S | P | R | U
Social Policy Research Unit

DEPARTMENT OF HEALTH
'HEALTH IN PARTNERSHIP' INITIATIVE
Involving children and young people with a chronic illness or physical disability in local decisions about health services development

PHASE ONE:
Report on National Survey of Health Authorities and NHS Trusts

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REPORT ON NATIONAL SURVEY
OF HEALTH AUTHORITIES AND NHS TRUSTS

INTRODUCTION

This report describes the first phase of a research project funded by the Department of Health's *Health in Partnership* Initiative. The overall aim of the Initiative is to contribute to the knowledge base for lay involvement in health care decision making. Our study is investigating the involvement of children and young people, in particular those who have a chronic illness or physical disability, since this is a growing group and includes heavy and long-term users of a wide range of health services. The focus of our research is on children's involvement in decision making about service development, as opposed to decisions about their own treatment, care and/or support. The full study will be completed by the end of January 2002, and a key output will be practical guidelines for NHS organisations wishing to involve this group of users in decision making about service development.

There are two main phases to the research. The first - reported here - is a national survey of Health Authorities and NHS Trusts in England. The aim of the survey was to 'map' current or recent practice initiatives (that is, within the last year) for involving this group of users. The survey returns were also used to select a sample of differing initiatives to explore in more depth in phase two. This second phase aims to identify factors which can promote children's involvement, and will be met through investigating and comparing the experiences of children and staff who have taken part in different initiatives. We currently know very little about how children view their experience of involvement and what for them would constitute 'good practice'. By filling this knowledge gap, the views of children with such experience will directly inform the guidelines for practice.

This report focuses on the methodology and findings of the national survey. We then go on to describe how the survey returns were used to select the sample of initiatives for phase two of the research. The report ends with a discussion of issues arising from the survey method and findings, the sampling method for phase two, and the need to seek children's views.

METHODOLOGY

Initially we envisaged a single stage survey to collect data on individual initiatives. However, since we did not know in advance how many initiatives any one organisation may be running, this posed a practical difficulty of making sure each organisation received the correct number of questionnaires. After consulting our project advisory group in September 1999, we decided to opt for a two-stage approach.

First stage

In the first stage, a short questionnaire was sent to all Health Authorities and NHS Trusts in England (n = 99 and 410 respectively). Copies of the questionnaires are in Appendix A. For the Trusts only, there was a prior screening question to ask whether the organisation provided services for children. There were then two main questions. The first question asked whether the organisation had undertaken any initiatives within the last 12 months involving consultation with children and young people (aged under 21 years) with regard to service development. We made it clear by way of a note that any initiatives being run in partnership with Local Authorities (and, in the case of Health Authorities, with Primary Care Groups) should be included.

We decided to limit reporting of initiatives to those taking place within the last year. This was to have a snapshot of up to date activity and to ensure that initiatives selected for more detailed study were likely still to be in the memory of the children and staff who had taken part. Defining an upper age limit was not straightforward, since we know that the ages of young people covered by child and adolescent services varies widely between Trusts and can extend well into adulthood. We selected 21 years as our upper age limit to capture initiatives where young people may have been consulted on the transition to adult services, while at the same time keeping our focus on a client group defined primarily as non-adult.

The second question asked, if the organisation *had* undertaken any initiatives, did these include any children with a chronic illness or physical disability? Where the organisation indicated that this was so, we asked whether we could send a follow-up, detailed questionnaire about each initiative, and requested a contact name and address for each.

It was not obvious who should be sent the initial questionnaire. Since attention to user involvement in the NHS is relatively recent, it seemed unlikely that there would be a person in each organisation with lead responsibility. While it seemed likely that many projects would be managed at the level of service delivery, it would not be feasible to access these directly via a survey. In consultation with our advisory group, we took a pragmatic decision to send the first stage questionnaire to a senior member of staff with a strategic overview of the organisation: the Director of Public Health (in Health Authorities) and the Chief Executive (in NHS Trusts). This decision was taken in the hope that the recipient would be able to forward our request for information to the right person - or people - within their organisation. A copy of the covering letters sent with the questionnaires is given at Appendix B. A project information leaflet was also sent to each person (see Appendix C). Although our choice of who to approach was pragmatic, it did risk information about relevant initiatives not being sent to us if these key staff did not know about them. To that extent our snapshot of activity is inevitably incomplete.

The first stage survey questionnaire was piloted in October and November 1999 in two Health Authorities and two NHS Trusts. All Health Authorities and NHS Trusts were subsequently sent the questionnaire in the last week of November, with one reminder sent in mid-January 2000. The response rates are shown in Table 1.

Table 1: Response rates for stage one survey questionnaire

	HAs	*Trusts*	***Total***
Questionnaires sent	99	410	509
Questionnaires returned	75	243*	318
Response rate (%)	*76*	*59*	*62*
Organisations requesting follow-up questionnaire	18	59	77
as % of valid responses	*24*	*26*	*26*

(* 224 with services for children)

Second stage

Just over a quarter of the NHS organisations with children's services who replied said that they were involving children with a chronic illness or physical disability in some way in decisions about service development (n = 77) and a total of 121 initiatives were identified by these organisations. However, examination of the questionnaire returns suggests that this is likely to be an over-assessment of the level of true activity. We had asked for one contact person per initiative to receive a more detailed second stage questionnaire. Several organisations gave us more than one name, so implying that there was more than one initiative. However in some cases it seemed likely that these were names of people working jointly on a single initiative, for instance where we were given the name of someone working in the NHS and another person working in social services. Where multiple names were given, we sent a follow-up questionnaire to each person, accompanied by a covering letter explaining who else had been sent a questionnaire and asking for one return only per initiative. The second stage questionnaire was designed to capture the characteristics of the initiatives, in particular features about the process and the outcome of children's involvement. A copy of the questionnaire is in Appendix D. Questions were categorised into six main sections, drawn primarily from our literature review:

1. *Characteristics of the children involved*: numbers, age range, types of illness or disability.
2. *Characteristics of the initiative*: aim and description, origins, partner agencies, funding, target group of children, recruitment, short or long-term initiative, whether children took part in the actual decision making, level of children=s participation.
3. *Methods of involvement*: written/verbal/visual/other, whether consulted individually and/or in a group, how children take part in decision making.
4. *Support:* for children and for staff (including support tailored for children with an illness or disability).
5. *Outcomes*: changes in service provision, changes in commissioning or in service priorities, any other changes, feedback to children.
6. *Evaluation*: results of any formal evaluation, staff views from their experience about what was helpful and/or problematic about the initiative.

At the end of the questionnaire we asked whether there was a post-holder in the organisation with designated responsibility for children's involvement. We also asked whether the person completing the questionnaire would be prepared to discuss participation in phase two of the study, if selected.

Second stage questionnaires were piloted in two Health Authorities and two NHS Trusts before being sent out during January and February 2000, on receipt of first stage questionnaires giving contact details. One reminder was sent after three weeks. A total of 46 second stage questionnaires were returned, which represents a response rate of 38 per cent. While the response rate appears low, we did consider - as reported above - that the total number of initiatives may have been over-stated. Reminders sent for both stages included duplicate questionnaires. From our experience on other surveys, sending second reminders would be likely to produce only a few positive responses. In the first stage of the survey it took longer than planned to obtain responses to initial and reminder questionnaires. We delayed sending out reminders for this stage in order to avoid the Christmas period. This survey was the first part of a two phase project and time was tight to complete the survey in order to go on to the second phase. In view of all these factors, our reasoning was that second reminders would not be used.

Of the 46 returns, 19 of these fell outside our criteria, for reasons set out in Table 2.

Table 2: Exclusion of initiatives from analysis

	Number of initiatives
Parents only involved	5
No evidence of involvement of children with a chronic illness or physical disability	5
Focus on involvement with individual care, not service development	2
Initiative just starting at time of survey	7
Total excluded	*19*

The first two categories for exclusion are arguably the most clear-cut, since the study aims to investigate the involvement of children who have a chronic illness or physical disability. Given that the questionnaire refers repeatedly to *children* being consulted, it is interesting that we received completed questionnaires from five respondents who felt that involving parents as a proxy was tantamount to involving children.

The third category, where the initiative focused on individual care, prompted us to reflect on the boundaries of the remit of our study. Clearly it is possible - indeed, arguably a desirable model - for service development to arise from routinely listening to children's views about their own treatment and care. In clarifying our remit we have been guided by the aims of the *Health in Partnership* Initiative, which differentiate between involving users in decisions about their own treatment, care and support and their involvement in broader planning and priority-setting. Within the Initiative, Bury and colleagues have been funded to investigate the first of these aims with regard to children, while we have been funded to focus on the second. So, we have taken the view that, in investigating children's experience of the process of involvement in service development, our remit is to look at initiatives where this is an *explicit* aim in seeking their involvement, rather than a by-product of children's involvement in decisions about their own treatment, care and support. We would not wish to deny that service development can usefully be informed in this latter way, only to make it clear that this is not a process we were investigating.

The fourth category of exclusion - that the initiative was just starting up - was taken on practical grounds, since respondents were unable to complete much of the questionnaire. It is worth noting that the survey revealed an apparent growing interest among NHS organisations in involving children and young people in service development. In the first stage questionnaire, several nil returns were annotated with comments suggesting that the organisation was intending to set up an initiative.

Excluding 19 of the 46 initiatives for which questionnaires were returned meant that 27 questionnaires were subsequently analysed.

FINDINGS

Characteristics of the children involved

Q1: How many children were involved in each initiative?

Table 3 details the spread of numbers of children involved in the 27 initiatives over the last year. The table shows that numbers varied widely, from less than ten to more than 50, the biggest single category being ten or fewer (n=8). In five cases, the number involved was unknown. In three of these cases, this was because the initiative extended beyond children with a chronic illness or physical disability, the target population being either children on a ward (n=2) or children at school (n=1). In these cases, although it was known that some participants would have had a chronic illness or physical disability, there had been no need to establish how many children fell into this particular group. In the other cases where the number of participants was unknown, the respondents did not have current information.

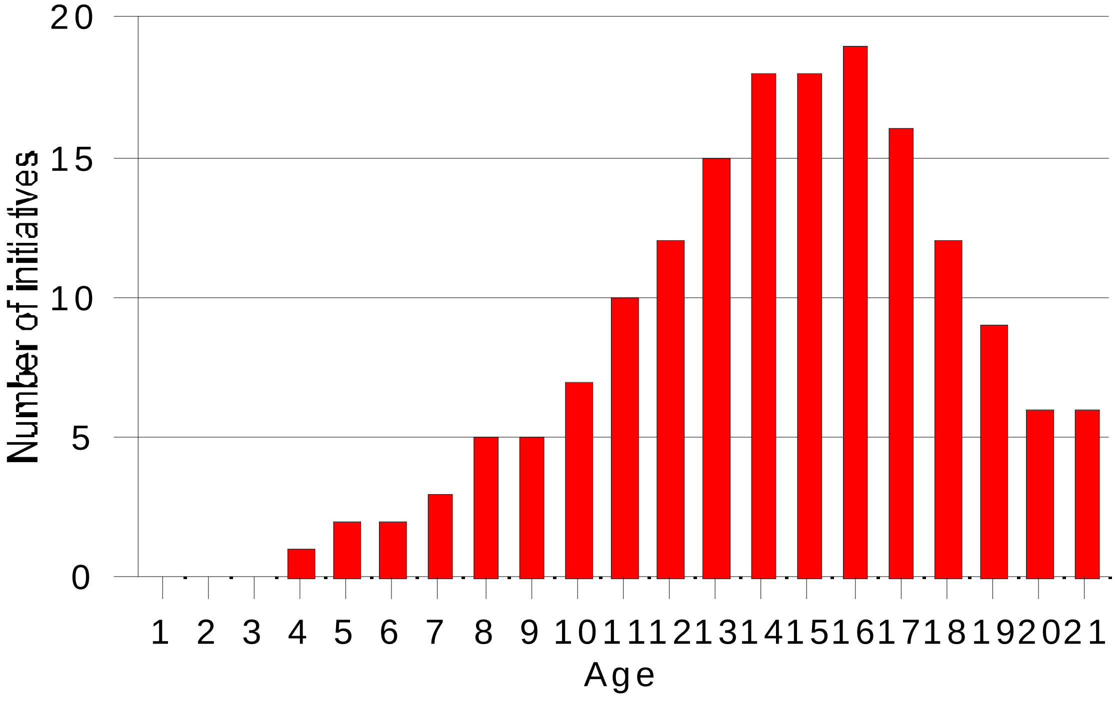
Table 3: Number of children involved in the initiatives

Number of children	*Number of initiatives*	*Percentage*
0 - 10	8	30
11 - 20	5	18
21 - 50	6	22
More than 50	3	11
Number unknown	5	19
Total	*27*	*100*

Q2: What was the age range of the children involved?

Two respondents were unable to report the age range of the children involved, since children's views had been given anonymously in writing. Among the 25 initiatives for which information was supplied, the youngest age reported was four years, which was in an initiative in which children were interviewed at home about their views on a recent stay in hospital. The upper age limit for the study was 21 years, although six initiatives reported ages higher than this (the oldest age being 55 years), where children were incorporated into initiatives for populations with a broader age range. In three of these cases, the focus of the initiative was local patients with cystic fibrosis, many - but not all - of whom were children. In the other three cases, the initiatives concerned services for children, young people and young adults with disabilities. Table 4 indicates the frequency of ages covered within the 25 initiatives for which these data were available.

Table 4: Frequency of ages covered by the initiatives



The most common age range was adolescence: 24 initiatives included young people of secondary school age, with 10 of these focusing exclusively within this age range. While seven initiatives included children of primary school age, none were working exclusively with this age group.

Q3: What types of chronic illness or physical disability did the children have?

Twelve of the 27 initiatives involved children with a single condition: Asperger's syndrome, asthma, autistic spectrum disorders, cancer, cystic fibrosis (n=4), diabetes (n=2), renal failure, and sickle cell disease. The other 15 initiatives were broader in scope, covering either all patients in a particular children's unit or general paediatric ward, or local children with disabilities.

Characteristics of the initiatives

Q4: What were the initiatives about?

Seventeen initiatives sought children and young people's views to inform developments in hospital in-patient services. Three of these had a specific focus on the physical environment in hospital, where there was a dedicated unit or part of a ward for young people.

One initiative focused on out-patient services, asking children about a paediatric out-patients clinic. Three initiatives could be described as community-focused, one of these seeking to find out the views of local school children about the school nursing service. In the other two initiatives, social opportunities were being developed for and with young people with particular conditions (Asperger's syndrome and autism spectrum disorders).

The remaining six initiatives were broad in scope: three were looking at arrangements for transition from child and adolescent services to adult services. The other three were gathering information about the needs of young people with disabilities.

Q5: What prompted the initiative?

Responses to this question were provided for 26 of the 27 initiatives. The largest category by far - 16 cases - mentioned the initiative as a means of involving children as *users* of services. In two of these cases, working in partnership was thought likely to bring an additional benefit of improved compliance with treatment regimes. In another of the 16 cases, the respondent felt that involving young users was taking a 'fresh and sideways look' at how services might be shaped in the future, an alternative to the incremental approach that the respondent felt stifled service development through joint planning groups which lacked vision.

Of the remaining ten responses, five focused on the need for changes to services (as opposed to children's participation *per se*), while four mentioned support for young people as the impetus for the initiative, for example the benefits for them of shared experiences and avoiding feelings of social isolation. In the remaining case, the initiative had been set up by a voluntary organisation as a pilot study.

Q6: Partner agencies

Sixteen of the 27 initiatives were being carried out with the support of one or more partner agencies (see Table 5).

Table 5: Partner agencies

Partners to Health Authority or NHS Trust	*No. of initiatives*
Local Authority and voluntary organisation	8
Voluntary organisation	4
Local Authority	2
Community Health Council	1
Architect	1
	16
No partners	11
Total	*27*

The largest partnership group (n=8) were initiatives including health, local authority and voluntary organisation partners. Next largest (n=4) was a group comprising health and voluntary organisations, while two further initiatives were partnerships between health and local authorities. In another case, an NHS Trust was working with the local CHC. In the remaining case - which involved discussions with children about decor and equipment in a new Unit - the architect was cited as partner.

Q7: Has the initiative received any dedicated funding?

Clearly all the initiatives required resources of some sort, for example staff time. In asking this question we were interested to know whether the initiative had received any *dedicated* (that is, specially ear-marked) funds. Just under half (n=13) of respondents said that their local initiative had received such funding. This did not necessarily mean that the whole cost was covered, rather that there was at least a contribution. Table 6 shows the varying sources of funding.

Table 6: Sources of dedicated funding

Funding source	*Number of initiatives*
Shared between health and other agency	8
Fund-raising/donations	2
Specified in mainstream (NHS Trust) budget	2
Wholly funded by social services	1
	13
No dedicated funding	14
Total	*27*

In the largest group of initiatives with some dedicated funding (n=8), the health organisation had shared funding, either with a local authority (n=6), a voluntary organisation (n=1), or both (n=1). Two initiatives had secured money through fund-raising or identifying suitable donations. In another two cases, the initiative was an identified part of the mainstream budget. In one of these cases - interviewing children at home about a recent stay in hospital - the initiative was funded from the corporate nursing budget. In the other case - a Young Adult Team to support transition from child and adolescent to adult services - the work had formerly been funded through Single Regeneration Budget monies. The remaining initiative with dedicated funding - a database of the needs of local children with disabilities - was now wholly funded by social services, having previously had joint finance funding.

Q8: Who comprise the target group for the initiative?

In this question, we were interested to find out whether initiatives were targeting children with a chronic illness or physical disability, or whether they were involved as part of a wider population group. Most initiatives (n=17) fell into the former category.

The other ten initiatives were including this group of children as part of a wider population. In six cases where the initiative was taking place on a hospital ward, the population included children with acute illness in addition to those with chronic illness. In a further three cases, the initiatives focused on children and young people with any disabilities, covering physical disabilities, learning disabilities and sensory impairments. In the remaining case where children with chronic illness or physical disability were not targeted specifically, the initiative was investigating the views of pupils on school nursing and the population of interest was children in specific year groups in local mainstream schools.

Q9: How were children recruited to the initiative?

Recruitment via health professionals was the most popular option, used in 20 initiatives. Examples of how this was done included contacting children from ward lists, putting up posters on NHS premises, and asking children face to face at clinics whether they would like to participate. Other methods of recruitment were via existing local groups (n=5); schools and colleges (n=5); social services (n=4) and a voluntary organisation (n=1). Most (n=22) used only one method of recruitment. Three initiatives used two methods, one initiative used three and another (a conference) used five methods.

Q10: What is the timescale of the initiative?

Respondents were asked to classify the initiative from a menu of possibilities: the results are shown in Table 7.

Table 7: Timescale of the initiatives

Category	*Number of initiatives*
A single 'one-off' exercise	7
Medium term (duration less than 1 year)	2
Long-term (duration of more than 1 year)	9
Permanent	9
Total	*27*

Two-thirds of respondents (n=18) described their local initiative as lasting at least more than one year, with half of this group classifying the initiative as 'permanent'.

Q11: In what ways are children involved in service decisions through the initiative?

We were aware that the term 'children's involvement' can be interpreted in a variety of ways. In this question we sought to establish a broad differentiation between involvement as *consultation* (that is, seeking children's views about services), and involvement as taking part in subsequent *decision making* (about service development). This is not, however, to suggest that these activities are mutually exclusive, since clearly it would also be possible for an initiative to involve children in both. Two later questions went on to ask for information about *how* children were involved; that is, the methods used for consultation (Q13) and decision making (Q15) with children.

Bringing these data together revealed inconsistencies on the part of some respondents between their answers to Q11 and the subsequent, more ‘concrete’ questions. For example, with regard to consultation, two respondents who had not indicated that children were consulted about their views on services (Q11) were nevertheless able to describe (in Q13) how they had done so! We have taken the view that, since Q13 and Q15 ask for descriptions of what was taking place, these ‘concrete’ data are likely to be more reliable than those in Q11. We have therefore revised the raw data from Q11 to take account of the inconsistencies we found.

The revised data show that consulting children about their views was a feature in all 27 initiatives and that their involvement in the process of decision making about service development took place in eleven cases. The more detailed data on *how* children were involved in these ways are presented under the headings of Q13 and Q15 of this report.

Q12: Degree of participation

We wanted to get a sense of respondents’ perceptions of the extent to which power and control was vested in the children taking part *vis a vis* the adults. This phenomenon is known as the ‘degree of participation’ of children and is commonly conceived as a hierarchy, as in Hart’s (1992) ‘ladder’ of participation. In the hierarchical approach, the further up the ladder the more power is in the hands of children. On the bottom rungs would be initiatives developed and run by adults, while on the top rungs would be initiatives developed and run by children themselves, with access to adults for support, if required.

The hierarchical model contains an implicit assumption that being at the top of the ladder is the ultimate aim, and so classification below this level is some measure of shortfall from the ideal. Such an assumption is likely to be simplistic in practice, since it overlooks the part played by the context in which children’s participation projects take place. Service development projects are much more likely to be initiated by staff in organisations than by children. Child-initiated projects may not be a sought-after goal in all situations, either by staff or children. It follows that many public service initiatives might never be placed towards the top of a hierarchical ladder, yet still might be viewed positively by participants. Arguably, then, the level of power and control *per se* held by participating children is less important than its ‘fit’ in the circumstances.

To avoid assumptions associated with a hierarchical model, we turned to Treseder’s (1997) ‘wheel’ of participation. By depicting degrees of participation as spokes of a wheel rather than rungs of a ladder, Treseder asserts that no one form of participation is inherently ‘better’ than the others, rather the most appropriate form will vary according to the circumstances of each case.

In Question 12, we summarised Treseder’s five categories and asked respondents to indicate which category best fitted their local initiative. Twenty-two respondents were able to classify their initiative in this way (see Table 8).

Table 8: Degree of participation

Classification	*Number of initiatives*
Adults design and run the initiative. Children volunteer to take part on the basis of understanding who decided to involve them and why.	4
Adults design and run the initiative but consult children on some aspects of this. Children understand the whole process.	12
Adults have the initial idea, but children are involved in making decisions at all steps of planning and carrying out the initiative	4
Children have the idea for the initiative. Children set up and run the initiative with adults offering advice, discussion and support.	1
Children have the idea for the initiative. Children set up and run the initiative, with access to adults available if required.	1 22
Unclassified	5
Total	*27*

The largest group (12 initiatives) was characterised by limited involvement of the children, but assumption of their understanding of the process. The four responses in category (1) suggest that it can be appropriate for children to volunteer to take part in initiatives designed and run by adults: a survey; a conference; a desire to find out information needs; and use of a complaints/suggestion leaflet. In respect of the initiative in category (5), the assertion that ‘children have the idea for the initiative’ seems to contradict what the respondent told us elsewhere in the questionnaire (Q5), where it was said that the initiative was prompted by staff reading a report on children’s involvement published by the National Children’s Bureau. It *is* the case, however, that staff in this initiative intend children to have more control in how the initiative is run than was reported by other respondents.

In five cases, respondents were unable to fit their initiative into Treseder's wheel, but provided comments. Comments from four respondents focused on ultimate control being in the hands of adults (staff). The fifth respondent felt that, among users involved, parents had been involved more than the children.

Methods for involving children

Q13: If the initiative involves consulting children/ young people on their views about services, which methods are used?

From this question we wanted to find out the range and popularity of different methods being used to consult with children. In designing the question we used published literature on practice initiatives involving children and young people in public service development to establish three broad types of consultation - written; verbal; visual art, design and drama - with a number of response categories in each. For each of these three types, we also included a response category for 'other', to find out about any additional methods in use.

All 27 initiatives included consultation with children, although data on methods were not available in one case. Here a core group of children were themselves to decide how they wished to consult other children and had not yet done so. Table 9 gives the breakdown of different methods in use and shows that, overall, verbal methods were the most popular. Most initiatives (n=19) used more than one method, the largest group of which (n=9) used two methods. Where just one method was used (n=7), in four cases this was a written questionnaire and, in the other three cases, individual discussion.

Table 9: Consultation methods

	Number of initiatives	*Total*
Written methods		
Questionnaire	13	
Suggestion box	5	
Creative writing	3	
Graffiti wall	2	*23*
Verbal methods		
Group discussion	16	
Individual discussion	7	
Question and answer session	5	
Steering group	1	
Relaxing/eating out	1	*30*
Visual art, design and drama		
Drawing	7	
Role play/drama	4	
Making a video	2	
Designing a display	2	
Photography	1	*16*

Q14: Were the children consulted individually and/or in a group?

Among the 26 initiatives for which data were available, just over half (n=14) consulted with children both individually and in a group. In the other 12 initiatives, children were consulted individually in eight cases and in a group in the remaining four.

Q15: If the initiative involves children/ young people taking part in decision making, in what way(s) does this happen?

Among the eleven initiatives in which this activity was taking place, children were *directly* involved in five cases. In four of these, children were described as having a seat in an established decision making forum of the organisation. In the other case, children took part in decision making via a committee set up as part of the initiative. Children were involved *indirectly* in seven initiatives (one of which was also involving children directly). Indirect involvement most often took place via close adults: parents, a nurse, an advocate, a youth or project leader. This type of involvement was mentioned in five cases. In the remaining two initiatives with indirect involvement in decision making, children's input was via a local youth group or forum.

Support for children and staff taking part

Q16 & 17: Support for children

Just over half (n=14) of the initiatives provided support for the children taking part in the initiative. We asked about both general support and any support tailored specifically to children with disabilities. Thirteen of the initiatives provided one or more forms of general support, and nine provided one or more forms of specific support. Eight initiatives provided both types of support. The breakdown of types of support provided is shown in Table 10.

Table 10: Support for children

	Number of initiatives	*Total*
General support		
Transport (provision or expenses)	7	
Information about the organisation's decision making processes	6	
Payment (in cash or in kind)	4	
Training	4	
Someone to give general advice and guidance	2	
Adults adopt an informal approach	1	*24*
Support for children with disabilities		
Advocacy	8	
Access to venues	6	
Assistance with communication	4	
Information (about services)	1	*19*

Q18 & 19: Support for staff

Support for staff was reported in 12 cases. In all cases, at least one form of general support was provided. Four of these initiatives also provided support for staff tailored to working with disabled children (although one respondent did not provide any details). Table 11 gives a breakdown of the types of support reported.

Table 11: Support for staff

	Number of initiatives	*Total*
General support		
Protected time	10	
Training on involving children	5	
Expert peer support	4	
Resources	2	*21*
Support re children with disabilities		
Project led by an RSCN	1	
Information	2	
Clinical supervision	1	*4*

Examples of ‘expert peer support’ included advice from a youth worker and group support and development through a Trust-wide network for improving services to patients. ‘Resources’ included office accommodation and support. Types of information to support working with disabled children included: information about the medical condition; disability awareness; child protection issues; and inter-agency working.

Outcomes

We wanted to find out whether the initiatives had in fact led to developments in services and, if so, what kinds of change had taken place. Since the survey covered both Health Authorities and NHS Trusts, in we asked about outcomes in terms of both changes in service provision *(Q20)* and changes in commissioning or service priorities *(Q21)*. Where no changes had taken place, we asked for a brief explanation. We also included a category for reporting any ‘other’ changes relevant to service development *(Q22)*.

Q20: Changes in service provision

Just over half (n=14) reported at least one change in service provision as a result of the initiative, although one respondent did not provide details. The types of change mentioned are summarised in Table 12.

Table 12: Changes in service provision

Type of change	*Number of initiatives*
Environment	7
Food	4
The participatory process itself	4
Clinic times	2
Ward routines	2

Changes to the environment were mentioned most often, which included ward decor, seating and recreational facilities (such as videos and CDs). Responses to complaints from young in-patients about the quality of food included, in one case, a pilot in which children could choose from a menu of frozen meals. This followed a period of eighteen months during which food had been ordered in regularly from a local fast food chain until the children grew bored with it. In another case, children are now offered meal tokens.

In four cases, the participatory process itself was thought to have constituted a service benefit. Two respondents mentioned that increased social contact and peer support was available to children who had been part of a group for the initiative. In another case, it was felt that establishing an on-going consultative group as a permanent mechanism for listening to young patients was in itself a service development. In the fourth case, an annual weekend holiday - much enjoyed by children and through which staff can learn more about how children live with the condition (diabetes) - has now been established as a annual event.

Two initiatives resulted in alterations to clinic times to suit young patients' preferences. Changes to ward routines were also mentioned twice, although details were only provided on one case. Here, the ward was described as now running on more 'hospital at home' lines in which patients (with cystic fibrosis) can leave the hospital (for example to go shopping) provided they have had their treatments and staff know what time they will return.

Thirteen initiatives reported that there had been no changes to service provision, and 11 of these respondents gave an explanation. The most common reason (n=7) was that the project was incomplete. In a further case, it was reported that there were insufficient resources to continue to work with children (although nothing was said about any service changes as a result of the work to date). In the remaining three cases, respondents made general statements which implied that changes might be made at some time in the future. This suggests that, in these cases, although the process of consulting children about services was complete, that of decision making was not.

Q21: Changes to commissioning or service priorities

Five respondents said that this sort of change had taken place, although in only one case was clear evidence given of the change being attributable to the initiative. In this case - a unit for people with cystic fibrosis - many patients had said that they would prefer not to stay in hospital so a home care IV programme is now provided. Patients administer their own intravenous antibiotics at home with supervision and safety checks from outreach staff. The timing of these visits has also subsequently been amended following consultation with patients who, although valuing the support, felt they needed it less frequently than the daily visit which was being provided. Of the other four initiatives from which changes to commissioning or service priorities were said to have developed, one respondent provided no details. In another case, although the respondent said that the initiative had ‘allowed us to prioritise some areas for the annual plan’, these were unspecified. In the remaining two cases respondents talked about an increasing profile for services for young people arising from major new developments in their respective Trusts - a cystic fibrosis unit and a hospital adolescent unit - although it was unclear whether these developments had resulted from children’s involvement *per se*.

The other 22 initiatives reported no changes to commissioning and/ or service priorities as a result of the initiative. Reasons were cited for 14 initiatives. In eight cases, the reason given was that the project was incomplete (this figure is one higher than in Q20 because, in one case, changes to the environment *had* taken place despite the project being unfinished). Four respondents reported along vaguely optimistic lines that something might happen in the future. The two remaining initiatives reported that there were insufficient resources. In one case, resources (including staff time) were insufficient to continue the project. In the other case, finance was cited as the reason preventing the development of a dedicated adolescent bed area, which was what young people would prefer rather than transfer to an adult ward.

Q22: Other changes relevant to service development

Nine respondents reported other changes relevant to service development. In two cases, respondents felt that a commitment to empower young patients had been given through a decision to provide information. In one of these cases, a proposal was being taken forward to develop an information leaflet for young patients when they are admitted to the children's ward. In the other case - a conference for people with disabilities - empowerment emerged as a key theme and so more effort is being made to provide information on access to services. In a further two cases, respondents mentioned that the initiative had encouraged them to make a commitment to involving children and young people. In one of these cases, a permanent adolescent steering group had been established to help ensure that their involvement would be sustained. In the other case, attention was being paid to extending methods for obtaining children's views. Currently only children present on the ward at the time of the consultation were included, but comment cards were to be developed for children who may not be on the ward at the time of verbal consultation, and/or who would prefer to give their comments in writing. In a further two cases, changes were focused on the specific needs of adolescents, including the creation of specific posts, although it was not clear whether these posts had arisen *directly* from young people's views.

In a sixth case, the respondent said that the initiative was likely to help prevent a call on services such as Child and Adolescent Mental Health Services (CAMHS). Here, a youth club had been set up for children with autistic spectrum disorders which was thought likely to help improve the children's self-esteem and their ability to cope with life. One parent was reported as having called the group a 'lifeline' for her son. In a seventh case, although the NHS Trust initiative was to end owing to insufficient resources, continuation of service was to be offered through a local voluntary organisation which had secured a government grant to offer a befriending service along similar lines. In the final case, the respondent said that the initiative had brought benefits in terms of a valuable training opportunity for staff to find out more about the needs of children with diabetes and an insight into how they manage their condition in everyday life.

Q23: Have the children received any feedback?

This question was intended to explore whether children had received any feedback on the *outcome* of the initiative. In practice, respondents interpreted the question as meaning feedback at any stage of the initiative. We have included all responses, since a commitment to keeping children informed is at the heart of the question.

Feedback to children was reported in just under half of the initiatives (n=13). Feedback fell into three broad categories. The largest category (n=7) was on-going feedback on progress so far. The second category (n=4) was where children were shown tangible evidence of the outcome of their involvement, including changes to the plans for a cystic fibrosis unit. Not all of these comments were specific: for example one respondent noted ‘they see the results in the service’. In the third category (n=2), children had received a copy of the project report.

Evaluation

Q24: Any evaluation of children’s experience in the initiative?

Since the second phase of our study will be investigating children’s experiences of involvement, we were interested to find out whether staff responsible for initiatives had sought to obtain this type of feedback from children and, if so, what the children’s views were. Where respondents had undertaken such an evaluation, we asked for a copy of any written reports.

Evaluation of children’s views of their involvement was reported in seven cases, although in two of these children’s views had been expressed spontaneously rather than actively sought. In a third case, where satisfaction questionnaires were used, the respondent suggested that these had usually been completed by parents, since the children had multiple disabilities. Of the remaining four cases reporting an evaluation, two respondents termed this ‘informal’. The other two initiatives had been more formally evaluated. In one case a written evaluation had been undertaken using a pro-forma. The forms were reproduced in the project final report, a copy of which was sent to us. Here, the four young people involved (all female and aged between 13 and 16 years) wrote about the opportunity to do things which they would not have otherwise done, and to develop their feelings of confidence, self-esteem and support in working with others in a group. No details were forwarded from the other initiative in which a formal evaluation had taken place.

Q25 & 26: Advice to others thinking of involving children with a chronic illness or physical disability in local service development decisions.

Involving children in local NHS decision making is a relatively new activity. Through reflecting on their experience, respondents in this survey may have useful messages to pass on to others considering similar work. In Question 25 we asked respondents what they would like to pass on as having been particularly *useful* about their experience in involving children and, in Questions 26, anything which had been particularly *problematic*.

Twenty comments were made (from 19 respondents) on aspects of their experience which had been *useful*. These comments fall into a number of themes, which are summarised in Table 13.

Table 13: Involving children and young people: what is useful

	Number of comments
To find out children's views as service users	9
Benefits for the child	6
A learning experience for everyone	1
Tips on how to do it (see commentary)	4
Total	*20*

As the table shows, the largest category of comments concerned the immediate purpose of consultation, that is finding out children's views. Respondents wanted to draw attention to the fact that young patients have different viewpoints from adult staff, that they have valuable and useful ideas, and that these cannot be known without asking them. Comments were sometimes couched in terms of the benefits of user involvement more generally. For instance, one respondent wrote about 'the need for 'real' users of our service to work with us to ensure we provide what they want when we can'.

Six respondents made comments about involvement having benefits for the child: that an opportunity to express their views helps children to vent their feelings (n=1) and to develop their confidence (n=1); that listening is part of caring for the child (n=2); and that involvement is likely to lead to other care benefits in terms of improved compliance and take-up of services (n=2).

Four respondents passed on specific tips about how to go about involving children and young people:

> 'Be honest and open, really listen, act on issues raised or explain why you can't, don't promise what you can't deliver, it's great fun and very worthwhile'.

'There is a huge need for people to provide things in accessible formats. I worked very hard to design a questionnaire specifically for people with a learning disability. Thought needs to go into information provision'.

‘(1) involvement in the planning stage; and (2) wording of questionnaires to account for cognitive development’.

‘I feel the ‘search conference’ approach we used to engage a wide range of stakeholders could be transferable to a younger age group’. The youngest participant in this case was aged 19. This approach - developed by the King’s Fund - brings together all stakeholders and uses activity-based techniques to encourage people to look beyond the immediate situation to identify common ground on what is important, work out what can be changed and develop an action plan.

Turning to what respondents wanted to pass on as being *problematic* about involving children in decision making, 11 comments were made (by ten respondents). Themes covered by these comments are summarised in Table 14.

Table 14: Involving children and young people: what is problematic

	Number of comments
Getting young people involved	2
Getting adults to take young people’s views seriously	2
Trying to please everyone	2
Raising expectations unrealistically	1
Representativeness	1
Specific practical problems (see commentary)	3
Total	*11*

Difficulty in getting young people involved was mentioned by two respondents. In one case, the difficulty was in motivating young people. In the other case, there had been difficulties in getting disabled young people involved, which the respondent attributed to parents’ customarily speaking on behalf of their disabled children. Two comments were also made about the difficulty of pleasing everyone involved. In one of these cases, the respondent stressed the importance of making sure everyone’s view was heard and that, provided people were willing to compromise, a conclusion on the way forward was possible. The issue of representativeness was raised by someone who felt that a difficulty was posed when people with extreme views claimed that their view was more generally held. The difficulty of raising expectations unrealistically was felt to extend beyond children to include their parents.

Three respondents passed on difficulties in respect of particular methods for obtaining children's views. Two of these comments were about how time-consuming the method was, in one case using questionnaires and, in the other, analysing individual interviews. The third difficulty was specific to children with cystic fibrosis, where the risks of cross-infection had prevented working with these children in groups.

Staff responsibilities

Given the increasing interest in user involvement in NHS policy, we wanted to find out whether organisations were designating responsibility for children and young people's involvement to a member of staff. A third (n=9) of our respondents reported that this was the case. In one case the person's job title - 'Patient's Representative, User Involvement' - implied a dedicated function. In the other cases, the responsibility appeared to be part of a wider role, for example, as a nurse or youth worker. Two initiatives reported shared responsibility between two members of staff (nurses and youth/play workers). Responsibility was most often located with someone close to front-line working: only two people with responsibility for children's involvement held managerial positions. In one Trust reporting two initiatives, a dedicated post-holder was reported in one case but not in the other, suggesting that this responsibility was not Trust-wide.

Classification of initiatives

We examined the data from the survey responses to look for patterns that would suggest classification of initiatives into a typology. However the data did not support any such typology. There were no clear links between variables such as involvement in decision making, level of children's participation, dedicated funding, length of initiative, partnerships, change in services resulting from the initiative. This may in part be because of the small number of initiatives identified by the survey and the early stage of development of children's involvement in service development.

The only link found was between children's involvement in decision making and change in services: 82 per cent of initiatives where children were involved in decision making resulted in changes in service provision compared with 50 per cent of those where children were not involved in decision making. However, the reasons behind this are likely to be numerous and complex, for instance changes had not yet happened in projects which were ongoing and these projects had not got to the decision making stage; projects which were specifically focused on producing change may have been more likely to involve children in making decisions about this.

SELECTION OF SAMPLE FOR PHASE TWO OF THE RESEARCH

The 27 initiative questionnaires were used to select a sample of six initiatives for in-depth study in phase two of the research. We used two inclusion criteria to arrive at a short list: (a) the contact person must be willing in principle to be approached about the second phase; and (b) since phase two involved collecting data from children, that the children who had taken part in the initiative were likely to be contactable for recruitment purposes.

A total of 12 initiatives was shortlisted from the original 27. Of the 15 not shortlisted, criterion (a) ruled out four initiatives. A further three were ruled out by criterion (b): in two of these cases, children had participated anonymously and, in the other, staff had approached children on a hospital ward opportunistically. After re-reading the questionnaire responses, at the margin we ruled out a further eight initiatives, for three reasons.

In the first group were four initiatives in which the focus was on developing services for the individual group in question, as opposed to broader service development. In these cases, a group of young people with a particular condition had been brought together for peer support/social reasons from the children's point of view, with staff taking messages for service development from listening to their discussions. It might be argued that these initiatives are a group parallel with initiatives focusing on a child's individual treatment and care, which we had earlier ruled outside our remit. We included these group-based initiatives in the survey, since the children were involved in taking decisions collectively about services for a group of young people (for example, activities to develop their social skills). However, while staff may have taken forward ideas for broader service development, the children were not participating on this basis, and therefore it would not be sensible to recruit them to phase two of the study.

The second category of initiatives we ruled out at the margin were those in which the children had what appeared to be too low a level of involvement for us to collect meaningful data from them. Three initiatives fell into this category. In the first case, involvement had been limited to children's comments on the appropriateness of questions in a draft questionnaire to be sent to families with a disabled child. The respondent also thought it likely that it would be a parent who would actually complete the questionnaire on behalf of the family. In the second case, the initiative described was a 'cystic fibrosis working party' of staff and users. However, the risk of cross-infection meant that children with cystic fibrosis were not on the group itself but were represented by their parents. The respondent spoke about informal discussion taking place between children and a cystic fibrosis nurse, and also assumed that parents on the working party would canvass the views of their children. In the third case, the initiative aimed to empower and support young people to take part in decision making about their own transition planning. Recommendations for wider transition system changes was also a stated aim, but there was no evidence that this had so far been pursued, or that it would be known by the children as an aim of their involvement.

One further initiative was ruled out on the grounds that only one young person was involved. We judged that selecting this initiative as part of our sample risked not using our scarce resources (to consult with children) wisely. In this initiative, the young person had sat on a management forum of a Young Adult Team (focusing on transition) and on its publicity sub-group. The respondent who completed the questionnaire commented that a number of disabled young people were recruited initially, but that they found it difficult to contribute. In deciding not to shortlist this initiative, we do not wish to imply that it has no value - indeed, in contrast to the majority of initiatives we were told about, this young person appears to have been actively involved in decision making - rather that one person's involvement is too narrow for us to include in a sample of six initiatives.

Throughout the project two young people, who are members of a local youth forum, have been involved as advisers. They advised on the topics to be covered in the questionnaire and played a central part in the sample selection for Phase Two. To make the final sample selection we met with these two young people. We wrote a short summary of each of the 12 shortlisted initiatives and sent this to the young advisors before the meeting, along with a covering note reminding them that the aim of the research was to develop guidelines on involving children and young people which would be based on what children and young people themselves thought about their experiences of involvement. At the meeting the two researchers and the two young people made individual choices and declared these anonymously by putting numbered selections in a container. We then counted up the 'votes' for each initiative.

There was a strong degree of consensus. Five initiatives were rated highly by everyone. The sixth place in the sample involved a choice between two initiatives. In the discussion about which to choose, one of the young advisors resolved the issue on the grounds that one of the initiatives showed evidence of children's involvement *throughout* the process of service development, whereas the other initiative 'just' asked children for their views about a service. He pointed out that the aims of our project suggested that we should prioritise investigating initiatives with more involvement. We were also able to select two reserve initiatives, should any of our main choices not progress for any reason.

The six initiatives are as follows:

- Finding out the views and ideas of young users of acute in-patient children's services.
- Finding out young people's views about a hospital paediatric out-patients' clinic and to develop a sustainable mechanism to involve young people in service decision making.
- Designing a young people's recreation room in a hospital kidney unit.
- Design and on-going review of adolescent and young adult cystic fibrosis unit.
- Design and on-going review of a hospital adolescent unit.
- Design and on-going review of young people's hospital unit.

DISCUSSION

The survey method

We carried out this survey at a time when user involvement was relatively new in the NHS and so information on involvement activities was not necessarily being collated systematically by organisations. Obtaining survey returns, therefore, necessarily depended in large part on the initial contact person in each organisation knowing what was happening locally and so who should receive our questionnaire. It is impossible to assess the extent to which staff running initiatives which would have met our criteria did not receive a questionnaire. We can only acknowledge the risk inherent in an early mapping exercise of under-stating the true volume of activity. Apart from the completed questionnaires we did receive, responses from several other organisations that they were actively interested in, or just embarking upon, initiatives involving children suggests that there is a growing body of interest in this activity. Future surveys may be more robust, following proposals in the NHS Plan (DoH 2000) to strengthen user involvement. These proposals are likely not only to increase the amount of activity, but also to make it more visible, for instance through identifying staff within NHS organisations to take responsibility for promoting user involvement and collating evidence of relevant activities for performance-related purposes. Our survey, then, is perhaps best seen as a preliminary 'snapshot' capturing a range of recent and current initiatives, describing their characteristics and outlining a number of issues arising from this work, information which we hope will be useful in developing this area of activity in the NHS.

Summary of survey results

In terms of the characteristics of the children involved, the numbers of children taking part in an initiative varied widely, from less than ten to over 50 participants. The age range of children and young people who were involved was also wide. The youngest participant was four years old, and six initiatives reported participants up to (and exceeding) our cut-off point for the study of 21 years. Although the spread was wide, the most common age range was adolescence (ages 12 to 18). With regard to chronic illness and physical disability, just under half of the initiatives focused on a single condition, the most common of which was cystic fibrosis, the subject of four initiatives. Just over half of the initiatives were broader in scope and so included children with a range of conditions, for example all patients on a ward, or children and young people with disabilities in the local area. By far the most common way in which children were recruited to the initiative was via health professionals, which was the case for 20 initiatives.

The aims of the initiatives varied, although the focus was primarily on practical aspects of service provision. In the largest single category by far (17 cases) children's views were being sought on hospital in-patient services. The most common rationale for involving children was to seek their views as service users, although a number of other likely benefits for children were raised by some respondents, including improved compliance with treatment regimes and opportunities for increased social contact through participating with other children. Sixteen of the initiatives were being carried out with one or more partner agencies, the most common combinations being a Local Authority and/or voluntary organisation. Access to funding could be problematic for this type of work, with under half of the initiatives having received some sort of dedicated contribution to their costs. With regard to timescale, two-thirds of the initiatives were described as either permanent or lasting for more than one year. Given that children's involvement in NHS decision making is a recent development - and so without evidence of sustainability - at the moment, such a declaration might seem somewhat aspirational. However, it does indicate a commitment to embed the process of involvement in organisational practice, at least on the part of our survey respondents who are closely involved with this type of work.

While consulting children about their views was a feature of all the initiatives, children were directly involved in decision making in much fewer cases (n=5). It is clear from respondents' assessments of the children's 'degree of participation' that, in nearly all cases, the balance of power rested firmly with adults.

A wide range of methods for eliciting children views was used across the initiatives, and most used more than one method. Verbal methods were most common, with group discussion the most popular form. Written methods were also popular, in particular questionnaires. Visual art, design and drama were also used, with drawing the most popular form in this category. In just over half of the initiatives, children were consulted both individually and in a group.

Just over half of the initiatives provided some sort of support for the children taking part. While some support was tailored to children with disabilities (for instance, advocacy, access to venues, and assistance with communication) other support was more general, for instance transport, information about the organisation's decision making processes, training, payment (in cash or in kind). Support for the staff taking part was provided in just under half of the initiatives, the most common forms of support being protected time and training on children's involvement.

Just over half of the initiatives reported at least one change in service provision and/or priorities as a result of the initiative. Improvements to the environment and to food quality were mentioned most often. Of those initiatives not reporting any service changes, the most common reason was that the initiative was not yet complete. A third of respondents mentioned other outcomes, including greater insight on the part of staff about children's needs, and a greater commitment to empowering children, whether that be at an individual level through provision of more and better information, or at a more collective level, through extending opportunities for children's participation in decision making about service development. Just under half of the respondents reported some sort of feedback to children on the process of decision making with which the initiative was linked.

In terms of participants' reflections on their experience, the limited information we have (from one initiative) suggests that young people valued the chance to do things that they would not have otherwise done, and the opportunity to develop confidence, self-esteem and a feelings of peer support through working in a group with other young people. The adults completing our questionnaire had found it useful to find out children's views, and wanted to draw attention to potential benefits for children in venting their feelings, developing confidence, feeling cared for, and perhaps improving compliance and service take-up. It could also be the case, however, that involving children could be problematic, for instance in getting young people involved, getting adults to take them seriously and trying to please everyone.

A third of the organisations represented in the survey were said to have identified someone with lead responsibility for children and young people's involvement. This was not, however, necessarily a strategic role within the organisation, but typically an additional responsibility for a practitioner working with children, such as a nurse or youth worker.

Sampling for phase two of the research

Since our research design meant ruling out initiatives where children would be difficult to contact and/or may not perceive what had happened as active involvement in service development, the range of initiatives for further investigation was limited. Types of initiative left out included one-off, sometimes opportunistic, consultations with children about their views on services. In excluding these initiatives, we are not suggesting that they are inferior approaches, but rather that they were inappropriate for selection in a study designed to investigate the views of children's experiences of involvement. It follows that the initiatives we did select were broadly similar in type (although varying considerably in detailed characteristics) where there had been a sustained investment of time and energy by children and staff over a period of time. We are aware that this model may not always be feasible - or even desirable - but that, for the purposes of our study, there is merit in investigating this type of approach.

The need to seek children's views

Through the survey, we have been able to obtain a 'snapshot' of the characteristics of a range of practice initiatives currently seeking to involve children and young people who have a chronic illness or a physical disability in local service development. We hope that these findings - including the reflections from adults responsible for them - may prove useful for staff in other NHS organisations who are embarking on this path. What are of course missing from these data are the views of the young participants themselves, yet understanding these will be crucial for successful involvement. Key questions we have in mind to understand children and young people's perspectives on their experience include: what motivates children and young people to take part? What factors help or hinder their initial and sustained involvement? What do children and young people see as the benefits and drawbacks of involvement, and of different methods? What does 'involvement' mean to them as participants - is being consulted sufficient, or is being part of subsequent decision making necessary? What do children and young people hope will happen as a result of their involvement? What do they consider to be 'good practice' in the process and outcomes of involvement?

Clearly children and young people are not the only participants, since staff are engaged in these practice initiatives too. Furthermore, the whole enterprise is set within the specific context of the individual organisation. So in phase two we will also be seeking the views of staff responsible for the local initiative in each case, to find out their perspective on their experience and to gain an understanding of how this work ‘fits’ within and has informed the decision making processes of their organisations. We will be using all of this new knowledge to develop guidelines for NHS organisations in early 2002, which we hope will be of practical use to those seeking appropriate ways of involving this group of young patients in future decision making about service development.

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APPENDIX A

Stage One Questionnaires (Health Authority and NHS Trust)

THE UNIVERSITY *of York*
Social Policy Research Unit

SPRU

INVOLVING CHILDREN AND YOUNG PEOPLE WITH A CHRONIC ILLNESS OR PHYSICAL DISABILITY IN LOCAL DECISION MAKING ABOUT THE DEVELOPMENT OF HEALTH SERVICES

Department of Health R&D Initiative: ***Health in Partnership***

office use only

NAME OF HEALTH AUTHORITY:

..

1. Has your organisation* undertaken any initiatives within the last 12 months involving consultation with children and young people (under 21 years) with regard to service development? [*Please also include any initiatives known to you being run in partnership with a Local Authority or by local Primary Care Groups]

Yes **Number of initiatives**

No

If *Yes*, please go to Q2

If *No*, please return the questionnaire in the envelope provided. Thank you.

2. Have any of these initiatives included children and young people with a chronic illness or physical disability?

Yes **Number of initiatives**

No

Don't know

If *Yes*, please go to Q3

If *No* or *Don't Know*, please return the questionnaire in the envelope provided. Thank you.

P.T.O.

3. Would you be prepared to complete a brief questionnaire about each of the initiatives involving children and young people with a chronic illness or physical disability?

Yes **No**

If yes, please provide a contact name for each initiative:

Name: ....

Address: ....

....

....

Telephone .... **Fax** .... **E-mail** ....

Name: ....

Address: ....

....

....

Telephone .... **Fax** .... **E-mail** ....

Name: ....

Address: ....

....

....

Telephone .... **Fax** .... **E-mail** ....

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Please return in the pre-paid envelope

THE UNIVERSITY of York

Social Policy Research Unit

SPRU

INVOLVING CHILDREN AND YOUNG PEOPLE WITH A CHRONIC ILLNESS OR PHYSICAL DISABILITY IN LOCAL DECISION MAKING ABOUT THE DEVELOPMENT OF HEALTH SERVICES

Department of Health R&D Initiative: *Health in Partnership*

office use only

NAME OF NHS TRUST:

..

Does your Trust provide any services for children and young people? **Yes ☐ No ☐**

***If YES please complete this questionnaire*.**
If NO, please return the questionnaire in the envelope provided. Thank you.

1. Has your organisation* undertaken any initiatives within the last 12 months involving consultation with children and young people (under 21 years) with regard to service development? [*Please also include any initiatives known to you being run in partnership with a Local Authority]

Yes **Number of initiatives**

No

If *Yes*, please go to Q2

If *No*, please return the questionnaire in the envelope provided. Thank you.

2. Have any of these initiatives included children and young people with a chronic illness or physical disability?

Yes **Number of initiatives**

No

Don't know

If *Yes*, please go to Q3

If *No* or *Don't Know*, please return the questionnaire in the envelope provided. Thank you.

3. Would you be prepared to complete a brief questionnaire about each of the initiatives involving children and young people with a chronic illness or physical disability?

Yes **No**

If yes, please provide a contact name for each initiative:

Name: ....

Address: ……..

..

..

Telephone.............................. Fax .... E-mail ....

Name: ....

Address: ....

..

..

Telephone.............................. Fax .... E-mail ....

Name: ....

Address: ....

..

..

Telephone.............................. Fax .... E-mail ....

THANK YOU FOR COMPLETING
THIS QUESTIONNAIRE

Please return in the pre-paid envelope

APPENDIX B

Covering letter to Director of Public Health and Chief Executive of NHS Trusts

L/TS/TF

E-mail: jrl4@york.ac.uk

25 November 1999

Dear Director of Public Health

Re: Department of Health R&D Initiative *Health in Partnership:* Involving children and young people with a chronic illness or physical disability in the process of local decision making about the development of health services

We are writing to ask you to take part in a national survey of Health Authorities and NHS Trusts in England. If you are short of time, please note that the enclosed questionnaire has only three questions. You may prefer to pass the questionnaire on to your lead for children's services. If you would like to know more about the research, then please read on.

The study is funded under the Department of Health *Health in Partnership* Initiative, which will provide research evidence to assist NHS organisations to involve service users and the public in decision making. Our own study will produce practical guidelines aimed specifically at helping you to involve chronically ill or physically disabled children and young people in local service development. As a first step, the survey aims to map the number and range of current or recent practice initiatives for involving this group of service users. More details about the rest of the study are in the enclosed project information sheet. A summary of the survey results will be available in summer 2000. The guidelines will be published on completion of the project, in January 2002.

To allow the study to keep to schedule, we would be grateful if you would *please return the completed questionnaire in the prepaid envelope by* **Friday 17 December**. If you have any queries about the questionnaire, or would like more information about the research, please do get in touch. Thank you for your help.

Yours sincerely

Jane R Lightfoot

Tricia Sloper

Jane Lightfoot
Research Fellow

Dr Patricia Sloper
Senior Research Fellow

L/TS/TF

E-mail: jrl4@york.ac.uk

26 November 1999

Dear Chief Executive

Re: Department of Health R&D Initiative *Health in Partnership:* Involving children and young people with a chronic illness or physical disability in the process of local decision making about the development of health services

We are writing to ask you to take part in a national survey of Health Authorities and NHS Trusts in England. If you are short of time, please note that the enclosed questionnaire has only three questions. If you would like to know more about the research, then please read on.

The study is funded under the Department of Health *Health in Partnership* Initiative, which will provide research evidence to assist NHS organisations to involve service users and the public in decision making. Our own study will produce practical guidelines aimed specifically at helping you to involve chronically ill or physically disabled children and young people in local service development. As a first step, the survey aims to map the number and range of current or recent practice initiatives for involving this group of service users. More details about the rest of the study are in the enclosed project information sheet. A summary of the survey results will be available in summer 2000. The guidelines will be published on completion of the project, in January 2002.

To allow the study to keep to schedule, we would be grateful if you would *please return the completed questionnaire in the prepaid envelope by* **Friday 17 December**. If you have any queries about the questionnaire, or would like more information about the research, please do get in touch. Thank you for your help.

Yours sincerely

Jane R Lightfoot Tricia Sloper

Jane Lightfoot
Research Fellow

Dr Patricia Sloper
Senior Research Fellow

Enc

APPENDIX C

Project Information leaflet

THE UNIVERSITY *of York*

SPRU
SOCIAL POLICY RESEARCH UNIT

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INVOLVING CHILDREN AND YOUNG PEOPLE WITH A CHRONIC ILLNESS OR PHYSICAL DISABILITY IN LOCAL DECISIONS ABOUT HEALTH SERVICES DEVELOPMENT

PROJECT AIMS AND OBJECTIVES

The overall aim is to contribute to the effective involvement of children and young people with a chronic illness or physical disability in health service development. The research objectives are:

- to establish the existing level of activity and methods by which this group of users are involved in local NHS service development.
- to identify factors which can support and promote such involvement.

WHY THE PROJECT IS NEEDED

This project is funded as part of the Department of Health's *Health in Partnership* Initiative, which is seeking to identify and promote effective ways of involving patients, carers and the public in health care decision making. Building on the 1996 *Patient Partnership Strategy*, this work reflects the policy commitment in *The New NHS* and *Our Healthier Nation* for increased lay involvement, and its status as a medium-term priority for the NHS. Although increasing attention is being paid to the importance of such involvement, to date policy and research have focused primarily on the involvement of adults, with children a potentially marginalised group. On numbers alone, children's voices ought to be heard: people aged under twenty comprise a significant proportion (about a quarter) of the population. Moreover, a sizeable and growing proportion (currently estimated at up to 20 per cent) of children and young people have a chronic illness or physical disability. Members of this group are likely to be both long-term and heavy users of a wide range of health services, including hospital and community-based treatment, care and support. It follows that they are likely to have much to contribute to NHS service development on account of their knowledge and experience. More broadly, under the United Nations Convention on the Rights of the Child, children also have a right to a say in decisions which affect them.

WHEN AND HOW THE PROJECT WILL BE CARRIED OUT

The project runs *from 1 July 1999 to 31 January 2002* and has three stages:

Stage One aims to 'map' the number and range of current or recent practice initiatives for involving children and young people with a chronic illness or physical disability in the process of local decision making about health service development. Mapping will be carried out through a survey of all health authorities and NHS Trusts in England. Information about the initiatives will be summarised, along with the key findings, in a published review intended primarily as a resource for health authorities, NHS Trusts and Primary Care Groups. We expect the review to be available in Summer 2000. The survey results will also be used to select a small number of initiatives (about six) for stage two.

Stage Two aims to identify factors which can promote children's involvement, through investigating and comparing the experiences of children and agency staff in differing approaches to involvement.

Children and young people's views
Where possible we will use focus groups as a method for investigating children's experiences of involvement and their views about good practice. Key themes are likely to include: what motivates children to be involved in health decision making? What factors help or hinder initial and sustained involvement? What do children see as the benefits and drawbacks of involvement, and of different methods? What do children hope will happen as a result: what would they consider to be effective involvement? Are their hopes met? Why/ why not? What do children consider to be good practice in the process and outcomes of their involvement?

Staff views
For each of the initiatives selected, we will carry out two individual interviews, one with a member of staff with responsibility for liaison with the children involved, and the other with a commissioner responsible for children's services. These data will provide an understanding of how, and the extent to which, such involvement is integrated into the strategy and process of decision making within the organisation. For example, at which point(s) in the process do children have a voice? How is children's involvement promoted and supported within the organisation? What effects has children's involvement had on the development of services?

Stage Three comprises two invited workshops in different parts of England, the purpose of which is to develop practical guidelines for health commissioners, NHS Trusts and PCGs on involving children and young people with a chronic illness or physical disability in decision making about health service development. Participants will be drawn from among the research respondents, including staff, children and young people; and representatives from PCGs.

At the end of the project we will publish a summary of the findings, including the guidelines.

YOUNG PEOPLE'S CONSULTATION GROUP

A consultation group of young people will be recruited at the outset to advise the project. The purpose of the group is:

- *To give young people the opportunity to influence the planning and conduct of research which aims to investigate the needs of people in their age group.* In this way, the project can: focus on issues of concern to young people; be sensitive to their needs as research respondents; and identify ways of disseminating the findings which are likely to appeal to young people.

- *To obtain specialist advice on topics for data collection from young people with experience relevant to the study*, for example: experience of using the NHS on account of having a chronic illness or physical disability; experience of involvement in decisions about public service development.

FOR FURTHER INFORMATION

Please contact Jane Lightfoot (jrl4@york.ac.uk) or Tricia Sloper (ps26@york.ac.uk) at the Social Policy Research Unit, University of York, York YO10 5DD. *Tel:* 01904 433608.

APPENDIX D

Stage Two Questionnaire

THE UNIVERSITY *of York*
Social Policy Research Unit

SPRU

Department of Health R&D Initiative: *Health in Partnership*

INVOLVING CHILDREN AND YOUNG PEOPLE WITH A CHRONIC ILLNESS OR PHYSICAL DISABILITY IN LOCAL DECISIONS ABOUT HEALTH SERVICES DEVELOPMENT

Survey of Current and Recent Initiatives in Health Authorities and NHS Trusts in England

☐☐☐ **NAME OF ORGANISATION**
....

☐☐☐ **NAME OF THE INITIATIVE**
....

Notes:

- The aim of the survey is to collect data about current or recent initiatives involving children and young people with a chronic illness or physical disability in local decision making about health services development.
- The phrase ‘children and young people’ refers to people aged under 21 years. The term ‘children/young people’ is used in this questionnaire for brevity.
- The term ‘current or recent’ initiative means an initiative which is either on-going or which has taken place within the last 12 months.
- Please return in the completed questionnaire in the pre-paid envelope provided. If you have any queries about completion, please contact:

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York Y010 5DD

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CHILDREN AND YOUNG PEOPLE WITH A CHRONIC ILLNESS OR PHYSICAL DISABILITY

1. *How many* chronically ill or physically disabled children/young people have been involved in the initiative over the last 12 months?
(Tick one box)

0 - 10
11 - 20
21 - 50
more than 50
number unknown

2. What is the *age range* (approximately) of the children/young people involved?

☐☐ youngest age

☐☐ oldest age

3. What *types* of chronic illness or physical disability do the children/young people have?
(Please give examples of the range of illnesses or disabilities included, e.g. diabetes, cerebral palsy)

....
....
....
....
....

GENERAL CHARACTERISTICS OF THE INITIATIVE

4. Please give a *brief description* of the initiative, including its *aim* (please enclose a copy of any documentation)

....
....
....
....
....
....

5. ***Why* was the initiative set up?**

....
....
....
....
....

6. **Please list any partner agencies (statutory or voluntary) involved in this initiative**

....
....
....

7. **Has the initiative received any dedicated funding?**

☐ Yes (if yes, please indicate source of funding)
....
....

☐ No

8. **Is the *target group*:**
(Tick one box)

☐ ill or disabled children/young people *specifically*?

or

☐ ill or disabled children/young people as *part of a wider group*?

9. **How were the children/young people *recruited* to the initiative?**
(Tick all which apply)

☐ via schools and/or colleges
☐ via existing local groups (for example, Youth Council)
☐ via local health professionals
☐ via local press
☐ other (please specify) ....

10. Which of the following most closely describes this initiative?
(Tick one only)

☐ a single, 'one-off' exercise?
☐ a medium term project (up to one year)
☐ a long term project (ie more than one year)?
☐ a permanent arrangement?
☐ other (please describe) ....

11. In what ways are children/young people involved in service *decisions* through the initiative?
(Tick all which apply)

☐ through being consulted about their views on services
☐ through taking part in the decision making process itself
☐ other (please specify) ....

12. Which of the 5 forms outlined below *most closely* describes the *degree of participation* of the children/young people in the initiative at the moment?

(Tick one only)

☐ Adults design and run the initiative. Children/young people volunteer to take part on the basis of understanding who decided to involve them and why.
☐ Adults design and run the initiative but consult children/young people on some aspects of this. Children/young people understand the whole process.
☐ Adults have the initial idea, but children/young people are involved in making decisions at all steps of planning and carrying out the initiative.
☐ Children/young people have the idea for the initiative. Children/young people set up and run the initiative with adults offering advice, discussion and support.
☐ Children/young people have the idea for the initiative. Children/young people set up and run the initiative, with access to adults available if required.
☐ Other (please describe) ....
....

Note: Adapted from Treseder, P. (1997) *Empowering children and young people: promoting involvement in decision making*, London: Children's Rights Office/Save the Children.

No one form is inherently 'better' than the others, since the most appropriate form of participation will vary according to the circumstances of each case.

METHODS FOR INVOLVING CHILDREN AND YOUNG PEOPLE

13. If the initiative involves *consulting children/young people on their views about services*, which methods are used?

a) Written methods
(Tick all which apply)

☐ questionnaire
☐ creative writing
☐ graffiti wall
☐ sentence completion
☐ suggestion box
☐ other (please specify) ....

b) Verbal methods
(Tick all which apply)

☐ group discussion
☐ question and answer session
☐ video/‘vox pop’ booth
☐ other (please specify) ....

c) Visual art, design and drama
(Tick all which apply)

☐ drawing
☐ photography
☐ making a video
☐ designing a display (eg collage**)**
☐ building a model
☐ role play/drama
☐ other (please specify) ....

d) Any other methods

☐ Please specify ....

14. **In this initiative, are children/young people consulted:**

(Tick all which apply)

☐ Individually?
☐ In a group?
☐ Both individually and in a group?

15. **If the initiative involves children/young people taking part in *decision making,* in what way(s) does this happen?**
(Tick all which apply)

***a) Children/young people take part in decision making <u>directly</u>*:**

☐ Children/young people have a seat in an established decision-making forum of the organisation
☐ Other (please specify) ....………...
………………………………………………………………………….

***b) Children/young people take part in decision making <u>indirectly</u>*:**

☐ Via a local youth group or forum
☐ Other (please specify) ....………
....

SUPPORT

16. **Did your organisation provide any *support for the children/young people* taking part in the initiative?**
(Tick one box)

☐ Yes
☐ No (go to Question 18)

17. What *type(s) of support* was provided for *children/young people*?

a) General support
(Tick all which apply)

☐ training (please describe briefly)..
....
☐ information about the organisation's decision making processes
☐ payment (whether in cash or in kind)
☐ transport (whether direct provision or expenses)
☐ other (please specify) ....

b) Support specifically tailored to disabled children/young people
(Tick all which apply)

☐ access to venue(s)
☐ advocacy
☐ assistance with communication
☐ other (please specify) ....

18. Did your organisation provide any *support for the staff* taking part in the initiative?
(Tick one box)

☐ Yes
☐ No (go to Question 20)

19. What *type(s) of support* was provided for *staff*?

a) General support
(Tick all which apply)

☐ training on children's/young people's involvement (please describe briefly below)
....
☐ protected time
☐ other (please specify) ....

b) Support specifically tailored to working with ill or disabled children/ young people

☐ Please specify ....

OUTCOMES

20. Has the initiative resulted in any *changes in service provision*?
(Tick one box)

☐ Yes (please outline briefly below)
....
....
....
....

☐ No (please outline reason(s) briefly below, for example, initiative not yet complete; insufficient resources to implement children's/young people's suggestions)
....
....
....
....

21. Has the initiative resulted in any *changes in commissioning or service priorities*?
(Tick one box)

☐ Yes (please outline briefly below)
....
....
....
....

☐ No (please outline reason(s) briefly below, for example, initiative not yet complete; insufficient resources to implement children's/young people's suggestions)
....
....
....
....

22. Has the initiative resulted in *any other changes* relevant to service development?
(Tick one box)

☐ Yes (please outline briefly below)
....
....
....

☐ No

23. **Have the children/young people involved received any *feedback* on the outcomes of the initiative?**
(Tick one box)

☐ Yes (please outline briefly below)
....
....
....

☐ No

EVALUATION

24. **Has there been any evaluation *with children/young people* of their experience of the initiative?**
(Tick one box)

☐ Yes (please provide details, including a copy of any written evaluation)
....
....
....
....
....

☐ No

25. **From what the *staff have learned* through experience of this initiative in involving children/young people with a chronic illness or physical disability in local decisions about health services development:**

a) ***what (if anything) would you want to pass on to others as particularly <u>useful</u>?***
....
....
....
....
....
....

b) ***what (if anything) would you want to pass on to others as particularly <u>problematic</u>?***
....
....
....
....
....
....

STAFF

26. Is there a *post-holder* in the organisation with designated responsibility for children/ young people's involvement?
(Tick one box)

☐ Yes (please state job title and brief outline of responsibilities)
....
....
....
....
....

☐ No

27. CONTACT DETAILS

In case we have any queries, please give contact details of the person completing this questionnaire:

Name: ....

Work Address: ....

....

....

....

Telephone number: ....

Fax number: ....

E-Mail address: ....

28. PUBLICATION

We plan to publish a summary of the results of this national survey. In addition to identifying general trends, we would like to include examples of different types of initiative with contact details so that interested colleagues in other organisations can find out more. In principle, would you be prepared to discuss with the researchers publication of details of this initiative, if we wanted to include it in the summary?

☐ *Yes,* I would be prepared to discuss inclusion of details of this initiative in the summary report

☐ *No*, I would not wish details of this initiative to be included in the summary report

29. FURTHER RESEARCH

There will be a further stage of the research to look in detail at selected initiatives (see information sheet for methods). If your initiative is selected, would you be prepared to discuss participation in Stage Two?
(Please tick one box)

☐ Yes

☐ No

Please return the questionnaire in the envelope provided.

Please remember to enclose any written documentation about this initiative, which we will treat in confidence.

Thank you for your co-operation.
