Hear Our Voice

A framework for service user and carer involvement

in drug and alcohol recovery services

in the Lothians

Contents

Introduction and Navigation

This report was commissioned in 2012 by:

- Mid and East Lothian Drug and Alcohol Partnership (MELDAP)
- Edinburgh Alcohol and Drug Partnership (EADP)
- West Lothian Tobacco, Alcohol and Drug Partnership (WLTADP)

The report is for:

- Service users and their carers (family, friends and supporters)
- Workers in services
- Service managers and management boards
- Service planners and commissioners
- Decision makers

What we hope the report will achieve:

- Shared understanding of the principles of service user and carer involvement at every level
- Consistent experiences by service users and carers of opportunities for involvement
- Improvements in service user and carer involvement over time.

Quick guide to this report

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Service user and carer involvement

Setting the scene

∝ First, we set out what service user and carer involvement is all about – what we want to achieve (outcomes) and what getting there would look like (objectives); and we describe some basic things everyone can incorporate into their work (principles and what these look like in practice)

∝ We suggest there are three levels of service user involvement that need to be explored:

> Individual – how the individual service user or carer relates to planners, researchers and service providers

> Grassroots – what goes on at local level bringing service users and carers together to get involved

> Wider horizons – what goes on at higher levels of decision making to involve service users and carers

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Drivers

Looking at what's behind it

∝ We provide some background to the national and local policies that are driving the interest in service user and carer involvement.

∝ There is a growing expectation that service users and carers have expertise to share and an important contribution to make to the design, development and delivery of initiatives to help people affected by drug and alcohol use.

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Framework and outcomes

Making it happen locally

∝ In this section we provide a logic model (a diagram) which brings together the outcomes and objectives we have already described in section 1, with some examples of activities and building blocks needed to make service user and carer involvement happen more widely.

∝ The activities mostly need to be taken forward in services. However, the alcohol and drug partnerships need to put some more building blocks in place to encourage and support services to do more service user and carer involvement.

∝ We suggest some ways of measuring progress for partnerships.

∝ We also suggest some ways of measuring progress within services, at each level of individual, grassroots and wider horizons.

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Individual service user and carer involvement

Building the foundations

∝ This is where service user and carer involvement often begins, in the relationship between services, their service users and the people not yet using their service. If service user and carer involvement is good at this level, it paves the way for work at

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other levels.

∝ We provide a continuum of individual involvement from personal engagement with the service to individuals being supported to express their views on wider issues.

∝ We run through a number of tools services use and summarise what service users and carers give and get back from these methods, to encourage practitioners to think of these as opportunities for personal growth for their service users.

∝ We offer some practical tips and pointers to preparing for more service user and carer involvement.

∝ We look at it from the service user and carers' perspective – not everyone is a 'joiner' and ways to be involved individually are important for some people.

∝ We provide some ideas on what to avoid.

5	Grassroots service user and carer involvement

Bringing people together

∝ There are different ways people can be involved collectively. Sometimes there are groups or other activities for people to get together in services; but sometimes people self-organise for their community. Services can often be the motivators and supporters for all of this activity.

∝ We provide a continuum of individual involvement from personal involvement to community leadership at the grassroots.

∝ We run through a number of tools communities use and summarise what service users and carers give and get back from these methods, in many of these there is both personal growth, empowerment and capacity building for the community.

∝ We offer some practical tips and pointers for services who want to support and enable this kind of collective involvement by service users and carers.

∝ We explore some of the challenges for practitioners when working with groups and trying to develop community-led initiatives, and some of the things to avoid.

∝ We also look specifically at developing peer to peer roles in organisations.

6	Wider horizons for service user and carer involvement

Connecting people with higher level planning and decision making

∝ Fewer service users and carers engage directly with Partnership-level decision making and national policy development. This section challenges us to think beyond traditional forms of representation.

∝ We provide a continuum of involvement from consultation to participatory budgeting in which service users and carers are directly involved in prioritising expenditure on drug and alcohol services.

∝ We explore the more challenging context of what service users and carers give and get back at this level, and provide ideas about preparing for a greater level of service user and carer involvement by alcohol and drug partnerships, as well as by services. We describe some key enablers which partnerships could take forward.

7	**Recommendations**
	What should happen next
	∝ Each alcohol and drug partnership has a different set of challenges to contend with.
	∝ In this section we have pulled together some common steps all the partnerships could take. These are some of the building blocks we have described in section 3 and some of the enablers we have described in section 6.
	∝ We have provided the alcohol and drug partnerships with a separate paper on ideas for boosting implementation with specific projects to develop service user and carer involvement.
8	**Tools**
	Stories from the front line
	∝ This section provides some tools which different services have found useful.
	∝ There are tools for each level of service user and carer involvement.
	∝ We have included some basic materials for peer support and peer research.
9	**Local findings and what the literature says**
	Service user, carer and service manager perspectives
	∝ We conducted two surveys:
	○ An online survey of the managers in services in the drug and alcohol sector
	○ A face to face survey of service users and carers led by peer researchers.
	∝ We backed both surveys up by meetings, focus groups and events.
	∝ What we found out is set out in this section, alongside a basic summary of what we read from a range of research papers, reports, guides and other documents which are relevant to service user and carer involvement.
	∝ We used this work to inform our thinking in all of the sections 1-8.
10	**Further reading**
	The best of helpful stuff we read
	∝ Many reports list references of everything reviewed when carrying out research or when developing reports. Who reads it? Very few people!
	∝ Instead we have created a readers' guide which quickly tells you if the document might be of interest to you, and where to find it.

1   Service User and Carer Involvement

Our vision for Service User and Carer Involvement in the Lothians is to inspire hope, and strengthen the capacity of people affected by drug and alcohol use to improve lives, services and treatment of people with drug and alcohol problems.

The outcomes we want to achieve are:

- Greater wellbeing of service users, carers and their communities, through creating meaningful connections with each other and with services and higher level decision making

- Effective services and planning, by sharing the challenges and search for solutions, with people with lived experience of drug and alcohol issues.

Objectives of service user and carer involvement:

These objectives provide the shared direction for the work of decision makers, commissioners, planners and services in community, voluntary and public sectors. They guide all work to empower service users and carers, and give opportunities for them to become fully involved.

- To hear the voice of people in the Lothians who have experienced drug and alcohol issues as service users and carers and promote their interests

- To improve understanding of drug and alcohol issues, with a view to challenging stigma and promoting the rights of service users and carers

- To create and promote opportunities for service users and carers to use their lived experience for the benefit of others

- To increase knowledge about resources, treatments and rights for service users and carers

- To share information and enable service users and carers to form networks

- To identify gaps in services and to raise awareness of the needs of service users and carers

- To promote cooperation between agencies concerned with drug and alcohol use and the wide range of other services which can enable service users and carers to improve their quality of life

- To empower service users and carers to participate in the planning, development and management of services.

> **The Principles** for Service User and Carer Involvement are based on promoting equality, mutual respect and shared learning.

Practices which reflect these principles include:

In research and evaluation

- Use methods which enable people to express their views in ways that suit them
- Allow time for diverse people to share their views
- Feed back the findings to all participants

In writing

- Use straightforward language and easy-to-follow style in all documents
- Make documents available in different formats
- Make definitions and meanings clear
- Make it easy for people who struggle to put thoughts and feelings on paper

In face to face contact

- Be honest, even when you can't agree
- Keep promises
- Be respectful and mindful of how much power a professional holds
- Provide advocacy (peers or others) to help people who struggle with communication to work out what they want to say and get their views across

In meetings

- Prefer dialogue to consultation
- Be clear about purpose, process and roles of people involved
- Organise meetings to suit service users and carers, rather than agencies
- Prefer equality rather than hierarchy

In general

- Create opportunities to foster solidarity
- Recognise and support diversity
- Simplify structures and make connections explicit
- Review progress together
- Communicate change
- State what can't change

At every level of service user and carer involvement, these principles should be met.

Three levels of service user and carer involvement

Service user and carer involvement encompasses a diverse range of activities that can be grouped into three areas:

Individual:

	Person with lived experience of substance use or caring ⇔ planner
	Examples: responding to a needs assessment questionnaire; attending an open consultation event

	Person with lived experience of substance use or caring ⇔ researcher
	Examples: taking part in a research interview or questionnaire; attending a focus group

	Service user ⇔ service
	Examples: being actively involved in own care plan; using a suggestions box; giving a worker views and ideas

Grassroots:

	People with lived experience of substance use or caring, working together as a group ⇔ planners or service providers
	Examples: a service user group meets regularly and shares their collective views with planners or service providers; service users acting as peer researchers and sharing their findings with planners or service providers

	People with lived experience of substance use or caring, working together as a group ⇔ community-led initiatives
	Examples: self-help or mutual aid groups; designing information for other people to increase understanding and access to services; social or activity groups; campaigning

	People with lived experience of substance use or caring collaborating with service providers ⇔ other people with lived experience
	Examples: peer support; volunteering; recovery coaching; apprentices

Wider horizons:

	People with lived experience of substance use or caring working together as a group ⇔ policy makers and decision makers
	Examples: forum meetings; groups providing representation on committees or working groups

	People with lived experience of substance use or caring working together as a group ⇔ the media and the wider public
	Examples: anti-stigma campaigns; education and prevention initiatives

All of the service managers and practitioners who participated in this study agreed that service user involvement is a worthwhile goal, but it is challenging.

'We have found that patients need to feel their views are important.'

'Challenging areas for us are competing demands, capacity change and attitudes.'

'Solutions to some of the challenges would be that SUI was meaningful, a priority of the organisation, and is creative.'

'Difficult to be creative when your funding depends on meeting targets e.g. HEAT.'

There is a clear expectation at all levels of public service (whether provided by statutory or voluntary services) that communities and people with lived experience of specific issues should be involved in designing and developing services, and decision making about resources relevant to their services.

At national level

The Scottish Government has issued national standards for community engagement, and in all areas of policy and public service from community planning to transportation, there is an expectation of service user involvement or community involvement of some kind.

Specifically in relation to drug and alcohol services, the Scottish Government says:

[Local Alcohol and Drug Partnerships should] ensure that these partnership arrangements enable the expression of the concerns of interested groups including (but not limited to) service users, carers and family groups, voluntary and private sector service providers and trades unions.

At local level

The local Alcohol and Drug Partnerships have responded to this within their local strategies.

West Lothian Tobacco, Alcohol and Drug Partnership

To ensure that service users have influence over the services they use, the TADP is keen to include a rigorous requirement for effective service user involvement in each of the contracts. We envisage this being in the form of a written plan for involving service users in service design and practice as a means of monitoring and improving service quality.

These will include:
- Suitable tools, strategies, and approaches
- Appropriate timelines for implementing the plan
- Training and resource needs
- Mechanisms for reporting on progress within the plan.

Edinburgh Alcohol and Drug Partnership

More service users and their families/carers are involved in the design, development and delivery of services.

The treatment and recovery system of care will be based around the needs and aspirations of service users (and their families and carers).

Mid and East Lothian Drug and Alcohol Partnership

MELDAP is committed to:
- the involvement of the wider family in treatment and recovery
- putting individuals at the centre of planning and the development of services
- the need to support and develop recovery communities.

In addition, the main authorities responsible for services have developed plans and resources for service user involvement:

Lothian NHS Substance Misuse Directorate: The Substance Misuse Directorate Strategy for Service User Involvement.

City of Edinburgh Council: Service User Involvement Good Practice Guide.

3 Framework and Outcomes

What is a framework?

A framework is a structure which helps to organise thinking and activity, which then helps to guide how decisions are made. A framework is not a detailed plan, it provides a basic mould for different organisations and institutions to develop their own detailed plans.

This framework is based on the vision, principles and objectives of service user and carer involvement set out in section 2.

Why a logic model?

The Framework is presented on the next page as a logic model to show the links between outcomes, objectives, activities, and the building blocks required to improve service user and carer involvement. Logic models are basically diagrams which can contain a lot of information in a visual format.

The features of a logic model which need agreement from all stakeholders are:

The outcomes – the difference we want to make in the long term.

The objectives – these are more specific goals which will help us achieve the outcomes, and will guide activities.

The actual activities can vary depending on the organisation, setting and target group. Activities are also dynamic and should change over time.

Two levels of activity are suggested:

Building blocks which may require leadership by the Alcohol and Drug Partnerships and support the next level of activity.

Activities which require all stakeholders to participate in development and may therefore vary for each stakeholder and each ADP area.

How will we know if we are achieving the outcomes?

Monitoring activity is needed to chart progress on service user and carer involvement. This can happen at service/activity level, but it is more powerful if this is collated to form an area-wide picture at regular intervals, to assess progress.

Any stakeholder developing service user and carer involvement should be interested in measuring what difference it makes, for individuals and services. Some measurement tools have been proposed for different levels of outcome associated with service user and carer involvement.

Service User and Carer Involvement Logic Model

Overall Outcome
Greater wellbeing of service users, carers and their communities
Effective services and planning

Meaningful connections between service users, carers and services	Meaningful connections between service users and between carers	Meaningful connections between service users, carers and decision makers	Effective services and planning designed in partnership with service users and carers

objectives

To hear the voice of people in the Lothians who have experienced drug and alcohol issues as service users and carers ,and promote their interests

To improve understanding of drug and alcohol issues, to challenge stigma and promote the rights of service users and carers

To create and promote opportunities for service users and carers to use their lived experience for the benefit of others

To increase knowledge about resources, treatments and rights for service users and carers

To share information and enable service users and carers to form networks

To identify gaps in services and to raise awareness of the needs of service users and carers

To promote cooperation between agencies concerned with drug and alcohol use and the wide range of services which can enable service users and carers to improve their quality of life

To empower service users and carers to participate in the planning, development and management of services

Individual

Standard approaches in all services
Within 1 year
- Suggestions box and feedback board
- Cycle of service user and carer feedback activity (appropriate to service) reported to funders

Within 2 years
- Consistent communication to service users and carers of opportunities to share views
- Agreed cross-sector protocol on seeking views of carers
- All service users and carers regularly informed of opportunities for collective service user and carer involvement

Within 3 years
- Availability of external advocacy to service users and carers to help them express their views

Grassroots

Cross sector commitment
Within 1 year
- Learning opportunities to enable and empower service users and carers
- Networked, designated professionals for service user and carer involvement
- Consistent approaches to recruitment, training and support for peer supporters/mentors/researchers

Within 2 years
- A calendar of local and regional activities for service user and carer voice
- Progression opportunities within and between services for peer supporters/ mentors/ researchers

Within 3 years
- Development support for community leaders and self-help groups for service users and carers

Wider horizons

Cross sector commitment
Within 1 year
- Collate and use data from local service user and carer involvement, at regional/national level
- Support and guidance for service users and carers engaging with the media / promotional work

Within 2 years
- A calendar of events enabling decision makers to meet constituents who are service users and carers
- A calendar of activities bringing service users and commissioners/planners together

Within 3 years
- Enable service users and carers to help design information and communication in an understandable way

activities

Within 1 year
- Services have a SUCI plan and state activities in monitoring reports
- SLAs/contracts/tender specs state outputs and outcomes

Within 2 years
- Designated development funding for SUCI training and development

Within 2 years
- Leadership at ADP level to inform elected members and decision makers in other services of SUCI views

building blocks

Within 3 years
- ADP-level consultation and agreement on protocols and templates for use in services
- ADP-wide support for training, information, collaboration between SUCI initiatives
- ADP annual progress report on service user and carer involvement to monitor progress over time and maintain momentum

The alcohol and drug partnerships' annual measurement of progress on service user and carer involvement should measure:

- the building blocks in place to support service user and carer involvement
- the collated outcomes and measures from services on service user and carer involvement activity
- the overall outcomes to which the building blocks and activities contribute.

Outcomes and measurement tools at partnership level

	Meaningful connections between service users, carers and services
	Commissioners ask services to report on their plan for service user and carer involvement; and subsequently their progress on implementation. Sample survey of service users and carers on perceptions of meaningful connections: • The level of trust that their views will be listened to • The quality of relationship between individuals and services • The ways in which service users contribute to their services (e.g. as peer supporters, volunteers, or promoting the service to their personal networks). Local bank of service reports on service users involvement activities (e.g. web based repository) to showcase range of activity and results – allowing meta-analysis of local findings.
Baseline picture 2012	19% of services surveyed have plans, strategies or policies for service user involvement Qualitative findings showed service users and carers held widespread suspicion and mistrust of expressing views honestly to services without this backfiring on them. In our 2012 work we identified 6 services with service users or ex-users involved in making a contribution.

	Meaningful connections between service users and between carers
	Partners and commissioners measure their own activity and ask services and infrastructure organisations to report on: • Network events enabling users and carers from different services to meet • Visits to and from service users from other parts of Scotland / the UK / internationally • Number of mutual aid groups operating locally (e.g. SMART, self-help) • Number of clients who access mutual aid direct from service support (e.g. peer or worker assertive referrals). The establishment of a service user and carer information portal (gateway to service, community and mutual aid sites) could enable measurement of the number of people who seek information and self- refer to self-help activities.
	Baseline to be established

	Meaningful connections between service users, carers and decision makers

	Partners and commissioners measure their own activity on:
	
	 • Numbers of reports which contain reference to service user and carer views on the content and recommendations
	
	 • Numbers of servicer users and carers who
	    ○ Provide written comment on partnership documents
	    ○ Attend partnership-led meetings or events
	
	 • Number of surgery or open sessions held by decision makers for service users and carers.
	
	 Partnerships set targets for:
	
	 • Annual celebrations of service user and carer involvement
	
	 • Annual reports profiling service user and carer involvement success stories.

Baseline to be established	

	Effective services designed in partnership with service users and carers
	Commissioners and service providers measure their activity on: • Number of service design processes / number of service users and carers involved • Number of service reviews in which service user and carer experience is sought • Number of exercises to gather information on unmet need of people affected by drugs and alcohol.
Baseline to be established	

Note that measures which *count* activity should also seek to assess the *quality* of activity in relation to the principles and practices outlined on page 8.

Outcomes and measurement tools at service level

Individual service users and carers

	Personal development - greater confidence, self-esteem, self-awareness and communication skills
	Example measurement tools: Outcomes Stars, Recovery Wheels, SQA qualifications (communications modules, Certificate in Self-Coaching).

	Purposeful use of time and structure when engaged on service user or carer involvement activities
	Example measurement tools: personal plans / logs; service participant registers.

	Progression towards further training, education or work in the drug and alcohol, or health and social care sectors
	Example measurement tools: follow up surveys; qualifications gained; birthday card tracking.

Individual workers

	• **Greater job satisfaction as workers are enabled to see the long term outcomes of their work with service users who make progress beyond their service** • **Greater sense of collaboration with the service user, carers and other services**
	Example measurement tools: staff satisfaction survey (e.g. integrated into quality improvement framework).

Organisational

	Effective and appropriate services
	Example measurement tools: service plans and reviews.

	Greater connections between drug and alcohol services and the wider range of services people need for their whole wellbeing, because we start to appreciate them as people with wider concerns and aspirations
	Example measurement tools: stakeholder and partner mapping.

Societal

	Signal to society that drug and alcohol users have rights and can make a contribution to society
	Example measurement tools: media monitoring (e.g. within public sector communications departments).

	Public health improvement, as we can learn more quickly from service users the trends, health issues and social issues they are facing; and learn from them what messages will be effective to prevent ill-health and promote wellbeing.
	Example measurement tools: drug deaths, blood borne virus trends, emergency admissions.

4   Individual service user and carer involvement

We asked service users for their views on seven different methods of individual service user and carer involvement.

Suggestions boxes widely accepted but needs to be high profile and feedback given:

'It would be good to get feedback from your suggestions.'

Face to face interviews highly dependent on quality of relationship:

'On the relationship with the worker, if it is not good I wouldn't be honest.'

Surveys can work for some who self-manage well:

'Anonymity, and space and peace to think of your answers.'

Online surveys prompt a high level of paranoia amongst respondents:

'Don't like computers. Seem to ask too many questions, take a long time. Don't know who is watching.'

Video boxes depend on confidence:

'There's no writing involved for some people who struggle with spelling'

Facebook generally seen as inappropriate:

'Some of my friends don't know I engage in the recovery community and neither do family members and this could be embarrassing.'

Mobile phones have pros and cons:

'Would need to be short and sweet. Would depend on issue under discussion. If it was something very relevant or important to me, I would respond.'

'Credit and giving out number.'

Individual service user and carer involvement is important in its own right, and because it is often the foundation of other levels of service user and carer involvement.

The most common route into service user and carer involvement for people who use/are affected by substances, is through direct service provision. There is a continuum of individual service user and carer involvement:

Personal ⟷ **Wider perspective**

Individual involvement in her own care or treatment plan	Individual views sought on her directly received service	Individual views sought on wider aspects of the service	Individual participant in research or consultation	Individual views sought on information or new resources	Individual views sought on service plans / reviews	Individual supported to express her views on local / national issues

Individual service user and carer involvement can be gained by using tools which engage individuals without necessarily involving them in groups or structures. It can be sustained, and will grow, if the 'give and get back' is clear for service users.

Tools which support individual level service user and carer involvement include:

Tools	Give	Get Back
Suggestions boxes Voting booths/boxes	Suggestions Votes	Information on the service response – a *"you said… we responded by…"* board next to the box
Research, evaluation, feedback forms	Survey completion	Summary of findings in user-friendly format
1:1 discussion with staff, induction to service, exit from service	Feedback to workers	Overview of collated findings e.g. quarterly news Personal thank you e.g. by letter
Inviting self-nomination to attend events etc outwith the service	Time and commitment	Information and support to attend (at least pre-brief and de-brief, help with travel)
Opportunities Board advertising opportunities for further involvement	Time and interest	Response/follow up by staff quickly with clear timeline for next steps
Interactive displays	Time and interest	Immediate feedback; information

The ultimate 'get back' from all service user and carer individual involvement is personal empowerment. Think: *In what way can our service user or carer develop and grow through this experience?*

There are practical ways services can start to create a service user and carer involvement culture that feeds involvement at other levels:

- Trust was one of the biggest issues raised by all service users in our research. A culture of respect and belief in people's potential is always transmitted primarily through staff, from receptionist through to key worker.
- Communicate your vision for service user involvement (ideally created *with* service users and carers) to staff, service users and carers really clearly – make it unmissable, clear, concrete and always present.
- Make it a standing agenda item for Board and staff meetings – especially if it is not your intention to involve service users and carers in these meetings.
- Identify a staff member who will champion service user and carer involvement.
- Include service user and carer involvement in job descriptions when recruiting staff, and in performance management frameworks.
- Promote your achievements in relation to service user and carer involvement, making progress visible to staff, service users and carers.

- Make service user and carer involvement a personalised experience – make opportunities fit the person rather than trying to shoehorn the person into the opportunity. Have a range of options to suit different people.
- Remember the needs of service users and carers with children. Work around school days and terms; consider how people with pre-school children can be supported to participate.

Preparing for service user and carer involvement – starting or improving

- Agree with staff and Board what service users and carers will be involved in – this may start at 'easy wins' and develop towards more sophisticated approaches over time.
- Think about who your service users and carers are – this is very challenging in drug and alcohol services, where there is such diversity of experience and recovery. However, it is essential that involvement is 'pitched' right, and that to be inclusive, there are different opportunities for different people. Institute for Research and Innovation in Social Services (IRISS) evidence suggests that for people considered 'hard to engage', participation needs to be well integrated into their actual use of the service and not a separate activity.
- Identify what time and resource is available. Consider networking with other organisations to pool resources and ideas. Cheap and cheerful is effective if some creativity is applied.
- Create a cyclical approach: regular periods in the calendar year in which service user and carer involvement is boosted as a theme in the service, or key events and activities happen at specific points in the year. It can then become fun and celebratory. Avoid school holidays unless you can afford additional childcare!
- Conduct a policy review (ideally with service users and carers if the documents are not turgid and full of jargon, see above) and ensure expectation of service user and carer involvement is integrated throughout your organisation's guiding documents.

'Joiners' and 'loners'

It is important to recognise that in an integrated service context, many people use several services at one time. Some people appear to become involved in every service user or carer involvement activity and risk burn-out. Services can help by enabling people to plan their participation, prioritise and identify what service users and carers 'get back' from opportunities, and respect that the service user or carer might prioritise active participation in another service and only passive involvement in our own.

Individual service user involvement is ideal for people who struggle in social settings and groups. This is their chance to be involved from within their comfort zone. If the opportunities successfully answer the question: *In what way can our service user/carer*

develop and grow through this experience? then people may, in time, become 'joiners' but we should be careful not to regard individual involvement as less important than collective involvement.

Approaches to avoid:

- Hand-picking service users to be single representatives on a group / activity, which is regarded as tokenistic by other service users and carers.
- Consultation on documents (plans and policies etc.) which have not been written with service users and carers in mind i.e. full of jargon, turgid writing.
- Any approach which fails to feed back to service users and carers what has been learned and what will happen as a result.
- Any passive approach which leaves information / requests lying around for service users and carers to notice – response will be low and this risks discouraging staff from further effort / confirming to sceptical staff that 'service users aren't interested'.

The culture, relationships and approaches used by services to involve their service users and carers impacts on grassroots level service user involvement and participation in planning and decision making.

5   Grassroots service user and carer involvement

In our service user and carer survey, there was strong support for methods of grassroots involvement, although some doubts about how different groups of service users could come together.

Group meetings were positive if managed well:

'Supportive way to get views, ideas across provided people are genuinely listened to'

'When you are attending a meeting you know you're being heard.'

'Confidentiality. Loudest folk would take over. I don't feel confident in group meetings'

Peer involvement was highly rated, again provided it was well managed and supported:

'Sometimes feel you're not listened too and feel like a pawn!' [peer supporter]

'If you are talking to people who have been through it themselves then you feel they can relate and you are then able to trust.'

Grassroots refers to community level engagement. This can be a platform for participation in wider horizons (Alcohol and Drug Partnership, council, NHS or government levels). However, it can lead to really positive outcomes for individuals, services and communities in its own right.

The grassroots community is not necessarily a geographic area. Grassroots communities also include the concept of a 'recovery community' (people in recovery coming together regardless of where they live) and other communities of interest, such as people affected by HIV, Hepatitis or other conditions such as mental illness and addiction.

There is a continuum of grassroots service user and carer involvement:

Personal ⟷ **Leadership**

Participation in interest groups, mutual aid or self-help groups	Involvement in groups developed by a service	Involvement in activities providing service user or carer perspective, e.g. developing information	Involvement in sharing experience or helping others e.g. peer support, group leadership	Involvement in local service design, development and delivery e.g. on working groups or service Boards	Service user-led or 'co-produced' services	Campaigning and advocacy for local issues and specific interests

At this level, the tools to enable and empower grassroots involvement vary widely. Service users and carers told us that the 'get back' in many of these methods is greater, even without some of the suggested tangible returns listed here. Some of the most common approaches are:

Tools	Give	Get Back
Community organising (some disallow professional support e.g. AA,NA; some have paid co-ordinators supporting volunteers, e.g. SMART)	Voluntary time Long term commitment Skills and experience	*AA, NA, CA etc.* Reciprocal support Standing in the community *Others* Training (SMART) Qualifications (e.g. Community Development)
Service User Involvement Groups led by services	Voluntary time	Group bonding Communication skills (can be linked to qualifications) Training (can be linked to qualifications)
Service user and carer involvement in tasks/activities	Voluntary time	Achievement of tasks Improved self-management Group bonding Communication skills Training Qualifications relevant to tasks/ experience gained Relevant experience and transferable skills for employment.
Service user and carer involvement in helping others	Voluntary time Emotional support	Satisfaction from seeing others progress (can be balanced by coping with others' regress) Greater self-awareness Training Qualifications relevant to mode of helping (e.g. Recovery Coaching, Counselling, Health & Social Care) Relevant experience for future employment.
Involvement in local design, development and delivery	Voluntary time Willingness to do background reading and preparation Willingness to participate in complex processes	Satisfaction from seeing change and development (can be balanced by frustration if no change) Transferable skills and qualifications (but only if designed into the process)
Service user-led or co-produced services	Voluntary time (lots of it) Willingness to take on responsibility and leadership	Satisfaction from seeing change and development and controlling it Standing in the community Training Transferable skills and potentially qualifications

With the exception of mutual aid, all forms of grassroots involvement benefit from professional support which may include:

- Initiation of ideas and approaches – provided service users and carers then inform development

- Facilitation of groups
- Training and support for community leaders / facilitators
- Assessment of qualifications
- Provision of resources (e.g. space) and support to manage resources (e.g. money)
- Development and co-ordination of peer researchers, peer supporters
- Personal support to individuals involved in groups
- Ensuring safety, inclusion and resolution of glitches, conflicts, drifts and ruts.

There are practical ways services can support grassroots involvement:

- Provide space, access to phones, photocopiers, computers
- Demonstrate partnership with grassroots initiatives such as Discover Recovery as role models
- Promote grassroots initiatives to service users and carers – these are often available outwith service hours and boost recovery capital
- Provide staff with training in community development approaches (so they in turn train service users and carers)
- Link with learning providers to explore how service users and carers can gain qualifications for their experience
- Link with other grassroots service user and carer involvement – create a network for resource and information sharing, collaboration.

Preparing for grassroots service user and carer involvement – starting or improving

The preparation already described for individual service user and carer involvement is relevant to this level of involvement. In addition:

- *Really* check the attitudes of professional staff towards service user involvement directly within their domain. Peer supporters, group leaders and other volunteers have reported feeling like 'second class citizens' for their efforts. Service users and carers usually do not imagine themselves replacing professionals (unless your recruitment has gone wrong somehow!) but are sensitive to lack of respect.
- Think ahead – what tasks could service users and carers be involved in? Peer research, production of information for service users, peer-led groups, consultations, reviews, decisions…it will not be quicker to involve service users and carers, but it will be authentic if these are genuine needs of your organisation.
- Reflect on the hugely influential role people with lived experience of HIV played in the world's response to this virus. Locally, service users are key informants in Crew's development of responses to new drug trends. As well as treatment and recovery, service users can inform prevention and harm reduction, in order to promote greater wellbeing of people affected by substance misuse.

Leadership and handing over the reins

Although there are some very successful examples of service user/carer-led initiatives, the rosy glow around service user and carer involvement obscures some of the challenges.

People involved in substance use and the recovery community are diverse. Addiction is associated with a range of behaviours that do not disappear easily once a person is stable or abstinent. For some people, underlying mental health issues or hidden disabilities (e.g. Asperger's) are part of their self-management challenge in recovery. Some difficult behaviours make service user involvement a difficult process, either for professionals or peer leaders to support.

There is an unusual dynamic in leadership of service user and carer involvement: letting people take forward their ideas and take the reins, whilst providing a solid scaffolding of agreed expectations, boundaries, back up and challenge. There has to be a continual eye on the greater good of the wider group or community which may at times involve re-directing the focus of individuals.

This is a delicate balance and service managers can support their team's service user and carer involvement by being aware of how challenging the role can be for both professionals and grassroots leaders.

Peer to peer roles and volunteering

There are a range of definitions being used by different services – consistency of language across the sector may be difficult to achieve but it would help service users and carers know what opportunities mean and what they can expect if they offer their time in a different service.

- Peer support is the natural reciprocity between people with shared experience which can be informally occurring when there is contact between service users and carers, or it can be developed through formal mechanisms such as self-help groups or attendance at e.g. groups of people in treatment by ex-service users
  Example: the LEAP model by which ex-service users accompany patients on outings, to appointments etc.
- Peer mentors are people with lived experience who are confident about their recovery and willing to offer support to someone to help them move along their own path.
  Example: the "in-reach" model by which people with lived experience make presentations to groups of patients
  Example: the recovery coach model by which people with lived experience are trained in coaching techniques using a recovery capital tool
- Peer educators are people with lived experience using their knowledge and insight to provide information and help others understand
  Example: Crew outreach team provide crisis support at festivals

Example: harm reduction information by people with lived experience in needle exchanges

- Volunteer is a misleading term because anyone who gives their time for no pay is a volunteer. However, in the context of service user and carer involvement it is most often used to describe either people in non-support volunteer roles; or people who are not in recovery or affected by substance misuse in unpaid support roles.

Preparing for peer involvement (see also Tools page 35)

Although peer involvement is the form of grassroots involvement most popular with service users and carers, and is increasingly desired by services, it also presents some of the greatest challenges. Services can prepare for peer involvement by:

- *Really* thinking about who you want to engage as a peer, what you want them to do, and why
- Creating job descriptions for the peer roles, and volunteer contracts
- Developing open and fair recruitment processes, in which recruiters must be prepared to decline unsuitable potential peers – clear criteria of qualities helps
- Thinking through the Disclosure issue and the implications for peers
- Considering what access peers will have to information, computers, desk space, staff-only areas, etc
- Designating significant staff time to supporting peers, throughout their involvement, including time for de-briefs and on-call support if needed
- Development of an induction process that will enable peers to fully explore and understand boundaries, policies, procedures and who is who in the organisation
- Development of, or links to, appropriate training.

Things to avoid:

- Lack of clarity about what you are developing and why – one of the greatest causes of service user and carer dissatisfaction is unmet expectations about their level of involvement and influence. Limits and boundaries may be part of your approach provided these are up front
- Replicating hierarchical, formal meeting formats and decision making processes in community level involvement – use participative group processes which enable inclusion of diverse people
- Focusing development efforts on a small number of individuals. One danger is that people are perceived to have power over others, another is that stress compromises recovery. However, also bear in mind that a lot of service user and carer involvement happens in the first few years of recovery; people move onto other things as their recovery becomes a way of life. Professionals need to ensure sustainability by engaging a pool of individuals and working on constant recruitment

- Fixed membership of groups. Although the developmental process can be hampered by constantly introducing new members, quite large groups can become small and unrepresentative with turnover re the above point
- Trying to be all things to all people. Because grassroots service user and carer involvement is yet to become mainstream, there may be pressure to 'provide' service users to participate in higher level consultations etc. losing focus on the group's own agenda.

6 Wider horizons for service user and carer involvement

> In our service user and carer survey, just over half the respondents identified positive aspects of becoming involved in decision making and policy development, although the majority were also cautious about tokenism.
>
> *'person would have to be carefully chosen, one person unlikely to be enough, not everyone will engage with this'*

'Wider horizons' refers to Alcohol and Drug Partnership area-wide and national service user and carer involvement. Good service user and carer involvement at this level requires service user and carer involvement at other levels (individual and grassroots) to be in good shape. Involvement at this level begs the question: who makes this happen? If local services are the engine of individual and grassroots involvement, then their willingness and collaboration to generate involvement at this level will be essential.

However, although success at this level of involvement requires effort at other levels, what happens at this level also provides leadership to the sector – good practice here will also encourage positive practice at individual and grassroots level. The Alcohol and Drugs Partnerships have a key role in facilitating and leading on this.

At this level, issues on which service users and carers are invited to engage are more abstract. Opportunities for involvement are often linked to formal (professional or political) decision making processes which follow timescales and procedures that challenge us to be creative about how we engage service users and carers meaningfully.

There is a continuum of service user and carer involvement at this level:

Information exchange ⟷ **Collaborative approach**

Decision makers and partnerships send information to service user and carer involvement initiatives for consultation	Regular surgery-type approach by partnerships and decision makers enabling individual service users or groups to express their views	Regular forum events in which partnerships and decision makers meet service user and carer groups using participatory approaches	Joint training sessions for partnerships / decision makers with service users and carers on participatory approaches	Service users and carers are involved in collaborating at all stages i.e. plan-do-review at this wider strategic level	Participatory budgeting – designated budget set aside to be prioritised by service user involvement initiatives

At this level, the 'give and get back' for service users is far less clear. There is a challenge to make service user and carer involvement meaningful as we found that many service users and carers in our survey and focus groups were deeply suspicious of tokenism.

Tools	Give	Get Back
Consultation / information for groups or individuals to respond to	Time	Final decision or outcome
Surgeries or other 'meet the partner / decision maker' opportunity	Views Personal experience Specific suggestions	Follow up letter Satisfaction that views were expressed and heard
Participatory events involving both service users, carers, and partners / decision makers; such as conversation cafes, charettes, dotmocracy etc (see Tools page 35 for details)	Views Time Personal experience Willingness to listen Courage to participate	Dialogue Understanding of different perspectives Knowledge of 'who is who' Feeling of being part of something Feedback on what happened as a result
Joint training sessions involving both service users, carers, and partners / decision makers; for example on approaches such as public social partnerships, or emerging health trends	Time Personal experience Courage and commitment to participate with professionals / decision makers	Knowledge of the issue Knowledge of 'who is who' Feeling of being part of something Feedback on what happened as a result Sense of equality
Service user and carer involvement in partnership cycle (plan, do, review)	*If an individual representative then:* Time Preparation and pre-reading Courage to participate *If a group in joint session with the partnership then:* Time Preparation as a group	*If an individual representative then:* Much depends on the level of inclusion in the process! *If a group in joint session with the partnership then:* Feeling of being part of something Feedback on what happened as a result Sense of equality
Participatory budgeting – the designation of budgets by partnerships for community prioritisation	Time Preparation to understand the process and implications Objectivity and wider perspective	Dialogue Understanding of different perspectives Feeling of being part of something Feedback on what happened as a result Sense of equality

Service user and carer involvement at this level is enhanced by the approaches of partnership staff and especially the partnership lead officer who is likely to be seen by service users as the 'go-between' service users, carers, professionals and decision makers. Positive approaches include:

- Meeting service users and carers on their own turf, informally, to build relationships and trust, independently of any other methods such as those above
- Providing service user and carer groups (and services, for individuals) user-friendly information on how decisions are made, who makes them, when and how – with head shots to personalise the information
- Writing to thank service users and carers for their involvement when they have given their time

- Raising the profile of good practice and service user or carer achievements by leading recognition amongst decision makers and other professionals.

Preparing for service user and carer involvement on the wider horizon

ADP-level protocols agreed between all partners. We have found that some procedures in different agencies require significant advance planning for activities such as peer research, which could present a hurdle for service users and carers who want to initiate local activity. Shared understandings would be beneficial in these areas:

- Research and peer research: when approval is required, who can give approval, and a streamlined approach to decisions.
- Peer involvement: when Disclosure Checks are required, how this process is managed, and how service user and carer involvement amongst those with criminal records can be managed.
- Consultation: what is the appropriate minimum period of consultation to allow service users and carers to meet, discuss and respond.
- Transparency in decision making: whether or not service users and carers are directly involved, what kind of information is made available and is it easily accessible.
- Expenses: what travel, food and carer expenses can be claimed at different levels of service user involvement, from participation in surveys to volunteering?

Some key enablers for alcohol and drug partnerships to consider

ADP-level support for training, information sharing and collaboration between service user involvement initiatives. We know from our discussions with services service users and carers, that local service user and carer involvement initiatives and the limited number of area-wide initiatives have limited staff time and resources to function. A shared programme would be cost effective and productive at all levels of service user and carer involvement.

An ADP-led annual progress report on service user and carer involvement. Local service user involvement is currently low profile which gives the sense that it is also low priority. Practitioners, service users and carers who are striving to improve service user and carer involvement should be given regular recognition.

A common approach to tender specifications / calls for grant applications. Specifications which ask for information from services on their approaches to service user involvement can help boost local activity.

Designated development funding to support service user involvement initiatives. Over time, the inclusion of service user involvement in service specifications will ensure that service user involvement is a costed element of service development packages. In the short term, development funding could boost practice and engage services, service users and

carers in pioneering effective approaches for wider dissemination. This approach would boost capacity, setting the stage for longer term integration of service user and carer involvement in service specifications. An alternative is for ADPs to lead this innovation directly.

Preparing for service user and carer involvement at higher levels of decision making

There is limited evidence that traditional, representative approaches to service user and carer involvement is effective in attracting a diverse range of people to become involved.

Service User Groups face a number of challenges:

- Infrequent meetings create little scope for group bonding between service users and carers, which reduces their effectiveness to work as a team when engaging with partners and decision makers
- There is high turnover of membership, which may be because of the abstract nature of discussions and lack of concrete tasks and issues to 'be involved with' reducing long term commitment – people get bored more quickly
- There is limited staff capacity to provide individual members with support and learning opportunities between meetings.

Some of the solutions suggested by staff focusing on service user and carer involvement in this field:

- Create open, long term groups which meet frequently and focus on tasks which further the aims of service user and carer involvement (peer research, service-user / carer-led investigations into themes or gap areas etc.)
- Collaborate, so that groups are supported by staff working in partnership and enhancing the limited resources from a single agency to support individual group members.

The challenge cannot be directed at service users and carers alone. Partnerships can do more to make engagement with service users and carers part of their annual routine:

- Create a "service user and carer involvement week" in which elected members, partners and the media celebrate the contribution of service users and carers
- Hold conversation cafes or other forum-type events to hear from service users and carers what are their priorities
- Train the partnership members to re-think there perspective on service user involvement (as opposed to directing all the training at service users and carers to change their approach to high level meetings).

Things for ADPs to avoid:

- Sporadic, rushed attempts at gaining service user and carer views. Improvement in service user and carer involvement requires 'practice' – regular, steady building up of relationships, experience and methods that work.
- Singling out service users and carers to 'represent' the service user and carer voice. Service users themselves are suspicious of this as tokenism or keeping 'pet service users'. Where a small number of service users or carers represent the target population, care should be taken to give them the means of seeking out the views they are to represent by peer research.
- Superficial processes in which service users and carers are involved in meetings or processes without a real role or chance of influence.

7 Recommendations

1. Gain agreement and buy-in to the framework across all partners and sectors

Within each partnership

- Consult with stakeholders on the final draft framework
- Give a high profile to the framework with a specific section on partnership websites dedicated to service user and carer involvement
- Ask stakeholders to share their commitments and plans aligned with the framework
- Integrate the outcomes and objectives into partnership strategies (at review dates) and all new plans.

Panlothian

- Provide a shared calendar of opportunities and events for service user and carer involvement
- Provide opportunities for service users and carers across the Lothians to meet and share experience.

2. Become role models for putting the principles into practice

Within each partnership

- Use a checklist for all reports, documents, consultation processes, meetings and activities in which service user and carer involvement is required
- Ensure partnership chairs and elected members are briefed on service user and carer involvement and champion proactive effort to develop it
- Identify a service user and carer involvement development lead within partnership teams or amongst partner organisations.

Panlothian

- Network across partnerships regularly to achieve synergy and cost efficiency in development of service user and carer involvement.

3. Prioritise development of building blocks as identified in the logic model

Within each partnership

- Integrate monitoring of service user and carer involvement activity at service level into partnership monitoring and evaluation processes
- Develop specifications for services which include service user and carer involvement as an expectation
- Develop a programme of engagement with elected members, service users and carers to raise awareness of the sector and the role of service users and carers in its development.

Panlothian

- Develop training for development of service user and carer involvement (collaborate with partners to secure funding for this)
- Develop shared protocols on core issues for service user and carer involvement, such as research approvals (NHS), peer support guidelines (all partners), service user and carer travel, childcare and care expenses (all partners).

4. Focus service providers and partners on collaboration and information sharing to promote and develop service user and carer involvement

Within each partnership

- Work with local services to achieve standard features of service user and carer involvement by developing action plans to implement the framework.

Panlothian

- Create a network of practitioners engaged in service user and carer involvement to support training, information sharing and collaboration between service user and carer involvement initiatives.

5. Give consideration to working in cross-sector partnerships to secure dedicated resources to develop flagship service user and carer involvement initiatives

Within each partnership and panlothian

- Agree in principle, so that external funding opportunities can be pursued quickly when these arise, to develop:

- Learning programmes for service users and carers to develop their contribution to design, development and delivery of services
- Training programmes for practitioners and community leaders
- Networking events and opportunities, including UK and international exchange.

8   Tools

This section contains some ideas for involving service users and carers in different ways:

- Tools for service user and carer involvement at all levels
- Peer research tips
- Peer support tips
- Where to find more tools

Tools for service user involvement at all levels

Monitoring and evaluation tool: Birthday Card Tracking	
Good for: following up service users and carers after they have exited the service	
Time: mainly on preparation, see below	**Size of group:** any number
Preparation: Administrative time compiling dates and sending cards; worker time to meet people who respond	**Materials:** cards and postage; incentive to reply (e.g. voucher)

The Challenge – funder wants to know long term results

A local drug and alcohol agency had positive contact with clients, often seeing them over a long period. However, when they progressed in their recovery journey it was generally other agencies that had the pleasure of seeing the final outcome of the significant groundwork the local agency had done. Staff in this local agency had limited feedback about their clients' progress in the long term. Some funders were also becoming more interested in the long term outcomes of the agency's work but the agency had little to show them.

The solution – using relationships positively

The staff realised they had key-worked clients and built an intimate relationship with them. They also knew their dates of birth. Putting both facts together, they devised a positive way of keeping in touch with clients who had moved on. They decided to send a birthday card in the first year after a client had left the service.

There were a number of risks:

- breaching the client's privacy – any who had opted out of receiving postal information on registration were excluded;
- the client may have moved on to a new location – a risk but not one worth abandoning the idea for;
- being ignored – they decided to incentivise getting back in touch by offering a 'birthday gift' for people who came in to collect it. This was a choice of vouchers.

It was decided the approach would be affordable because the alternative to this idea would be commissioning additional evaluation, which even for a small scale piece of work would be more expensive than if 50 service users came in over one year to claim their birthday gift.

A named member of staff was the contact for the ex-service user, and time was allocated for her to spend an hour catching up with the client, hearing their news, and recording their progress.

The outcomes

33% response rate over two years – increasing as word got around and people started to expect a card

(this rate is quite high compared to survey methods); high quality evidence on client's long term outcomes; some ex-clients returned as volunteers.

Method:

- Ensure all clients are asked to opt in or out of receiving information at home.
- Remind clients on exit that you want to keep in touch and to let you know of any change of address.
- Insert birth dates into a central administration calendar when clients are registered, and make sure your filing system allows for easy retrieval of the address when a birthday pops up. Then send the cards.
- Develop a set of structured questions to guide the interviewer. If something like a recovery capital assessment has been done during service engagement, this could be repeated to assess distance travelled.
- Allocate time to reviewing records of the interviews periodically to draw out themes and collate measures of progress.

Tips: local companies may sponsor the cards/vouchers.

Monitoring and evaluation tool: Outcomes Stars

Good for: Enabling service users and carers to self-assess progress towards their goals; providing evidence of distance travelled towards achieving personal outcomes over time

Time: depends on individual, easily integrated into case work	**Size of group:** 1:1 or circle of care (individual and their supporters/carers)
Preparation: align the outcomes star with your person centred planning process; training for staff	**Materials:** Stars can be used as electronic tools but can easily be used on paper

The challenge: a contracted organisation needs to provide 'distance travelled'

A care provider which specialised in providing support to tenants with mental health and substance use problems realised that clients made small (but important) gains over quite a long period of time, often on intangible aspects of clients' confidence and motivation to self-manage. The service commissioner was making grumbling noises about 'dependency' and the care provider was seriously concerned that in spite of all their hard work and individual successes, overall their service may be rated poorly when their contract was due for renewal. The care provider needed key workers to provide stronger evidence of the progress their clients made, so that the 'client journey' was clear to all stakeholders.

The solution – a person centred planning and measurement tool

The care provider got hooked onto Outcomes Stars as a way of showing 'distance travelled' by clients. The 'drug and alcohol' star was downloaded from Triangle Consulting's website to trial it with a handful of clients. Key workers found it easy to discuss with clients where they were on each scale (the points of the star) using the descriptors provided.

- Clients liked the visual representation of their situation provided by the star. The descriptors created quality discussion with the clients, but also helped them identify progress – the descriptor of the next point along the scale allowed them to be clear about what they were working towards.
- Key workers felt the star tool added value to their interaction with clients, without overloading them with complex paperwork; this had been their main fear when the agency started asking for more evidence of progress. Their caseload left little scope for writing masses of notes and reflections on each client.

The pilot was positive and the care provider then invested in the training for the staff group in order to

use the licensed version of the stars. Six months down the line, the agency had data from two 'star assessments' with each of its clients done at three monthly intervals. This provided a wealth of data on 'soft outcomes' that had previously been invisible to commissioners but told an important story about client journeys.

Method: This agency used paper-based outcomes stars because key work took place on an outreach basis.

Download outcomes stars appropriate to the service areas, become familiar with the descriptors of each point on the scale.

Use positive questioning, challenging and collaboration to enable the service user to use the star to set their own goals and measure their own progress alongside the worker.

Ensure the frequency of using stars with clients is agreed – it may be a different frequency for individual clients but the service itself needs to plan to use the data provided by the stars at regular intervals.

Tips: The key feature of Outcomes Stars is the scale with defined measures. It is possible to adapt this concept to an in-house development of a client progress measurement tool. Other systems also use scaling, such as the Rickter Scale.

www.outcomesstar.org.uk   www.rickterscale.com

Monitoring and evaluation tool: Recovery Wheel

Good for: helping clients explore and set goals to strengthen aspects of their lives that will support recovery; providing evidence of a wide range of 'recovery gains' in addition to substance use.

Time: depends on individual, easily integrated into key work	**Size of group:** 1:1 or circle of care (individual and their supporters/carers)
Preparation: ensure understanding of recovery capital throughout the organisation	**Materials:** paper print outs of recovery wheel

The challenge – narrow concept of recovery hampered holistic measurement of progress

A community organisation provided support to people post-treatment, during the early stages of their recovery. During this period many of them experienced multiple transitions and were unprepared for the emotional and practical challenges that such a significant life change as abstinence would bring. Relapse was common; it seemed to be most common amongst people who lacked "life support resources" that some researchers have described as 'recovery capital' – recovery-supportive friends and family; stable housing and finances (e.g. benefits); opportunities for continued learning and growth; health and wellbeing supports; and hope for their own future.

The community organisation provided support through peers who were in recovery themselves. However, this support could be narrow and focused primarily on 'not picking up' rather than helping people prevent crisis by looking at building up their resilience.

The solution – a visual, holistic self-assessment tool

The community organisation developed a visual representation of recovery capital in a 'recovery wheel', which peers could use to help people consider all aspects of their lives which could help or hinder recovery.

- The wheel uses scales (0-10) to enable people to self-assess their strengths and resources and to identify which aspects of their life might need more work to build up.
- The Recovery Wheel helped peers to take a more holistic view of recovery – they already had intuitive knowledge that this was important, but as people in recovery their 'helping model' had been learned in treatment from therapists.
- The recovery wheel helped peers avoid trying to copy therapists and gave them something tangible to introduce to their helping relationship with peers.

Peers learned the skill of powerful questioning and listening, which shifted their helping from 'telling' to facilitating, strengthening the utility of the tool for the people learning to self-manage their recovery.

Method: The recovery wheel simply places the different aspects of recovery capital on a circle diagram with 'spokes' representing the scales from 0 to 10.

- The points are: hope and commitment | redefining myself | values and beliefs | taking personal responsibility | learning | supportive relationships | feeling empowered and contributing | hobbies and interests | recovery knowhow | security and home base.
- It is not important to provide fixed definitions of each aspect of recovery capital, as people's own priorities and meaning is what counts when deciding how they want to make progress.
- The person identifies where they feel on a scale of 10 = completely satisfied with this aspect of my life to 0 = couldn't be worse. The scales also help them to see whether there are associations between low-scoring aspects of their current reality; e.g. struggling to redefine myself in recovery is affecting how I engage in relationships.
- The wheel provides a snapshot of someone's thoughts and feelings that can be revisited over time to measure progress. This can be used in monitoring and evaluation to capture progress – this is how the person *feels* about their situation; it is highly subjective because it uses their own definitions of each point on the recovery wheel.

Tips: This tool can stand alone; in this organisation it is integrated into a peer recovery coaching programme.

Individual service user and carer involvement tool: Ask It Basket

Good for: an eye catching 'suggestions box'

Time: minimal, regularly check the box and allocate time to respond	**Size of group:** N/A
Preparation: create the box and feedback board, identify a 'champion' and ensure team time to discuss suggestions/comments.	**Materials:** The visibility and attractiveness of the box does make a big impact – changing its look regularly makes even more of an impact.

The challenge – making a standardised method suit the client group

A service had two main inlets to its clients: a shop-front by which people could seek information and initial help; and a waiting room where people receiving 1:1 services sat in the minutes before their appointment. The overall image the service portrayed was of being hip, in touch with people's lived experience and personal schema (clients did not relate to addiction per se), and user-friendly. The service did not want to come across as an institution, quasi-health clinic or bureaucracy. And yet, the service was attracted to one of the most simple, standard formats of service user involvement found in all those settings – the suggestions box:

- It is simple and cheap
- It easily demonstrates a willingness to listen to service users' ideas and feedback – there are many methods of this within the organisation but for casual or first time users, this simple, visual method established the culture easily
- It provides anonymity – other methods in the organisation relied on relationships between staff or volunteers and service users to enable honesty; this method just allows honesty without having to feel you can trust the worker/volunteer to hear it
- There is no real reason not to - however the staff and volunteers did expect a low level of use.

The solution – let methods suit the organisation's style

To address the potentially low level of use, the challenge became "how to make it more likely service users will use the suggestions box", not whether to have one at all.

Staff and volunteers developed the concept:

- The box became the 'Ask It Basket' rather than the suggestions box
- The box was backed by a "You said…… We did" board which gave service users feedback on what was suggested/commented in the box and how the organisation proposed to respond
- The box was colourful and eye-catching (it needed to be, the organisation has a lot on display to distract people).

A member of staff was designated to check the box weekly, and bring items to the team meeting for discussion where a response would be agreed and posted on the Feedback Board.

Method: Consider:

- Placement – must be both visible and discrete
- Resources – pens and paper have to be stocked next to the box

Tips: It would be easy to get hung up on "what if we can't respond" when inviting random suggestions from clients. However, most suggestions are reasonable and it is better to say "we got this suggestion but we can't respond because…." than never to invite suggestions at all.

Grassroots service user and carer involvement tool: Feedback Week	
Good for: focusing staff, service users and carers on hearing their views by designating a week of exercises and interactive displays for service user and carer involvement.	
Time: depends on range of activities - could be extensive or smaller scale	**Size of group:** from individual to group depending on activities
Preparation: as above	**Materials:** depends on activities chosen

The challenge: struggle to maintain focus on service user involvement in small organisation

A small organisation had a lot of part time staff in its team. It was difficult to co-ordinate the sharing of information between team members and difficult to download from staff the feedback they picked up from service users. The organisation had a strong community base and also really wanted to get the views of family members and other carers.

Solution: making information gathering easier by focusing efforts on a 'snapshot' week

The team agreed to co-ordinate a range of exercises in a themed week, to become an annual event, which would provide a snapshot of the service user experience. The exercises they came up with included:

- A 'census' – a profile of who used the service within the designated week, including calls, information pick-ups and scheduled appointments; this provided a 'week in the life of' story for the organisation.
- A reunion lunch – an open invitation to current and former service users and carers to come along to an informal lunch. At the lunch people were encouraged to tell their stories about their experience of the service using a digital audio recorder and ordinary pen and paper. All staff were on hand to meet and greet and take notes; this provided a wide range of personal stories of progress.
- A graffiti board in reception for the full week. Initially this didn't work well but when staffed used it for 'polls' or to pose a new question each day, there was more of a response, especially when receptionists specifically encouraged people to use it. This provided commentary on things such as waiting room development.
- Each worker with a scheduled 1:1 used a short questionnaire at the end of their session. This provided data on a reasonable sample of clients about their use of the service.
- Each worker running group sessions dedicated 20 minutes of the session to a discussion using the same open ended questions about people's experience of the service and suggestions for

development. This provided a range of stories and comments.

Method: A themed service user involvement week can be on a large or small scale, depending on capacity. Important things to bear in mind:

- If you gather a lot of data you have a lot of analysis to do, set aside time for it
- Ensure all service users attending the service that week consent to their views being used and can opt out easily
- Promote the event widely well in advance
- Prepare staff with briefings or training in research techniques – it's not rocket science but it helps of people understand the importance of open questioning and faithful recording of what people say.

Tips: Some students have to do a research exercise as part of their course (e.g. community education). With guidance and supervision students can provide valuable additional capacity.

Grassroots/wider horizons service user and carer involvement tool: Charettes

Good for: getting people together to create solutions to specific issues or problems; the process originated amongst designers but is widely used for community engagement	
Time: at least 3 hours but a good in-depth process could take a few days	**Size of group:** minimum 12 as the group is divided into sub-groups
Preparation: as above	**Materials:** depends on activities chosen

The challenge: how to involve service users and other stakeholders in a process where ideas and experience have equal space

A small organisation had a limited budget and wanted to self-facilitate a session to involve people in considering ways to help its service users access a wider range of community resources. The organisation's service users had negative experience as they felt stigmatised; however the organisation also knew that some organisations were willing to engage with substance users but didn't know how.

Solution: a structured forum for dialogue and designing new approaches

The organisation decided to hold a forum for service users and other services together, to see how positive links could be made that would benefit service users.

The held a four hour session with lunch, so that people could network informally during the session. They held lunch after the introductory session, so that it would work well to 'loosen people up' for the main discussion sessions.

The process:

- The facilitator used an ice-breaker to ensure everyone knew each other
- The facilitator 'set up' the problem by introducing a scenario – a service user, John, with a range of different unmet needs including housing support, welfare benefits advice, wellbeing, nutrition and social contact.
- The facilitator then put people in small groups, mixing workers and service users; each small group had one of the organisation's team members in it to facilitate and record discussion.
- The first discussion was about agreeing 'the box' – the limits in which the solutions would have to operate. An example included "no new money for services"; other ideas that came out of discussion were "within one bus ride"; "child-friendly"; "confidential" etc.
- The limits and boundaries for development that each group came up with were brought together on one large sheet of wallpaper as a visual reminder of 'the box' for the next session.
- The session then broke for lunch. During lunch all of the team worked pro-actively to introduce service users to workers and promote relationship-building.
- The second discussion reminded people of the scenario, and focused on generating ideas to fill

the box. This time each group was given a specific theme to explore: 'how John finds out about services'; 'how to make services accessible and welcoming to John'; 'how to meet John's needs' etc, covering all of the dimensions of linking John to services.

- Each group noted their discussion on the flip chart. The group lead had the task of ensuring the discussion focused on ideas and solutions. People tend to fall back on describing the problems in different ways – these are 'downloaded' onto separate paper so that people feel heard, but the focus is pulled back to solutions.
- At the end of an hour of discussion, each group summarises their discussion and ideas for the other groups. The facilitator then allows time for the other groups to comment on, and add to their discussion. This is time consuming but brings out richer ideas.
- The facilitator finalises the process by drawing out links and themes between each of the sub group's ideas.
- The facilitator then invited people to opt into a small working group to take forward the ideas. This working group met three times; first to finalise the report and share it with all the participants and other services in the community, then to work directly on making some of the ideas happen, such as a local directory of information.

Method: More on Charettes:

http://hanksconsulting.com/Charrette.html

http://www.wbdg.org/resources/charrettes.php

Tips: Make sure all sub group leaders have good briefing on facilitation techniques that allow people to share their views, manage dominant group members and draw out quieter members.

Grassroots/wider horizons service user and carer involvement tool: Dotmocracy

Good for: managing group discussions in groups where members have tendencies to meander, argue, go off at tangents, subvert, dominate or sabotage.

Time: the process works within your normal meeting process – it can actually make things quicker	**Size of group:** N/A
Preparation: None	**Materials:** Flip charts and pens or stickers

The challenge: how to manage group meetings with unruly groups

A community-led organisation worked with a large group of service users who met regularly to try to develop and implement their community action project. Many meetings ended in frustration – some people left because they got so fed up of circular discussions and people losing the focus of discussion. People were in different stages of recovery: some were having emotional ups and downs, some had very poor concentration and memory, some were domineering and some were very timid.

The group found traditional approaches to running meetings were not working. Instead of tasking someone to try to chair such a difficult group, they decided to change how discussions were managed.

Solution: democracy not consensus

The group realised that because of people's quirks and characteristics, reaching a consensus on every issue might rarely happen and frustration would escalate. They agreed that people would accept a majority decision if it was clear how the decision had been arrived at. They started to use dotmocracy.

- Everyone's ideas and views could be clearly seen on the wall – everyone knew their own view had had a fair chance
- Every individual had an equal share of votes, no matter whether they were loud or quiet
- The straightforward process of listing ideas/suggestions and voting cut the length of discussion by half, because there was less competing and circular debate

- People with poor memories and concentration could follow the process much more easily
- Decisions were made, and a sense of achievement grew.

Method: Dotmocracy is a four stage process:
- Agree the ball park of the decision required, often this is a statement starting with "how to…." E.g. "how to spend the training grant from Volunteer Development Scotland"
- Put this at the head of a flip chart, and list underneath it every idea or suggestion that anyone makes. The golden rule here is that no-one is allowed to question or comment on others' ideas, they all go on the flipchart without censorship.
- When everyone has exhausted their supply of ideas, people are allowed to ask clarification questions to check they understand the ideas and suggestions. Again, no backchat is allowed.
- People then have three votes each. They are allowed to vote tactically: all three votes on one idea or spread them over three ideas in any configuration they wish. They can vote for their own idea too. People physically place a sticker or a marker-pen dot next to the ideas on the flip chart. Once everyone has voted, the dots are counted up and the option with the most votes is accepted as the majority winner. The golden rule of this stage is acceptance – no re-hash of ideas or challenging the decision.

Tips: Do your maths – in this organisation there was only one occasion of vote-rigging where someone used four dots instead of three; but it happened to be on a close-run decision and when someone realised there was one more dot placed than there should have been, uproar ensued. But that was just one occasion out of many times it was successfully used!

Grassroots/wider horizons service user and carer involvement tool: Conversation Cafe

Good for: introducing new concepts or gathering experience from a wide range of people in one event

Time: a conversation café takes at least a few hours to execute.	**Size of group:** can be used with large groups
Preparation: significant preparation in terms of getting people along	**Materials:** Flip charts and pens,

The challenge: how to encourage different groups to share their experience on a topic
A local service wanted to get both service users and carers to share their views on support for families. The service knew it would be an emotional issue, and yet they felt there could be a lot of shared learning by holding a session together rather than separating people into groups.

Solution: conversation cafe

The service chose to hold a session which would be both loose and informal, whilst providing a safe structure for people. They chose a conversation café model.
- The café was set up with three individual tables seating four people, for a group of twelve.
- Team members were allocated to each table to take notes on discussion and facilitate to keep things on track.
- The overall theme was 'family support' but the team chose three different stimulus: one photo of a granny with children; one photo of an older couple with an adult service user; one photo of a woman and children with a man disengaged in the background.
- Service users and carers were invited from a range of services in the area, not just the local service itself, so that there would be a mix of perspectives.

Method: Conversation cafes roughly follow this process (it can be more casual if preferred):
- Agree a topic as the initial stimulus
- Find a "talking object" – this can add stimulus, such as a photograph related to the topic. The purpose of the talking object is also to encourage people to take turns and to listen to the

speaker holding the object.

- Round 1: Pass around the talking object; each person speaks briefly to the topic, no feedback or response, just listening.
- Round 2: Again with talking object, each person deepens their own comments or speaks to what has meaning now they have heard others.
- Dialogue: Open conversation, now people have warmed up. Use the talking object if there is domination, contention, or lack of focus.
- Final Round: With the talking object, each person says briefly what was meaningful to them

Tips: There are different ways of recording the dialogue. Giving each small group a scribe is a minimum; some groups also use paper table cloths on which people can write their own comments during discussion.

Wider horizons service user and carer involvement tool: reporting template

Good for: establishing an expectation that service user and carer involvement is integral to decision making

The challenge: how to make service user and carer involvement an established consideration in high level decision making

A partnership of senior decision makers from different sectors wanted to ensure that service users and carers' views were considered whenever this was appropriate. The partnership did not feel that having one or two service users present at meetings gave sufficient depth to feedback on partnership decisions.

Solution: reporting template

The partnership introduced a template to be included in all reports to the partnership. This required officials to justify not seeking service user and carer views; and to describe how service users and carers had been involved if they had been consulted.

It was recognised that not every report would warrant scrutiny by service users and carers so the partnership agreed some key areas where it felt service user and carer involvement should be expected:

- Plans to change or develop service provision in any way
- Reports on new policies which may impact on services or service users
- Reports on progress in implementing plans; reviews; annual reports
- New strategies or action plans

Each partner agreed that when supplying a report to the Partnership, compliance with this approach would be expected.

Method: this template was used as a section of relevant reports:

Service user and carer perspective

What	*This section briefly outlines what was done to seek service user and carer views*
	e.g. consultation meeting with Service User Group of x organisation
	e.g. open consultation event for service users from all services
Who	*This section describes the specifics of who was involved, to ensure people with relevant experience were involved*
	e.g. 5 men and 3 women ages 23-49 years with a history of using 9 different services in the last five years
	e.g. 3 men and 1 woman who self-identify as problem alcohol users; two women who self-identify as carers of problem alcohol users

How	*This section briefly describes the method used to gain their views* e.g. open dialogue on report content e.g. structured interviews on key topics in the report
Outcome	*This section describes the feedback that service users and carers gave* e.g. - Agreement to sections 1, 5, 6. Feedback was positive and section 1 particularly welcomed. - Mixed response to section 2. Men felt the proposed service was good but women commented that it may not be safe for women. - All consulted felt sections 3 and 4 were challenging; however there were no alternative solutions proposed.

Tips: Initially people were concerned about potential abuse of the reporting by officials, so completed reports being sent to the partnership by partners were also sent to the service users and carers whose views had been sought.

Note that service user and carer *endorsement* was not necessary for the Partnership to make a decision; however seeking views helped partners consider a wider perspective.

There was also concern about the time it would take officials to seek views on each report, but over time, this was assessed:

- The Partnership only met four times a year
- Each partner on average only contributed a report once every five meetings; the additional burden for them was not so great and eased once people stopped imagining they had to do a major survey each time they wanted to complete a report
- Those who had a disproportionate number of reports were working on issues where everyone felt service user and carer involvement was a high priority so additional resources were allocated to gather views on these issues
- Collaboration between high level decision makers and service providers/ practitioners increased, as this was needed to get service users and carers to share their views. This collaboration increased positive dialogue and was in itself a positive outcome.

Peer Research

Not all issues for research are generated by service users and carers themselves. Often, it is workers who identify that a particular issue is problematic and needs to be addressed. However, service users' and carers' own feelings and understanding of the issue may be crucial to finding a solution, so it is important to consider why and how service users and carers will want to be involved in research.

Many service users and carers welcome the opportunity to work in partnership with professionals as peer researchers.

Practical considerations before embarking on a peer research project

Is the project suitable for peer research?

Becoming a researcher will not suit all service users and carers. Although researchers can be involved at different levels from design through to analysis, it can be a significant commitment and studies heavily reliant on service users or carers may run into difficulty if

the scale is too large or aspects of it turn out to be too complex. Training for peer researchers involved at any level is essential unless they have previous experience. The higher the scale and complexity, the higher the requirement for close project management.

Accessing service user and carer 'subjects' in other services

Organisations often have to work hard to get service users and carers interested in participating, to get them along to group or individual sessions, and to support their involvement before and afterwards. Their time should therefore be respected. The face-to-face workers should be properly informed themselves in order to inform the service users and carers, and their views on the `workability' of your plans with their clients accepted. After all, it is the workers' credibility that may be damaged if they encourage service users and carers to participate in something that they then feel is not worthwhile.

Check organisations' ethics, guidelines and protocols

Some organisations may have specific procedures in order to approve proposed research on their staff, service users or carers. These are designed to protect people from bad practice but processes can be time consuming and plans should account for this, or peer researchers may feel thwarted.

Ownership of findings

Even if peer researchers are not directly involved in analysis of findings (which can be technical if it involves statistics or an intensive piece of work if it is qualitative analysis), the outcomes of the research should be shared with them and their views on the conclusions of research considered collaboratively. This can be challenging when a wide range of stakeholders are involved.

Peer researcher involvement should be acknowledged.

Feeding back to participants and organisations

Some organisations will want to collaborate with research because they have ideas about how they may be able to use the findings within their own organisations. Provide progress reports, feedback to participants, staff or management boards etc, and give organisations user friendly feedback to pass on to service users and carers.

Ensure shared understanding with peer researchers

The aims of the research and the approach should be clear to everyone, especially as peer researchers will be in the 'front line' of the research. There should be clarity about who will be doing what, when and why. Keep everyone up to date with the progress of the work, and what directions it is taking at different times.

Training peer researchers

Foundation training topics:
- Consent by subjects to be involved

- Confidentiality and data protection / keeping information safe in transit
- Avoiding exploiting subjects' views and experiences
- Protecting subjects
- Keeping researchers safe
- Active listening skills
- Faithful research: not leading or imposing own views.

Survey/Interview skills training:
- Note taking
- Good endings to a 1:1.

Focus group skills training
- Group work techniques
- Note taking
- Good endings to a focus group.

Different levels of peer research

Snap Shot

A one-off activity such as an event, focus group or workshop can help involve service users and carers in an in-depth discussion about a particular issue which will provide a snap-shot of their views and experiences. The picture will be limited to the experiences of those particular participants at that point in time (many factors may affect their views on the occasion you are working with them). In a one-off exercise it would not be possible to suggest that their views or experiences are typical of any other group or situation.

Snap shot exercises can be useful to inform future planning or practice, or perhaps to resolve with service users and carers a problem within their group or a specific aspect of provision for them.

Peer researchers can play the role of:

- Discussion facilitators
- 'Animateurs' by sharing an experience or story to stimulate discussion
- Recorders, writing down what people say.

Exploring

A series of sessions which is structured and progressive, may involve a range of activities over a short period of time. Each activity may be designed to explore issues raised by the last in more depth. This approach may also be small scale and focused on a specific and quite well defined issue, and efforts may be made to involve a cross-section of service users and carers or to compare findings with the results of other pieces of work.

This exploring approach may help organisations to scope the scale of a problem or help define issues more clearly in order to inform a response. The findings are worth disseminating with other workers to inform their thinking, and it is likely that studies like this will highlight areas for more in-depth investigation.

Peer researchers can play the role of:

- Partners in development of the approach

- Discussion facilitators

- Commentators, providing analysis and choosing priorities for the next stage of exploration

- Recorders, writing down what people say.

Investigating

A planned investigation which takes place over a period of time would become a more systematic approach to action research. It may take place on a small or large scale, but issues of sampling who/what kind of service user or carer is involved), and of using a range of methods to tease out issues, would be important.

Work at this level can generate findings which are sound, and which could inform policies and provision affecting service users and carers. When several similar investigations generate common findings, it could be suggested these are reliable indications that policies or practice on a wide scale could be changed for the better, based on this evidence.

Peer researchers can play the role of:

- Partners in development of the approach
- Survey conductors or focus group facilitators
- Data input / recorders
- Commentators, providing analysis.

Research methods

Regardless of the approach to research, there are some fundamentals:

- Capture basic data on participants
  - Who took part (age, gender, location or other identifying characteristics)
  - How they took part (e.g. survey, focus group)
- Start the process by thinking of the purpose and who the audience is
- Keep it simple – for every data gathering exercises, hours of sorting the data follow.

1:1 Interview

Can use more or less structured formats:

- highly structured - involving answering specific questions, and sticking to a pre-defined agenda

- semi-structured - attempting to balance the demands of covering certain subjects within a specific time frame, and allowing the participant to develop the discussion, and depart from the agenda to explore issues.

The purpose of a one-to-one interview is to explore issues in some depth. Interviewing can take a while. People may disclose more personal information and peer researchers need to be trained to manage this process so that people do not use it as a counselling session.

Interviews can use:

- Questions (open/closed)
- Stories or pictures to prompt views
- Scenarios to prompt ideas.

Focus group

Can involve small or large groups, usually constructed from a sample of the people whose views or experiences are of interest. Because people may not know each other, the process of a focus group can be challenging to manage, starting with breaking the ice and progressing gradually to more in depth discussion.

Focus groups can use:

- Open questions as discussion prompts
- Stories, pictures or scenarios
- Exercises or games.

Analysis

The process of sorting out, collating and analysing data can be laborious.

- Counting methods are best done using an excel spreadsheet which needs to be carefully structured to allow for data to be explored using different variables (e.g. did young men have different experiences than young women?) or compared (e.g. what was the difference between people in Craigmillar and Gorgie).
- Qualitative methods involve reviewing material (notes, flip charts, DVDs, sound recording etc) and identifying themes, or codifying data. This is less technical but it is time consuming (it can take many more hours to analyse a sound recording than the interview or group itself took). Analysts need to be cautious to avoid being selective or only codifying what they agree with.

Peer support

The ideas here are transferable to any form of peer involvement: peer support, peer mentoring and peer education. We will use the generic term peer support in this section. We have deliberately kept the tools in outline form rather than presenting off-the shelf examples, because it is essential that local circumstances and the view of service users and carers shape the actual tools in your setting.

Volunteering policy

Example 1 – standard volunteering policy in an organisation context

Context

- the vision statement of the organisation
- volunteering ethos

About volunteering in the organisation

- definition of volunteer
- why we need volunteers
- the range of roles open to volunteers
- where volunteering 'fits' with paid staff team
- diagram of organisational structure

Expectations

- what the organisation expects of volunteers
  - timekeeping , scheduling, notice of leave etc
  - compliance with policies
- what volunteers can expect from the organisation
  - references (after what period)
  - development and progression
  - review of contribution and opportunities to express views

Recruitment and Training

- who can volunteer
  - should include statement on stage in recovery journey
  - could include a checklist of skills/qualities required
- any minimum training required before volunteering can begin
- further training opportunities, mandatory or optional
- how applications are made
- how interviews are conducted
- police checks
  - how long these take
  - what kinds of criminal record make someone unsuitable (this is important as many potential volunteers have a criminal record for crimes which do not necessarily discount them from support roles)
- how recruitment decisions are made

Induction and training

- what happens in the first week/month
- probationary period – how this is assessed
- who will support and monitor the volunteer

Volunteering

- expenses
- supervision and support
- accountability

Conduct

- code of ethics (including confidentiality, data protection)
- boundaries
- relationships
    - staff/volunteer
    - volunteer/client
- what happens if code of conduct is breached

Example 2 – volunteering in recovery community-led context

- What the project is

- Why we involve volunteers

- Who can volunteer (this specifically provides a definition of recovery and stage of recovery journey expected before volunteering can be considered)

- Who volunteers may work with (this asks prospective volunteers to consider if they can work with people at different stages of recovery or active substance use)

- Our core values- what you can expect from us and what we expect from you

- Volunteering opportunities within the project

- Volunteers moving on

- How we respond to relapse (this includes support to the individual and expectations regarded absence from, and return to volunteering)

- Volunteer expenses

- Volunteers and paid work opportunities within the project (this refers to occasional opportunities for sessional work, and how progression from volunteering to paid roles is managed, so that expectations are clear that volunteering does not automatically pave the way to paid work)

- Insurance

- Health and safety (includes advice on disclosing health issues such as blood borne viruses, prescribed medication and other treatments so that the correct support can be in place)

- Volunteer complaints procedure and how we handle complaints about volunteers (this includes information on code of conduct and what will happen if there is gossip or other behaviour that threatens the reputation of the project)

- PVG checks (encourages prospective volunteers to discuss their criminal history and be open minded about the checks)

This information is also accompanied by a Policy Handbook which describes:

- Confidentiality and data protection

- Equality and inclusion

- Working with the media

- Lending/borrowing equipment to volunteers/community members

Role definition

Role definition is a tricky area for both staff and peer supporters to decide where responsibilities begin and end. It is not always easy for peer supporters to get their heads around the limits of their role, or to self-assess their experience and expertise until they learn from hard experience – which can be hard on both the peer supporter and the person they are supporting.

This training tool helps staff and peer supporters think through their respective roles.

<div style="border:1px solid #999; padding:1em;">

Grey Matters

The organisation decides a range of client-facing support tasks which peer supporters may engage with but which professional support is also likely. Each of these is presented as a spectrum with extreme examples at each end.

Example: the client wants to discuss reducing a methadone prescription

The client wants to know if reduction is possible		Changing the prescription

Staff and volunteers create a range of client scenarios in between the two extremes and place them on the spectrum.

Each individual in the group is then asked to draw a line on the spectrum where volunteer responsibility definitely ends and staff responsibility definitely takes over. This can be done over a coffee break so that people are not watching individuals place their mark.

It might look like this:

</div>
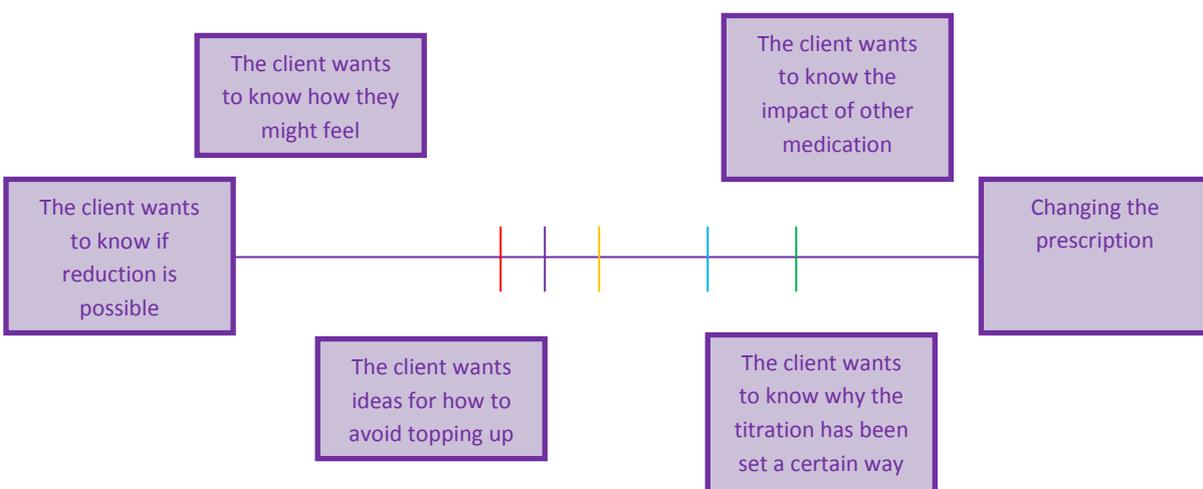
The different markers on the spectrum are then discussed, with different views surfaced about the skills, experience and accountability issues of each scenario. It's important that the facilitator ensures that peer supporters are enabled to express their views without being over-run by professional territorialism – the purpose of this stage is *learning*, not creating a hard and fast rule.

There is then an opportunity for participants to move their marker following the discussion, before proceeding.

The facilitator then circles the point on the spectrum where the markers are placed. This is the "grey area".
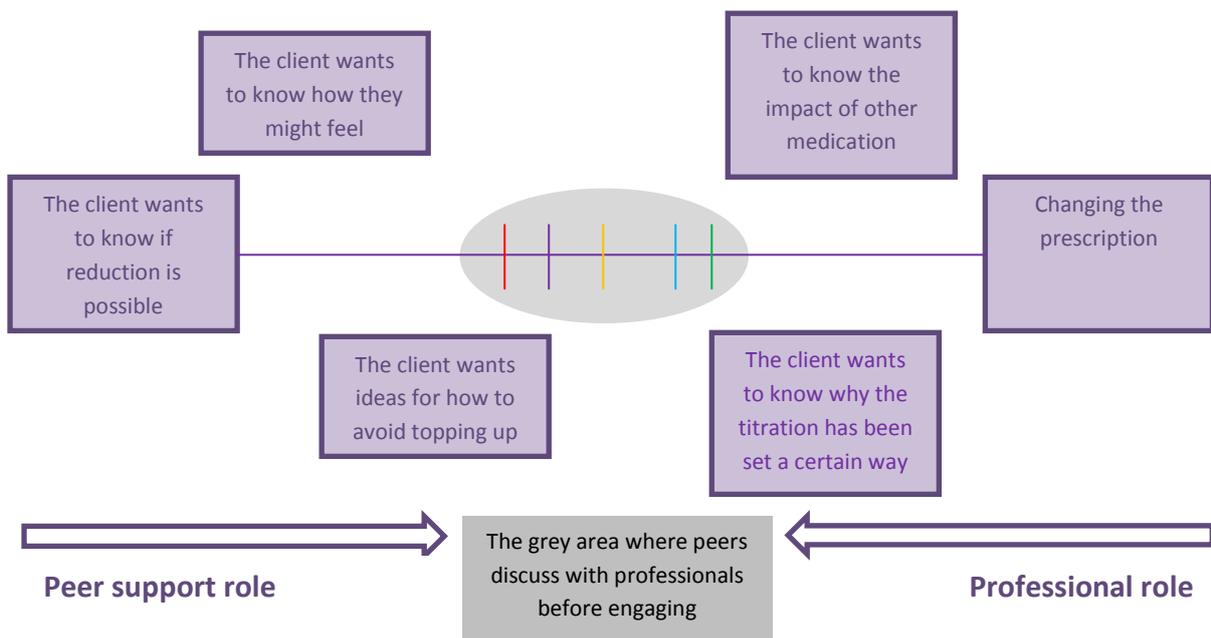
Being conscious of grey areas encourages peers to be more aware of boundaries and limits on their role and experience.

Recruitment

Recruitment processes help ensure that people who are not yet suited for peer support are re-routed to other opportunities. This is important for the peer supporter and the person they are supporting: both are kept safe and there is a higher chance the experience is positive. Recruitment options include:

- Running an open training course and making peer support roles available to graduates – with this method it is essential that there are clear criteria for achieving graduation; but it allows people's qualities to be assessed in less stressful circumstances than an interview.
- Running an application process followed by an interview; the process could be preceded by information sessions for interested candidates.

Sample job description

Peer mentor in <organisation>

Who

- People in recovery
- People who are stable, have a solid foundation for their recovery
- People who aware of themselves and aware of their impact on others
- People who have already done other volunteer roles in <organisation>
- People who have undertaken a PVG check

How to get involved

- Attend a peer mentoring information session
- Be nominated by two others in recovery who are participants/volunteers in <organisation> who can describe how you meet the criteria above
- Attend peer mentor training

Tasks

- Commit to two sessions per week (3 hours each), be on time and reliable
- Guide participants who are new to <organisation> on how to get the most out of their time with us
- Help participants develop personal goals for their involvement with <organisation>
- Provide support, encouragement and feedback to help participants progress
- Give information and share experience useful to participants
- Hold participants to account in their personal goals
- Monitor participants' progress and help them move on to new opportunities
- Attend training and meet your supervisor regularly

Opportunities/training

- Regular training sessions on mentoring, leadership and relevant issues
- Peer support from other peer mentors to further develop the mentoring programme, with supervision from a Volunteering Development Worker
- Visits to other organisations to share experience and learn from them

What you can get out of it

- Personal development plan, feedback and support from peers
- Personal feeling of reward from helping others
- Experience of supporting individuals on a 1:1/small group basis
- Regular review of strengths, skills, and training log which can form the basis of references for employment or education
- Transferable skills for future employment / education

Peer Mentors will work to guidelines and policies for their role

Sample application form

<table>
<tr><td colspan="2" align="center">**Application to become a peer mentor in <organisation>**</td></tr>
<tr><td>**Your name**</td><td></td></tr>
<tr><td>**Your address and Contact number**</td><td></td></tr>
<tr><td>**Are you willing to undertake a criminal record check?**</td><td>**Yes ☐ No ☐**</td></tr>
<tr><td colspan="2">**Please tell us a little bit about yourself, by writing <u>3 points</u> that describe you in relation to each of the issues we have identified**</td></tr>
<tr><td>**Your recovery experience**</td><td>1.
2.
3.</td></tr>
<tr><td>**Things in your life which support your recovery**</td><td>1.
2.
3.</td></tr>
<tr><td>**Strengths and qualities that people look up to**</td><td>1.
2.
3.</td></tr>
<tr><td>**Things about you that help you to help others**</td><td>1.
2.
3.</td></tr>
<tr><td colspan="2">**Tell us about any other volunteer roles or previous work roles**</td></tr>
<tr><td colspan="2"></td></tr>
<tr><td colspan="2">**Give us the name of two people from <organisation> who have agreed to nominate you for this role and can tell us about your qualities**</td></tr>
<tr><td></td><td></td></tr>
</table>

Tell us about any training you have attended that would help you with this role

Tell us what days you would be available to provide peer mentoring in <organisation> if you are selected by ticking the sessions you can work ✓ and putting a cross where you are not available X.

	Monday	Tuesday	Wednesday	Thursday	Friday
Morning					
Afternoon					

We will contact you within one week of receiving this application to talk to you about next steps. We always interview people before they can become peer mentors. The interview will take place with <name of worker> and a peer mentor who has experience of the role.

At this interview we will get to know you and your suitability to become a peer mentor. We will also ask you about your health and any issues which might affect your involvement as a peer mentor (an example could be something like dyslexia which might mean you need more time to read information). This is so that we can support you properly in your role. If you want to tell us about any issues in advance, please use the space below.

Where to find more tools

- **You can find more tools at:**

  www.participationworks.org.uk (aimed at children and young people's participation)

  www.involve.org.uk

  http://www.scottishhealthcouncil.org/patient__public_participation/participation_toolkit/the_participation_toolkit.aspx

  www.peopleandparticipation.net

- **Sources of support for graphic facilitation / recording of workshops or participation events**

  http://envision-uk.org/index.htm

  http://albitaylor.com/

http://www.edg-sco.org/graphicrecording.htm (and consultancy to develop person-centred planning using visual approaches)

- **Sources of support for interactive media work**

  http://mediaeducation.co.uk/

- **Tools for online surveys**

  www.surveymonkey.com (free up to 10 questions and 100 responses) American, subscription in dollars if paying

  http://freeonlinesurveys.com/ (free up to 20 questions and 50 responses)

- **Tools for group text messaging / text polls**

  www.skype.com (pay per text, receive texts back to nominated mobile number)

  http://www.smspoll.net (free packages quite limited, but cheap options available)

  http://www.polleverywhere.com (free packages quite limited, but cheap options available) American payment in dollars if paying, minimum one month subscription even if one-off poll

9 Local findings and what the literature says

What we set out to do

The Lothian Alcohol and Drug Partnerships commissioned this report to provide recommendations for commissioners (and other service planners), service providers and other stakeholders on involving service users, their carers and family members in the development and design of services and strategies. The work conducted to arrive at these recommendations should include:

- Consultation with a representative sample of all stakeholders on the development of an ADP Service User Involvement Framework.
- Assessment of effective practice in engaging with service users.
- An overview of the different needs of the diverse population of service users, and comment on innovative approaches to reach people.
- Gathering of data on current service user involvement across the Lothians, with suggestions on further data collection over time.
- Involvement of service users, practitioners, managers, planners and commissioners in the study.
- An overall contribution to increasing the number of people achieving sustained recovery from substance use.

Who shared their views

Service users and carers survey by interview

Sample	East Lothian	West Lothian	Midlothian	City of Edinburgh	Total
1. Young people: girls and boys (interviewed in pairs)	1			2	3
2. Drug service users: men, women, parents	4	1	1	9	15
3. Alcohol service users: men, women, parents	2	2	1	10	15
4. Families and carers	4	4		4	12
5. People in recovery not engaged with services (e.g. using mutual aid only)		2		1	3
6. Ethnic minorities					0
7. People with co-existing substance/mental health	1	1		3	5
8. Unclassified					18
Total	12	10	2	29	**71**

Service managers online survey

Location of main office		
ADP Area	**%**	**No.**
East Lothian	16.7%	4
West Lothian	20.8%	5
City of Edinburgh	54.2%	13
Midlothian	16.7%	4
Other	8.35%	2
Geographic scope of service		
Area Covered	**%**	**No.**
City and Lothians-wide	34.6%	9
Local Neighbourhood	11.5%	3
Neighbourhood Planning Area	0.0%	0
Local Authority Area	50.0%	13
Community Health Partnership Area	7.7%	2
Other	7.7%	2
Sector		
Organisation	**%**	**No.**
NHS	12.5%	3
Local Authority	16.7%	4
Partnership (NHS, Local Authority, Voluntary Sector)	16.7%	4
Local Voluntary Sector	54.2%	13
Local Unit of National Voluntary Sector	0.0%	0
Recovery Community	0.0%	0
Other	12.50%	3
Focus		
	%	**No.**
Alcohol	91.3%	21
Drugs	87.0%	20
Blood Borne Viruses	17.4%	4
Tobacco	8.7%	2
Caring / Parenting	8.7%	2
Other	35%	8

Attendance at consultation meetings and individual interviews

Focus groups		
Groups and Consultations	**Area Covered**	**Number of participants**
SUC Focus Group	City of Edinburgh	7 SUCs / 3 Peer Researchers / 2 Professionals
SUC Focus Group	West Lothian	2 SUCs / 1 Professional
SUC Focus Group	East Lothian	4 SUCs / 2 Peer Researchers
SUC Focus Group	Midlothian	0 SUCs / 2 Peer Researchers / 1 Professional
SUC Consultation	4 ADPs	3 SUCs / 2 Peer Researchers
Peer Researcher Consultation	Services Across 4 ADPs	7 Peer Researchers
3RT	City of Edinburgh	3 SUCs
SMART Recovery Group	West Lothian	4 SUCs
SMART Recovery Group	Midlothian	7 SUCS / 1 Professional
Total		**51**

Professional Participation			
Meetings and Consultations	**Position**	**Area Covered**	**Number of participants**
MELDAP Consulation	Managers	East and Midlothian	6 Managers
WLTADP Meeting	Commissioning Members	West Lothian	3 Members
Professionals Consultation	Managers and Staff	4 ADPs	8 Professionals
NHS 1:1	SUC Lead	Lothians	1 Professional
Crew Meeting	Senior Managers	4 ADPs	3 Senior Managers
NHS SMD Quality Assurance 1:1	Manager	Lothians	1 Manager
NHS 1:1	SMD SUCI Strategy Lead	Lothians	1 Manager
4 ADP Commissioning Group	Members	4 ADPs	4 Members
Total			**27**

Who helped to gather views

Peer researchers in recovery were recruited to conduct individual interviews and assist with focus groups involving service users and carers:

John Clusker | Bruce Budge | Colin Wallace | Paula Duffy | Phil Rainford | Yanni Yannoulis | Kane Duffy | Davy Tomlins | Kevin Gibb | Karen Maclean

The evidence from local findings and the literature we reviewed.

This evidence is organised in the same sections as this report.

	What our local findings tell us – *an overview*

Services across the Lothians which actively seek the views of service users and carers, use a range of methods at local level.

Individual level

76% seek views from individuals

40% have suggestions boxes

60% use individual plans to identify needs and wants

64% use exit interviews

28% involve individuals as 'key informants' or champions

Grassroots level

72% seek views using groups or forums

36% use events to get people together

44% seek views through peer to peer initiatives or volunteers

	What researchers and organisations with practical experience tell us about service user involvement *drivers and challenges*

Service User Involvement in the field of drugs and alcohol follows many years of work in the wider health sector, mental health and social care on involving people with lived experience in design, development, delivery and decision making relating to their services.

Across all these sectors there are some common principles, which are more or less summed up in the National Standards for Community Engagement:

Involvement should include everyone with a relevant interest

Support is needed for effective engagement

Planning is required to consider how best to involve people within the time and resources available

Methods used for involvement need to be fit for purpose

Working together, between planners, services and service users, needs some clear rules and procedures

Information will be shared with people involved, to reduce power inequalities. See in further reading:

National Standards for Community Engagement

	What our local findings tell us

96% of the services responding to our survey actively seek service users' views; however 65% of the services don't seek the view of people in their target group who do *not* currently use their services.

Only 25% of services felt they had enough capacity to develop service user involvement further, and 56% felt that they could only allocate more time to service user involvement at a stretch.

81% of services did not have plans, strategies or policies for service user involvement.

	What researchers and organisations with practical experience tell us about the *outcomes* of service user and carer involvement

Although outcomes depend on the setting and the people involved, most studies and evaluations point to positive outcomes from service user and carer involvement for: the individual service user and carer; the staff involved; the organisations and the planners and commissioners. Some outcomes are about greater credibility and authenticity of information, strategies and policies; some outcomes are directly related to greater wellbeing.

See in further reading:

A review of the literature on peer support in mental health services

Nothing About Us Without Us

Building Global Citizenship through Network Leadership

	What service users and carers told us

Service users have experienced both good and bad outcomes from service user involvement. The ingredient that turns the experience from a bad to a good outcome is usually being listened to and taken seriously.

> *'If having spilt your heart out on tape and then nothing is done/ or no feedback given this can be very negative for the individual and you could loss their support.'*

> *'Great way for others to learn from others experiences being positive or negative.'*

> *'It is good for folks' confidence.'*

> *'Makes you feel involved.'*

	What researchers and organisations with practical experience tell us about *individual* service user and carer involvement

Willingness on behalf of staff and service users to communicate and negotiate with each other appears to be the cornerstone of effective user involvement. User involvement can contribute to clients feeling satisfied with treatment. This, in turn, can lead to them staying engaged with services for longer and potentially having better treatment outcomes. (Drug User Involvement in Treatment Decisions)

Offering a variety of activities and ways to get involved, such as helping others, learning, or socialising, helps more service users and carers to get involved (IRISS)

See in further reading:

Effectively engaging and involving seldom heard groups

Drug User Involvement in Treatment Decisions

Engaging with Involuntary Service Users in Social Work Good Practice Guide

	What our findings tell us

86% of service users and carers in our survey had been asked for their views on the service they received. 74% had been asked what the service could do better.

50% had been asked what their friends and family need, and only 42% had been asked for their views on what others affected by substance abuse need.

We have provided the most popular responses – where the most popular response is positive this is in green, where the most popular response is negative this is in red. We have

summarised the themes from why people said these methods were good or bad:

Suggestions boxes
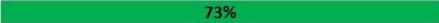
- Good   73%
- Easy   71%
- Respond   56%
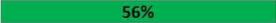
For: anonymous

Against: nothing will happen/ won't be seen

Face to Face Interviews (worker)
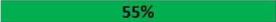
- Good   63%
- Easy   55%
- Respond   68%

For: 1:1 personal connection

Against: suspicion and lack of trust

Postal Surveys

- Good   44%
- Difficult   38%
- Respond   44%

For: anonymous

Against: users would ignore it

Online surveys

- Good   37%
- Easy   47%
- Respond   54%

For: easy if you have access to a PC

Against: inaccessibility of PC and lack of IT skills

Videobox

- Bad — 36%
- Difficult — 39%
- Ignore — 46%

For: freedom to express yourself in own words
Against: lack of confidence and lack of anonymity

Facebook

- Bad — 43%
- Easy — 52%
- Ignore — 45%

For: open, easy, 'everybody uses it'
Against: no anonymity, open to abuse

Mobile phones

- Good — 41%
- Easy — 59%
- Respond — 49%

For: easy, accessible, immediate
Against: cost / need credit?

What service users and carers told us

On suggestions boxes:

'Whether they get taken seriously! As a service user I have experienced suggestion boxes before in different establishments and maybe it sounds good to the benefactors, that they take on board service users suggestions but nothing changes.'

'I have never knew it was there, I have never knew anyone to put anything in the box and I don't see the point of having one and I have never been told about it.'

'It would be good to get feedback from your suggestions.'

On face to face interviews:

'On the relationship with the worker, if it is not good I wouldn't be honest.'

'Questions can be explained to me.'

> *'You might not want to tell a worker what you really think.'*
>
> *'Could back fire on you.'*
>
> *'Worker must be accurately recording what they are told, not their interpretation. Risk that they influence / put their own spin on it.'*

On surveys:

> *'I can be prone to losing my mail, let alone return it.'*
>
> *'Anonymity, and space and peace to think of your answers.'*
>
> *'We never find out the results'*

On computers – a high level of paranoia amongst respondents:

> *'Don't like computers. Seem to ask too many questions, take along time. Don't know who is watching.'*
>
> *'No good if you cannot use computers, think people could be watching, hackers, etc.'*

On video boxes:

> *'Own words. Exact thoughts-verbatim'*
>
> *'There's no writing involved for some people who struggle with spelling'*
>
> *'You would need to know what you're saying wouldn't affect what happens to you.'*

On Facebook:

> *'Depends where you are in your own personal recovery.'*
>
> *'I wouldn't want confidential info on a social network.'*
>
> *'Some of my friends don't know I engage in the recovery community and neither do family members and this could be embarrassing.'*
>
> *'If it were a closed group, maybe.'*

On mobile phones:

> *'Don't always know who a text is from.'*
>
> *'Would need to be short and sweet. Would depend on issue under discussion. If it was something very relevant or important to me, I would respond.'*
>
> *'Easy and accessible'*
>
> *'Immediate.'*
>
> *'Credit and giving out number.'*

What researchers and organisations with practical experience tell us about *grassroots* involvement

There is a significant body of research from the USA and other countries which highlights the positive impact of grassroots organising in partnership with professional services, leading to better recovery outcomes for individuals.

Peer to peer initiatives have grown in mental health, employability, offending and other fields. There are a wide range of successful examples in peer support and peer research

which identify positive outcomes for those being supported or researched and those providing it.

See in further reading:

Glasgow employability peer support development group

If you could do it so could I

Nothing About Us Without Us.

📊📈🥧	**What our local findings tell us**

The 22 services who responded to our service managers' survey reported 195 volunteers between them.

In our service user and carer survey, there was strong support for methods of grassroots involvement, although some doubts about how different groups of service users could come together.

Group meetings

- Good — 72%
- Easy — 29%
- Respond — 78%

For: talking and listening, ideas generation
Against: people not listening, lack of confidence, potentially chaotic

Group meeting – all services together

- Good — 45%
- Difficult — 38%
- Respond — 55%

For: wider range of views, networking
Against: potential for clashes, lack of safety

Peer support

- Good — 91%
- Easy — 61%
- Respond — 78%

For: understanding, participation, give and get back

Against: may not be ready, lack of support

	What service users and carers told us

On group meetings:

'Depends on what stage they're at and whether they have the confidence to voice their opinions.'

'Disagreements may get out of hand. Could be chaotic.'

'Supportive way to get views, ideas across provided people are genuinely listened to'

'When you are attending a meeting you know you're being heard.'

'confidentiality. Loudest folk would take over. I don't feel confident in group meetings'

On peer involvement:

'You are as vulnerable as the other person but sometimes you can be seen as the expert who can be leant on a bit more than you can handle e.g. not able to respond to others needs due to your own. Need to understand boundaries, have to have boundaries.'

'Do gooders.'

'Sometimes feel you're not listened too and feel like a pawn!'

'If you are talking to people who have been through it themselves then you feel they can relate and you are then able to trust.'

'Very good idea, as long as, they have some understanding or experience.'

'Talking to people who have been through the same.'

'A way to give back; way to get support; empowering.'

	What researchers and organisations with practical experience tell us about *wider horizons* for service user and carer involvement

Some case studies point to successful high level leadership of participation in all aspects of public life, including drug and alcohol services (e.g. Citizen Power in Peterburgh) – the top down decision to change creates bottom up engagement.

Most studies, however, promote participation and although there are many good practice guides, there is limited information on how to resolve all the difficult things that can happen

in service user and carer involvement. There is a danger of seeing it as a universal good thing that is straightforward to achieve, without allocating sufficient resources to really do it well.

See in further reading:

RSA projects: Citizen Power in Peterburgh 1 year on

Right Here Right Now, taking co-production into the mainstream

Creating stronger and more inclusive communities which value everyone's right to contribute

What our local findings tell us

77% of service users and carers in our survey said that they did not know how decisions are made in their area. 56% didn't know of anywhere were service users and carers could express their views.

Only 28% of our survey respondents could recall ever being asked by services for their views on wider area issues. However 40% thought they had been asked for their views on the government's agenda.

Although service users agreed they thought some form of service user representation at higher level decision making was important (53%) this was qualified by 75% of people identifying potentially bad points about representation.

What service users and carers told us

'May not be a true representative.'

'Depends on who they are and how representative of the group they are.'

'They get sucked up into the machine.'

'People may feel less than.'

'Will these people actually listen?'

'Intimidated, daunting, overwhelming.'

'Feeling less than just a number to them, they are just reaching a target, ticking boxes.'

'Mostly just a tokenistic exercise.'

'Lip service,'

'I did it and felt intimidated.'

'person would have to be carefully chosen, one person unlikely to be enough, not everyone will engage with this'

10 Further reading

NSUN National Involvement Partnership Baseline Standards				
http://www.nsun.org.uk/modules/downloadable_files/assets/baseline-standards-handout-may-2011.pdf				
National Involvement Partnership / NSUN / May 2011				
Focus	**Easy Read**	**Grassroots**	**Participation**	**Decision making**
Monitoring and evaluation of service user involvement. Straightforward 3-page guide with useful overview of features in service user involvement which can form a baseline to work from.	★★★★☆	★★★☆☆	★★★★☆	★★★★☆

RSA projects: Citizen Power in Peterburgh 1 year on				
http://www.thersa.org/__data/assets/pdf_file/0007/409273/citizen_power_peterborough.pdf				
Rachel O'Brien / RSA Project / July 2011				
Focus	**Easy Read**	**Grassroots**	**Participation**	**Decision making**
Report on city-wide development of citizen-led initiatives including a project on recovery capital and idea to establish a Recovery Champion Network. Well laid out magazine-style 30 page report on progress, good for inspiration and wishing for the high level commitment that enables this project.	★★★☆☆	★★☆☆☆	★★★★☆	★★★★☆

Building Global Citizenship through Network Leadership				
http://www.interrelate.info/downloads/BuildingGlobalCitizenshipThroughNetworkLeadership.pdf				
Anne Beales and Daniel Fisher / NSUN and National Coalition for Mental Health Recovery USA / September 2010				
Focus	**Easy Read**	**Grassroots**	**Participation**	**Decision making**
Paper on leadership in service user involvement in mental health, highlighting international links and good practice. A 6 page conference paper not well laid-out but very thought provoking about service user leadership.	★★★☆☆	★★★★★	★★★★★	★★★★☆

User and Carer Involvement: a Good Practice Guide				
http://twocanassociates.co.uk/pdfs/CarerUserpractice.pdf				
Bec Hanley and Kristina Staley / Long-term Medical Conditions Alliance / February 2005				
Focus	**Easy Read**	**Grassroots**	**Participation**	**Decision making**
Guide for voluntary organisations working with people with long term health conditions. A 40 page practical guide, easy to skim for the main points, with useful case studies and check lists.	★★★★☆	★★★★☆	★★★☆☆	★★☆☆☆

Involving Service Users Toolkit - Croydon Drug and Alcohol Action Team
http://www.nada.org.au/media/26886/croydon_involving_service_users_toolkit_2005_smaller_version.pdf
Drug and Alcohol Action Team (DAAT) and the Service User Representation Group (SURG) in Croydon / The International Centre for Drug Policy (ICDP), St. George's, University London / June 2005

Focus	Easy Read	Grassroots	Participation	Decision making
Local toolkit which contains a strategy and some tools and templates for local use, covering individual, service and strategic level service user involvement. A 46 page document more suited to professionals than service users, recommending quite a traditional approach. Policy on payment to service users.	★★☆☆☆	★★★☆☆	★★★☆☆	★★☆☆☆

Engaging with Involuntary Service Users in Social Work Good Practice Guide
http://www.socialwork.ed.ac.uk/__data/assets/pdf_file/0020/62273/Good-Practice-Guide.pdf
Dr Heather Wilkinson, Mark Smith, Dr Michael Gallagher and the Knowledge Exchange Team at CRFR / The University of Edinburgh / February 2011

Focus	Easy Read	Grassroots	Participation	Decision making
Explores the person to professional engagement in non-voluntary services. Simple PDF document with useful reminder that some service users don't initially engage in services of their own volition.	★★★★★	★★★☆☆	★★★☆☆	☆☆☆☆☆

A Helping Hand – Consultation with Service Users About Peer Support
http://www.together-uk.org/wp-content/uploads/downloads/2011/11/helpinghand.pdf
Alison Faulkner and Thurstine Basset / Together for Mental Health / 30 September 2010

Focus	Easy Read	Grassroots	Participation	Decision making
An evaluation of service users' experience of becoming peer supporters in the mental health field from a range of organisations. 11 page document which relates views under simple headings. Interesting reminder of expectations of progression, relates to WRAP Pyramid of Peer Support	★★★★☆	★★★★☆	★★★☆☆	☆☆☆☆☆

If you could do it so could I – learning on peer support and mentoring for employability services
http://www.employabilityinscotland.com/sites/default/files/articles/7557/%27If%20you%20could%20do%20it%2C%20so%20can%20I%27%20-%20Peer%20Support%20and%20Mentoring%20Report.pdf
Employability Learning Network / Scottish Government / October 2009

Focus	Easy Read	Grassroots	Participation	Decision making
Case study research focusing on employability projects for people with addictions or mental health, which use peer mentoring and peer support in service delivery. 43 page magazine-style document which provides an overview of the outcomes for service providers, service users and peer supporters and mentors, and critical success factors.	★★★★☆	★★★★★	★★★★☆	★★☆☆☆

Effectively engaging and involving seldom heard groups

http://www.iriss.org.uk/sites/default/files/iriss-insight-2.pdf

Insights 02 / IRISS / November 2010

Focus	Easy Read	Grassroots	Participation	Decision making
Useful summary of evidence in social services on involving "seldom heard" groups of all kinds, with simple pointers for practice in 1:1. 6 page pamphlet with easy to pick out bullet points of key messages.	★★★★★	★★★★★	★★☆☆☆	★★★★★

Drug User Involvement in Treatment Decisions

http://www.jrf.org.uk/sites/files/jrf/2012-drug-user-treatment.pdf

Jan Fischer, Nick Jenkins, Michael Bloor, Joanne Neale and Lee Berney / JRF / March 2007

Focus	Easy Read	Grassroots	Participation	Decision making
Research into the level of involvement between service users and treatment providers on individuals' treatment decisions. 56 page document but good 3-page Executive Summary with key findings and 10 recommendations.	★★★☆☆	★★★★☆	★☆☆☆☆	★★★★★

A review of the literature on peer support in mental health services

http://www.iimhl.com/IIMHLUpdates/20120115a.pdf

Julie Repper and Tim Carter / Journal of Mental Health, 20(4): 392–411 = Informa Health Care/ August 2011

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on peer support within statutory mental health services 20 page journal article pulling together key findings from research.	★☆☆☆☆	★★★☆☆	★☆☆☆☆	★★★★★

Mutual support and inspiration - Developing an Employability Peer Support Model

http://www.otbds.org/employabilitypeersupport/

Glasgow Employability Peer Support Development Group / Outside the Box / March 2010

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on peer support within employability mental health services. 32 page magazine style report which is in itself an example of service-user led work to explore how peer support works in employability/mental health settings	★★★★☆	★★★★☆	★★☆☆☆	★★★★★

Nothing About Us Without Us. Greater meaningful involvement of people who use illegal drugs, a public health, ethical and human rights perspective

http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1314

Ralf Jürgens / Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance, Open Society Institute / 2008

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on involvement in the context of blood borne viruses and international examples. 83 page report with very useful reminder of the role people affected by HIV and AIDs have played in public health through information, shared experiences and development of services.	★★★☆☆	★★★★☆	★★★★☆	★★★☆☆

A review of the literature on peer support in mental health services

http://www.iimhl.com/IIMHLUpdates/20120115a.pdf

Julie Repper and Tim Carter / Journal of Mental Health, 20(4): 392–411 = Informa Health Care/ August 2011

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on peer support within statutory mental health services. 20 page journal article pulling together key findings from research.	★☆☆☆☆	★★★☆☆	★☆☆☆☆	☆☆☆☆☆

User involvement and user organising in harm reduction

www.emcdda.europa.eu/attachements.cfm/att_101264_EN_emcdda-harm%20red-mon-ch12-web.pdf

Neil Hunt, Eliot Albert and Virginia Montañés Sánchez/European Monitoring Centre for Drugs and Drug Addiction/April 2010

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on peer support within statutory mental health services. 21 page journal article on key findings from drug user involvement, user led organisations, networks and organisation of harm reduction across Europe.	★★☆☆☆	★★☆☆☆	★☆☆☆☆	★★☆☆☆

Empowering Citizens: Realising service user involvement in UK Third Sector organisations

http://www.gold.ac.uk/media/Empowering%20citizens%20-%20Realisation%20of%20User%20Participation%20in%20SRIs%20V7%20final.pdf

Jeannet Lingan and Michael Hammer / Goldsmiths University of London / Jan 2011

Focus	Easy Read	Grassroots	Participation	Decision making
Focus is on accountability principals in the self-regulation of Third Sector Organisations who want to realise service user involvement. 22 page report reviews a group of self-regulation initiatives in the UK addressing best practice and quality in social service delivery, as well as, how they involve service users in their good practice.	★★☆☆☆	★★☆☆☆	★☆☆☆☆	★★☆☆☆

Framework for Public & Service User Involvement in Health and Social Care Regulation in Ireland

http://www.imb.ie/images/uploaded/documents/Final%20Framework%20for%20Public%20Service%20User%20Involvement.pdf

Health and Social Care Regulatory Forum / December 2009

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on the regulation of public and service user involvement within health and social care in Ireland. 40 page report considers national and international examples of regulation, defines well what it means by public and service user involvement and provides some helpful templates in the appendices.	★★★☆☆	★★☆☆☆	★☆☆☆☆	★★★☆☆

Perspectives and Expectations: Service User Involvement in Research

http://media.johnwiley.com.au/product_data/excerpt/27/14443347/1444334727-12.pdf

Elizabeth Morrow, Annette Boaz, Sally Brearley and Fiona Ross / *Handbook of Service User Involvement in Nursing and Healthcare Research*, First Edition / 2012

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on the involvement of service users within healthcare. 15 page 1st chapter provides clear definitions of service user involvement in research. It outlines the political and historical background, as well as, approaches, perspectives and challenges to service user involvement in research.	★★★☆☆	★☆☆☆☆	★☆☆☆☆	★★★☆☆

Treatment Service Users (TSU) Project: Phase One Report

http://www.aivl.org.au/files/AIVL%20_TSU_200804.pdf

Australian Injecting and Illicit Drug Users League (AIVL) and National Centre in HIV Social Research (NCHSR) / 2008

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on what the meaningful and active participation of drug users in Australia would be. 117 page report on the findings of the TSU Projects 1st Phase. Key objectives were to describe: the participation opportunities as outlined in policy; service user and providers experience of participation; current activities of participation at individual, organisational and political levels; and determine the support for service user participation across the board.	★★☆☆☆	★☆☆☆☆	★★★☆☆	★★☆☆☆

Treatment Service Users (TSU) Project: Phase Two Final Report

http://www.aivl.org.au/database/sites/default/files/resources/AIVL%20TSU%20Project%20Phase%20Two%20Final%20Report%20-%20WebReady%202011.pdf

Australian Injecting and Illicit Drug Users League (AIVL) and National Centre in HIV Social Research (NCHSR) / 2008

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on 5 project areas prioritising the education and training recommendation on participation from the 1st Phase Project. 142 page report had 2 key objectives: to refine and apply the model of service user participation from 1st Phase; to conduct an independent evaluation of the impact and suitability of the expanded model.	★★☆☆☆	★☆☆☆☆	★★☆☆☆	★★☆☆☆

A literature review of service users' views: What do people with multiple and complex needs want from services?

http://www.pathproject.scot.nhs.uk/literature/PATH_literature_review.pdf

Annette Gallimore, Laura Hay and Phil Mackie / Partnerships for Access to Health (PATH) Project NHS Highland and NHS Lothian / March 2008

Focus	Easy Read	Grassroots	Participation	Decision making
Focus of this literature review is to explore what those with multiple and complex needs want from health, social care and voluntary sector services. 80 page report questions the personal capacity of service users with multiple and complex needs to access services they need. It examines the necessary resilience, service users require to overcoming potential barriers to accessing care and identifies a starting point for policy makers, commissioners, etc in redesigning services to better promote the participation of service users.	★★★☆☆	★★☆☆☆	★★★☆☆	★★★★☆

Involving users in commissioning local services

http://www.jrf.org.uk/sites/files/jrf/user-involvement-service-commissioning-full.pdf

Silvia Schehrer and Stephanie Sexton / Joseph Rowntree Foundation / May 2010

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on service user involvement in commissioning service but in particular strategic commissioning. 58 page report is described as a 'think piece' to allow service users, commissioners, etc to: look at what's been; examine the evidence; reflect on the researchers findings; synthesis the learning to move forward.	★★★☆☆	★★☆☆☆	★★☆☆☆	★★★☆☆

Putting People First: Planning together – peer support and self-directed support

http://www.puttingpeoplefirst.org.uk/_library/Resources/Personalisation/Personalisation_advice/PT_Final.pdf

Department of Health – Putting People First Programme / January 2010

Focus	Easy Read	Grassroots	Participation	Decision making
Focus is on engaging people as active participants in their care planning to enable them to direct their own support. 39 page report has 5 key principals: grow your own co-production networks; proactively build partnerships around personalisation; leadership within co-production; investment in co-production; empower people to learn and use support planning skills. This report has 8 summarised case studies and 2 indepth case studies.	★★★☆☆	★★☆☆☆	★★★☆☆	★★☆☆☆

Policy Briefing 3: Young People Involvement

http://www.cypmhc.org.uk/resources/policy_briefing_3_young_people_involvement/

Children and Young People's Mental Health Coalition / November 2011

Focus	Easy Read	Grassroots	Participation	Decision making
Focus is on young people between 16-25 being involved in the development, delivery and commissioning of mental health services. 8 page briefing on its key recommendation around Reaching Adulthood. It is easy to read with its evidence highlights which include either case studies on what works or looks at potential failure to address problems.	★★★☆☆	★★☆☆☆	★★★☆☆	★★★☆☆

A Young Peer Trainer's Guide – To Provide Sexual Health and Drug-related Harm Reduction Education

http://youthrise.org/sites/default/files/files/RISE%20UP!%20A%20Young%20peer%20trainers%20guide.pdf

MTV's Staying Alive Foundation (SAF), Espolea and Youth R.I.S.E / December 2010

Focus	Easy Read	Grassroots	Participation	Decision making
Focus is on young people being peer trainers for an education programme on sexual health and drug-related harm reduction. 80 page toolkit is well laid out if not a little wordy. Its design lacks a young person's touch with little in the way of graphics.	★★☆☆☆	★★☆☆☆	★★★☆☆	☆☆☆☆☆

Peer Support: A guide to how people with a disability and carers can help each other to make the most of their disability supports.

http://www.dhs.vic.gov.au/__data/assets/pdf_file/0009/716463/peer-support-guide.pdf

Collaboration of People involved in Disability Services Division / State of Victoria, Australia / May 2012

Focus	Easy Read	Grassroots	Participation	Decision making
Focus is on peer support in the disabilities field in Australia. 36 page guide considers peer support, couching, led groups, etc in the disabilities field with particular attention paid to self-direction (personalisation in the UK). It is easy to read, clearly presented with great graphics.	★★★★☆	★★★☆☆	★★★☆☆	★★☆☆☆

Lived Experience Leading - The Way Peer Support in Mental Health

http://www.together-uk.org/wp-content/uploads/downloads/2011/11/livedexperiencereport.pdf

Julie Repper, Elina StamouAlison, Faulkner and Thurstine Basset / Together for Mental Health / 30 September 2010

Focus	Easy Read	Grassroots	Participation	Decision making
Focus on peer support in mental health field in the UK. 23 page report gives us types of peer support, the current policy outline, the cost of mental health, principles of peer support, benefits and challenges in participating in peer run groups, benefits and challenges service users as paid providers of services; and the recommendations for future work and research.	★★★☆☆	★☆☆☆☆	★★☆☆☆	★★★☆☆

Additional references

- **Mid and East Lothian Drug and Alcohol Partnership Implementation Plan 2010-13**
  http://www.meldap.co.uk/data/uploads/00676meldapimplementationplan.pdf
  MELDAP / Midlothian / 2010

- **Edinburgh Alcohol and Drug Partnership Strategy 2011-14**
  http://edinburghadp.co.uk/Resources/EADPPublications/Documents/FINAL%20EADP%20Strategy%20document%20(2).pdf
  EADP Partnership / CEC / 2012

- **West Lothian Tobacco, Alcohol and Drug Partnership Commissioning Plan 212-15**
  http://www.westlothianchcp.org.uk/publications/misc/tapd
  WLTADP / WL / 2012

- **Consultation with Alcohol and Drug Partnerships on Information Needs**
  http://www.drugmisuse.isdscotland.org/publications/local/ADPconsultation042012.pdf
  Substance Misuse Programme, Information Services Division / ISD Scotland and NHS Scotland / March 2012

- **Consultation with Stakeholders on Substance Misuse Information Needs**
  http://www.drugmisuse.isdscotland.org/publications/local/Evidencestrategy042012.pdf
  Substance Misuse Programme, Information Services Division / ISD Scotland and NHS Scotland/ March 2012

- **The Road to Recovery: A New Approach to Tackling Scotland's Drug Problem**
  http://www.scotland.gov.uk/Resource/Doc/224480/0060586.pdf
  RR Donnelley B54521 / Scottish Government / May 2008

- **'A Sense of Belonging' A joint strategy for improving the mental health and wellbeing of Lothian's population 2011-2016**
  http://www.nhslothian.scot.nhs.uk/OurOrganisation/Strategies/Documents/SenseOfBelonging.pdf
  Linda Irvine, Rachel King, Sheena Lowrie and Alison McEwan / Lothian's Joint Mental Health and Wellbeing Strategy Programme Board / October 2011

- **NHS Lothian Substance Misuse Directorate Service User Involvement Strategy**
  Jim Shanley / NHS Lothian Substance Misuse Directorate (SMD) / Nov 2011