



## **Involving volunteers and groups**

### **Questions to ask when setting up a user group**

Patient user groups are one of the ways in which the voice of the patient can be heard and acted upon in a constructive manner. With careful planning, commitment and enough time, user groups can provide a valuable resource for both the Trust, the staff involved and, eventually, the patients themselves.

Here are a series of *questions and options* to consider when setting up a group.

They are based on discussions with St. Mary's Colorectal Cancer Services patient user group which has been running since September 2001.

<http://www.4ps.com/pfa/evidenceinvolve2.htm>

#### **Think point**

It is important to bear in mind that the way this group was set up is not the only way, and may not suit every context

#### **There is no right answer**

It is important to know *why* you want to set up the group and that you have considered the

- range of functions
- options for membership
- forms of meetings
- accountability
- ways of sustaining and renewing interest
- process issues.



## **Clarify the function of the group**

It could be a

- support group
- user feedback group
- user focused monitoring, e.g. **Sainsbury Centre for Mental Health User Focused Monitoring Project**
- consultative, advisory or reference group
- audit group
- fundraising group
- group providing service to patients
- patient education group
- a combination of several of these functions.

Remember that a patient or member of the public who gets involved as a volunteer may be tomorrow's chair of your consultative group, provided their experience is empowering and developmental.

### **Think point**

Function influences membership

### **How should members be recruited?**

By

- asking people whom you know will be good or who are interested?
- randomly selecting from a database?
- asking all patients if they will participate, getting nominations and holding an election?
- holding an open meeting and getting nominations for a committee?
- selecting people who have specific skills or from specific sub-categories of patients?



## **Who should be in the group?**

You might consider

- all patients free to self select
- people who live in a particular area
- whether staff are eligible
- patients who have recovered following treatment
- patients in active treatment
- representatives from advocacy and community organisations
- recruiting people with special skills
- having a proportion of places reserved for each subset of patients, staff, advocacy organisations (stakeholders).

## **What decisions will the group be expected to make?**

Answers to this question will help you decide on membership.

## **Do you want members of the group to speak *for* patients or speak *as* patients?**

- a membership of patients may be appropriate for a support group
- people who can represent patients and the public may be more appropriate for a reference group.
- if you want to set up a fundraising group it makes sense to involve people with a background in fundraising
- if setting up a user monitoring group, in addition to patients you may need someone with research skills.

## **Forms the meeting might take**

This is linked to how you have chosen the membership.

It could be

- an open meeting - everybody who comes can speak
- a closed meeting - members of the group only
- a mixture of both, part closed, part open



Think about assigning a special role for people coming for the first time

- giving them a “buddy”
- giving them observer status.

### **Think point**

How will decisions be taken - consensus or majority opinion?

### **Forms of accountability**

- hold regular meetings for all eligible patients
- produce a newsletter about the group's activities
- hold an annual general meeting when membership and representation is reviewed
- the user group could be linked to local or national advocacy agency or voluntary organisation
- members should be expected to reflect on how representative their views are.

### **Terms of membership**

- specify a fixed term for members
- welcome new members but they must have to have induction or a training period
- carry out an appraisal of members' contribution at periodic intervals
- ensure open access and exit without pressure
- new members can be actively recruited in order to meet gaps in skills or experience of the group.

### **Process Budget funds for**

- hiring meeting rooms, stationery, members' expenses, postage, refreshments, travel allowances
- treats, flowers, cards for members who are ill etc.

# 4<sup>Ps</sup>

## *Development programmes for people in healthcare*

### **Think point**

Are you going to pay an attendance allowance? If so get advice on payments to people on benefits

### **Who should chair?**

- patient members?
- staff members?
- joint?
- rotating chair between patients and staff?
- an independent person?

Are you going to provide an induction programme for members?

What access to training can you arrange for skill development?

### **Think Points**

- user groups are about involving
- plan to actively involve all members in the running of the group
- patients have a myriad of skills and competencies they can bring to the group that staff may not have: computing, writing, advocacy, secretarial, chairing, minute taking, and, or, experience of the organisations as users. They may also have time!

### **Exercise**

Re-read the St. Mary's Colorectal Cancer Services patient user group case study

<http://www.4ps.com/pfa/evidenceinvolve2.htm>

- think how they answered these questions
- in terms of the routes they took, what do you think were the benefits and problems?
- construct your own answers
- write down the reasons for the form and structure you have selected

# 4<sup>Ps</sup>

## *Development programmes for people in healthcare*

- decide if you want the group to have terms of reference and an operating code, or you want a loose organic structure.

Remember the process of setting up the group will shape its success. The structure can be changed, the functions added to - provided people feel they have been able to contribute