Module 3
Involving Service Users and Carers

Welcome to Module 3

Involving service users and carers is about promoting people’s ability to lead their own care and treatment, and to be involved in partnerships to develop services. This module aims to support you to develop service user and carer involvement locally.

Learning outcomes
After completing the module, you will be able to:

- describe the links between service user involvement, carer involvement and the 10 ESCs;
- discuss service user and carer involvement at individual, organisational and strategic levels;
- explore local approaches to increasing service user and carer involvement in their own care and in service design;
- describe the approach to service user and carer involvement you would like to see developed in the team, service or project in which you work;
- present ideas on how this improved approach can be achieved, defining the role you and your immediate colleagues can play.

Additional notes for this module

- You should use some of the time you spend on this module finding out about local service user and carer groups, their contacts, activities and priorities.

- The module looks at both service user and carer involvement. It recognises that the needs of the two groups may differ, but that there is also much similarity between them. Each group wants a mental health service that is modern, up to date, well resourced and staffed by hopeful workers who listen and respond to their needs.
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Estimated time to complete learning activities
4 hours
SCQF level 8
Module 3

1. Introduction

Policy, legislation and local strategies related to service user and carer involvement

Policy developments in Scotland since devolution have encouraged public sector bodies to be more accountable to service users and carers. NHS boards have a legal duty to involve the public in planning and developing services, and the Changing Lives Implementation Plan (SEHD, 2006) means service users and carers have a big say on social work service improvements. Service user and carer involvement is now central to the work of a range of statutory bodies.

Mental health services have been required to involve service users and their carers since the production of the Framework for Mental Health Services (Scottish Office, 1997). This is reflected in the national plan for mental health service improvement, Delivering for Mental Health (SEHD, 2006), and in the development of Community Planning Partnerships, which aim to ensure that people are included in making decisions about public services across the sectors.

Carers’ rights are identified in the Community Care and Health (Scotland) Act 2002. These include rights to carers’ assessments, that carers be treated as partners in care by professionals and a duty on NHS boards to develop a carers’ information strategy.

Scotland’s mental health act – The Mental Health (Care and Treatment) (Scotland) Act 2003 – puts service users and their carers at the centre of the mental health care and treatment system.

Involving people in designing and delivering services is admirable, but the services they contribute to, and the experience of people within them, have to be shown to be improving. A new national service user organisation called Voices Of eXperience (VOX) has been formed to deliver improvements in people’s experience of services, strengthen their voice and influence planning and practice. See www.voxscotland.org.uk
## 2. Exploring service user and carer involvement

### Activity 3.1

<table>
<thead>
<tr>
<th>Thinking about your own practice, how do you currently involve service users in their care?</th>
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<table>
<thead>
<tr>
<th>Thinking again about your own practice, how do you currently involve carers?</th>
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<table>
<thead>
<tr>
<th>Do you think service users and carers need the same support to be involved?</th>
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<table>
<thead>
<tr>
<th>In your view, what prevents service user and carer involvement in practice?</th>
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This could be considered by thinking through:

- organisational reasons;
- values-based reasons;
- care orientated reasons;
- others – please describe.
Levels of involvement

Service user and carer involvement can happen at different levels and in different ways.

We can identify three levels where service user and carer involvement takes place.

**Individual**
Individuals being involved in their care and treatment in ways that meet their needs, give them choices and involve them in all steps of the process. Equally, carers want to be recognised, listened to and supported as partners in providing care.

**Organisational**
Service users and carers being able to influence the service, project or organisation. It can mean quite practical, hands-on, joint work involving service providers and service users and carers.

**Strategic**
Service users and carers being able to influence legislation, policy and service developments at all levels and in all relevant spheres, not just mental health planning. Often it is about influencing service commissioners, multi-agency planning partnerships and committees (such as Community Planning Partnerships) and local funding bodies.

**Activity 3.2**
Do you have examples of involvement at any of these levels? If so, describe them.

You will be able to compare the examples you have identified with those provided later in the module.

**Involvement at an individual level**
This means people having easy access to information and advice around, for example, the range of possible care and support options.

Direct payment systems are the most obvious example of individuals being facilitated to choose what support they would like through purchasing services necessary to meet their needs. For more information on direct payments, see [http://www.dpcaledonia.org.uk/](http://www.dpcaledonia.org.uk/) A policy on the use of direct payments in mental health is due to be produced by the Scottish Executive in 2007.
Being involved at an individual level is also about people being actively involved in assessment, planning and decision making and having opportunities to direct their own recovery and care. They may, for example, prepare and own a personal plan such as a Wellness Recovery Action Plan. For more information see [http://www.mentalhealthrecovery.com/](http://www.mentalhealthrecovery.com/)

Another example of personal involvement can be found in making an Advance Statement (as recognised by the Mental Health Act), which is an agreement on what happens if the person becomes unwell. A service user who has made an advance statement said the following.

> “Writing an advance statement has made me feel that I have taken control of my care and treatment. I feel more empowered and the whole process has given me an opportunity to think through my mental health history and what works for me.”

For examples of preparing and using advance statements, see The Principles into Practice Network of the Mental Welfare Commission ([www.principlesintopractice.net/web/site/principlesintopractice/Resources/resources.asp](http://www.principlesintopractice.net/web/site/principlesintopractice/Resources/resources.asp)). You can also find out about guidance on advanced statements produced by the Consultation and Advocacy Promotion Service (CAPS) ([http://www.edinburgh.gov.uk/CEC/Recreation/Libraries/Local_Organisations/local_Consultation_and_Advocacy_Promotion_Service__CAPS__.html](http://www.edinburgh.gov.uk/CEC/Recreation/Libraries/Local_Organisations/local_Consultation_and_Advocacy_Promotion_Service__CAPS__.html)) and Advocard ([http://www.advocard.org.uk/](http://www.advocard.org.uk/)), two independent organisations based in Edinburgh.

An independent advocacy worker can enable people who use mental health services to have more say in their care and feel more able to make choices about support options on offer. For more information about independent advocacy, see [www.siaa.org.uk](http://www.siaa.org.uk)

**Example - involvement at an individual level**

Louise is in her mid thirties. She lives alone in her own flat, works as a volunteer in a local project and has a very active social life.

She has been a user of mental health services since she was a teenager and has regular meetings with a psychiatrist, a social worker and community psychiatric nurses. Louise has an independent advocate and a circle of friends with whom she discusses her support.

She has written her own Advance Statement, which includes a person-centred plan, and has given a copy to all those involved in supporting her. When she wants to review or alter her care, she and her advocacy worker meet with the professionals involved to agree changes.
Involvement in care and treatment planning

It is essential to involve people in assessments, reviews and decision making about their care, support and treatment.

Core components of effective service-user involvement have been identified. They include people:

- having the information they need to be involved;
- knowing what options and choices are available to them;
- feeling free to express views and wishes;
- being listened to and understood and having their views respected;
- being able to influence what happens and make decisions that matter.

Activity 3.3

We are going to use a rating system to explore involvement in care and treatment planning in your team or service. This will help you think about what promotes people’s involvement and the ways in which service user and carer involvement can develop at an individual level.

What is your experience in your current role or setting with regard to each of the statements given in column one below?

<table>
<thead>
<tr>
<th>Service users:</th>
<th>Always</th>
<th>Occasionally</th>
<th>Rarely</th>
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<tbody>
<tr>
<td>Know what is written in their assessments, care plans and reports.</td>
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<td>Write in their care plan.</td>
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<td>Have regular opportunities to discuss their care and treatment with their key</td>
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<tr>
<td>worker.</td>
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<tr>
<td>Have the information they need to be involved and know what their options and</td>
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<tr>
<td>choices are.</td>
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<tr>
<td>Are able to express their views and wishes in their care plan and in their own</td>
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<tr>
<td>words.</td>
<td></td>
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<tr>
<td>Are asked if their main carer can be involved and receive information about their care.</td>
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</table>
What actions could you take to increase service users’ involvement in care planning?

What actions could you take to increase carer involvement in care planning?

**Person-centred planning**
Person-centred planning focuses on what individuals at the centre of care and treatment want and on their strengths, rather than weaknesses.

Its success depends upon a willingness to come up with solutions that are not always traditional. Programmes and services need to be geared to assisting the individual, rather than people being asked to fit into the service’s approach and structure. It takes account of particular requirements people may have such as shortage of money, health issues, safety, legal orders and the rights of carers.

Key characteristics of person-centred planning include:

- a focus on the individual and his or her whole life, not just health or social care needs;
- control being with individuals, their advocacy workers and carers.

_Adapted from Allies in Change (2001)_

There is a close link between person-centred values and approaches and effective involvement of individuals in their care planning.

Some other models, such as the Tidal Model for acute mental health care, have been devised to ensure all assessments and care plans are developed by the person receiving care and treatment and are expressed in his or her own words. For more information about the Tidal Model, see _http://www.tidal-model.co.uk/_
Overcoming barriers to service user and carer involvement at an individual level

Barriers can occur at several levels:

- individual: for example, people lose hope and confidence through their period of mental health problems or lose touch with friends, relatives and communities and may feel excluded;
- service-related: some service users and their carers have had negative experiences of mental health services;
- societal: the stigma of mental health problems may mean that people are discriminated against, for example when looking for a job. Discrimination and setbacks can have negative effects on someone’s desire to keep trying to engage in activities related to their well-being, and in contributing to service development.

The 10 ESCs highlight things you can do to overcome barriers to service user and carer involvement:

- **ESC 3 Practising Ethically** …by ‘acknowledging power differentials and minimising them whenever possible’;
- **ESC 6 Identifying People’s Needs and Strengths** …by ‘working to agreed needs…preferred lifestyle and aspirations’;
- **ESC 9 Promoting Safety and Positive Risk Taking** …by ‘empowering the person to decide the level of risk they are prepared to take with their health and safety’.

Actions that can contribute to developing people’s confidence include:

- listening to their needs and aspirations;
- providing information;
- working to develop constructive relationships with people;
- basing assessments and plans on individuals’ strengths;
- including people in planning.

**Activity 3.4**

**Service users and carers** often say they are not given all the information they need to be able to take a full part in making decisions.

**Carers** often say they are not given the respect or information they need to be partners in care. Carers have a right to an assessment of their own physical and emotional needs and to get the right information to enable them to access services and provide the best possible care and support.

Consider this in relation to the example given overleaf.
Example - Frank
Frank is in his mid-thirties. He keeps in close contact with his older brother, Paul, who has used mental health services for many years. He supports Paul as much as he is able in his day-to-day life and always visits him when he is in hospital.

Frank says that his brother gets very down from time to time. Paul has been told he has ‘schizophrenia’ but doesn’t agree with this diagnosis; he feels his troubles are spiritual in nature.

Both Paul and Frank agree that Paul needs more than just medication and would benefit from some form of employment. Both are very wary of mainstream mental health services following negative experiences in the past. Frank has never spoken to a mental health worker, even though he could be described as Paul’s main carer.

What do you think Paul needs to know?

What do you think Frank needs to know?

Why did you opt for these issues?

How could Paul and Frank access the right information? Think of as many possible means as you can.

What might stand in the way of them accessing this information?
Paul was quite happy for Frank to be involved in his care and for information about him to be shared with Frank, but this is not always the case. Consider the example below.

Example - Jenny
Jenny is 20 years old, works in a local supermarket and lives with her mother and sister. She has recently become distressed and has been referred by her GP to a community mental health nurse, who she has been seeing on a weekly basis. Jenny’s mother is very worried about her and has been to see both the GP and nurse to try to find out how they think she is doing. Jenny has been asked by the GP and nurse whether she will give permission for them to speak to her mum about what is happening, but Jenny has refused to give her permission. When told this, her mother said she found it hard to believe and felt it was an indication of just how unwell her daughter was. She told the GP she was finding it increasingly difficult to support Jenny while she was being completely shut out in this way.

How do you think Jenny’s mother might be feeling?

What support do you think the care providers can offer Jenny’s mother in this situation?

What do you think the consequences might be if the care providers gave Jenny’s mother the information she wants?

Difficulties arising from ‘confidentiality’ have been a constant source of concern for carers over many years. They often feel that confidentiality is presented as a barrier to them getting the information they need to be involved in people’s care.
While individuals’ confidentiality must always be respected, guidance on the issue of confidentiality and carers has been developed by the Mental Welfare Commission, see http://www.mwcscot.org.uk/web/FILES/Publications/Carers_Confidentiality_web.pdf.

The Royal College of Psychiatrists is developing a framework for best clinical practice in situations where mental health professionals are faced with a service user refusing consent for them to share information with their carers (see http://www.rcpsych.ac.uk/pressparliament/pressreleases2006/pr873.aspx).

Providing information alone is not enough for partnership. An environment in which people are encouraged to speak up and take part is equally important. Values integral to creating this sort of environment are reflected in several of the ESCs, for example:

- **ESC 2 Respecting Diversity**, which is about working with individuals, families and carers, accepting each person for who he or she is and celebrating and embracing differences;
- **ESC 3 Practising Ethically**, which highlights the importance of recognising the rights and aspirations of service users;
- **ESC 4 Challenging Inequality**, which highlights the need to address the causes and consequences of stigma, discrimination and social inequality, all of which can be barriers to service-user involvement.

Promoting service-user and carer involvement means that service users and their carers should be treated as equals, but existing or historical relationships of unequal power between service users/carers and service providers can present a barrier to this.

**Activity 3.5**

Keep in mind **ESC 3 Practising Ethically** and **ESC 9 Promoting Safety and Positive Risk Taking** as you read through the scenario below.

**Alice’s admission**

Alice is in her mid-forties. She is admitted to the Accident and Emergency department (A&E) after taking a small overdose. This is the first time she has taken an overdose in 25 years. The staff at A&E are generally helpful.

Alice is interviewed by a mental health nurse in the early evening. From the start of the interview, the nurse seems to be intent on discharging her. The nurse offers no help and says on a number of occasions, ‘I am doing what’s best for you by letting you go home’. Alice is not keen to go home, where she lives alone.

After the interview with the nurse, one of Alice’s friends arrives. She talks with Alice and decides to try to get her admitted to the psychiatric unit. Alice is eventually admitted around midnight and remains in the psychiatric unit for two weeks before being discharged home.
Here are some questions to consider.

What do you think was influencing the nurse?

How do you think Alice and her friend felt?

What did the nurse do that was unhelpful?

Suggest something helpful the nurse could have said or done.

Power is an important issue in involving service users and carers. Misuse of power by workers leads to poor experiences for service users and carers. As Thomson (1998) puts it:

“Power is the ability to influence and control people, events and processes... It is an ever-present phenomenon.”
Activity 3.6

Think of times when you have power, or lack power, in your current role in mental health services.

I have power when:

I lack power when:

Discuss where there may be a tension or conflict relating to power in your relationship with carers and service users.

How can you use your power to help others become empowered?

Another way of overcoming barriers to promoting service-user and carer involvement is linked to ESC 6 Identifying People’s Needs and Strengths, which is about acknowledging and building on individuals’ strengths and supports in your work. This is explored in more detail in Module 6.

Involvement at an organisational level

Individuals have opportunities to work with others who also use services or care for people who use services in, for instance, an active service user/carer group, collective advocacy group, patient/public involvement group, service management or planning group. These forums give people an opportunity to speak up about concerns, evaluate services, suggest improvements and decide on action. If involvement is effective, changes will result.
Example: involvement at an organisational level

One national voluntary organisation has employed a service-user involvement officer to support service users to get involved. She has supported the setting up of local service-user forums around the country. They meet regularly and feed into a national forum which raises their issues with the strategic management team of the voluntary organisation. Two service users are now on the board of the voluntary organisation.

We are going to use the same rating system we used in Activity 3.3 to help us think about ways in which involvement can happen at the wider organisational level.

Activity 3.7

What is your experience in your current role or setting?

<table>
<thead>
<tr>
<th>To what extent are service users and carers able to:</th>
<th>Always</th>
<th>Occasionally</th>
<th>Rarely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design and take part in surveys/audits/research on care issues?</td>
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<tr>
<td>Join self help, service user or campaigning groups which raise issues and are consulted by service providers?</td>
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<td>Become representatives on management, clinical governance or planning groups?</td>
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<tr>
<td>Take part in learning events for people from across the mental health community?</td>
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<tr>
<td>Find employment in mental health services?</td>
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<tr>
<td>Find employment in mental health services, where their lived experience is a key skill and attribute necessary for the job, such as a peer-support specialist?</td>
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<td>Interview and help to appoint staff?</td>
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<tr>
<td>Be involved in finance, policy and activity planning for a service(s)?</td>
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<td>Run services?</td>
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</tbody>
</table>
What could you do to influence the areas where this is only occasionally or rarely happening?

With whom might you form alliances to bring about change?

Services have begun to recognise the strengths and contributions of people who have experienced mental health problems and mental health services by introducing ‘peer-support specialist’ roles into the workforce. Peer-support specialists are individuals who are employed in recognition of their experience of mental health problems and the value they bring in providing care and support to others (peers). The specialists are trained, salaried, supervised, supported members of care teams who perform a range of functions.

The peer-specialist role is currently being developed in Scotland to reflect our local health care context. Papers and articles on formalised peer support can be accessed from the Scottish Recovery Network website (www.scottishrecovery.net).

**Activity 3.8**

What impact might peer-support specialists have in relation to service-user involvement in your service?

**Involvement at a strategic level**

This level of involvement is about influencing policy, strategy and planning through, for example, local planning committees. It’s important to ensure that when people are invited to be involved, steps are taken to ensure their involvement is meaningful rather than tokenistic.
Activity 3.9

Imagine you have been invited to represent your organisation on a strategic planning group with senior civil servants from the Scottish Executive and chief executives from NHS boards and local authorities.

What sort of support and preparation would you need to be meaningfully involved in this group?

Compare your answers with the good practice points below.

**Good practice in strategic involvement**

Examples of good practice in strategic involvement show that time and effort spent in facilitating individuals’ and groups’ active participation results in better-informed contributions and stronger partnerships.

For example, networks or groups looking for strategic involvement should work with individuals who take part in strategic planning to:

- support organisations that help individuals to be involved;
- set up meetings at convenient times and locations;
- acknowledge individuals’ backgrounds and circumstances, including diversity of age, culture, race, disability, gender, sexuality and spirituality, and take these into account when asking for involvement;
- find out about training and development opportunities that will facilitate greater involvement;
- be aware of and use person-centred approaches to commissioning services;
- provide information in a timely and accessible manner;
- set out tasks clearly;
- run meetings and events in ways that promote participation;
- allow enough time in meetings for debate and consultation;
- involve service users in decision-making processes from the beginning and make it clear how, where and when decisions are made;
- have a jointly agreed approach to involving service users and carers which covers practical aspects, such as payment and expenses, and difficult points such as ways of resolving differences of opinion.
Examples of strategic involvement
Examples of strategic involvement exist throughout the country in the work of service-user groups like the Highland User Group (HUG), which has over 10 years of experience. It is a network of 14 branches throughout the Highlands which champions work on tackling stigma and discrimination, speaking out for change in services and publishing research and opinions on a range of subjects from employment issues to the closure of a local psychiatric hospital (for more information, see www.hug.uk.net).

A national mental health service user organisation called Voices Of eXperience (VOX) was set up by service users in Scotland in 2006 with the aim of strengthening the collective voice and influence of people who experience, or have experienced, mental health problems. (See www.voxscotland.org.uk).

VOX – involvement at a strategic level
Vision: VOX seeks to take a leading role in creating an environment in which mental health problems are not a barrier to participating in any aspect of Scottish society.

Mission statement: We will achieve this vision by providing a national structure of, for and by people, who have experienced mental health problems, to make our voices heard, to assist people in speaking out and to maximise the impact of our message while seeking recovery and taking our role in society as active citizens.

VOX is drawing together a statement of good practice in service-user involvement which will be available in 2007.

Activity 3.10

What is the name of your local mental health service-user organisations or collective advocacy organisation(s) which work with people who have mental health problems?

What mental health carer organisations or carer workers exist in your area?
Give examples from your own experience of the work these organisations do.

Choose one group you are not already in touch with who may be useful to the people with whom you work. Make a list of what you’d like to find out from them (this might include their aims and objectives) and get in touch as soon as possible to make a link and ask for information you can pass on.

For more information on different levels of involvement and helpful approaches to increasing involvement, see Route Map to User and Carer Participation (Allies in Change, 2001) (see: www.sdchmh.org.uk/publications).

**Developing skills in involvement**

**Activity 3.11**

This is a chance to think about the skills you already have and those you’d like to acquire to facilitate building partnerships with service users and their carers.

Describe a skill that helps you provide service user-centred care.

Describe a skill you need to develop further.
3. Levels of influence and evaluating involvement

People’s involvement will have varying levels of influence. One way of analysing existing involvement in your area, with a view to increasing service users’ and carers’ influence, is to consider where current examples of involvement sit on a continuum of involvement and participation.

Goss and Millar (1995) developed a continuum to promote the development of service user and carer-centred community care. It works towards the goal of equal partnership.

The diagrams below use this continuum as a basis to show variations in involvement in two aspects of developing services and service-providing organisations – gathering information and defining need, and analysing/considering information and making decisions.

1. Identifying need

Set a small achievable goal that will help you develop this skill.
2. Developing solutions and deciding on actions

<table>
<thead>
<tr>
<th>1 No involvement</th>
<th>2 Information collected</th>
<th>3 Start of communication</th>
<th>4 Listening and responding</th>
<th>5 Partnership</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff develop solutions.</td>
<td>Staff use information collected to develop solutions.</td>
<td>Staff develop options and consult with users, collate feedback and decide on solutions.</td>
<td>Users and carers involved in analysing problems, and discussing options.</td>
<td>Users and carers and staff work together to analyse problems, discuss options and decide and implement appropriate solutions.</td>
</tr>
</tbody>
</table>

**Activity 3.12**

Look at the continuums in the diagrams above and discuss with colleagues and/or fellow learners which level (1-5) the example(s) you gave in Activity 3.3 correspond to, and why.

Discuss and make notes on what needs to be done to improve service-user and carer involvement in the examples you have given.
We have to keep in mind that while service-user and carer organisations and individuals in many cases want to move towards a position of partnership, some people may not want this. They might prefer to be consulted but not included in decision making (Level 3 of influence). The implication is that people must be given choice about the extent of their involvement.

**Activity 3.13**

The impact of service-user and carer involvement on the experience of service users and carers can be evaluated in a number of different ways.

Is the impact of service-user and carer involvement currently evaluated locally? To investigate this, talk to your local service-user and carer groups, Patient Focus and Public Involvement (PFPI) representatives and service managers.

If so, what methods are being used?

What methods do you think would be useful for the areas you work in?

If there is no recent evaluation of the impact (nor one planned), think of something practical you can do to promote a participatory evaluation of the impact of service-user and carer involvement in the areas you work in.
4. Conclusion

Hopefully, this module has given you time to reflect on how your own and your organisation’s current practices promote service-user and carer involvement and how they can be improved to strengthen involvement.

It will take time to put into effect the learning you have gained. You should regularly review progress towards the goals of increasing partnership working and improving experiences for service users and their carers.

Activity 3.14

Partnership is a theme across the 10 ESCs – there are strong links between developing the capabilities and strengthening service-user involvement.

Concentrating on the level of involvement your work most closely relates to (individual, organisational or strategic), which capabilities when applied to your work would do most to promote service-user and carer involvement?
Activity 3.15

Which existing process(es) could you use to practise developing your skills in service user and carer involvement?

When, and how often, can progress reviews take place?

How can you (or your team or organisation) support and develop opportunities for shared training and learning with service users and service user and carer organisations?
Resources to Support Further Learning

Allies in Change (2001) Route Map to User and Carer Participation
www.sdchmh.org.uk/publications


Mental Welfare Commission Principles into Practice Network
http://www.principlesintopractice.net/web/site/principlesintopractice/Resources/resources.asp

http://www.saheliya.or.uk/ Saheliya is a black and minority ethic women’s mental health organisation

Scottish Independent Advocacy Alliance www.siaa.org.uk

Voices of eXperience. www.voxscotland.org.uk

Wellness Recovery Action Planning http://www.mentalhealthrecovery.com/

References


