

checklists for meetings

Involving people who are in touch with health services, and the family, relatives and other people who care for them, in planning and running services is crucial. Most people are trying to do this well, but find it is harder than they - or other people - expected.

These checklists are intended as a practical resource for all people who use or are interested in health services and who go to meetings about health services or related issues.

They are also a resource for people who set up meetings that will include patients or service users or their families and friends.

Introducing Partners in Change

Partners in Change was outlined by the Scottish Executive in section 5 of the Health Plan, and is one of several ways for people in touch with health services and the public to have their say in the National Health Service (NHS) in Scotland. The project aims to help develop local arrangements for involving people who use health services. By 2002, there will be at least one Partners in Change project in each NHS Board area.

There are 2 stages:

- a planning/development year until early 2002
- then implementation of the projects from 2002 onwards

Why we developed the checklists for meetings?

There are many ways for people to contribute their ideas and experience about health care and other services.

One way is through formal meetings - usually meetings set up by the NHS to which people using health care, relatives of those using health care, or representatives of both groups are invited. People have told us that they often find these meetings difficult: they find it hard to raise matters important to them. This pack is intended to help make this type of meeting less confusing and more productive for everyone involved.

During the development stage, Partners in Change will provide training, packs and practical suggestions about other ways for people to participate. For further information on these resources contact Partners in Change - see back cover for contact details.

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.

How we developed this set of checklists

This pack was first put together by people involved in Allies in Change. Allies in Change is a project to promote the involvement of people who use mental health services and their carers. The initial ideas came out of discussions people in touch with services, relatives of those using services, and staff.

Many people commented that the suggestions also applied to work to involve people who used other types of health care. We have developed these general checklists, and included suggestions from people in a wide range of settings and roles.

We are grateful for the help of people in:

- patients' and relatives' support groups
- NHS boards
- NHS trusts
- local authorities
- voluntary organisations.



How to get more copies of this set of checklists

The Partners in Change team is sending out copies of the set of checklists to national and local patients' and relatives' support groups, local health councils, local and national involvement co-ordination projects, Community Care Forums, NHS Boards, NHS Trusts, local authorities and voluntary organisations.

Further copies are available from Partners in Change - see back cover. You may also photocopy the checklists to pass to others.

Introduction to the checklists

This booklet is part of a set of four checklists which together provide a comprehensive guide to taking part in, organising and leading meetings which involve people in touch with health services, their relatives, and the public.

This 'checklist for meetings' is an introduction to the general issues and themes to consider when getting involved in such meetings yourself or when supporting people in getting involved. These issues include:

- avoiding jargon
- clarifying roles at meetings
- differences between people in touch with health services and relatives of people in touch with services
- working in pairs
- using substitutes
- expenses
- practical concerns
- what to do if someone raises a personal experience or becomes upset

The other checklists look at more specific aspects to do with individuals, groups and people organising meetings.

checklist 1 provides:
information for individuals: both for people who are experienced and for those who are new to attending formal meetings.

checklist 2 provides:
information for groups nominating individuals to represent them at meetings.

checklist 3 provides:
a starting point in good practice for people setting up and convening meetings involving people using services and their relatives.

The aims of the checklists

This set of checklists is concerned with meetings that are about planning and developing services or examining wider issues facing those services, rather than about one person's care. Partners in Change is developing another pack which will draw together experience and ideas on planning your own care.

The key questions that these checklists will help everyone think about are:

- what makes people feel more comfortable in meetings?
- what makes people feel better able to contribute to meetings?
- what will help people make a significant impact on decision-making process?

Some of the ideas in these checklists are particularly related to the circumstances of people with particular health problems. Much of it, however, is drawn from evidence of good practice in organising meetings and how best to enhance the contribution of any and all participants.

How you might use this set of checklists

Groups that support people using services or relatives of people using services can:

- use the set as a resource for their members
- talk about the information in checklist 2 within the group
- make sure that people going to meetings have a copy of the set
- meet with staff in the local health services to discuss the ideas in these checklists.

Individuals going to meetings about services can:

- use checklist 1 (see page 4) to plan their approach to a meeting
- use checklist 2 (see page 4) to think about how they can represent a group at a meeting
- ask the people who organise the meetings they attend to look through the checklists too.

Staff in large organisations who are involving people using health services and others in meetings can:

- use checklist 3 (see page 4) to help them think about how to involve those people
- send a copy of relevant sections to colleagues - for example administrative staff who send out papers for meetings
- discuss with each person who attends a meeting what helps them prepare and feel confident in joining in
- make sure that everyone who attends a meeting has a copy of the set of checklists
- give the checklists to any group who supports people coming to meetings.

Directors and senior staff leading health and social care organisations can:

- make sure the staff in health organisations who are interested in involving people have a set of checklists
- send copies to colleagues involved in training, inspection, quality assurance and the commissioning or purchasing of services
- if the organisation has a 'good meetings guide', consider how the suggestions in here can be incorporated
- use the ideas to think about the issues people using health services might raise
- use the ideas to think about how to work with other organisations to develop a common approach to meetings.

General Issues

This introduction to the general issues looks at the themes and situations that often crop up in or through meetings. It will encourage discussion of what helps meetings work well particularly for people who are in touch with health services, their relatives, and interested members of the public.

Avoiding jargon

The use of jargon is a key element in preventing people from participating fully in meetings. It is important to:

- ensure agendas and minutes are written in readable language which is clear and to the point
- encourage participants in the meeting to explain unfamiliar or technical terms
- discourage use of abbreviations
- add a glossary to the minutes of any terms used there.



“ I was feeling very much at sea. And this man was going on and on about stuff in words I didn’t understand. I caught someone’s eye and realised they were struggling too. After that we took it in turns to ask about things that weren’t clear, which felt much better. ”

Clarifying roles at meetings

People who are at a meeting as someone in touch with health services or as a relative of someone using services may be there **either** as a representative **or** as an individual in their own right.

Will the people attending the meeting:

- bring either a general service users' perspective or a relatives' perspective without covering the wider experience of others
- draw on the wider experience of all people who have a connection with health services
- formally represent people in touch with health services or relatives, and report back to the wider network in that area
- represent people from a group which supports people - or relatives - in a particular situation or with a specific health difficulty
- cover the interests of all people with health problems, or all carers, in a particular area?

It is important for everyone at a meeting to understand the role of everyone else.

Is someone a representative or a delegate?

The difference between a representative and a delegate is that a representative is informed by the collective view but is empowered to act on his/her own judgement, while a delegate acts on collective instructions. So, for example, an MP is a representative. People in touch with health services or a relative of someone using a service who are from a particular group usually act as a representative rather than a delegate.

The distinction between a representative and a delegate is important. People setting up and taking part in meetings should recognise and respect the difference between the two roles.

It is also helpful for professionals who take part in meetings to explain whether they are a representative of or a delegate from their organisation, or if they are there as individuals.

Differences between people in touch with health services and relatives of people in touch with services

Many people feel it is important that people who use services and relatives do not speak for each other as a matter of course. Other people feel that both groups of people share a common view. If someone is ever asked to take on representing the viewpoints of both people who use services and relatives of people using services, this should be discussed with him or her beforehand.

Working in pairs

Many people feel that there should be a balance between the numbers of people at a meeting in a paid role and those representing people who use services and/or relatives. In practice, however, there are often a lot of staff from many organisations but only one or two others.

In these circumstances people who use health services and relatives often prefer to work in pairs of two users or two relatives. It is therefore important to check out the possibility of two people coming to the meeting together.



Using substitutes

There will be times when the nominated person who uses health services or relative cannot attend meetings. So people arranging meetings should allow for substitutes, in the same way that a colleague will cover when a member of staff cannot attend. The person setting up the meeting should discuss with the service user and/or relative and with the individuals joining the meeting, how they want this arrangement to be handled.

It is helpful to send an extra set of minutes or papers to the person or group identified as the substitute, ensuring they are kept up to date.

Expenses

The payment of expenses is a crucial issue as many people attending meetings are not able to claim expenses in the way that staff can. Further, some people in touch with health services and some relatives of people with long term or serious health problems live on benefits or have lower than average incomes.

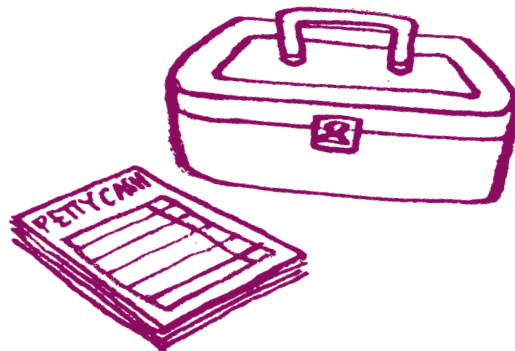
Points that need to be clarified include:

- how the expenses will be met, and what information is required when the person claims?
- will payment of expenses be in advance or on the day?
- will expenses cover the costs of lunch, parking, drinks from the coffee machine or cafeteria?

Participants in meetings may need to be paid expenses for:

- travel
- childcare and/or other care responsibilities
- other out of pocket expenses, for instance photocopying.

People attending meetings may also need access to telephones, stationery, a photocopier, computers and relevant software to keep in contact with the people they represent and to be active in the work of the committee. Many people who take part in formal meetings are in contact with a group supporting people in touch with services or relatives that is funded to provide this type of input. Some people, however, will be from smaller groups that do not have these type of resources, or are meeting these costs out of their own pocket, and will need to have such expenses met.



It is important to have a budget assigned for all these expenses and for the management of this to be delegated to a named individual. Always be clear in advance who will pay for what.

Asking for expenses as an entitlement is the responsibility of the group nominating the person to represent them. Ensuring that the expenses are paid promptly is the responsibility of the person organising the meeting.



Making payments

Sometimes the agency making payments cannot handle cash. It is possible to transfer funds to a voluntary organisation who can provide cash on the day. Most organisation, however, have a 'petty cash' system.

‘ Everyone else at that meeting is being paid to be there. It’s taken me 10 months just to get my travel expenses paid. And then they say, ‘It’s so useful having a carer here. We value your input so much.’ Aye, sure they do. ’

Practical concerns

Information sent out about the meeting should include:

- details and a map of how to get there
- details of parking, bus routes, train times
- an internal map of the building where the meeting is held.

Send out the information well in advance whether to people in touch with health services, relatives or staff.

When selecting a venue consider the following:

- access for people who use wheelchairs or have difficulties with mobility
- likewise, access to toilet and disabled toilet facilities
- any concerns about safety in or around the building
- whether public transport runs close by and regularly at that time of day.

Is it helpful to anyone at the meeting to have:

- written materials in large text, other languages, on audio-tape, in Braille, or through a screen-writer?
- support with written materials due to difficulties with note taking, reading or writing?
- signing interpreters, lip speakers or an induction loop at the meeting?
- an interpreter for someone who's first language is not English?

Think too about any additional support people might need such as:

- particular help with transport because of a disability
- childcare or other services to help with care responsibilities
- induction training so people understand the context of the meeting
- training in skills for taking part in meetings.

These practical concerns can be relevant to anyone who is attending the meeting.

What to do if someone raises a personal issue or becomes upset

Two potential situations that can cause concern to anyone attending or organising a meeting are how to work with someone raising a personal issue, and what to do if anyone becomes upset. Aspects that worry people include embarrassment - what to say? will it make things worse? and how this affects confidentiality.

This section sets out what some people in touch with health services would regard as helpful and good practice on the part of people running meetings. The suggested ways for people to respond apply to all the people who are present, not just the person who is chairing the meeting. We all have a responsibility to make other people feel included and welcome, and to help each other to make our points in an effective way.

If someone raises a personal issue

- recognise the anger and the hurt if these are expressed, and the legitimacy of these feelings
- listen for the general point, and help the person to draw it out if they need help with this
- encourage other people at the meeting to develop the discussion of that general point
- confirm/emphasise to the meeting that what the person has said is in confidence to this meeting
- consider if this issue needs to be checked out more thoroughly before the next meeting
- suggest the person pursues the matter further with the support of others at the meeting.

If anyone gets upset

- recognise and legitimise their being upset, and try to deal with the underlying issue
- check out if something at the meeting has contributed - perhaps someone's approach or a simple misunderstanding
- if the person has come with a second person (see working in pairs on page 10) see how they can help
- suggest a break or time out for the meeting.

Afterwards:

- check the person is OK
- discuss with them if there is an underlying issue they could take forward
- be willing to talk over with them how they handle future meetings, if they want to talk about it.

‘ She’s been great. The first person to say ‘this is what I can do’, and then to do it. She doesn’t promise the earth, but she does keep her promises. ’

Please contact Partners in Change - see details below - if you would like:

- further copies of this checklist or others in the set
- copies of the set in an alternative format such as on audio tape
- copies in a different language.

You can also download these checklists from the Partners in Change page of the Scottish Human Services Trust website (www.shstrust.org.uk).



1a Washington Court, Washington Lane, Edinburgh, EH11 2HA

Telephone 0131 538 7717

Text telephone 0131 477 3684

Fax 0131 538 7719

Email pic@shstrust.org.uk

Web www.shstrust.org.uk

published December 2001