

4Ps

Development programmes for people in healthcare

Involving volunteers and groups

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 Hospital Trust, the staff involved and, eventually, the patients themselves.

Questions to ask when setting up a user group

There is no one right answer

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

- the range of functions
- the options for membership
- the forms of the 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. link to 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/member of the public who gets involved as a volunteer may be tomorrow's Chair of your consultative provided their experience was empowering and developmental.

Think Point

Function influences membership

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How should members be recruited?

- ask people whom you know will be good or who are interested
- randomly select from database
- ask all patients if they will participate, get nominations and hold an election
- hold an open meeting, get nominations for committee
- select people who have specific skills or from specific sub-categories of patients

Who should be in the group?

- all patients free to self select
- people who live in a particular area
- staff are eligible
- patients who have recovered following treatment
- patients in active treatment
- advocacy and community organisations
- Recruit people with special skills
- 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?

- 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.

- open meeting, everybody who comes can speak
- closed meeting members of group only
- mixture of both, part closed, part open
- assign a special role for people coming for the first time,
 - give them a “buddy”,
 - give them observer status

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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
- members should be expected to reflect on how representative their views are
- 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

Terms of membership

- specify a fixed term for members
- welcome new members but they must have to have induction or 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.

Think point

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

Who should chair

- patient members
- staff members
- joint
- rotating chair between patients and staff

Are you going to provide an induction programme for members? What access can you arrange for skill development?

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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:
 - computer skills, writing skills, advocacy skills, secretarial skills
 - chairing experience/ skills in minute taking
 - experience of the organisations as users
 - time

Exercise

Reread the St. Mary's Colorectal Cancer Services patient user group case study Link to <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
- 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.