP".

Flintshire Sorted have involved YP in the evolution of their service by setting up a steering group that meets at regular points in the year. The YP involved have come up with innovative ideas including renaming the service and making it YP friendly whilst addressing issues such as stereotyping and confidentiality. They have also completed a project, by identifying an issue, researching the risks and dangers, planning the project and creating a DVD called 'You Won't Always Get Lucky' which is now used in every High School and secondary education provision in Flintshire raising awareness about alcohol.

Flintshire Sorted have also involved YP receiving Tier 3; one2one and therapeutic support to better develop as a service. Engagement projects have been set up and carried out, utilising the initiative and skills of those already affected by drug and alcohol, as well as those recognised as likely to be. This has had many preventative benefits for the young people, those close to them and their community. A targeted group of YP that were identified as needing additional support by their school have recently completed an artistic project from start to finish. The group initially met and discussed diversionary activities that they believed would help them make the right choices over the school holiday period. They decided to renovate an open space at the back of the office and following a beach theme have created a remarkable area for the team to work with young people. The project allowed the YP to gain valuable skills in research, building, creative arts and design. It also provided an opportunity for pro-social modelling from workers to YP and allowed them to build positive adult relationships. Many of the skills gained by the YP are transferable to the work place and support was on hand to aid with applying for college and completing CVs.

Annexes and Appendices

The following annexes are referred to in the framework:

Annex 1. **Definitions of key terms**

Annex 2. **10 National Principles for Public Engagement in Wales**

(From 'The National Principles for Public Engagement in Wales', Participation Cymru, March 2011)

Annex 3. **Checklist for Service User Involvement**

(adapted from "Stronger In Partnership"– Adult Mental Health Services Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales Policy Implementation Guidance September 2004).

Service commissioners and providers can use this tool to evaluate the current level of service user involvement in their work. The list is not comprehensive but aims to trigger further consideration of how to involve and consult with service users.

These appendices are examples of tools that you may find helpful.

Appendix 1. **Useful Links**

Appendix 2. **Sample Charter for Service User Involvement**

(adapted from "Stronger In Partnership". Adult Mental Health Services Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales Policy Implementation Guidance September 2004).

A sample Service User Involvement Charter which includes designing and planning, commissioning, delivery and monitoring of services.

Appendix 3. **Personal Qualities**

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority).

Sets out personal qualities that are essential to successful user involvement initiatives.

Appendix 4. **Skills Required**

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority).

Identifies the need for providing users with specific training to support them in user involvement initiatives.

Appendix 5. **Skills for Workers**

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority).

Stresses the importance of investing time in skilling up and equipping staff to work with users.

Appendix 6. **Involvement Forums**

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority).

Identifies some approaches, tools and good practice for improving user involvement.

Appendix 7. **Mapping Service User Involvement Activities**

Appendix 8. **Developing a service user involvement strategy and implementation plan**

Annex 1: Definitions

Service User

The term 'service user' is used throughout this guidance, and refers to people who have used or are using substance misuse services. Other terms used to describe this group are just as valid, but for consistency and ease of use the term service user has been used throughout this document.

Throughout the document the term service user is used to refer to people who may have at one time used a substance misuse service, are currently using a substance misuse service or at some point in the future may access a substance misuse service. Therefore, for the sake on consistency, the term also includes people who consider themselves 'ex-service users'.

Please note: service users consist of both voluntary service users and those who access services as a result of a criminal conviction or a condition of discharge arrangements from custody as part of a parole licence.

Substance Misuse Services

The term 'substance misuse services' or 'services' is used through out the document. It refers to all services that provide support or treatment for substance misuse problems. The term includes all organisations aimed at preventing or treating substance misuse or at supporting recovery. The term covers structured and unstructured treatment, as well as primary care, secondary care or care provided by the third sector.

Involvement

The term 'involvement' is the focus of this guidance and is used throughout. The term is used in a broad sense to cover both active, ongoing joint working and true and full participation (actively taking part in) and the consultation process (looked to for information and advice). However 'involvement' means working towards and aspiring to full participation.

Participation

Participation is based on empowering the individual to regain more control over their lives, develop their capacity, confidence and self esteem and 'add value' in helping to contribute positively to improving the lives of others.

Recovery

Recovery from problematic drug or alcohol use is defined as a process in which the difficulties associated with substance misuse are eliminated or significantly reduced, and the resulting personal improvement becomes sustainable.

Carer

A carer is anyone, of any age, who provides unpaid care and support to a relative, friend or neighbour who needs care and support.

Annex 2: 10 National Principles for Public Engagement

The National Principles for Public Engagement (2011) provide 10 core principles for service user engagement in Wales

1. Engagement is effectively designed to make a difference

Engagement gives a real chance to influence policy, service design and delivery from an early stage.

2. Encourage and enable everyone affected to be involved, if they so choose

The people affected by an issue or change are included in opportunities to engage as an individual or as part of a group or community, with their views both respected and valued.

3. Engagement is planned and delivered in a timely and appropriate way

The engagement process is clear, communicated to everyone in a way that's easy to understand within a reasonable timescale, and the most suitable method/s for those involved is used.

4. Work with relevant partner organisations

Organisations should communicate with each other and work together wherever possible to ensure that people's time is used effectively and efficiently.

5. The information provided will be jargon free, appropriate and understandable

People are well placed to take part in the engagement process because they have easy access to relevant information that is tailored to meet their needs.

6. Make it easier for people to take part

People can engage easily because any barriers for different groups of people are identified and addressed.

7. Enable people to take part effectively

Engagement processes should try to develop the skills, knowledge and confidence of all participants.

8. Engagement is given the right resources and support to be effective

Appropriate training, guidance and support are provided to enable all participants to effectively engage, including both community participants and staff.

9. People are told the impact of their contribution

Timely feedback is given to all participants about the views they expressed and the decisions or actions taken as a result; methods and form of feedback should take account of participants' preferences.

10. Learn and share lessons to improve the process of engagement

People's experience of the process of engagement should be monitored and evaluated to measure its success in engaging people and the effectiveness of their participation; lessons should be shared and applied in future engagements.

Annex 3: Checklist for Service User Involvement

Service commissioners and providers can use the following tool to evaluate their current level of service user involvement. The list is not comprehensive but aims to trigger further consideration and innovation surrounding how to involve and consult with service users.

Commissioning and Planning Structures	Assessment
Does your partnership actively seek to involve service users in its work?	
Has your partnership or group considered user involvement when developing its terms of reference and structures?	
Is service user involvement solely meetings-based or are other mechanisms employed to engage with a range of service users?	
Is information on the structure and aims of the partnership or group readily available to service users?	
Do commissioners and planners have a clear understanding of the importance of user involvement? Is this demonstrated in practice?	
Are service users involved in the needs assessment process?	
Are service users involved in the development of service specifications to meet identified need?	
Are there opportunities for service users to be involved in the commissioning or procurement process?	
Are service users involved in the monitoring and evaluation of services? Are there clear and robust compliance and whistle blowers procedures in place?	
Is performance and activity information fed back to service users?	
Are changes and developments reported to service users?	
Would commissioners accept the finding of user-led research?	
Are there regular opportunities for service users to provide feedback on services either as an individual or as a group?	
Do commissioners allocate resources to support service user involvement?	
Are service users regularly asked how they would like to be involved in commissioning?	

Commissioning and Planning Structures	Assessment
Do you regularly review your approach to service user involvement?	

Meetings	Assessment
Are meetings held at times and in locations that are accessible to and appropriate to service users?	
Are your meetings promoted in areas where service users will be?	
Are all meeting papers sent out at least one week in advance of all meetings and is support offered prior to meetings?	

Means of participation	Assessment
Has a range of participation methods including the use of new technology and social media been considered?	
Are minutes of your meetings readily available to service users?	
Are you able to provide training and support to service users wishing to participate in meetings/events?	
Are you able to give enough time for service users to prepare for meetings/events?	
Do you support service users by meeting their out of pocket expenses incurred through attending meetings/events?	
Do you use jargon and technical terms in your meetings/events?	
Do meeting/event attendees have a clear understanding of the importance of service user involvement?	
Do you use means of communication other than e-mail?	
Is the structure and culture of your meetings/events such that service users will feel able to contribute?	
Is it clear to service users that it is their decisions to attend meetings/events?	
Have the needs of Welsh speakers been considered? Are there arrangements in place to specifically engage with Welsh speakers?	
Have you considered the language needs of all service users?	

Service Providers	Assessment
Do you have a service user charter?	
Is information on how to make complaints or pay compliments made available to service users?	
Are staff trained in delivering client centred support and involving service users in their care plans?	
Are clients able to access advocacy support?	
Are service users involved in the staff recruitment process?	
Are there regular opportunities for service users to provide feedback on services either as an individual or as a group?	
Is there regular interaction between service users and senior management?	
Are service users aware of who the commissioners of the service are and how they can escalate any concerns to the commissioners?	
Are service users involved in the development and review of their care plans?	
Are service users involved when changes are made to the service base e.g. redecoration or renovation?	
Are service users involved when changes are made to the structure of the service e.g. opening times, staff structures, out of hours support?	
Are service users or ex-service users involved on your board of management?	
Do service users have the opportunity to use their skills to support the delivery of the service e.g. peer support, befriending at drop-in?	
Are service users involved in budget setting or management?	
Are there opportunities for service users to represent the organisation?	

Means of participation	Assessment
Do you operate any peer education or user led assertive outreach schemes?	
Do you involve service users in the delivery of harm reduction messages?	
Is the advice of service users sought when seeking to work with specific groups e.g. black and minority ethnic groups, stimulant users?	
Are service users asked how they would like to be involved in services?	
Are service users involved in the induction or general training of staff?	
Are service users involved in the induction of new service users?	
Do you advertise and promote service user forums?	
Are service users informed of the range of treatment options available to them?	
Are service users encouraged to take a proactive lead in the development and review of their own care plan?	
Do you regularly review your approach to service user involvement?	
Do you have appropriate mechanisms in place to engage with service users with diverse needs; children with young people; expectant mothers and families and carers?	

Appendix 1

Useful Links

www.dan247.org.uk/

www.nta.nhs.uk

www.aidslaw.ca/publications/publicationsdocEN.php?ref=67

www.awsum2012.org/

www.wales.gov.uk/topics/people-and-communities/safety/substancemisuse/?lang=en

www.wales.nhs.uk/sitesplus/899/home

www.wales.gov.uk/docs/dhss/publications/131023substanceframeworken.pdf

www.participationcymru.org.uk/

www.wedinos.org/

Appendix 2

Sample Charter for Service User Involvement

Design and Planning of Services

Involving service users in the process of planning services should lead to services that are more responsive to the needs of people who use them.

Personal planning of services

Service users have a right to:

- Be full partners in the planning for their own service needs and in the design and drawing up of their own care plans.
- Have access to independent advocacy.
- Be present when their needs are assessed and their services planned and reviewed.

Joint planning and commissioning of services

Service users have a right to:

- Be treated as full and equal partners within the planning process.
- Be supported during meetings.
- Have meetings held in an appropriate format, including the use of technology and social media where appropriate, at appropriate times and in appropriate venues.
- Have other mechanisms available for ensuring effective involvement, e.g. representatives of planning groups visiting user and carer meetings to obtain views.
- Be involved in the formal processes for gathering the views of service users and carers separately and seeing them integrated into the planning structure.
- Receive remuneration for expenses incurred during involvement in planning processes.
- Receive information in good time to enable effective consultation.
- Receive quality training.
- Have clearly agreed roles and responsibilities.
- Be kept informed about how their contributions have influenced planning and service delivery.

Service Delivery and Monitoring

Service user involvement in the delivery and monitoring of services will make services more responsive to need.

Service users have a right to:

- Be treated as full and equal partners and fully involved in the delivery of services.
- Be involved in the recruitment and induction of staff as appropriate and be supported to do so.
- Have their views taken into account and be provided with feedback if they are not satisfied with services offered.
- Be made aware of alternative services where these exist.
- Be informed of how to make a comment or complaint and have them fed into the monitoring and evaluation process.
- Be given the opportunity to inform service providers of whether or not their identified needs are being met.
- Be involved in the design and collation of monitoring and evaluation procedures and be informed of the results of monitoring and evaluation of services.

Appendix 3

Personal Qualities

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority)

Some approaches, tools and good practice for improving drug user involvement.

One of the most significant findings of this project is the identification of specific personal qualities that are essential to successful user involvement initiatives. Interviews with professionals and drug users who had played pioneering roles in the field showed that they shared key personal qualities:

- **Energy** – the key activists scored highly in an energy audit score sheet. The work in Lambeth, in particular, showed that people with high levels of energy are likely to last the distance in developing projects.
- **Belief in a common good** – the activists interviewed showed a strong sense of not only being interested in making things better for themselves but for other users as well.
- **Solution focused** – many people are aware of the problems that they and others face, however, only a few relate to or focus on solving them.
- **Sense of personal responsibility** – the activists distinguished themselves by seeing themselves as part of the solution.
- **Focus on results** – they measured progress by results achieved, rather than the process used to get them.

Skills

Some models of user involvement that were explored during the project showed that both users and staff need to be geared-up for involvement to work successfully. The core skills needed may be different in the two groups and may also vary from one organisational context to another and between one user and another.

Equipping users

Drug users have often been viewed as unreliable, incapable of organising things well, or unable to manage resources effectively and competently. Work on this project challenged these views. Drug users are an extremely broad and diverse group displaying a wide range of skills and competencies. There are many examples of well-run and successful drug user led initiatives.

Appendix 4

Skills Required

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority)

Some approaches, tools and good practice for improving drug user involvement.

New skills

This project identified the need for providing users with specific training to support them in user involvement initiatives. The training should support individuals who may not be accustomed to working in organisational or professional contexts.

Training on organisational issues should include the following:

- Basic finance and budgeting.
- Approaches to planning and strategy development.
- Meetings and communications, including minute-taking and chairing.
- Basic understanding of national drug strategies.

Equipping to deliver

This is an exciting area of skills development; successful service delivery by users is a powerful weapon to counter the negative perceptions and generalisations that exist about drug users.

Examples of successful service delivery include: training and equipping users to conduct Models of Care mapping work; engaging users to develop, manage and deliver a small scale Real Time Community Change project; involving service users in delivery of peer to peer training in harm minimisation.

Some of the skills needed for service delivery are outlined above; these additional ones could also be considered:

- Information and research – improved knowledge of basic research skills and methodologies can help users bid for and run either full research projects or their components.
- Training and education – users have a vital role to play in educating both other users and professionals. Developing and improving presentation skills and delivering quality training are important in furthering this.

Appendix 5

Skills for Workers

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority)

Some approaches, tools and good practice for improving drug user involvement.

Equipping staff and agencies

Much emphasis has been placed on equipping users. J Bentley, from the Alcohol Recovery Project, stresses the importance of investing time in 'skilling up' and equipping staff to work with users.

It is important not to underestimate the degree of attitudinal change needed when staff and organisations are asked to relate to drug users in entirely different ways.

Staff training areas to consider are:

- Consultation and informing. Consultation is one of the first steps on Arnstein's ladder. Staff need to be skilled in the different approaches and techniques to collating and disseminating information and feed back from users.
- Educating and encouraging peers. Staff leading user involvement initiatives need to communicate with colleagues about the reasons for and benefits of user involvement.
- Mentoring. During the project several user activists identified the importance of the mentoring and support they had received from staff members.

Make progress

Drug users are still an excluded group. Many user involvement initiatives are still at the information and consulting stages of Arnstein's Ladder. Investment and commitment to training of both users and agencies is therefore vital in moving from this stage.

Appendix 6

Involvement Forums

(From "Lessons Learnt", London Drug User Involvement Project, Greater London Authority)

Some approaches, tools and good practice for improving drug user involvement.

In the project pilots, forums were found to be popular ways of furthering drug user involvement. Their flexible and open nature suited the exploratory and developmental approach to user involvement.

Forums can and do work well and are a good means to:

- open dialogue and build relationships between different groups;
- keep users informed, especially those without easy access to e-mail or telephone;
- allow individuals to have different degrees of commitment to user involvement;
- encouraging members to voice concerns or air views in a context removed from direct service provision.

Forums and Arnstein

User involvement strategies that are solely based on forums are located around the lower (consultation and information) rungs of Arnstein's Ladder of Participation.

Users are attracted to involvement activity by different issues and they characteristically have different levels of commitment and expectations. It is therefore important to realise that forums, by themselves, cannot meet the needs and expectations of all users.

It is possible to identify three distinct groups of users:

- **Group A**
A group highly committed to user involvement and very keen to be involved in furthering it.

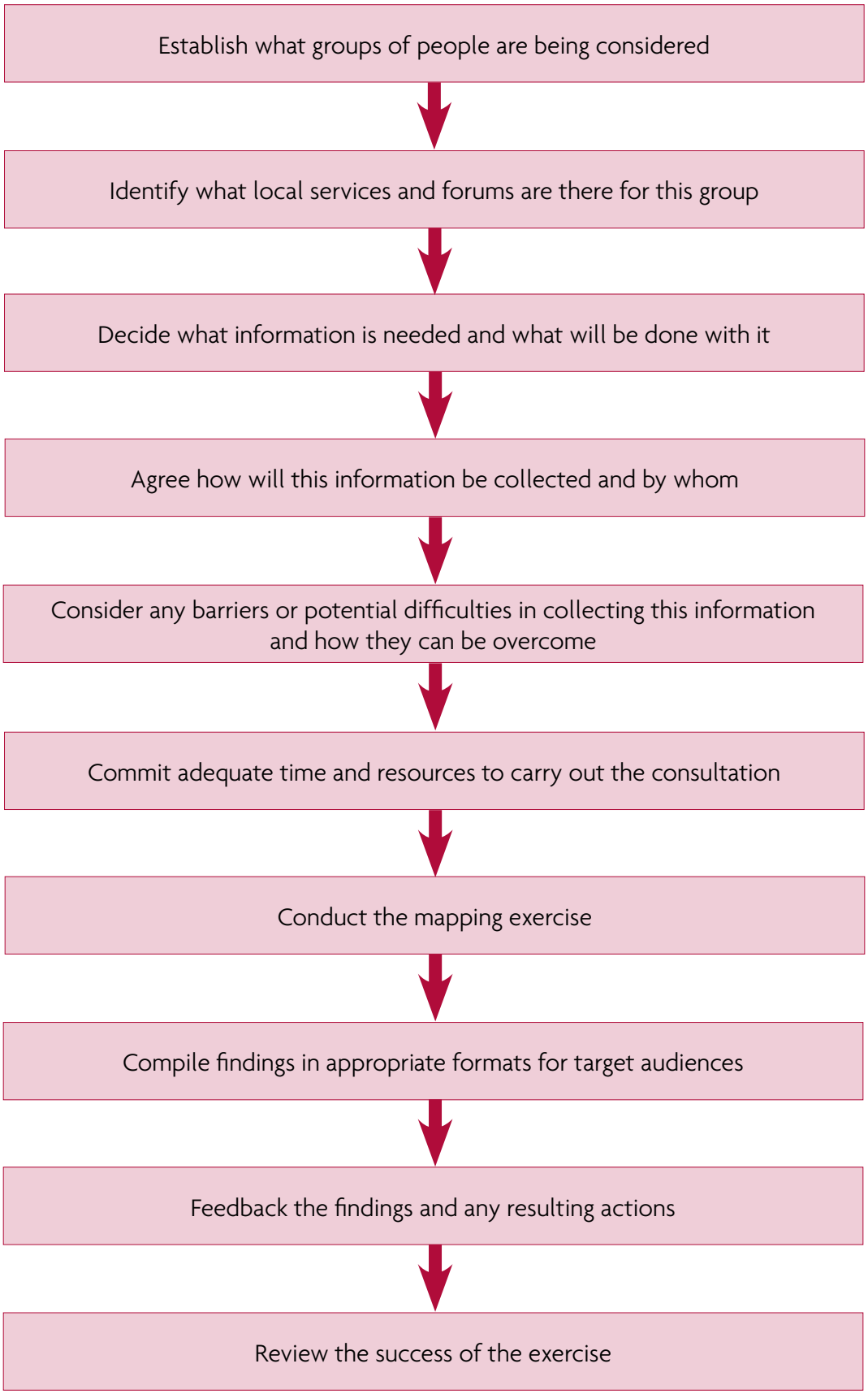
- **Group B**
A group that agrees in principle will follow a strong lead and may also be prepared to give a limited amount of energy to furthering involvement.

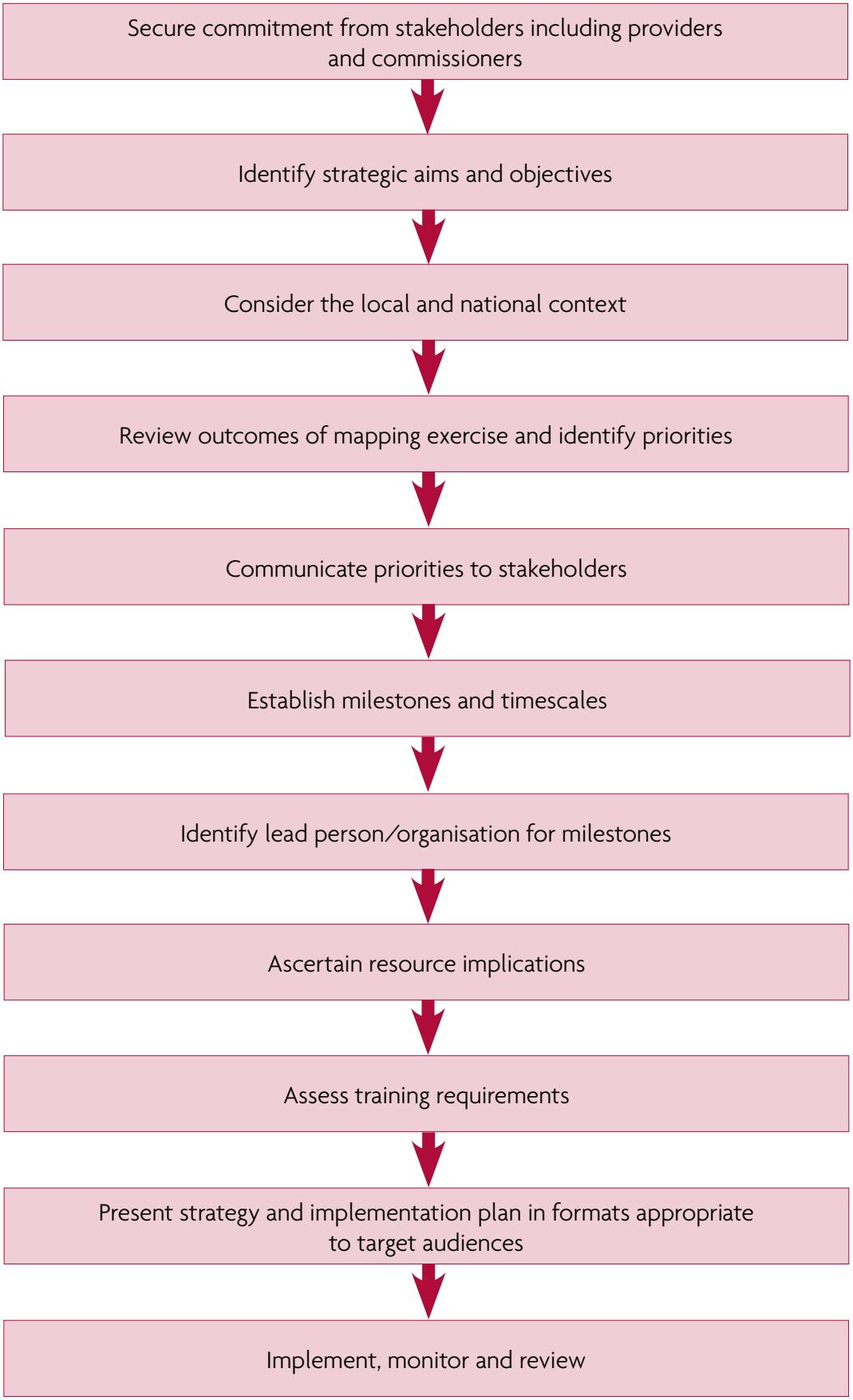
- **Group C**
A group resistant to user involvement who are not willing to contribute in any significant way.

The forum approach works well with users of Group B, where there is not significant commitment but users are kept informed and are given the opportunity to communicate about issues that affect them. Used in isolation, forums are less likely to be effective with people in Groups A and C, where different approaches may be more appropriate.

Appendix 7

Mapping Service User Involvement Activities



Appendix 8

Developing a Service User Involvement Strategy and Implementation Plan