

# checklist I

**For people in touch with health services, relatives of people using services, or representatives of either group of people, who are going to formal meetings**



## **Before the meeting**

### **Skills and experience**

Remember that you have important skills and experience to draw upon. These could include:

- how an illness or health problem can affect every day life
- what it is like to get access to other health care or local authority services
- practical experience of supporting people in giving their views and in feeding views back to people
- experience from other local community initiatives
- experience of lobbying people who make decisions
- skills learnt from your life including supporting a family, organising a group, working whether paid or unpaid

# About the phrase 'people in touch with health services'

When using health services people can call themselves patients, service users or members of the public. In this checklist the term 'people in touch with health services' or a variation on this is used to cover everyone using health services.

## Responsibility to yourself

Always think carefully about your involvement in formal meetings. The ideas listed here will help you do this:

- do not take on too much
- feel pleased with your achievements rather than worrying about discussions that seem less successful
- be prepared for the meeting and for the journeys to and from the meeting
- are you too busy to go to the meeting? Is there another way of sorting out the issue(s)?
- do you need to get more information on a topic of which you have little direct experience?
- you could set a time limit to your involvement, for example by agreeing to serve on a committee for a year.

Keep in mind that your involvement, the experiences and skills you bring, will make a real difference to the quality of services that are provided now and in the future.

**“ We need this. We need service users at the table, having their say and being listened to. It’s still too slow and there isn’t enough real change, but this is where it starts. ”**



# Preparing for the meeting

## **Purpose and scope of the meeting**

Find out from the person organising the meetings:

- whether the meetings are ongoing or will last until a task is completed
- which services and what situations it will look at
- what your role is
- how the meeting fits into the wider decision-making processes
- how to get hold of other background information you need.

If people who use services and relatives of people who use services are going to a meeting together:

- make contact with each other beforehand
- think about ways to support each other at the meeting
- make a 'what to do if ...' plan together if either of you is worried about a particular difficult issue.

If two people are attending the meeting together, one person can act as a back up to the other. Spend time together beforehand thinking about:

- the issues you want to raise
- issues or situations that feel particularly difficult and how you might handle them
- best case scenarios, so you are not thrown when things go well.

Explain to the meeting if someone is there to support or back you up and/ or if someone is working with you - or shadowing you - and will cover when you can't be there.

## **Reading the papers for the meeting**

You should receive the papers for the meeting well in advance; these should include all the topics to be discussed, background information, and the record - often called the minutes - of the last meeting. Ask the organiser how far in advance of the meeting you will receive the papers, and say if this is not enough time. If you need support in understanding or reading the papers, again contact the organiser.

## Outcomes of the meeting

It is useful to build a full picture of what the meeting can achieve.

Questions you might ask include:

- is it a decision-making meeting or does it have an advisory role?
- what impact will it have on services for individual people?
- what impact will it have on services overall?
- will it help people who use the services and their relatives to be more involved in developing these services?

## Information about other people attending the meeting

It is helpful to know who else will be there so ask the organiser for their names, the organisations they represent, and the roles they play.

## Finding a link-person

Ask whether you, and anyone else interested, could meet beforehand with someone who already attends the meeting so that you get a better sense of what happens and what it is useful to know more about.

# Practical help

The person organising the meeting should be able to offer practical support in the following areas:

- expenses such as travel or childcare
- using office equipment such as phones and computers
- information on how to get to the meeting
- providing interpreters and different formats for information, for example on audio-tape or computer
- support with travel arrangements, and access to buildings and toilets if you have difficulty walking or use a wheelchair.

See pages 11 to 13 of the general 'checklists for meetings' for fuller details.



# At the meeting

## Introductions

There will probably be brief introductions at the beginning of the meeting. You may find it helpful to prepare what you are going to say about yourself.

## Breaks

There should be adequate breaks. However, other people's ideas on what is adequate may not match yours. Possible ways of handling this include:

- ask beforehand or at the start of the meeting when the breaks will be
- suggest a time, perhaps 10 minutes at the end of every hour, or a 20-30 minute break if the meeting lasts over 3 hours
- check if there's a topic which is not too important to you which would allow you a quick break.

During a break:

- get up and move about the room if you find this more comfortable
- drinks including tea, coffee and water should be available to you.



## Agenda/Minutes

Speak to the person chairing the meeting at the beginning about points you want to raise, especially if it is not clear where it can fit in the agenda. Consider keeping your own diary or record too, noting down the key points you and others made on the issues important to you, and the action agreed.

## **Contributing to the meeting**

At many meetings people speak 'through the chair' - everyone directs their comments to the person who is chairing the meeting. In other meetings the discussion is more general, and comments in response to something someone has said are addressed directly to them.

Some people feel that speaking through the chair is an outdated way of having a discussion. Other people feel more comfortable fitting in with the approach that everyone else adopts. Listen to how people make their contributions at the meeting you are at. This is also something you could check out beforehand with the person who set up the meeting.

## **Not feeling part of the meeting**

You may feel that you are not truly part of the meeting, more there as a token gesture. These suggestions may help:

- prepare well for the meeting to increase your confidence
- make general, wider points about how a group of people are affected, going beyond one person's experience.

If you are still not feeling part of the meeting talk to somebody who you trust, may be someone who attends too or a friend from outside the meeting. They may well be able to give you ideas about what is happening or what you could do differently. Alternatively speak with someone who has experience of leading meetings; perhaps someone from a local community group or from your local Council for Voluntary Organisations.

## **Working in pairs**

If someone else who is in touch with health services or who is a relative of someone using services is going to the same meeting as you, think about how you could work together at the meeting:

- sharing out the topics on the agenda between you
- backing each other up on a point(s) that needs to be made strongly.

## People in touch with health services and relatives of those using services: can they speak for each other?

Many people feel strongly that only people who have experience of an illness can describe and comment on what it is like to use health services. Relatives and friends have their viewpoint which is valuable, but different. Other people think these two groups of people have a shared interest and voice. For this reason, some formal meetings include both a service user and a family member.

If you find yourself speaking on behalf of someone from the other group of people, perhaps because they cannot be there:

- say if you know an issue is important to the other person
- note when you are drawing on your experiences and when you are drawing on the other person's
- don't claim to speak for the other viewpoint if this is something that is important to your situation
- if other people comment that you are giving 'the service user and carer view' explain if you feel that you cannot do this
- encourage the meeting to formally seek the views of those absent
- if you know the other person has strong or different views on a subject, suggest the discussion is postponed.



# After the meeting

## Getting support

Meetings, and the travel to and from them, can be hard work so it is important to have space to wind down afterwards. The issues raised can also bring up strong feelings which you may need to talk over with someone else.

This can be with someone in your own network or with a friend or relative.



*‘It is a big responsibility, going to a meeting at the health board to speak up for other users. It helps a lot when you know you can telephone someone that evening and say ‘it was awful’, or ‘it went ok’, or whatever.’*

## What was the meeting like?

- is there anything you want to get explained or to check up on?
- was the meeting useful for you?
- are the issues you and others have raised being addressed?
- is there anything that would help make the next meeting more productive?

## Feeding back

What are the arrangements for you to report back to your group or network?

How will you follow up any issues outstanding from the meeting to take to the next meeting?