

ROUTE MAP TO USER AND CARER PARTICIPATION

**PART 1
INTRODUCTION AND GUIDE TO USING THE ROUTE MAP**

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The Route Map to User and Carer Participation has been compiled by the Scottish Development Centre as part of the programme of work carried out by Allies in Change. It has been tried out with a number of different groups of service users who commented on the Map in its draft format. Many of the suggestions have been included in the Map, so thank you to all those who contributed.

WHAT IS THE ROUTE MAP?

The Route Map is for people who use services or their friends and families. The Route Map provides a way of reviewing how well organisations and services involve people from the perspective of users and carers. The 'you' in the questions asked by the Map is addressed to you as a user or carer. By carer, we mean friends, family or neighbours.

The Map:

- provides a means of identifying gaps and strengths within current arrangements to involve users and carers in influencing services
- focuses on action and continuous improvement, by encouraging people to consider how gaps might be filled and strengths sustained
- offers suggestions on how difficulties might be overcome
- provides a systematic approach to reviewing different aspects of involvement, acknowledging what is working well and drawing attention to areas where changes are required
- encourages people to consider local involvement arrangements in relation to good practice.

HOW DOES IT WORK?

You can use the series of booklets called the Route Map to enable you to work out where you are currently, where you want to get to and to identify the route you need to take to arrive there:

- Firstly, the Map aims to get you to think about what is happening just now to involve users and carers. The questions are designed to enable you to take your bearings and to plot your current position
- Secondly, the Map gets you to think about where you want to go from here, by asking you to select specific areas to work on to improve involvement and achieve greater influence
- Thirdly, it prompts you to consider the route you are going to take to get to that destination. It asks questions that encourage you to think critically about what makes a difference and provides examples of approaches that can be helpful.

The Map explores involvement on three different levels:

BOX 1 • LEVELS OF INVOLVEMENT

INFLUENCING YOUR PERSONAL CARE AND SUPPORT

This looks at how you and your friends or family are involved in the care and support you receive

INFLUENCING ORGANISATIONS PROVIDING SUPPORT

This level looks at how you are involved in a service, project or organisation that provides services

INFLUENCING THE PLANNING OF MENTAL HEALTH SERVICES

This level looks at the opportunities for people to take part in planning and developing services, policies and strategies within an area.

The four booklets are:

PART 1

INTRODUCTION AND GUIDE TO USING THE MAP

PART 2

INFLUENCING YOUR PERSONAL CARE AND SUPPORT

PART 3

INFLUENCING ORGANISATIONS THAT PROVIDE CARE AND SUPPORT

PART 4

INFLUENCING THE PLANNING OF MENTAL HEALTH SERVICES

The Introduction explains what the Route Map is and how you can use it. It also provides an overview of the important issues for involvement at each of the three levels.

Parts 2, 3 and 4 ask a series of questions to get you to think about what is currently happening in your organisation or area. The questions concern the following eight issues and similar issues are covered on all three levels:

- Individual resources of users and carers
- Skills
- Time and timing
- Structures and administration
- Information and communication
- Attitudes, culture and values
- Different types of care and support
- Reviewing and learning.

The questions asked in the booklets are not neutral. They aim to get you to analyse where the problems are and to recognise what is going well and can be built on for the future. The Route Map looks not only at how involved people are, but also at how much you can influence services for the better. Some questions and issues are repeated. This is because people will choose to review certain elements from the Map and it is important that the key issues are covered.

Answering the questions leads on to action planning, where you decide which areas you are going to work on and what you want to achieve. The pack includes Action Planning sheets (see table 1, page 10), so that you can compile an action plan for the issues you want to tackle.

WHO IS THE ROUTE MAP FOR?

The questions are directed to users and carers. The Route Map covers arrangements to involve people, whether as users or carers. Some of the issues examined apply to users, some apply to carers and some have relevance to both groups.

In reviewing what is happening currently, you need to be clear whether you start off by looking only at users or only at carers and the opportunities they have to participate. Or you may want to consider both groups at the same time, recognising the distinctions between the two. Different groups can use the Map in the following ways:

BOX 2 • GROUPS USING THE MAP

IF YOU ARE AN INDIVIDUAL SERVICE USER OR CARER

You may want to get together with others who use the same services - maybe you live in the same house, or go to the same drop-in, or are supported by the same team - to look at how you are involved in that service.

You may want to link with other people with mental health problems in your area, other women with mental health problems, or other older people, for example.

IF YOU ARE A USER OR CARER GROUP

Use the Route Map to suggest that local organisations review the way in which people participate in services. Talk to them about the role you want to play in this process.

User and carer groups can use the Map to provide feedback on how things are working, where the pressure points lie and possible solutions.

IF YOU ARE A MEMBER OF A JOINT PLANNING GROUP OR FRAMEWORK GROUP

You can use the Map to review your own arrangements for involving people.

Suggest to NHS trusts, health boards, social work departments and other service providers that they use it to review what they are doing to enable people to participate.

IF YOUR ORGANISATION PROVIDES SERVICES

Why not ask service users and carers to review what you are doing to promote the fullest possible involvement? Consider the support they may need to undertake this work.

BRINGING PEOPLE TOGETHER TO REVIEW INVOLVEMENT

There are various ways that the Route Map can be used to review involvement. How you go about it will depend on whether you are looking at one organisation, at a network of organisations or at planning structures. You could:

- set up a task group within the organisation to take a lead in reviewing involvement, made up of a range of people including users, carers and staff
- bring together a group that comprises people from various organisations and includes service providers and planners or commissioners of services, as well as users and carers
- take the initiative in approaching an organisation or network and prompting a review. This may include situations where an organisation is initially reluctant for its work to be assessed in this way.

In following the Route Map, it would be useful if user and carer groups could secure the agreement and support of service providers or planning organisations. Establish some ground rules to guide the process so that expectations are clear and the different groups agree to take part. Discuss what needs to happen to bring about change and take this into account when planning with your partners what to do.

A STEP BY STEP GUIDE TO USING THE ROUTE MAP

STAGE 1 STARTING OFF

Use the Overview of key issues (table 2, page 11) as a starting point for discussion between users, carers and/or workers about what is currently happening. Decide where you want to start. For example, you could:

- Take one level and select a few issues within that level that are causing concern, or
- Start working on issues which you are comfortable with, to build up confidence and to become more familiar with the process, or

- Consider a single issue for example, information and communication, across two or three different levels.

Establish ground rules with which all participants agree.

STAGE 2 EXPLORING CURRENT ARRANGEMENTS

Work through the issues you have selected, following the questions in Parts 2, 3 or 4 and answering them as fully as possible. Remember that people may get services from several different organisations. It will be important to note your experience of involvement in relation to those different organisations. Note also whether your involvement is happening now or was in the past.

- Remember that you should be finding out what you think about these issues and looking at your experiences of being involved
- Workers can provide information but it is crucial to identify users' and carers' views of what is happening to involve them.

Write down your answers individually or as a group and use them to work out what needs to be changed.

STAGE 3 IDENTIFYING ACTION POINTS

Use the questions to:

- Identify what is effective
- Identify problems and what you want to change.

Decide what has to be done and list action points. Be clear about who has responsibility to make the changes desired. Complete an Action planning sheet (see table 1, page 10) and set down what outcome you want to achieve and what is to be done, by whom and when.

STAGE 4 FEEDBACK

Ensure that wider groups of people- both users and carers and professionals - are kept informed about what is happening.
Allow time to work on the action points.

STAGE 5 REVIEW AND SUMMING UP

Review where you have got to in tackling the issues identified and keep other groups informed.

STAGE 6 IMPLEMENTATION

Individuals and organisations take action to implement the points identified in the discussions. This can include:

- Changing their behaviour - how they do things and engage with other people
- Improving communication, decision-making or planning arrangements
- Providing feedback on progress of service plans
- Beginning to change how resources are used

STAGE 1 STARTING AGAIN

Once a year come back to the overview and reconsider both the areas that have been worked on and any that could still do with some attention. You could then repeat the process.

THE ROUTE MAP IS NOT THE ONLY ANSWER!

Please note that the Route Map does not claim to cover all the territory. It would not be possible to include every issue. The Map has selected key issues for you to explore and sets out an approach that could be extended to cover other issues that people in your local area want to add. If you are not sure of some of the terms used, there is a glossary on page 14.

You can add other issues or add your own categories and questions to an issue that is important to you.

The Route Map will provoke lots of questions and discussion. If you are not used to thinking about how you are involved in an organisation you may find it useful to have someone to help you use the Route Map.

TABLE 1 • ACTION PLANNING SHEET

Date completed			
Problem or issue	What do you want to achieve or change?	Action points	Who and when

TABLE 2 • OVERVIEW OF THE KEY ISSUES FOR USER AND CARER INVOLVEMENT AT EACH OF THE THREE LEVELS

You can use this overview together with Parts 2, 3 and 4 to work out which issues you want to choose.

Issue	Influencing your personal care and support	Influencing organisations that provide support	Influencing service planning
Individual resources of users and carers	Whether you have choice Can ask questions? Can get advice? Can make contact with other users and carers?	How to build up skills and confidence - individually and collectively Opportunities for users to work together Involving a range of people	Support from wider groups Training and development Challenging professional opinion
Skills	Listening Negotiating Skills in person centred planning	Staff skills in bringing people together Training for users to take part in staff recruitment and training Person centred approaches	Users' experience and skills used to brief managers Skills required for participants in working groups Person centred approaches to service commissioning

Time and timing	Timing of services	Is there long term commitment to involvement? Time for staff to listen and make proper assessments	Enough time allowed for meetings Involvement at an early stage Timing work programme to allow members to consult with others
Structures and Administration	Decision making How assessments are carried out Where and when reviews happen Confidentiality Meeting the costs of attending review meetings	Policy on involvement embedded in practice How the project and service works and how decisions are made Resources for training and development	Joint approaches Criteria for making decisions Expenses payments Establishing structures that make it easier for users and carers to contribute
Information and Communication	Getting advice Access to records Information about reviews Making advance agreements to say what happens if you become ill	How people make concerns known Feedback on decisions Keeping carers in the picture	Dissemination Information about how decisions are made The bigger picture Financial information

<p>Attitudes, culture and values</p>	<p>Getting the service you want</p> <p>Problem solving</p> <p>Risk taking</p> <p>Respecting users' and carers' experiences and knowledge</p> <p>Daily living</p>	<p>Taking responsibility for decisions about services</p> <p>Asking views of a range of people</p> <p>Professional attitudes</p> <p>Adapting to fit individual requirements</p>	<p>Openness about criteria used to make decisions</p> <p>Flexibility</p> <p>Long term commitment to sustain involvement</p> <p>How conflict is dealt with</p>
<p>Different types of care and support</p>	<p>Good individual planning as foundation for services</p> <p>Finding out about the range of possibilities</p> <p>Advocacy services to enable user voice to be heard</p>	<p>Involvement of users and carers an essential requirement</p> <p>Making changes to services</p> <p>New approaches to services</p>	<p>Infrastructure of local user groups and carer groups</p> <p>Finding out about the range of possible options</p> <p>Spending and resources</p>
<p>Reviewing and learning</p>	<p>Influencing services</p> <p>Working through issues and concerns</p> <p>Making changes in services and in working practice</p>	<p>How change is handled</p> <p>Culture of learning from mistakes</p> <p>Users' and carers' experiences in decision making and evaluation</p>	<p>How organisations learn and develop</p> <p>Reviewing decisions at critical points</p> <p>How change happens</p>

GLOSSARY

Advocacy	an individual or group being supported to speak up for themselves or others
Carer	friend, relative or neighbour offering care or support
Framework Group	a group of agencies set up to support the development of services as set out in the document 'A Framework for Mental Health Services in Scotland'
Joint Planning Group	a group of several different agencies set up to plan mental health services in an area together
Person centred approach	where organisations base their work on the values of person centred planning
Person centred planning	an approach which helps people work out how they want to live, what they would like to achieve and the support they might want to do that
Service commissioning	negotiations to decide which services an organisation will be funded to provide
Service provider	an organisation offering care and support, such as a hospital, social work department or voluntary organisation



Allies in Change is an alliance of people and organisations who want to see the participation and inclusion of people with mental health problems, their friends and families, promoted and developed.



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The Scottish Development Centre is an independent organisation that works with others to promote better mental health services and to improve mental health and wellbeing.

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