



Top tips

for effectively involving and recruiting patients & carers

Involving patients and carers

Approaching patients & carers...

- Have clear aims and objectives - this will enable patients/carers to make an informed decision about participating
- Be clear about the role you want them to play - do you want them to offer a personal perspective or are you asking them to work with other patients to present a broader view?
- Clearly explain the constraints that operate and the potential outcomes you hope to achieve
- Involve more than one patient/carer - this avoids tokenism and will allow them to offer each other support and encouragement
- Be aware that involving patients who have recently or are currently using the service may present difficulties to both the patient and health care professional
- Identify patients/carers who will help you meet the aims of your initiative
 - target patients/carers' skills appropriately
 - some patients/carers may only want to give their views on a one off basis others may want to be involved longer term
- Involving patients/carers early on in the project will enable them to influence the agenda

Consider the most suitable method...

- Ensure that you have a range of views which reflect those of the patients/carers likely to be affected by the outcomes of your project
- Consider using a variety of methods to connect different types of patients/carers. For example, a focus group methodology will preclude the housebound, so think about supplementing focus group work with individual interviews with the housebound
- Allow plenty of time if you are using several approaches, it is worth the effort to make sure you don't end up with inappropriate services
- Make sure the patient/carer you are working with are happy to take part in the activities you have planned

Induction and training...

- Provide some form of induction and training for patients/carers
- Provide training to the health care professionals who will be working with patients/carers on the project - consider joint training
- If you recruit patients/carers to interview other patients then consider what specific training and support might be required

Offer resources and support...

- Think about emotional support that patients/carers may need; the work might not be easy and mentorship may be appropriate
- Make sure that you provide appropriate access to information and resources i.e. contact numbers, library access, phone, computer and administration support, etc
- Organise payment and travel costs; wherever possible arrange payment on the day or before - this may help your attendance with those from the lower socio-economic backgrounds
- Childcare and respite care may be required

Access...

- Schedule meetings at times and places that are convenient to patients/carers
- Check that the meeting date is not going to clash with any religious or cultural holiday
- Make sure that your venue is accessible for those with disabilities
- Consider the need for interpreters for those from different ethnic groups or those with hearing difficulties

Before the first meeting...

- Provide adequate background information (send copies of previous minutes if appropriate)
- Provide information in user-friendly language
- Invite patients/carers to add items to the agenda
- Provide patients/carers with a contact number in case they have any further questions
- Arrange for someone to meet them and escort them to the first meeting
- Allow time to consult with other patients/carers and to have a system of 'feedback' in place

During the meeting...

- Review format of meeting - does it always need to be formal?
- Avoid jargon - verbal and written

- The chair is crucial in ensuring that patients/carers can actively participate in the meeting
- Think about different formats for meetings e.g. small groups
- Provide refreshments and consider special dietary needs or the needs of religious groups

After the meeting...

- If you agree recommendations which involve patients/carers make sure they happen
- Keep everyone informed of progress and developments and provide regular feedback on the outcome of any initiatives
- Allow sufficient time between meetings for patients/carers to consult with their peers
- Seek feedback from patients/carers about their involvement; look for ways of making improvements

Recruiting patients and carers

- Posters or information stands displayed in public areas can be used to advertise a project and attract volunteers
- In a hospital go to where patients are waiting
- Make use of contacts in the community e.g. health and social care workers
- Use the media: local press/radio/TV/ hospital radio and ask for volunteers or people with a 'story to tell'
- Think about your target groups and where they might be found e.g. libraries, local shopping centres, post offices, community centres
- Use the expertise of the voluntary sector where appropriate
- Contact groups in your local area: patient's associations, carer's forums, disability organisations, ethnic minority groups, faith groups, parent groups, community representatives and outreach workers
- Use local networks in the area - generally there are umbrella organisations with large membership of voluntary and community groups
- PALS manager may be able to help
- Use existing patient/carer representatives to recruit others
- Consider recruiting and training patients and the public to talk to others; people may be more willing to express their real views to their peers than to those who are involved in the service
- Hold local events e.g. coffee mornings, parties, galas, and meals

Checklist

- ✓ Involve patients/carers from the beginning and throughout every stage
- ✓ Are appropriate resources and support available to help you engage with patients/carers?
- ✓ Recruitment of patients/carers - how easy is it going to be to get a broad section of views? Where do you need to go to gather the information needed?
- ✓ Take time to consider the best methodologies that will give you the breadth of information/viewpoints from patients/carers that you need
- ✓ Take into consideration when involving patients/carers the four Rs: Remit, Role, Relationships and Responsibilities - is everybody clear about these?
- ✓ Capture lessons learnt as you go along (who did you involve, how and what worked well and what would you do differently?)

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