

Involving young people in health service development

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RESEARCH FINDINGS FROM THE
SOCIAL POLICY RESEARCH UNIT

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Increasing attention is being paid to involving NHS patients, including young people, in local service development. However, we know little about the views and experiences of young patients, especially those with a chronic illness or physical disability who have wide experience of health services, which could inform how best to include them in developing services. This project investigated how the NHS currently consults with this group, and sought to identify factors which could support and promote young patients' involvement in service development. The key findings were:

- consultation activities with chronically ill or disabled young patients are few in number, but encompass a range of ages and service settings and use a variety of methods. Young patients are rarely involved in subsequent decision-making to develop services.
- work with young patients appears to be developing independently from general NHS Trust strategies for patient and public involvement.
- involvement can bring a range of benefits for young people and staff.
- young people want a say over consultation topics and to be kept informed about the progress of their ideas for service change.
- there is no single 'right' method for consultation. In addition to more formal consultation, young people would like a 'listening culture' that encourages them to approach staff at any time.

Background and project objectives

Involving patients and the public in local NHS development is at the heart of health policy. Until recently parents' views have been sought as proxies for their children, but there is now an awareness of the need to listen to children and young people themselves. Although there is growing interest in **how** to involve young patients, we know little about their experiences of involvement, which could inform good practice. Chronically ill and disabled young people are frequent and long-term users of a wide range of health services, and potentially have much to contribute. We set out to investigate the involvement of this group in local service development, to:

- ▶ find out the current level and types of involvement activity with chronically ill and disabled young patients;
- ▶ identify factors which could support and promote their involvement, and develop guidelines for NHS staff.

Findings

Current involvement activity

In a survey of all health authorities and NHS Trusts in England, we identified 27 local projects involving young patients with a chronic illness or physical disability. Half were carried out with other agencies, 13 with some dedicated funding. The age of participants ranged between four and 21 years, with teenagers the

group consulted most often. All projects asked for young people's views; 11 also involved patients in subsequent decision making to change services. Consultation methods varied, including written and verbal methods and activities such as drawing and drama. Seventeen projects reported changes in services: improvements to the physical environment and to food quality were mentioned most often. We investigated six projects in more depth. *Box 1* gives an example of one of these.

Young people's involvement and broader NHS Trust strategies

All six projects had developed separately from the local Trust's patient involvement strategy. Strategy documents made no mention of young people. Project staff found Trust strategies limiting,

Box 1

A hospital recreation room for young people and an on-site youth club

The NHS Trust employs a full-time trained youth worker to befriend young patients, advocate on their behalf and involve them in service development. Talking with patients over time identified a need for improved recreational facilities. The hospital youth worker recruited a group of seven young people who raised money for and planned a recreation area on the renal ward and an on-site weekly evening youth club for any local young people with a chronic illness. Six members of the group have now formed an on-going Hospital Youth Committee.

as they focused on large-scale quantitative methods for finding out patients' views which they felt were not always appropriate for working with young people. Taking a separate approach meant that Trust user involvement staff were unaware both of involvement activity with young patients and of opportunities for learning to be fed back into general strategy development.

Benefits of involvement

While some young people were ambivalent, others reported a range of benefits from their involvement (*see Box 2*). Staff reported three benefits: that young people have worthwhile comments; that these cannot be second-guessed by adults; and that this could lead to significant change in their own professional behaviour:

'It really did change my whole outlook on nursing...I became from that point on 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?' (ward sister)

Box 2

Benefits of involvement for young people

- a chance to make a difference
- personal development (confidence, self-esteem, taking responsibility)
- feeling valued and respected
- useful in a cv for potential employers
- having fun and meeting new people (in group work)

Motivation for involvement

Young people were motivated primarily by altruism, both to make improvements for future patients, and to help staff. Taking part was also seen as useful in other ways, such as to let staff know what needs to change, and the challenge of doing something new. However, young people's decision to participate was conditional on feeling confident that they would be listened to, and so it was important for staff to provide plenty of 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)

Approaching young patients

Young people and staff felt it important to avoid assuming that all young people should 'feel lucky' to be asked to take part since, like adults, not everyone would be comfortable doing so. Young people needed a clear explanation of what was required, rules for anonymity and confidentiality, and the flexibility to opt out.

Consultation topics

Where adults decided topics, these did not cover everything young people thought important, such as doctor-patient communication and privacy. However, a 'starter list' was thought helpful to get ideas flowing, ideally with topics

identified by other young people. Young people needed to know that they could add extra issues important to them.

Consultation methods

Young people felt there was no single 'right' method, since young people's preferences differed, and different methods suited different purposes (see Boxes 3 to 5). Young people thought offering a choice of ways to take part would broaden the appeal of participation. Young people wanted a 'listening culture' among staff in addition to involvement 'projects', so they could approach staff with concerns at any time and be taken seriously. Young people could feel intimidated about approaching staff, unless they were reassured that this would be acceptable.

Feedback

Young people valued post-project feedback for three reasons: to find out the views of other young patients; to know what is planned to change and when; and to understand the reason(s) if their ideas for change are not taken up.

Whether or not feedback was given to patients could be important for shaping young people's attitude to future participation. Tangible outcomes were ideal but, where progress was slow, being kept informed was reassuring. Young people understood that not all their ideas may be taken forward, but wanted to understand why.

Box 4

Advice from young people on consulting one to one

- consider a questioner from another Department or organisation so that young people can criticise staff if they need to
- a conversational style is better than asking direct questions: there are no 'right' or 'wrong' answers and young people can raise topics important to *them*
- keep clarifying what is being said to avoid misunderstandings

Box 5

Advice from young people on using group work

- include social activities: to get to know each other and to mix work with fun
- good facilitation and a relaxed atmosphere are important
- think how to include people who cannot join a group: for example, use an advocate, or a video link
- when a project comes to an end, consider establishing an on-going group for routine consultation

Box 3

Advice from young people on using questionnaires

- explain what the information will be used for
- is it anonymous? Make this clear
- keep it short: no more than 10 minutes to complete
- involve young people in designing the content and layout

Implications

Policy

In not specifically identifying young people as service users, local NHS Trust strategies reflected national policy documents on user involvement, which assume that national policy and local strategies can apply across all patient groups. However, the evidence suggests that young people may have particular needs (for example, for reassurance) and value ways of working (for example, in small groups, with social activities) which are not readily accommodated within conventional adult-centred strategies. Identifying young people as service users in their own right and promoting ways of working appropriate to their needs could increase the quantity and quality of activity with this group of patients. In turn, learning from such work could feed into further strategy development for this and other patient groups.

Practice

Involving young chronically ill or disabled patients in NHS service development is at an early stage. While there is evidence of local consultation, patients' input beyond consultation into decision-making

processes is currently under-developed. Factors supporting involvement work include allocation of staff and other resources, giving young patients a say over consultation topics, offering choice in methods of working, and providing feedback after consultation. In addition to more formal consultation exercises, young patients would like a 'listening culture' to be developed, in which they can approach a staff member of their choice with their ideas and/or concerns. Achieving such a culture raises training issues for all staff working with young patients.

Methods

The project was funded by the Department of Health's *Health in Partnership* Programme and was carried out in two stages between July 1999 and January 2002. Stage One comprised a national survey

of Health Authorities (n=99) and NHS Trusts in England (n=410), to map current involvement work with children and young people with a chronic illness or physical disability. The data were analysed quantitatively and qualitatively. Stage Two was qualitative, comprising data collection from respondents in a sample of six local involvement projects drawn from the survey. The sample was selected to include a range of involvement methods. All six projects were in hospital NHS Trusts. Individual interviews and focus group discussions were carried out with 23 young people, aged 13 to 20 years, from the six projects. Seven local involvement project staff, and six members of staff with responsibility for patient and public involvement (one in each Trust), were interviewed. Following analysis of the data, eight young people and two project staff attended a workshop to prioritise the content of guidelines for NHS staff.

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Copies of the stage one survey report (Ref DH1786, price £3.50) and free copies of Guidelines for NHS staff are available from SPRU's Publications Office. **Contact** Ruth Dowling on 01904 433608 or email spruinfo@york.ac.uk

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