



Involving the wider community

Content notes

The Patient as Resource and as Citizen

2 Setting up groups

Participants often ask about setting up of groups. To arrive at the answer they need, some basic questions need to be asked. The function of the group will determine its composition, how members are recruited and what resources are needed.

Other issues may arise from bad experience like concerns about confidentiality, difficult patients, patients who only speak about their own problems or, increasingly, patients who want to change the agenda, write a new strategy or in some other way hijack the existing agenda or behave inappropriately.

There is a separate sheet on questions to ask that relate to all the following sections. These can all be turned into exercises so that the group can come up with the questions that they need to address to meet their specific needs.

What sort of group?

It is important for the participants when exploring answers to questions to first work on why, and what, the group is for.

One way to get the discussion going is to get the group to list the sorts of groups they are familiar with. What function do these groups serve? How does that fit in with what is needed in their area? What priority they would give to what sort of group? Different participants will have different needs and these change with development. A self-help group may become a fundraising group, which in turn may become a patient service review group.

Whatever group they are going to set up they will need to consider the basics. What is important is not what is set up, but that thought has been given to why and that the how follows the why.

Structure

The group may be a loose group that meets periodically or it may be more formal with a chair and minutes. Is it a public meeting or a committee style? Participants could go through the separate sheet as a way of clarifying for themselves which model is most likely to be best for their patch.

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educational programmes for people delivering healthcare

For example, an open membership can cause problems for a group, if there is no system for briefing the new members on the issues the group has already discussed. If however, the group is largely educational an open membership will work.

Recruitment

A self-help group will be different from a user-monitoring group but one may develop into the other. A self-help group may be advertised to all comers while a user feedback group may want a specific section of patients. It may want patients who have been treated recently, or it may want patients who are now out of treatment or a mixture of both.

Accountability

There are two crucial questions. The first is, are the participants of the group speaking as patients or are they speaking as representatives of patients? If they are as representatives, what forms of accountability are in place? Are there systems in place for confirming that the views and opinions, choice and options can be verified or quantified in relation to the rest of the patients or population?

Equally important is the issue of decision making powers. Is the group going to take decisions or is it an advisory or consultative body? Many problems will be solved if these two questions are addressed before a group is set up.