

Having a say in health:

guidelines for involving
young patients in
health services development

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SEPTEMBER 2002

These Guidelines have been developed from research funded by the Department of Health. They draw together advice for NHS staff from young patients and staff with experience of health service development projects.

Purpose of the Guidelines

The purpose of these Guidelines is to provide information to support NHS staff to involve children and young people – particularly those who have a chronic illness or physical disability – in local decisions about health services development.

Why involve young patients in service development?

Benefits for staff

Staff with experience of involving young patients draw attention to three benefits:

First, the intrinsic value of the points young patients make:

'The young people have so many worthwhile things to say, I'm really evangelical about it now. I feel that they really have a voice.'

(facilitator of young people's group)

Secondly, that staff cannot second-guess what really matters to patients:

'What I've learned is that it's important to find out what it is that patients actually want. Much as you think that you're a good doctor and a good communicator, often what is important to you is often the last thing that's important to the patients. To find out what is important to them and to deal with it will make them feel better.'

(consultant physician)

Thirdly, that experience of working with young patients can have a profound effect on the personal and professional development of the staff involved:

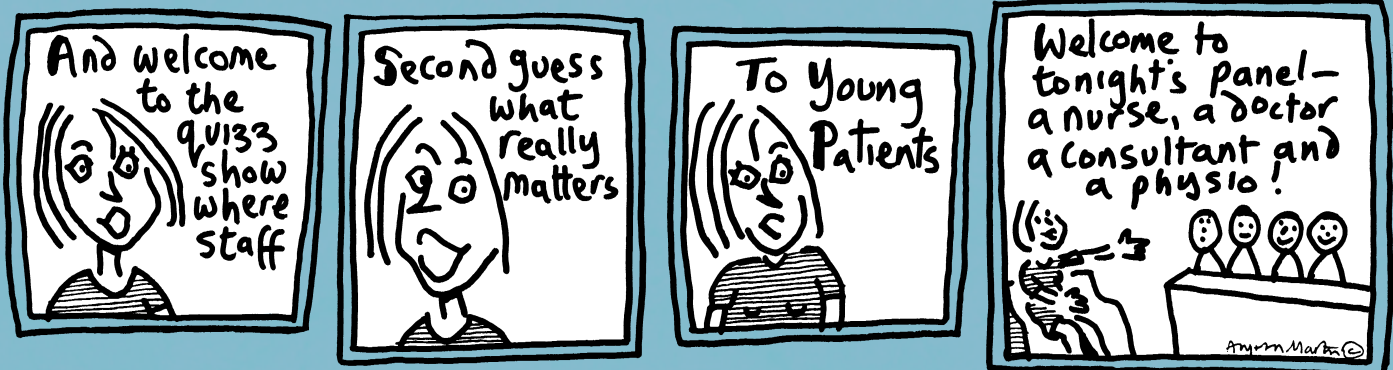
'It really did change my whole outlook on nursing... coming back onto the ward, my attitude and my practice completely changed... from that point on, I was the person who was always saying "Why are we doing this? Why do we need to do it like that? Have we asked patients what they want?"'

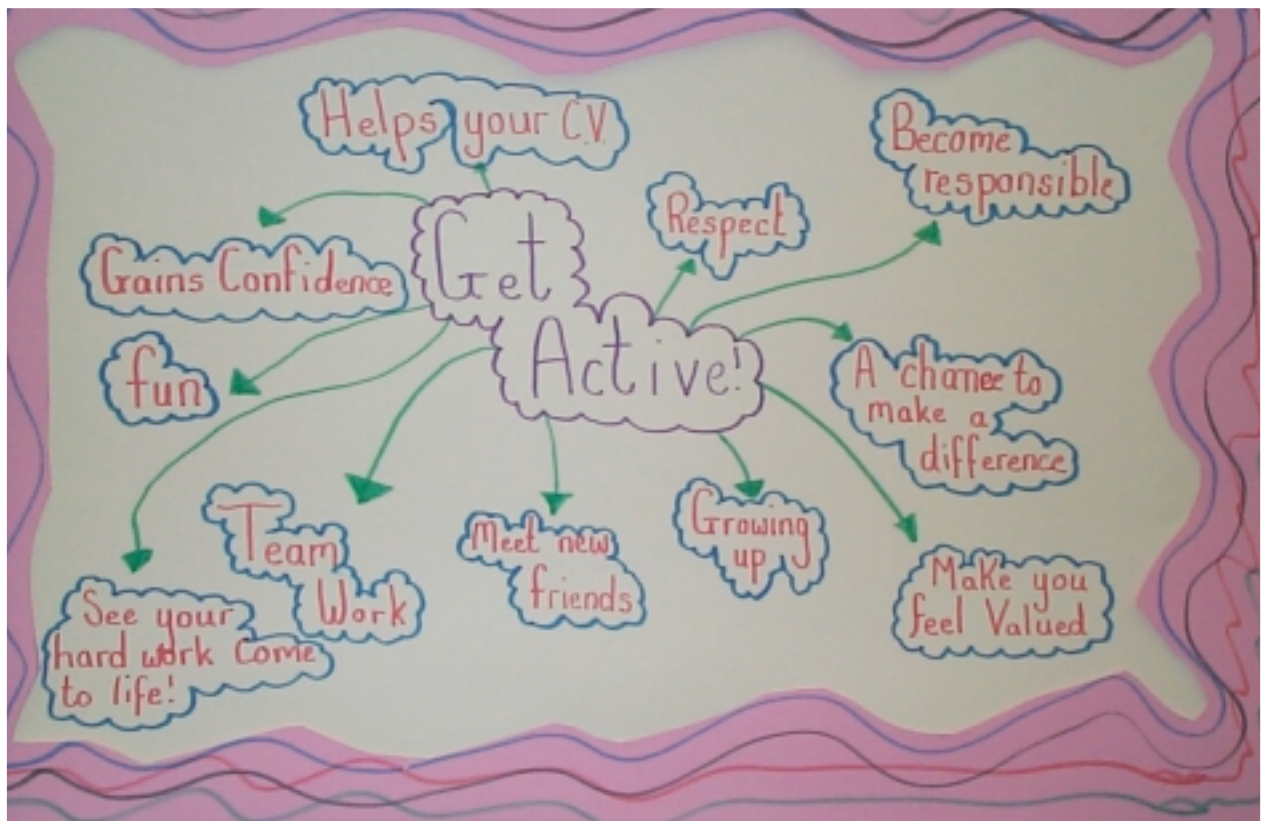
(former ward sister)

Benefits for young people

Young people report a range of benefits from their involvement in service development.

The two posters opposite were designed by eight of the young people who had taken part in the research and who came together in a workshop to develop these Guidelines. Their posters show the messages they would like to pass on to other young patients who may be approached by staff to take part in service development projects.





Poster designed by Paul Brittain, Chris Leckie, Ricky Scott and Rachel Wagner.



Poster designed by Craig Kane, Emma Pennington, Jenny Wiper and Tom Winlow.

Understanding motivation, approaching young patients and valuing their contribution

What motivates young patients to become involved?

Understanding motivation is important for staff in thinking how their project might appeal to patients. Young people say that they are motivated by:

- ◆ wanting to make things better for other young people.
- ◆ the opportunity to let staff know what needs to change.
- ◆ feeling confident that something will happen as a result.
- ◆ wanting to give something back to the staff.
- ◆ a challenge, a chance to do something different.
- ◆ feeling valued by having their opinions heard.
- ◆ something interesting to do in hospital – especially if it sounds like fun.

Approaching young patients to become involved

General advice

- ◆ get to know young people's interests and approach them individually;
- ◆ **always** check that the young person is willing to be involved:
'I hate it when people take things for granted...not everyone feels comfortable doing it.'
(young person aged 18)

When to ask

- ◆ ideally, consult young patients while at hospital because:
 - they are bored and have time to do it;
 - when not in hospital, it is harder to think about what needs to change:
'Being asked in hospital is better because when you're actually there your memory of what it's like doesn't falter.'
(young person aged 13)
- ◆ be sensitive about timing: do not approach someone who is undergoing treatment, in pain, if they have just had bad news, or just before exams or results.

What to say

- ◆ explain what you want, and in a straightforward way.
- ◆ make it clear that the young person can opt in and out at any stage.
- ◆ make it clear (as appropriate) that it will be anonymous and confidential.

Valuing young people's contribution

- ◆ provide reassurance:
'A lot of young people think that it won't make a difference, that they won't be listened to... I think that reassurance is a huge part of consultation. You have to feel that your opinion is valued and will be considered.'
(young person aged 18)
- ◆ 'payment': young people advise that, if you want to offer money, do so **after** people have agreed to take part. Only if involvement is high and over a period of time – such as working in a group project – is 'payment' needed. Treats such as trips and meals out make young people feel just as valued as cash.

The process of consultation: what works when?

General advice: topics

- ◆ a starter list of topics can be useful:
'... because for young people to pluck things out of the ether is a bit difficult.'
(young person aged 18)
- ◆ the list should comprise other young people's ideas:
'... so they could pick from what has already happened elsewhere and add their own ideas.'
(young person aged 15)
- ◆ young patients need to know that they can add issues important to them:
'They weren't asking the right questions, when you're in hospital you don't care about the colour of the duvet cover, it's OK to ask about those things, but they should be asking about other things too, like privacy.'
(young person aged 17)
- ◆ young patients need information about any topics which are 'off-limits': for instance, health and safety restrictions on bringing in food and using mobile phones may be obvious to staff but need explaining to patients who want a more homely environment.

General advice: methods

- ◆ There is no 'one right method' to consult young patients, for two reasons:
 - different methods suit different people: written methods do not work for people who cannot read or write well, or who do not like writing. Shy people do not like group work. If staff offer a **choice** of methods, more patients may be happy to take part.
 - different methods suit different purposes: consider the 'fit'.
- ◆ It is important to find methods which 'feel right' for young people. The rest of this section outlines advice from young people and staff on when and how to use a range of methods for involving young patients.



The process of consultation: what works when?

Written methods: Questionnaires

Advantages

- ◆ a quick and easy way to get information from lots of people.
- ◆ if anonymous, people can say what they think.
- ◆ can be used for routinely obtaining patients' views (*see box*).

Patient discharge questionnaire

The young person can reflect on their whole experience, and it may be easier to be honest about any criticisms; **but** a leaving questionnaire should not be the only consultation mechanism, as it does not give the young person an opportunity to have any concerns resolved during their stay.

Disadvantages

- ◆ the patient cannot ask for clarification.
- ◆ the response rate can be poor.
- ◆ can seem at odds with the aim of **involving** patients:
'I find questionnaires cold and faceless. They have their value, I suppose, but they don't have the same feel for working with users.'
(*senior nurse child health*)
- ◆ unsuitable for finding out how people feel, what they want to change and why: for patients who like writing, consider letter-writing instead (*see box*).

Letter-writing

A staff nurse asked teenage in-patients to write her a letter about what it was like to be on the children's ward and how they might like it to be different. She had a good response, and the letters revealed common concerns, which gave her the enthusiasm to press on and set up an adolescent unit.

Advice

- ◆ publicise the questionnaire, explaining what you want the information for.
- ◆ give out questionnaires in hospital, where patients are a 'captive audience'.
- ◆ make it clear whether it is anonymous.
- ◆ keep it short: should take no longer than 10 minutes to fill in.
- ◆ involve young people in designing questionnaires (both content and style):
'We got a lot of questionnaires back and I think that was because young people put the questionnaire together. It makes a difference to how you ask the questions and to the presentation, we used a lot of pictures.'
(*young person aged 17*)

The process of consultation: what works when?

Verbal methods: one to one

Advantages

- ◆ the patient can ask the questioner for clarification.
- ◆ more personal than a piece of paper, you know someone is listening.
- ◆ can find out a lot (delve deeper/ask why/find out feelings).
- ◆ easier than a questionnaire to say what you mean, to get your views across.
- ◆ more reliable than groups for finding out the individual's own view.

Disadvantages

- ◆ cannot develop own ideas via discussion (as in a group).
- ◆ whether or not the young person knows the questioner can be a problem with some topics (a reluctance to criticise someone you know and like; or a reluctance to talk about personal matters with someone you do not know).
- ◆ time-consuming for staff to talk to patients.

Advice

- ◆ consider a questioner from another department or from outside the organisation so that young people can criticise staff if they need to.
- ◆ a conversation is better than asking direct questions: no right or wrong answers, and young people can raise topics important to **them**.
- ◆ keep clarifying what is being said so there are no misunderstandings.

Verbal methods: group work

Advantages

- ◆ different viewpoints come together, can develop a compromise.
- ◆ not so 'full on' as one to one encounter: quieter people can 'hide' for a while.
- ◆ working together over time gives young people opportunities for deeper involvement and personal development through team-work, learning to compromise and sharing responsibility for action with adults.

Disadvantages

- ◆ joining a group is difficult for young people at risk of cross-infection (for instance patients with cystic fibrosis), or for those who lack confidence, or who think their friends would see it as a 'geeky' thing to do.
- ◆ groups can become too formal.
- ◆ groups can get stuck (at the beginning if the remit isn't clear; during the project if people don't come to meetings, or if the work gets very time-consuming).
- ◆ endings can be difficult (it can 'fizzle out'; feels hard to say goodbye).
- ◆ it can be difficult to achieve a representative group.

Advice

- ◆ experience shows that small groups (six or even fewer) can be a productive way of working with young people, since (a) the most committed people are involved – contriving a larger 'representative' group may backfire; (b) participants get to know one another, so can have good discussions yielding plenty of ideas.
- ◆ time is needed for social activities: at the beginning for group members to get to know

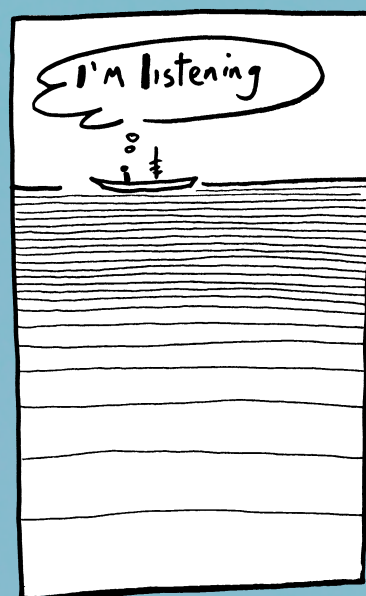
The process of consultation: what works when?

each other and feel relaxed; and later on for mixing hard work with some fun (this can help to counter the 'geeky' image too).

- ◆ groups need a good facilitator, someone who:
(a) will not seek to lead the group – but has strategies to help if the group gets 'stuck';
(b) will stick with the group over time, to keep motivation going; and (c) will take care about endings.
- ◆ a relaxed atmosphere at meetings is important: avoid sitting in chairs in a semi-circle; have drinks and snacks, maybe even some music.
- ◆ think about how to include people who cannot easily join a group: for example use an advocate or a video link.
- ◆ when an initial project comes to an end, consider the possibility of developing a standing group for consultation, such as a Hospital Youth Committee.

Developing a 'listening culture'

- ◆ young people and staff urge the development of a 'listening culture', so that young patients can raise issues when the time is right for **them**, not just when they are asked by staff through a one-off 'involvement project'.
- ◆ a 'listening culture' means that staff hear young patients' concerns and take them seriously by acting on them.
- ◆ do not assume that young patients will know it is OK to bring concerns to staff: *'Young people can feel intimidated to approach a member of staff to ask for help with a problem. It would help if staff said "if you have a problem you can come and talk to me, I'm willing to help." Then you would know that you can go to them.'* (young person aged 17)
- ◆ different patients feel comfortable with different staff, so encourage openness among all staff rather than designating one person with a 'listening' role.



Models of working

- ◆ involvement projects use different models of working, some facilitated by staff internally, others externally. Internally, staff may be working informally or as a formal part of their role. A formal involvement role might be on a temporary basis, such as a secondment, or permanent, such as a hospital youth worker.
- ◆ in practice, each model has pros and cons. Young people and staff agree that what is most important are the skills and personal qualities of individual staff, so that a young person can find someone he or she can relate to.

Staff skills and personal qualities

- ◆ an approachable adult:
 - is welcoming, and so makes the young person feel comfortable;
 - is interested in the young patient as a person, not just in their illness, and so is someone a young person can have an ‘ordinary chat’ with;
 - explains things in a straightforward way;
 - can help a young person express his or her opinions;
 - will not patronize or judge the young person, but take them seriously;
 - will take forward issues raised with the relevant staff;
 - will mediate where there is conflict between patients and staff.

Staff training needs

Involvement workers

- ◆ involving young patients in NHS service development is a relatively new activity. While ‘learning by doing’ is thought valuable, staff would welcome formal training, for instance in participation techniques.
- ◆ staff can feel isolated in this work, and would welcome peer support from peers in other organizations, ideally via an email network.

If other staff resist the idea of involving patients

- ◆ they could be encouraged by improved knowledge through a post-project workshop to explain how the project had been done, and what came out of it. With support, young people might be asked to feed back at such an event.
- ◆ hands-on experience can be a powerful way to change attitudes:
‘I really think you’ve got to do it [yourself], you’ve got to have that aah moment of enlightenment, I don’t think I’ll ever forget that moment.’
(former ward sister)
- ◆ the attitude of senior staff is likely to be influential:
‘If our clinical director hadn’t been keen then there would have been a ripple effect resulting in less commitment’
(senior nurse child health)

Non-staff resources to support involvement

- ◆ aside from staff time, a budget for other support is needed, in particular for group work. Examples include transport to meetings and ‘treats’, such as meals out, swimming or bowling trips, and/or money.

The importance of feedback to young patients

Feedback on results of consultation

- ◆ feedback is important for young patients, who want to:
 - know the views of other patients;
 - understand the reason(s) if their ideas for change are not taken up;
 - know what is planned to change and when.
- ◆ feedback can be crucial for shaping young people's attitudes to participation:

'I'd definitely do it again because I've seen the results and it encourages you.'
(young person aged 17)

'Although I've taken part I don't feel it was worthwhile, because there was no feedback from the questionnaires, I had no idea what happened...you wonder why you are doing it.'
(young person aged 20)
- ◆ some ideas for giving feedback: a noticeboard on the ward for young patients (not parents); a newsletter (ideally written by patients).

Feedback when young patients' ideas are not taken forward

- ◆ not all young patients' ideas are taken forward; if staff explain why, the decision is more likely to be understood and accepted. Without explanation, young patients may become cynical about the value of consultation.
- ◆ staff rejecting young patients' ideas for change is **acceptable** when:
 - the idea is clearly unaffordable and/or physically impractical – young people are clear about their responsibility to make reasonable suggestions:

'There's a lot of things you would like, but it's a hospital not a youth hostel. They only have so much money to spend on comfort, compared with things like medicines. So you have to think about the necessities, not the luxuries.'
(young person aged 17)
 - the change contravenes wider hospital rules and regulations;
 - different groups of young patients have conflicting ideas, and staff have to prioritise one group over the others.

The importance of feedback to young patients

- ◆ staff rejecting young people's ideas for change is **unacceptable** when:

- adults are simply refusing to take young people's ideas seriously:
'Some staff think that because you're young you don't know what you want, and others just ignore you completely.'
(young person aged 16)
- ward staff are supportive, but more senior staff block the modest resources required:
'I think she [staff nurse] does everything in her power but people above her stop things. People go on about the money, so why do they ask us the questions?'
(young person aged 16)

Feedback on progress in implementing change

- ◆ where changes are planned, give young patients an idea of the timescale and keep them informed about progress, including any delays (so that young patients are up to date and understand there is still a commitment to change):
'We always knew it wasn't going to happen overnight. The staff made that clear to us from the start, that it would be a gradual process by which they would get better and better. But we know that they took notice...'

'Because they actually showed us the plans of what the hospital is going to look like, so we knew they had been listening.'
(young people's group)
- ◆ tangible outcomes are very important for young patients as evidence that they have been listened to and their opinions taken seriously:
'When I first saw the [Adolescent] Unit it was a nice surprise because I hadn't thought they would pay attention to children's views. I was really amazed at the outcome we got... It's great, if I'm ill, so long as it's in a place like this I don't mind.'
(young person aged 18)

Development of the Guidelines

These Guidelines arise from research funded by the Department of Health's *Health in Partnership Programme* and carried out by researchers from the Social Policy Research Unit, University of York between 1999 and 2001. Following a mapping survey of involvement activity among Health Authorities and NHS Trusts across England, the researchers used a mixture of focus groups and individual interviews to seek the views and advice on involvement from 23 young patients and seven staff with experience of six local NHS service development projects. All the projects studied had taken place in hospital settings with patients aged between 13 and 20.

In preparing the Guidelines, the researchers are especially grateful to ten of the participants – eight young people and two staff – who took part in a workshop following preparation of a first draft of the Guidelines by the researchers. The workshop delegates were Pippa Bell, Paul Brittain, Donna Hilton, Craig Kane, Chris Leckie, Emma Pennington, Ricky Scott, Rachel Wagner, Jenny Wiper and Tom Winlow. We are also grateful to Angela Martin, who developed the cartoons.

The views expressed are those of the authors and not necessarily those of the Department of Health.

Further information

Copies of the survey report *Involving children and young people with a chronic illness or physical disability in local decisions about health services development: report on a national survey of Health Authorities and NHS Trusts*, by Jane Lightfoot and Tricia Sloper, are available from the SPRU Publications Office, price £3.50: telephone **01904 433608** or email spruinfo@york.ac.uk

A summary of the research and further copies of the Guidelines are available from SPRU's Publications Office and on-line: www.york.ac.uk/inst/spru

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