

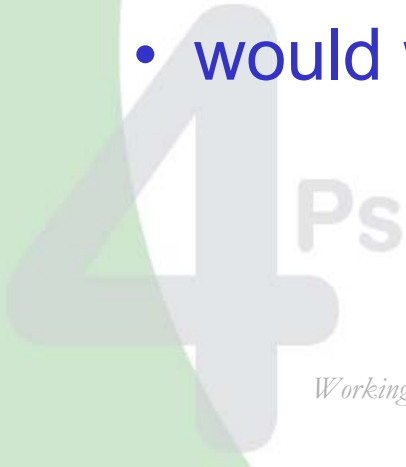
Public Involvement

Setting up groups



Audit of Groups You Already Work With

- brainstorm around the room
- share the good experiences of patients contributing to care
- can any of the rest of us learn from this?
- would we like to know more?



Representation FAQs

- how do you get users?
- who do you get?
- are they representative?
- whom do they represent?
- how are they held accountable?
- confidentiality?
- how do we measure benefits?

Types of Groups

- self Help Group
 - support Group
 - fundraising Group
 - service provision
 - advocacy Group
 - campaigning Group
 - interest Groups
 - representative Groups
- AA
Cancerlink
local charity
British Red Cross
Age Concern
Animal Rights
Consumer Assoc
BMA

Department needs

What kind of involvement?

With a magic wand, list what you would ideally like from a users group



Patient as Citizen

Issues

- clarity of function
- selection of representatives
- accountability
- structural clarity



Issues in group formation

Selection
Representation
Accountability



Setting up the Group

- what do you want it for?
- support for you
- to tick a box
- to be a resource to other patients
- to provide feedback
- to share decisions with you?
- what decisions?

(“the ordinary patients”)

Politics of Presence

Speaking as a Patient

Anecdotes/individual experience

Value depends

on aims

on individual's personal skills

insights may need to be checked



Politics of Representation

Speaking for patient/user/carer

Members from interest group may be

Mandated delegate

Representative with discretion



Types of Membership

1. Representatives of interest groups/ stakeholders.
2. Individuals with relevant expertise, not representing specific interest group.
3. Explicitly unaffiliated.

Powers of Members

1. Formal members, formally selected, who can vote.
2. Co-opted members, selected for expertise who can vote.
3. Ex-officio members, who can speak, but not vote.
4. Observers, who can attend, but neither speak nor vote.

Recruitment of the Group Who?

- existing patients
- past patients
- relatives, carers
- people with special skills /professionals
- people who share the aspirations of the group



**Open meeting or
Executive plus**

Patient Members

1. Never experienced problem/disease.
2. Now experiencing problems disease.
3. Had problem, now past.



Who Should Run the Group?

Varies depending on age of group.

Could be

- you
- elected/selected chair
- delegate from local voluntary organisation
- other member of staff.

For Consideration

Transport

Venue

Fees

Honorarium

Covenant to charity

Budget for group

Other



Embed in System

- Consider having a titular head
CEO/Lead Consultant -get them to make an appearance periodically. Influencing up
- Ask key people to present as way of informing/ influencing /influencing laterally
- Get your action points on to other agenda's
- Support for you/ your members.

Protocols

- agree aims and tasks of group
- agree membership/observers
- confidentiality/circulate widely
- agree roles

INVOLVE

agree what happens when.... death, illness etc

- review dates for all of above.



Don't have to do it all at once

But

- be clear about the options and why you took a particular pathway
- you don't have to do it all yourself

INVOLVE

Others will help including with their mistakes.

Dealing with success

- visitors can motivate but they cost
- have a member tell them about the success -the PR role
- write up a summary - the person in the group who most likes to write
- have open days when members are present
- have a donation fund for....



Projects

- itemise the work in progress
- document the needs
- celebrate the success.



Evaluation

- enhanced clarity about functions and forms of public involvement
- confidence to set up a group
- confidence to challenge why a group want a patient member
- agree a protocol for recruiting and introducing a member to a policy or planning group.