Evaluating Children's Health Services

The Adolescent User Perspective

A Report by Action for Sick Children

Edited by: Christine Cooper   Project Leader: Susan Langley

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An Action for Sick Children Section 64 Project

Funded by The Department of Health.

Edited by: Christine Cooper

Project Leader: Sue Langley

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A special vote of thanks to John Needham, researcher, who participated in this research by undertaking the pilot of the questionnaire in Hospital sites 5, 6 & 7. It was a tremendous help with this research project.

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Foreword

Adolescents are a resource group mostly underused when planning provision to cater for their needs within healthcare. Action for Sick Children has long held the view that children and young people should have a right of involvement in the planning and provision of their health treatment and be given the opportunity, where appropriate and possible, to make informed choices when they have to visit hospitals. The health care needs of young people are now a government priority, and it is emphasised within the National Service Framework for Children (Department of Health 2003) that it is necessary to have services designed to meet their specific needs.

The report aims to demonstrate how Action for Sick Children developed a unique survey tool to assess the views of adolescents undergoing treatment within the health service.

The findings of this report highlight the importance of engaging adolescents in the planning and evaluation of services in which they are treated. It shows they are able to recognise good practice and to give credit where it is due. The project demonstrates the need for continuing the study in order that all young people have access to healthcare, which is compatible with their requirements.

Pamela Barnes
Chairman Action for Sick Children

Abstract

This report is the culmination of a two year research project undertaken by Action for Sick Children, made possible through the provision of a Department of Health Section 64 Grant. The aim was to develop and test a tool to explore the views of adolescents[1] within the National Health Service. The project was in three phases, with this report relating to the design and testing phase. The questionnaire was designed by adolescents for adolescents and, as a result, brings a unique perspective to the development of a tool for use with adolescents. The tool was tested across seven sites that care for adolescents in Acute Hospital settings. The findings were not intended to be a true representation of all adolescents, but to provide a snapshot of the views of the adolescents involved, and find opportunities to test the validity of the developing tool. Each Trust involved requested, and was provided with, an individual site report on their hospital findings.

Introduction

> ***"There are many opportunities for children and young people to take an active part in shaping where they live, the services they use and the decision making of local and national organizations in the voluntary sector and across government. They have a right to be involved in decisions that affect them."*** [2]

This is the philosophy that underpins this research. The two year project was designed to explore the views of the young people who use healthcare services, and devise a tool that can be utilized in a variety of healthcare settings.

Although recent decades have seen an increasing interest in listening to children's views (Prout 2002, Hutchby & Moran-Ellis 1998), and the use of adolescents in research (Balding 1997, McCormick et al 1999, Armstrong et al 2000, Pryor 2001) which includes healthcare issues (Winn et al 1995, Armstrong 2000), adolescents as a resource group in the healthcare services are underused and generally not engaged in the planning or development of services.

The Court Report (1976), although now 30 years old, still has relevance today. It clearly states that:

> ***"Adolescents have needs and problems sufficiently distinguishable from those, on the one hand of children and on the other hand adults, to warrant consideration as a distinct group for healthcare provision."*** [3]

This implies that we cannot anticipate the needs of the adolescent because, as adults, we do not share their perspective. This factor emerged as this research progressed; highlighting a difference between the perspective of professionals working with adolescents and claiming to be experts of their views, and the actual views of the adolescents themselves. Adolescents are increasingly seen as offering valuable insight into their experiences and interaction with the world in which they live (Prout 2002). It is important not to underestimate the views of adolescents, which is emphasized within the results of this research. NAWCH (1990) identified 15 years ago:

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[1] The terms adolescent and young person may be used interchangeably within this document and are used to represent the views of participants aged between 11 and 19 years.

[2] National Youth Agency and local Government Agency for Department of Health: Involving Children and Young People – An Introduction, 2003.

[3] Department of Health and Social Security (1976): Fit for the future – the report of the Committee on Child Health Services (Chairman –SDM Court) London, HMSO.

"Young people are articulate and should be involved in reviewing and monitoring services provided for them." [4]

Today there is an increasing acknowledgement of the competence of young people, which is seen in the growing body of knowledge and literature on involving children and young people in decisions around the design process and interpretation of research (Hill 1997, Schwab 1997, Thomas & O'Kane 1998, O'Kane 2000). The challenge of using young people in any research, is to understand and facilitate methods of collecting data that encourages and enables them to speak for themselves, and have their views interpreted in meaningful ways.

In order to facilitate this research it was essential when involving young people that the involvement be not merely "lip service". Not only were the views of the adolescents collated but ways were provided in order for them to participate in the design and development of the project. In this way there would be validity in the views expressed by the participants. The questionnaire needed to be presented in such a way that the adolescents designing this questionnaire felt comfortable with this tool and were able to identify with the style and the content.

Action for Sick Children (previously NAWCH) has always campaigned, since its inauguration in 1961, to enable the voice of the child and parent to be heard. It is exciting to see the emphasis of this theme emerging in a number of government documents which aim to integrate the views of young people into plans to develop children's health services (DoH 2002, DoH 2003). There are still only limited resources available to enable the voice of young people to be heard.

The Department of Health action plan supports listening to children (2002). It identified the need for toolkits that could be distributed to each Primary Care Trust (PCT) to collate the views of children and young people as part of the government Public/Patients Involvement (PPI) initiative. Our project, commissioned in 2002 and completed in 2003/2004, set about designing such a toolkit by devising a questionnaire that enabled young people to express their views on the services provided for them. Thus this report and questionnaire tool is timely. It offers a way to gather data from young people, designed by young people, for young people, and gives them a voice which is, at present, under represented in the healthcare arena.

Design of the study

The overall project was in 3 phases:

Phase 1: Recruitment of a project manager; the initial collation of the literature to support the project; the establishment of the steering group (see Appendix 1).

Phase 2: Development of a database of contacts and NHS Trusts which provide care for adolescents; identification of the key sites to conduct the research; the gaining of ethical approval for same.

Phase 3: A two part process:

(1) Establishment and utilisation of an adolescent group to develop the questionnaire tool using the Delphi technique.
(2) Utilisation of NHS Acute Hospital Trust sites to pilot and refine the developed tool.

Phases 1 and 2 have already been completed and copies of the reports, as submitted to the Department of Health, can be found in Appendix 6.

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[4] NAWCH Quality Review Series (1990): Setting Standards for Adolescents in Hospital.

Ethical approval was granted through the West Birmingham Local Research Ethics Committee for the pilot study, and the West Midlands Multi-site Research Ethics Committee for the multi-site wider project following the pilot. The process of ethical approval was not smooth, due to the changes in gaining approval for multi-site research and the need for indemnity insurance for charity organisations. The impact of the changes to ethical approval was articulated in an editorial in Paediatric Nursing (Langley & Cooper 2003). (See Appendix 5)

This document relates to Phase 3 of the project:

(1) The Establishment and utilisation of our adolescent group to develop the questionnaire tool, using the Delphi technique.

(2) Utilisation of NHS Acute Hospital Trust sites to pilot and refine the developed tool.

Aims of the study

The aims of this phase of the study were to:

(1) Develop a questionnaire tool for use in the acute hospital setting utilising an expert panel of young people.
(2) Pilot and refine the questionnaire by testing them within identified NHS acute hospitals that care for adolescents.

Questionnaire development

Expert panel

To develop a questionnaire that had validity for adolescents, a group of adolescents with experience of healthcare in the NHS was selected to design and develop the questionnaire tool.

The possible participants were identified through both professional and lay contacts that provided the lead researcher with names. Due to the constraints of child protection and promoting safe environments for children, it was not possible to approach the children directly. Thus it was necessary to negotiate access through the parents. The parents became 'gatekeepers' in providing permission to invite the young person to join the group.

Informed consent for this project was based on the belief that the young person was able to voluntarily agree to participate in the research. Current legal and ethical guidelines suggest that children over 16 years of age and above are able to provide their own consent (DoH 2002). The Gillick judgment (Gillick vs. West Norfolk AHA [1986]) states that, with regard to medical treatment, children who fully understand a decision affecting their lives, automatically have the capacity to reach their own decision and provide consent. Given the vulnerability of children involved in the healthcare system, it was deemed appropriate to gain consent from either the parents or those who had parental responsibility (in the case of the two 'looked after' young people) and also the adolescents taking part in the questionnaire design and testing.

The criteria for inclusion of the young people was:

- aged between 13 and 19.
- some experience of healthcare.
- able to speak and read English.

We were concerned that this might limit the group representation, particularly with regard to ethnic minorities. Despite these concerns, the group was diverse with regards to representation of ages and ethnic minorities as can be seen below.

10 young people were invited but only 7 young people turned up on the day. The group characteristics included:

Aged between 13 and 19 years (one of each age bracket)
1 boy and 6 girls
3 were from ethnic minorities (They described themselves as black (2) and Asian (1))
3 had chronic health conditions. Cystic Fibrosis, dermatological problems and one who did not identify their illness
2 'looked after' children with experience of healthcare
1 had only visited A&E
1 had received no direct acute hospital healthcare but had views about the care and facilities through visiting

We acknowledge the group was unbalanced as regards to boys on the day. It does appear that boys on this occasion were not able to attend and we may need to consider how to improve the involvement of boys in future projects.

Questionnaire design

The challenge of developing the questionnaire was in providing a method that facilitated the views of the young people, and reduced the effects of the researcher bias. Various influences needed to be taken into account, such as the power relationship between the researcher and the young person (Holmes 1998); the environment where the research will take place (Broad & Saunders 1998); the influence of older participants dominating the discussion and the impact of the method of enabling the voice of the young person to be heard. To lessen the impact of these factors it was agreed a Delphi technique would be utilised (See Appendix 2). The Delphi technique involves developing broad themes, which are then refined with the participants through a series of generated questionnaires (Schmidt et al 1997).

Focus group

To identify the topics for the broad themes of the Delphi process, it was essential that a way be found that enabled the young people to generate their own themes and reduce the influence of the researcher and adult bias. To facilitate this, a focus group was chosen as an appropriate forum to allow the young people to express their views. Young people can feel more relaxed in groups than when responding to direct questions; groups provide space to raise issues they want to discuss (Wilkinson 1998). However, focus groups are not always appropriate for all young people and some may feel inhibited about speaking out in a group with their peers, fearing ridicule or reprisal as a result of their comments (Balen et al 2000). There was also the possibility that dominant voices could significantly influence the discussion. These issues were addressed by carefully facilitating ground rules for the day. The rules were devised by the young people and included an agreement that they would listen to and respect each other's views. In addition a graffiti board activity was devised to combine the discussion with an alternative method of contribution that encouraged wider participation (NCB 2002).

All participants were invited for the day by letter (see Appendix 2) and the focus groups were held in rooms provided by the University of Central England. It was considered a neutral environment which was a central location for all the young people to easily access. The day was structured and lots of refreshments and a pizza lunch were provided; which proved to be the most popular event!

To facilitate the day, two children's nursing professionals joined the focus group. We were aware that these individuals considered themselves experts on adolescent care and there was a possibility of influencing the group through suggestions for topics to discuss. Thus, it was agreed that they would not guide the participants and during the graffiti board exercise they were encouraged to do their own separate board. This was not a part of the research, but the results indicated they judged adolescents priorities differently from those of the young people themselves. **This highlighted for us the danger of assuming that adults understand the needs of young people.**

It was recognized that the facilitators of the research had to be sensitive to any signs of distress the young people may exhibit, particularly if the research reminded them of any unpleasant or difficult experiences in hospital care (Thomas 1992). Although no difficulties were encountered with the "Delphi group" on the day of the focus group, we had ensured that they knew they had someone to contact if they were concerned or upset about the research, or any issue of which they were reminded. Contact details for both the Lead Researcher and the Chairman of Action for Sick Children were provided, in case any of the young people wished to talk to someone not directly involved with the research. Broad themes were generated on the day, which were then utilised to develop the first questionnaire to be sent to the participants as part of the Delphi process. (See Appendix 2)

The questionnaire subsequently went through a series of refinements, but the process raised awareness of one of the difficulties of using this approach with young people. Although they are experts regarding their experiences, they do not have the necessary expertise to devise a short questionnaire. At one point the document was eight pages long and took one hour to complete. This would have had an impact on the return rate of those using this as a form of data collection. The issue was resolved by providing some training and support for the young people to reduce the questionnaire to a manageable document that would take 10-15 minutes to complete. (The finalised questionnaire document is in Appendix 3.) This reduction maintained a balance between retaining the essence of the themes, and a significant loss of the issues to be addressed in the way the young people wished it to be presented.

The questionnaire had some key areas that the young people felt were priorities for them in a hospital setting:

Food needs
My choices
How people treated me
My needs

The style of the questionnaire was determined by the Delphi group. It was interesting to note that they adopted a layout which resembled one that could be used in children's magazines. This may in part be due to their experiences. It is worth noting, that it is something which is recommended as a format to researchers undertaking this approach, which may help children complete a questionnaire (Balen et al 2001).

To thank all the young people for participating in the research a certificate was provided. A free prize draw was also held for a basket of fruit amongst the group to give a sense of reward for participation (Weithorn and Scharer (1994)). We would have preferred to give each one a voucher but at the time of the ethics application, the committee did not consider this appropriate. Rules since that date have been relaxed.

Pilot study

Three hospitals were included in the pilot study to test the questionnaire. The Lead Adolescent Advisor/Researcher for the Health Authority was involved in administering the tool. This facilitated access to Outpatients, Accident and Emergency and the Acute Hospital Wards. The work was covered by Trust indemnity. The project leader met with the Advisor to ensure the ground rules (See Appendix 1) for administering the questionnaire and the sample requirement for the pilot study were understood.

The questionnaire proved successful and no further alterations were made. Thus it was agreed to include these findings in the main summary of findings. The three pilot sites are managed under one Trust so the data was compiled into one report.

Data collection

The questionnaire was taken to four acute hospital sites and distributed to the adolescents who were in the Outpatients, Accident and Emergency Department and Acute Hospital wards (as appropriate for each Trust) on the day designated for each hospital. The aim of distributing the questionnaires was not to gain a representative sample of adolescent views, but to provide data on the feasibility of using the tool within clinical practice to gain the views of young people on the services provided. The data from the sample does have value and provides a perspective on the information that may be collated when using the tool. Thus it is presented here as an exemplar of the use of the tool. It should be re-iterated that the sample can only be a 'snapshot' of the day and does not represent the views of all adolescents.

The data from each Trust was fed back to each Trust individually to preserve confidentiality.

Data analysis

The data generated was from a mixture of open and closed questions providing data which was both quantitative and qualitative (Punch 1998). The analysis is presented as descriptive statistics with supportive quotes generated from the comments provided. It was felt that the comments were not sufficiently detailed to provide themes for most questions except Question 8 (My needs), which provided data that generated some key issues to discuss.

Findings and discussion

The findings will be presented briefly as one sample from all seven sites. The data is presented under each topic to provide an overview of the views of the young people.

Sample characteristics

This is a convenience sample and the information provided only represents the views of the young people included within the population data 'captured' on the day each Trust was visited.

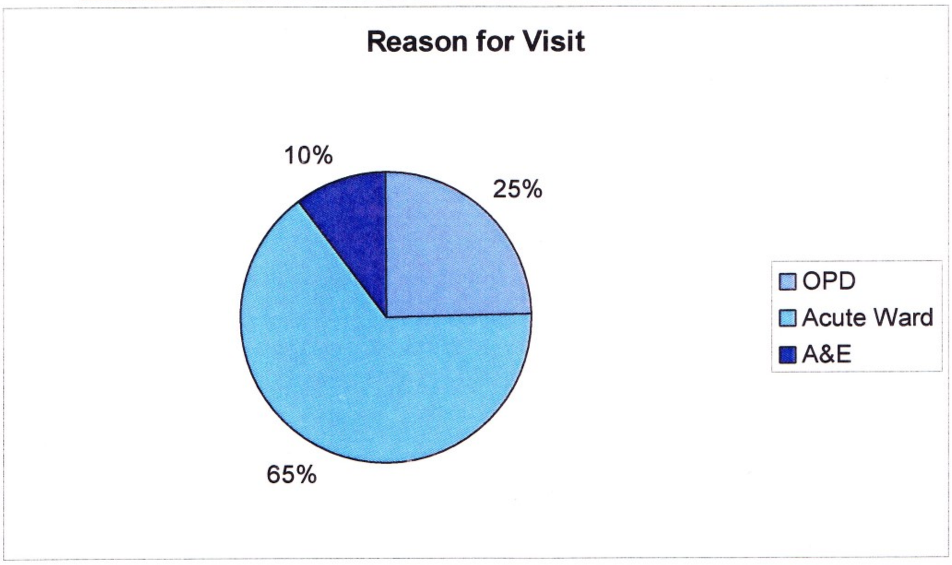
The cohort consisted of 91 adolescents who were either visiting or were inpatients in the seven Acute Trusts over the data collection period of three months. Each of the seven Trusts was only visited on one occasion.

All adolescents receiving or awaiting treatment on the ward, in Outpatients or the Accident & Emergency department were asked if they would like to complete a questionnaire. They were informed this was part of a large study to find out what young people thought of the facilities and care they received in the NHS. Confidentiality was confirmed and it was emphasised that participation was voluntary and that withdrawal from the study at any time was acceptable and would not affect their treatment in any way. A copy of the consent form, information leaflet and questionnaire was left with them and the researcher returned 20 minutes later to collect it. No one refused to complete the questionnaire.

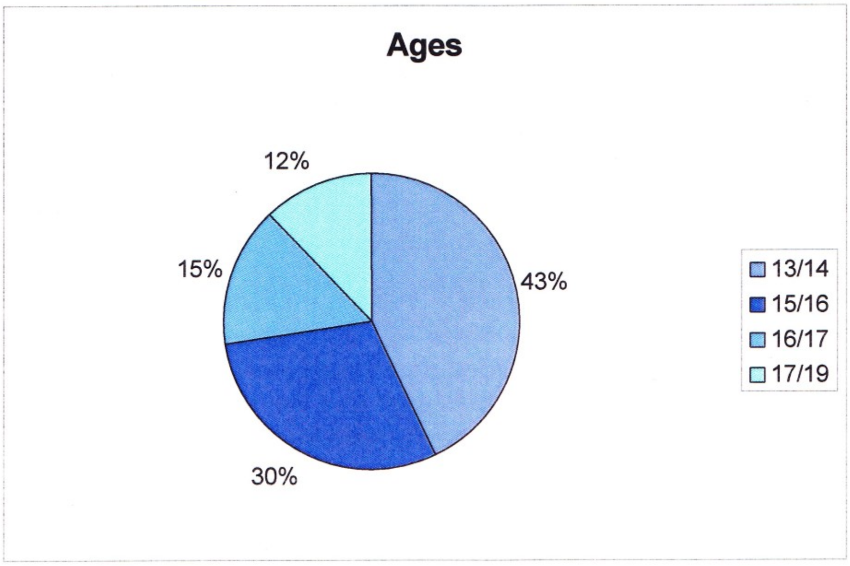
Demographic details are presented in Table 1.

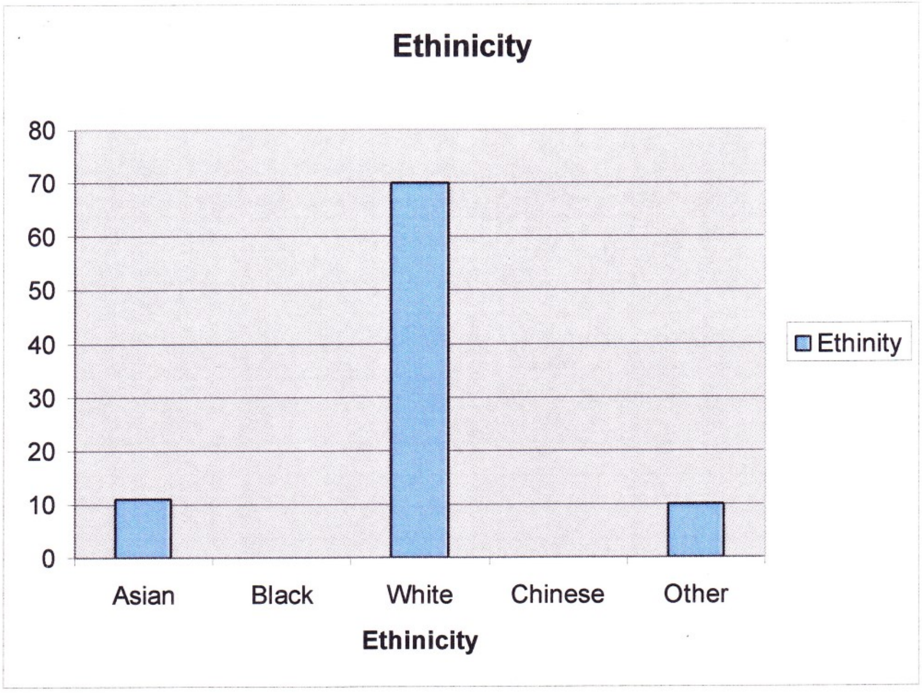
Table 1

Demographic details	Reason for visit	Ages	Ethnicity	Gender
OPD	17			
Acute Ward	45			
A&E	7			
13/14		39		
15/16		27		
16/17		14		
17/19		11		
Asian			11	
Black			0	
White			70	
Chinese			0	
Other			10	
Male				41
Female				50

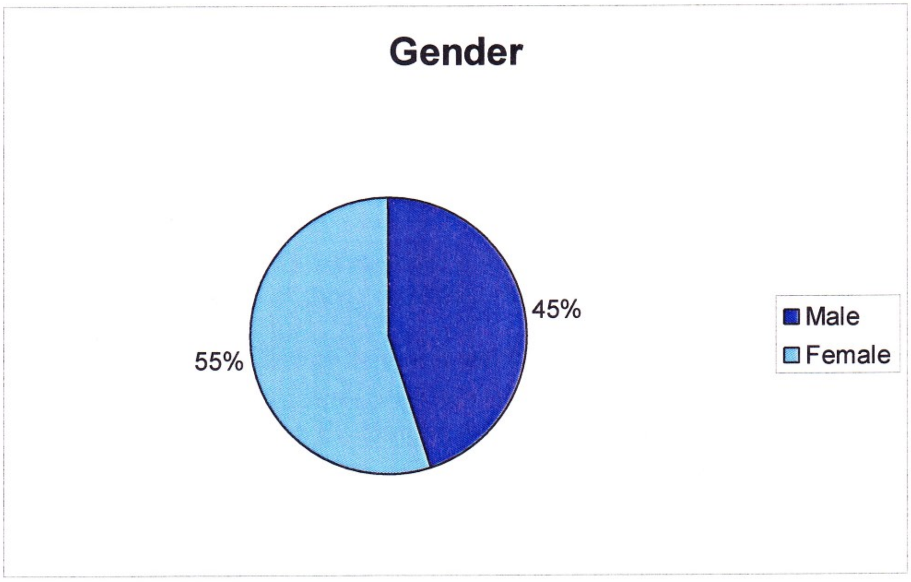


Only one young person indicated that this was their first visit to the hospital. No young person was cared for in an adult setting.





It is noted that the sample had no black or Chinese participants although ten indicated they were in the other category but did not choose to indicate what 'other' meant for them.



Food Needs

The closed questions received a mixed response. These questions required only one response.

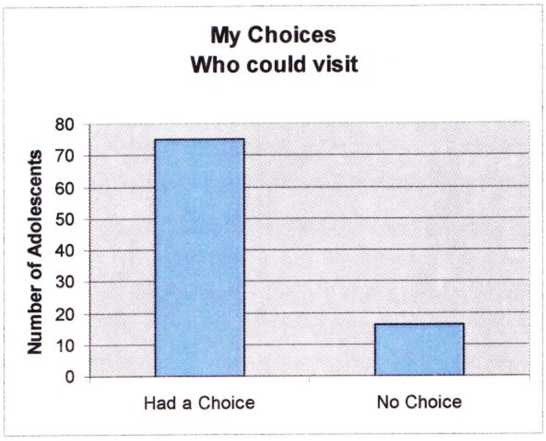
Nearly 30% (n19) of the sample did not have food due to just visiting or not eating due to treatments, but from those who received food only 44% (n29) indicated that the portions were good, and only 30% (n20) felt that it was hot, with 42% (n25) relying on snacks and sweets as 40% (n26) felt that the food they wanted was not available.

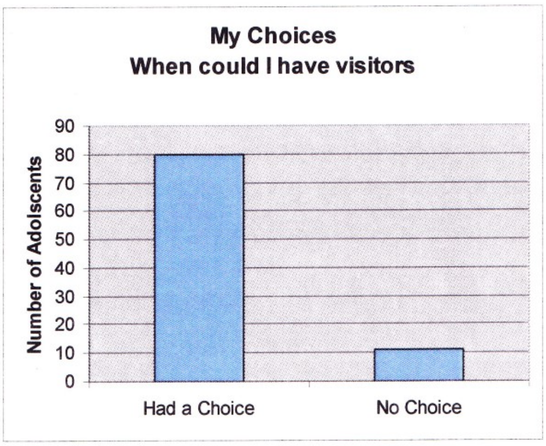
The main criticisms in the comments supported the quantitative data emphasising that the portions were too small and they got hungry between meals. A few relied on food being brought in from home, particularly as most commented that there was little choice, it was not very healthy, it lacked taste and imagination or was aimed at meeting the needs of young children. As one adolescent commented:

"I want more options, and more food, less sandwiches, smiley chicken faces and more jacket potatoes." (Aged 15/16)

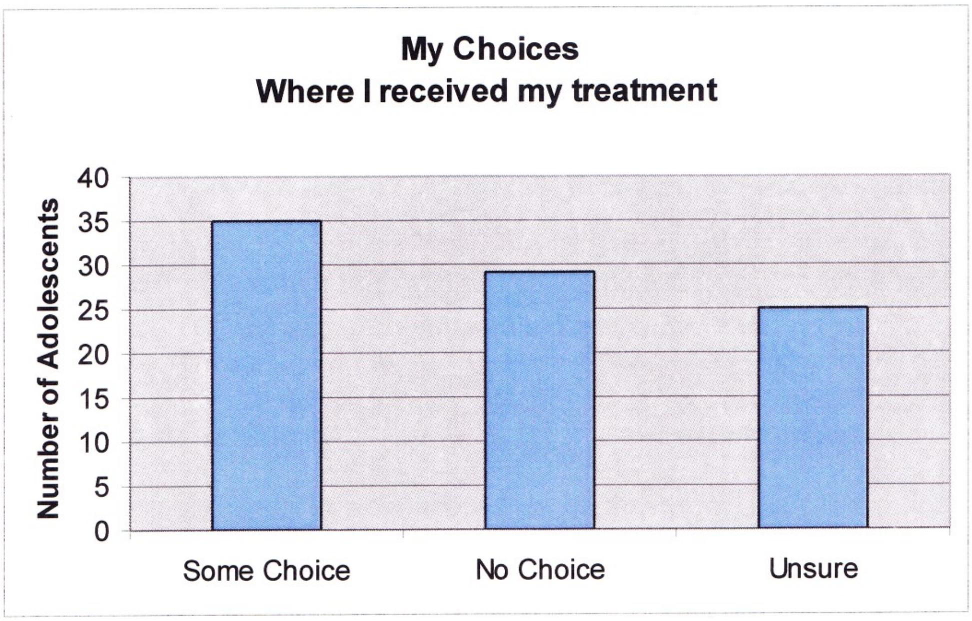
My Choices

The results regarding choices received a mixed response. 82% (n75) believed they had choice about who could visit them and when they were visited (88% - n80) but the response showed a marked difference when it came to where, when and how they received their medication.

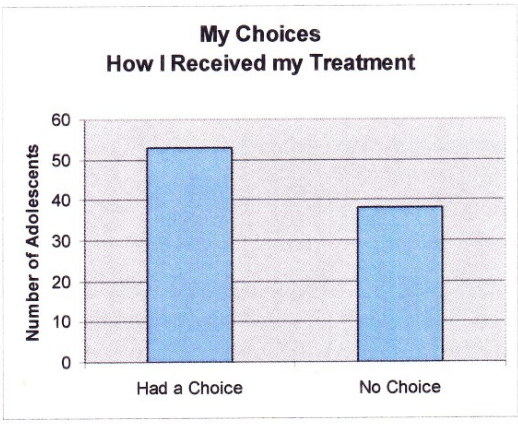


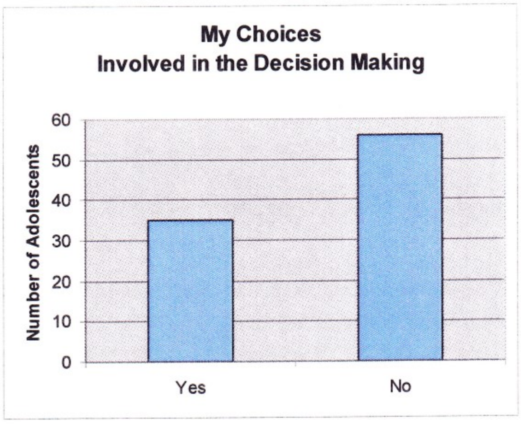


38.7% (n35) felt they had some choice about where they received treatment. 32.5% (n29) felt they had no choice and 27.5% (n25) were not sure. With regard to when they received treatment, the proportions of those who were unsure were roughly consistent with the "where they received treatment" results, except those who felt they did have choice fell to 38% (n35) and those who felt they had no choice rose to 45% (n41).



As to the choice about how they received their medicines, 58% (n53) felt they had choice but only 38% (n35) felt they were involved in the decision about who gave them the treatment.





Overall the adolescents in the younger age bracket 13-15 felt they had good choice and felt they were consulted. The picture was very different for those who were 16-19 years as they indicated that the choice and consultation with themselves was unsatisfactory. They appreciated that the reason for their admission could influence treatment, and choices should be available as long as it did not compromise the treatment outcomes. As an asthmatic noted:

> *" Limited due to being an asthmatic but they are normally OK cos the doctors explain everything before they do it and I like that."* (Aged 16/17 years)

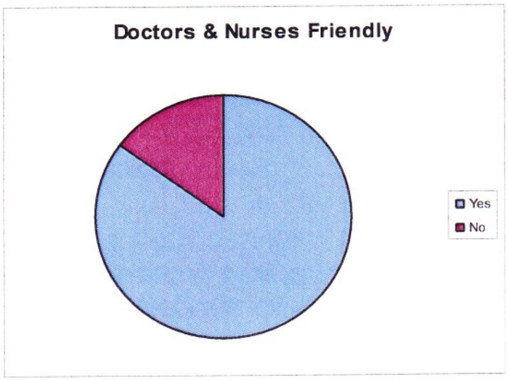
The young people felt that, at times, there was very little choice offered; although they indicated that they were listened to if they asked for something.

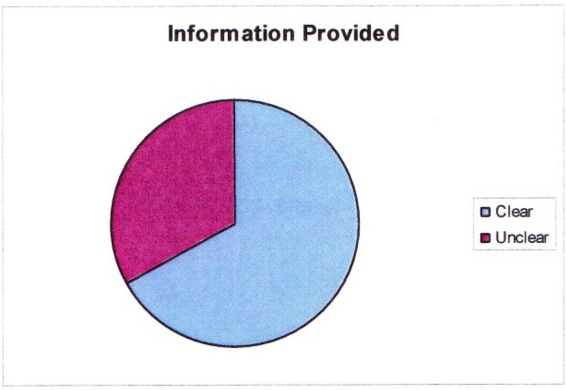
How people treated me

In this section adolescents could choose as many words as they wanted which matched the way they felt people had treated them. Thus, adolescents circled several words so the percentages for each section may add up to more than 100% (n91)

The picture with regards to how people treated the adolescents was very positive. Overall 69% (n63) felt they were treated with respect and doctors and nurses were friendly (85% - n77) and they gave the adolescents clear information (67% - n61). Some still felt that they were not treated with respect or talked to appropriately. As one adolescent noted:

> *"What they told you wasn't that bad but I thought that doctors were speaking like you weren't at their level."* (Aged 16/17)

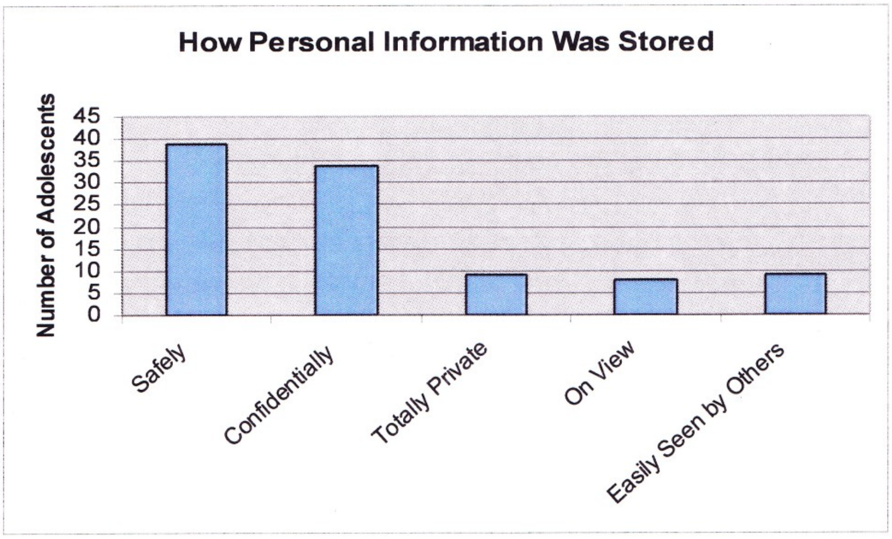




The picture with regard to how information was given and stored raised a number of issues for the young people:

When the young people were given information by the nursing or medical staff, over 70% (n64) were given information with their parents, 14.3% (n13) with others, but only 27% (n25) were spoken to "in private" or (7.6% - n7) "on their own". This has implications for how much the young person may be willing to reveal when the information is confidential and sensitive, and questions the need that young people should be able to discuss issues more openly without their parents.

The issue of confidentiality of the information on the young people indicated that although 43% (n39) felt it was stored safely, confidentially (37.4% - n34) and in private (10% - n9), a number felt it was on view (9% - n8) and easily seen (10% - n9). Again this may be a barrier to the young person revealing personal details if they were not sure how the information was stored.



My needs & other comments

This section invited the young people to write about their experience in their own words with a series of words as cues to help them get started. The comments about the facilities were mixed depending on whether the young people were on an adolescent unit or a general paediatric ward.

The key themes identified were:

'It was hot and stuffy and uncomfortable'
'We need things to do'
'Crying babies'
'Keeping up with their school work'

'It was hot and stuffy and uncomfortable'

Many adolescents commented on the temperature of the hospital, particularly in the ward areas. Many felt that although members of staff were friendly the beds were hard and they felt the hospital was unclean and they found it difficult to settle. These comments sum up many of the responses from the general wards:

"It was so hot and stuffy and uncomfortable ... the toilets leaked and the bed sheets were static and the sheets had stains." (Aged 14/15 years)

"The floor was stained and the room I am in is noisy." (Aged 15/16 years)

"The ward was hot and stuffy and there was no people of my own age." (Aged 16/17 years)

Whereas, those on the adolescent units felt the temperature was fine and facilities good. They felt it was comfortable. As one young person said:

"It was clean and comfortable, clean and tidy, there were young people to talk to, my electric bed was brilliant." (Aged 13/14 years)

"The temperature was fine, quite comfortable, young people were the only people there and clean." (Aged 15/16 years)

The temperature is a key factor and may be higher on general wards due to the presence of very young infants and children. It does not meet the needs of the young people.

'We need things to do'

Most of the adolescents commented on the facilities and about having activities to do which made all the difference. A few stated they were bored and the DVDs and TVs were not good in the general paediatric ward:

"We hardly had any TV channels." (Aged 13/14 years)

"Boring at first but I enjoyed myself in the school room as there were people to talk to." (Aged 14/15 years)

"We need more activities, computers and more channels. I could go to sleep at any time but I didn't like the fact the TV was turned off at 9 p.m." (Aged 15/16 years)

"I was comfortable but there were no activity rooms. It was tidy. There were no DVDs." (Age 17/18 years)

This contrasted sharply with those on the adolescent unit where the issue of having lots to do was a common feature of the comments:

"There was a LOT to do – schoolroom, videos, games and computers" (Aged 13/14 years)

Although not everyone felt **all** of the facilities were so good:

> "There *were good computers and although we had access to portable TV, the picture was rubbish as it was an indoor aerial*" (Aged 15/16 years)

'Crying babies'

The issue of the crying babies was a recurring theme for those not nursed in an adolescent ward. It affected their sleep, particularly the younger age group, throughout the night. It was noticeable there were no comments from any age group other than the 13/14 year olds.

> *"It was very stuffy and noisy and a long wait for medication at times and crying babies stopped me sleeping at bedtime."* (Aged 13/14 years)

> *"School in the morning was a shock. Crying babies all through the night."* (Age 13/14 years)

> *"It was hot but tidy and one crying baby."* (Aged 13/14 years)

> *"There was a crying baby too but he was strapped up and looked very uncomfortable so I can understand."* (Age 13/14 years)

'Keeping up with their school work"

The issue of going to school and keeping up with schoolwork was a key feature particularly amongst those doing their GCSE's. As one young person commented:

> *"There should be more facilities to enable patients to keep up with their school work, especially when concerning exams – GCSE and A levels."* (Aged 15/16 years)

This issue had some overlap with the noisy atmosphere of the wards, which made going to school during the day difficult if the young person had a disturbed night (see above : Crying babies).

Conclusion

The data from the seven sites draws attention to the need for specific, separate services for this group (NAWCH 1990) and the importance of engaging young people in the planning and evaluation of the services.

Some issues are captured by existing audits but there are a number of key issues which are of concern to the adolescents themselves, which have not been explored; particularly with regard to who is present when information is discussed with them and how that information is stored. A further issue that arose was the amount of choice the young people felt they had with regard to involvement in decisions regarding treatment.

Summary

The report demonstrates that the questionnaire tool is of value as part of a toolkit in gaining insight from the adolescent user perspective highlighting the issues that are important to the young person. The project has demonstrated that young people are able to evaluate the service they use (DOH 2002).

There is a need for further development of this kind of initiative, which promotes a dialogue and involves organisations, such as Action for Sick Children, to enable and empower young people to have a voice in the healthcare arena.

Recommendations

This project has demonstrated the value of the tool in promoting the voice of young people, but a further consideration would be to use the young people themselves to collect the data. This would require careful consideration for ethical approval and indemnity, but adds an appropriate dimension to adolescents evaluating their own services.

From this study we recommend that:

- Adolescents are involved in planning services and highlighting good practice.
- Adolescents are used to evaluate services planned and delivered for themselves.
- The tool developed is valuable and workable.
- There is wider consultation and development of the Action for Sick Children tool.

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Appendices

Content

Appendix 1

Project - Adolescent Services: User Perspective Project

Terms of Agreement

Introduction

Funded by the Department of Health, Action for Sick Children's project is to develop a qualitative tool, which could be applied nationally to access the views of Adolescent user's about their experience of acute services. The research aims to develop this tool utilising a cyclical Delphi Technique process to determine recurrent themes. The principal objective is therefore to capture the essence of the themes generated around three topics:

- what health services they are receiving,
- what is required to meet their needs and
- what are the issues that they consider most important in meeting their needs.

Initially the research focuses on the development of a questionnaire and a pilot of the resultant questionnaire (tool) at Birmingham City and Birmingham Children's' Hospitals.

This project is essentially in two parts.

- The first part is to create a focus group from the adolescent groups within your area and use that group as the expert panel to develop a questionnaire as a tool to evaluate the services adolescents receive.
- The second part is to then pilot the questionnaire to assess adolescent services within a number of NHS Trust's locally using the questionnaire tool developed.

The following are the terms of our working relationship.

(1) The research project will be managed by the Action for Sick Children Project Manager who will liaise with the NHS Trusts and personnel where the project will be undertaken.

(2) The Local Researcher will be accountable to the Project Manager, who in turn will be accountable to the Board of Trustees for Action for Sick Children. Regular meetings, between the Local Researcher and the Project Manager, and the Project Manager and the Steering Group, will be undertaken to discuss pertinent situations and project progress.

(3) The findings from the project will then be compiled in a report for the DOH. Thus until the final report is released, the findings will remain confidential. The researcher will not make use of or develop any of the materials or processes particular to this project for their own purposes until after the report is finally released and without the prior permission of Action for Sick Children.

(4) The Local Researcher will:

- Gain approval for their involvement in the project through their appropriate NHS management.
- Seek indemnity for the research project through each NHS Trust, via an appointed member of the Trust personnel.
- Negotiate operational access to the Trust. Each Trust will provide access to the adolescents who will form part of the sample for the focus group and/or questionnaire, as per agreement with Project Manager.
- Obtain consent from the adolescents and the appropriate parent/guardian before the adolescent may be eligible for inclusion in the research project.
- Collect and collate information from the adolescents and ensure this remains anonymous and confidential.

5) The Project Manager will ensure that ethical approval for access to the adolescents has been obtained through the host Trust where the focus groups will be accessed and/or the questionnaire distributed.

10 Action for Sick Children will not be accountable for the costs incurred through time spent by the NHS Trust personnel agreed to be involved in the project.

(11) The processes, production and publication of the questionnaire document will be managed through Action for Sick Children and remain the copyright of Action for Sick Children, who are also responsible for costs involved.

In Conclusion.

The key objective of the Evaluating Children's Health Services: The Adolescent Perspective is to acknowledge and value the views and contribution of adolescents in the planning and provision of their services.

Action for Sick Children has obtained funding from the DoH to develop a tool to access the views of adolescents when they use acute services. Therefore, the processes, publication and production of the questionnaire document will be managed through Action for Sick Children and remain the copyright of Action for Sick Children, who are also responsible for costs involved.

Thus, until the final report is released, all the findings will remain confidential. No unauthorised person can make use of, or develop any of the materials or processes particular to this project for their own purposes, until after the report is finally released and without the prior permission of Action for Sick Children.

Local Researcher.. Date........................

Project Manager.. Date ....

PROTOCOL

Title

Evaluating Children's Health Services:
The Adolescent User Perspective

Background

For in excess of forty years Action for Sick Children, formerly the National Association for the Welfare of Children in Hospital (NAWCH) has researched to provide guidelines with regard to service standards for children, young people and their families when they access healthcare in hospitals (Hogg 1990,1996: Vine and Kean 1998) with the emphasis on the user and carer view.

Current changes in practice within the Health Service have lead to a greater commitment to service users registering their individual views on service requirements to influence change and identify best practice. To date children and young people have not generally been included in discussions about services provided for them even if their parent/carer has. This is based on the provider's view that listening to the parent/carer is enough; that children cannot express their view in a way that is useful or appropriate; that young people have not been identified as a separate group with particular problems and needs, who are capable of speaking up for themselves. Added to this, is the uncertainty on behalf of commissioners and providers of how to consult to children and young people which when combined with a lack of experience and confidence can lead to consultations which do not deliver.

Action for Sick Children is seeking to establish a tool for evaluating acute health services for children and young people from their perspective, as well as from that of their parent/carer.

Service commissioners and providers have been slow to recognise that adolescent health service users have different needs when compared to children or adult service users. Much of the currently commissioned services are based on service providers' perceptions of these needs. Thus, there has been in many cases, a general failure to incorporate the perceptions of the young people themselves. Moreover, evidence of best practice within these services nationally has not been widely circulated or acted upon.

Purpose of the Research

Funded by the Department of Health, Action for Sick Children intends to develop a qualitative tool, which could be applied nationally to access the views of child health service users when they experience acute services. The current phase of the research aims to develop this tool for adolescent service users utilising a cyclical Delphi Technique process to determine recurrent themes. The principal objective is therefore to capture the essence of the themes generated around three topics:

- what health services they are receiving,
- what is required to meet their needs and
- what are the issues that they consider most important in meeting their needs.

This stage of the research focuses on the initial development of this process and a pilot of the resultant questionnaire (tool) at Birmingham City and Birmingham Children's Hospitals.

Description of the Study Tool
The study tool which will be utilised within this study is the one which is constructed as a primary phase of the research. The tool will be a questionnaire formulated following a qualitative process to provided descriptive data.

Design of the Study
The research will involve the development of a cyclical expert adolescent Delphi Technique (Appendix 2), constructed from small focus groups of adolescent acute service users. From this process a qualitative questionnaire tool will be created. Once constructed and peer reviewed, the aim is to pilot the questionnaire at Birmingham City and Birmingham Children's Hospital. Resultant data would then establish the reliability and validity of the tool in addition to supporting the descriptive data obtained. The subsequent report would detail the adolescent service users' perspectives in relation to dominant themes. The next phase of the research would be to collect data from a further 6-8 hospitals. This questionnaire tool could then be made available to other service providers as a way of establishing current practice and involving users in the planning and delivery of care.

Patients
Young People between 13-19 years of age accessing acute hospital healthcare services.

Patient Selection
Approximately 50 participants will be used at the hospitals. The Delphi process will have a panel of 10 adolescent members.

Inclusion Criteria
Age 13 -19 years accessing services at either Birmingham City Hospital or Birmingham Children's Hospital, who have parental consent to participate.

Exclusion Criteria
Patients >13 or <19, or those aged 13-19 years who do not have parental consent to participate.

Method of Obtaining Consent
The young person will be approached by the researcher and invited to participate in the study. If both they and their parents agree, they will be given an information leaflet. Those who read this leaflet and remain agreeable to participate will be asked to sign a consent form by the researcher.

Duration of the Questionnaire
Each participant will require approximately 10 minutes to complete the questionnaire.

Method of Analysis
Qualitative analysis will be conducted utilising a computer package. Independent peer review will be utilised to support the coding and analysis. Descriptive statistics will be created.

Patient Confidentiality
Patient anonymity and confidentiality will be assured. At no point will paperwork be included to record the patient's name or address.

Hospital Confidentiality
Each hospital although listed as a participant in the resultant report would also remain anonymous in the findings. The aim of the research is to identify pertinent perspectives and to highlight areas of current and best practice. Therefore, in order to access a broad spectrum of provision this policy of anonymity will be assured to each participating acute service.

Intended Use of the Results
The resultant research data will be incorporated in a report to the Department of Health to be considered by working groups on the Children's National Service Framework. This report will be jointly published by both Action for Sick Children and the Department of Health. Participants wishing to obtain a copy of the report can do so by contacting the Action for Sick Children Head Office listed below:

Method of Research
The Delphi Technique

Action for Sick Children
The National Children's Bureau
8 Wakley St
London. EC1V 7QE

Appendix 2

Delphi Technique

Delphi is a structured process that uses a panel of experts to investigate a complex or imprecise issue using a series of structured statements. It was originally designed for use by futurologists at the RAND Corporation during the 1960s. It has since been used in many other areas, most recently in the health care sciences.

The Delphi Technique attempts to eliminate interpersonal interactions as the controlling variables in decision making as usually happens when groups of experts interact at meetings.

The purpose is to generate discussion and enable a judgement on a specific topic to be made, so that policy decisions can be taken which can claim to represent a given group's wants and views.

The process occurs in three stages:

Stage 1: A panel of experts formulate a series of ideas pertaining to the subject in question. This is done individually and anonymously.

Stage 2: The statements from stage 1 are collated and sent to all members of the expert group. They indicate their level of agreement with each statement using a Likert scale.

Stage 3: Each statement is fed back to the panel with their own, and the rest of the group's previous opinions. All feedback is anonymous. Numerous iterations may be necessary.

References: Linstone H. A., Turoff M: The Delphi Method: Techniques and Applications, Massachusetts: Addison Wesley publishing, 1975
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Appendix 3

Action for Sick Children Project
Evaluating young people's views on health services in hospital

This questionnaire is about **you** giving **your views** about **your care**

Please could you complete the following questions. The questionnaire should take you about 20 minutes. Thank you for your help

I am (Please tick the box which you feel is true for you)

1. Male ☐ Female ☐
2 White ☐ Black ☐ Asian ☐ Chinese ☐ Other ☐ (please say)......................
3. 13-14 ☐ 15-16☐ 16-17☐ 17-18 ☐ 19+☐

I am here today for

1 Out patients visit ☐ A&E visit ☐ Ward admission ☐ Children's ☐ or Adult ☐
2. 1st Visit ☐ Been before to out- patients ☐
. A&E ☐
ward☐

My food needs

The food that I had was (You may put a tick on more than one box)

Hot ☐ Sweets ☐ Fresh ☐ Snacks ☐ Healthy ☐ Good portion ☐ None ☐

Was the food you wanted available?

Yes ☐ No ☐

(Please write in your own words)

I would like the food to be..

....

....

....

My choices

When I went to hospital I felt I had some choice about (Please tick the box which you feel is true for you)

Where I received treatment	Yes ☐	No ☐	Not sure☐
At what time I received treatment	Yes ☐	No ☐	Not sure☐
Who could visit me	Yes ☐	No ☐	Not sure☐
When people could visit	Yes ☐	No ☐	Not sure☐
How I received my medicines	Yes ☐	No ☐	Not sure☐
What treatment I had	Yes ☐	No ☐	Not sure☐
Who was involved in giving me treatment	Yes ☐	No ☐	Not sure☐

(Please write in your own words)

When I visited I felt the choices I had were...

....

....

How people treated me

When you visited did you feel that (Please circle the words you feel fit best)

The doctors were	Friendly	Happy	Respectful	'Grumpy'	Unfriendly
The nurses were	Unfriendly	'Grumpy'	Respectful	Happy	Friendly
Nurses spoke to me….	with respect	in jargon	'at me'	with interest	sensitively
Doctors spoke to me…	with respect	in jargon	'at me'	with interest	sensitively
Information given to me was	clear	wrong	helpful	in jargon	what I wanted
Information was given	in private	on my own	just to me	with others	with my parents
My medical information was	stored safely	on view	easily seen by others	kept confidential	private

(Please write in your own words)

I felt the way I was treated was………………………………………………………………………

……

……

……

My needs

Look at the words below to help you, and then write in your own words what your experience was like in hospital.

hot cold DVD clean stuffy tidy soft pillows electronic beds telephones TV computers stains smelly noisy waiting time young people comfortable unpleasant activity room crying babies bed time choices

When I was in hospital (Please write in your own words)

……

……

……

……

Thank you for helping us today.

Please write here anything which you feel we've missed out but was important to you.

……

……

……

(You can continue overleaf)

PATIENT INFORMATION SHEET

ACTION FOR SICK CHILDREN

Study Title

Evaluating Adolescent Services: The Adolescent User Perspective

Version 2 Dated: June 2003

Invitation to participate:

You are being invited to take part in a research project that is specifically designed for you to tell us about your experiences when you have been to the hospital for treatment or a check up. This is about what you think and what you would like to make what you experience better for your needs. Before you decide it is important for you to understand why the project is being done and also what it will involve. Please take time to read the following information carefully and talk it over with others if you wish. Ask those of us doing the project if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?
The purpose of the study is to find out what is important to you and what you would like when you use the hospital services.

Why have I been chosen?
The project wants to find out what those who use the hospital facilities think of them. We are particularly interested in young people between 13 and 19 of age who are attending hospital.

Do I have to take part?
It is up to you whether you take part or not. You will not be pressurised into doing so and your treatment will not be affected in any way. If you decide to take part and then change your mind you can leave the project at any time.

What will happen if I take part?
The information you give us will be used to help improve the hospital services in a way that meets the needs of young people. If you decide to take part we will ask you to sign a consent form and you must get this signed by your parent/guardian if you are under 16.
Once we have agreement that you want to take part from both of you we will ask you to complete a questionnaire.

What will I have to do?
The questionnaire will take you about 10 minutes to complete. You will then put it in an envelope, which we will give you and we will collect the form later. The information you put on the form will be confidential and no one will know which is the form you filled in.

Are there any disadvantages of taking part in this study?

There are no risks to your health in this study but we would like you to give us 10 minutes of your time.

What are the possible benefits of taking part?

You will be given the opportunity to give your views and these will be put together with information from other questionnaires to enable us to see what the experiences of young people are like in hospital. The results of the questionnaires will be collated and information given to the Trust about their services for young people. This may help change future services and will show those who plan and provide services what is important for young people like your-self.

What if something goes wrong?

You are welcome to talk to us about anything that concerns you and you can use the complaints procedures in place in the hospital or within the Action for Sick Children Charity in the event of any incident that cannot be resolved by discussion informally.

Confidentiality- who will know that I am taking part in the research?

All of the information, which is collected from you during the course of the research project, will be kept strictly confidential. The questionnaire will not have your name and address on it, which means that no one will know which is your questionnaire - you will not be recognised.

What will happen to the results of this research?

This research report is part of a bigger study, which aims to gain the view of young people in a number of hospitals. At the end of this project the results of this research will be put in an independent report written by Action for Sick Children and given to the Department of Health. A copy will go to the trust board at this hospital. The report covering all the hospitals participating in this research will be published once all the surveys have been conducted nationally, in Spring 2004. This report will be published and made available through Action for Sick Children in Summer 2004.

Who is organising the research?

This research is being organised by the charity Action for Sick Children. The person conducting the research today is a member of their staff.

Who has reviewed this research?

The study pilot was reviewed by the West Birmingham Local Research Ethic Committee and this phase was reviewed by a Multi Site Research Ethics Committee.

Contact for further information?

If you require further information, please contact either Sue Langley from Action for Sick Children on 01455 446229. If you have any concerns about the study and wish to contact someone who is not collecting the information, you may telephone Pamela Barnes on 0207 843 6444

Centre Number: :

Study Number:

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Evaluating Children's Health Services: The Adolescent User Perspective

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated June 2003 (version 2) for the above research project and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to take part in the research project. ☐

______________________ ______________ ________________

Name of Patient Date Signature

______________________ ______________ ________________

I have read the information leaflet and I understand that my son/daughter has agreed to take part in t study. I agree that they can take part.

Name of Parent/ Carer Date Signature

....

Name of person taking consent Date Signature

______________________ ______________ ________________

Researcher Date Signature

1 for young person; 1 for parent; 1 for researcher

Appendix 5

Editorial as published in Paediatric Nursing 2003

Research Action

Action for Sick Children has a history of promoting and championing the needs of children, yet our focus has largely been parents or professionals. There is a great need to see how young people perceive their needs in the 21st century. In February 2002 we started work on a project titled 'Evaluating Services: The Adolescent User Perspective'. This DoH-funded research project set out to develop a questionnaire by adolescents for adolescents with the aim of helping young people find a voice to express their needs.

As we began the project there were wide-ranging changes to the way ethical approval is obtained. The changes were intended to simplify the process so that local committee approval would enable access to a number of sites and there would be equity between the different ethical committees. However, there has been some confusion about whether we needed local (LREC) or multi site (MREC) approval. Prior to these changes this type of 'social research' was seen to be outside the remit of the formal medical ethical review process and there was no need for indemnity insurance; now it was no longer exempt and we had to find indemnity insurance. This has had a significant impact on already tight funds and timescales for the research. Being creative we were able to gain ethical approval and indemnity through the local researchers through the employing NHS trusts.

We felt that the most expert people to provide the perspective and devise a research tool would be young people. We were half right! The young people were excellent at providing a young person's perspective through focus groups but not so expert at devising the questionnaire. The topics and questionnaire they generated created a six-page document – brilliant, but too unwieldy. We learned a lot from them during the development of the questionnaire; particularly with regard to confidentiality and what they saw as most important. This reminded us to listen to the young people and not assume that we know what they want or need.

The pilot has evaluated well and has given us confidence in the questionnaire but we await an MREC decision on the main study. The research path and the ethics process have not been smooth but we would do it again as the voice of the young person is coming through loud and clear. Our next objective is to publish a toolkit for involving young people. We aim to launch this at our joint conference with the RCN in London on 6th March next year.

Paediatric Nursing, Editorial (Langley & Cooper) 2003

Appendix 6a

ACTION FOR SICK CHILDREN

DEPARTMENT OF HEALTH SECTION 64 GRANT

EVALUATING CHILDREN'S HEALTH SERVICES

PHASE 1 REPORT

December 2002

by

SUE LANGLEY
PROJECT MANAGER/RESEARCHER

Evaluating Children's Health Services

Introduction

- Action for Sick Children received a Department of Health Section 64 grant to undertake consumer perspective research. This research has the key aim of providing a mechanism to access consumer and their family/carer views on children and young people's health services on a recurring basis.
- ASC Chairman and the Project Manager/Researcher met with the Department of Health on 23rd January 2002 to agree Phase 1 time scales and tasks/key objectives.
- Report making mechanisms have been agreed with the DOH and this is the first report pertaining to Phase 1 activity levels.

Phase 1 key objectives

- Formulate a work plan and job descriptions for the proposed Researcher/Project Manager.
- Establish project methodologies.
- Begin the process of recruitment.
- Consult to identify key areas of concern with the Department of Health, RCN/CHI, RCPCH.
- Research surveys which have previously been conducted by Action for Sick Children..

Activities - Phase 1

The activities conducted for each key objective will now be outlined.

a) Formulate a work plan and job descriptions for the proposed Project Manager/Researcher

In late December and early January the job description and work plan for the Project Manager/Researcher was formulated.

A draft copy of this work plan was discussed at the meeting with the Department of Health on 23rd January 2002. This work plan has had to be reviewed and a contingency plan instigated in the light of the changes to the ethical approval process and the need for participant indemnity see section b.

The job description formulated allowed for the recruitment process to begin.

b) Establish Methodologies

Charity personnel identified that qualitative data would be the most rich data to collect in order to detect current themes. Quantitative aspects will therefore be incorporated within a qualitative format to enhance robustness and rigour.

First objective concerning methodology was the development of a mechanism, which could be applied nationally and be modified for different patient/topic groups. Produce revised project outline as agreed April 2002

Adolescents were proposed as the initial group with whom to develop and pilot the mechanism.

Academic expert advice was then obtained to support this stance.

Meetings with Coventry University were conducted on 5th February and 5th March 2002 with representatives from their Research Department and the Psychology Department. The Research Department are experts in methodology and the Psychology Department are experts in current published and grey matter concerning research on children and young people's perspective and emotion.

A second university, University of Central England was approached for further academic advice, and relevant meetings were conducted on 20th February and 15th March.

Liaison with the two universities, Coventry University and The University of Central England resulted in the following:

- Support for the notion that the Delphi Process would be the most appropriate and robust methodology to employ initially.
- The need to develop an Expert Panel to inform the research. In this case it was unanimously agreed, that people 'most expert' at evaluating adolescent services from the consumer perspective, would be an adolescents themselves.

Subject to ethical approval six to ten individuals have been identified from differing demographics to be members of the Expert Panel. (Six to ten being an optimum size for such a panel according to most recent cumulative research employing for this methodology).

The charity then identified that recent changes within the Ethical Approval Process (including the need for indemnity) would cause a delay in the inception of the research interviews and consultations. These changes would in addition mean that the key project staff (principally the project manager/researcher would need to undergo training.)

This information was immediately referred to the Department of Health.

Following a training needs analysis three training days have been attended by the key researcher on 4th March, 22nd March and 11th April, to ensure the most up to date accommodation of ethical requirements.

The issues of ethical approval and indemnity for participants are now actively being investigated. There appears to be great variations in these processes nationally, between ethics committees based on local interpretations.

c) Initiate recruitment process

The recruitment process for a project manager and researcher has been completed.

As identified on 23rd January, an interview process was conducted on 10th January and Susan Langley was appointed to commence duties in this post on 1st February.

A Steering Group to oversee the project was set up on 8th February and the first meeting of the steering group was on 27th February. Further members were suggested for co-option. These were duly asked to join and have agreed. The Members of the Steering Group are:

Carole Myer	Chairman
Chris Cooper	University of Central England
Leslie Robertson	Action for Sick Children Trustee and Department Head at Thames Valley University
Jessica Datta	Researcher for the National Children's Bureau
Marcelle de Sousa	RCN- Chair of the RCN Adolescent Health Forum
Susan Langley	Project Manager/Researcher
Pamela Barnes	Chairman (Ex Officio)

Advisor to the Steering Group: Dr Deepak Kalra

We are currently still trying to co-opt a parent and an adolescent.

A project administrator was also recruited and commenced duties on 8th April.

d) Consult to identify key areas of concern with the DoH, RCN/CHI, RCPCH.

The meeting on 23rd January identified key areas of concern for the Department of Health. Consequently the project will focus on adolescent services and palliative care services as preliminary target areas.

Key areas of concern for the RCN were not seen to differ from those proposed by Action for Sick Children and the RCN have, therefore, agreed to liaise with, and support the project.

Some interest in co-operative working has also been suggested by CHI. Communications are currently being exchanged regarding the format and content of the co-operation.

Liaison with the RCPCH has also been initiated and we are currently awaiting a response.

Additional activities undertaken in Phase 1

- ***Conference attendance:***

1. Patients Forum Conference in London on Involvement in the NHS: Meeting the challenge of Working with Hard to Reach Groups, highlighted issues concerning appropriate communication techniques. This was attended to identify increased issues currently under discussion in the public domain.
2. The second conference jointly organised by the NHS Information Authority, ASSIST and the West Midlands NHS, Modernising Clinical Services: Can Telemedicine and Telecare Help? Was attended on 27th March to identify possible themes for the research panel regarding the most recent avenues of modernising clinical service.

- ***Establishing links with other charities and organisations***.

  A programme of activity in this arena has additionally included establishing links with the British Dental Association (BDA)

e) Research surveys which have been previously conducted by Action for Sick Children

Previous research work conducted by Action for Sick Children has been assessed for relevance. The following were considered appropriate for reference and comparison:

'Health Services for Children and Young People'
'Health for All Our Children'
'Emergency Health Services for Children and Young People'

These reports are broad based and cover all aspects of health services for children and young people.

Pertinent to the initial pilot on adolescent services are:

'Setting Standards for Adolescents in Hospital'
'Too Young or Too Old: How and Where Adolescents should be Nursed'
'Youth Matters'
'The Emotional Needs of Children Undergoing Surgery,' is currently being updated and will have ongoing relevance for consideration.

Conclusion

Building on the experience of Action for Sick Children when researching children and young people it is seen as more robust to include levels of quantitative analysis as part of the project methodology.

Relationships with trusts and academic institutions have been forged to produce a project undertaken with expert advice. As this report identifies, the work proposed in Phase 1 of the project has been completed and additional tasks undertaken. The new regulations appertaining to ethical considerations have been incorporated, training undertaken and the application process has been instigated. Links have also been established with other charities and organisations to produce rigorous outcomes in future stages which are based on currently published and also grey matter relating to the children and young people's health services. Looking forward, a plan of activities has been formulated for Phase 2 and contingency plans identified. A revised time scale for the project was formulated (Appendix 3.). In consideration of the progress of the project in Phase 1, to take full advantage of the research it may be necessary to seek further funding for certain aspects.

Recommendations

Four recommendations are suggested following consultation with the steering group relating to the success of Phase 1 and tasks of Phase 2. These are:

1. To continue to develop ways of accessing adolescent input via 'adolescent friendly' mediums e.g. Internet and Mobile Phone Text Services.
2. To establish an up to date database of contacts, trusts and health service providers willing to participate in the project.
3. To monitor and respond to ongoing changes apropos the ethical approval process.
4. To investigate a wider literature base to inform the current research project.

Appendix 6b

ACTION FOR SICK CHILDREN

DEPARTMENT OF HEALTH SECTION 64 GRANT

EVALUATING CHILDREN'S HEALTH SERVICES

PHASE 2 REPORT

January 2003

by

SUE LANGLEY
PROJECT MANAGER/RESEARCHER

Evaluating Children's Health Services

Introduction

- Action for Sick Children received a Department of Health Section 64 grant to undertake consumer perspective research. This research has the key aim of providing a mechanism to access the young consumer and their family/carers views on children's and young people's health services, on a recurrent basis.
- Following correspondence with the Department of Health, Phase/time scales and tasks/key objectives were agreed.
- Report making mechanisms have also been determined with the Department of Health and this is the second report, which appertains to Phase 2 activities.

Phase 2 – key objectives

The following four recommendations were made by the steering group relating to the success of Phase 1 and tasks of Phase 2:

- To research and develop ways of accessing adolescent views via 'adolescent-friendly' mediums e.g. Internet and Mobile Phone Text Services.
- To establish an up to date database of contacts, trusts and health service providers willing to participate in the project.
- To monitor and respond to ongoing changes apropos the ethical approval process.
- To investigate a wider literature base to inform the current research project.

These in conjunction with the activities assigned to Phase 2 lead to the following key objectives being identified.

a) Prepare and devise questionnaires
b) Form a database of NHS Trusts
c) Contact NHS Trusts to participate in surveys
d) Researcher to work with Action for Sick Children local branches and locality
e) Researcher to distribute surveys and obtain information
f) Produce first surveys and disseminate.

Phase 2 - Activity

The activities conducted for each key objective will now be outlined.

1. *Prepare and Devise Questionnaires:*

The slippage in the project action plan due to the evolving requirements for ethical review and indemnity insurance has resulted in a recognisable delay for this key objective. This meant a delay in recruiting the Delphi Group to advise in the preparation and construction of the questionnaire. Without their consultation this objective had, to a degree, to be put on hold. Some consultation, however, was undertaken with key groups of service user representatives. Key groups were identified for service users with chronic conditions including diabetics, asthmatics, arthritics, those with cystic fibrosis and muscular dystrophy. The latter groups have traditionally been considered paediatric specialities. It was considered important to include them because of the emerging need for specialists to care for adults with these conditions where life expectancy has increased. This could be seen to be particularly relevant for the adolescents and young people involved in the current research and their expectations/experience of accessing transitional services. The professionals providing these services were contacted and Delphi Group membership was actively promoted. Subsequent to ethical approval the Delphi Group members were recruited.

2. *Form a database of NHS Trusts:*

The process of data collection was undertaken via the NHS contacts of our network of branches throughout England. In addition individual members of Action for Sick Children have provided details for the database. As a result there is an easily accessible list of contacts. The intention of the project team is to audit the database systematically thus ensuring that the details remain relevant and correct. Therefore 3 monthly reviews will be incorporated into the current project.

3. *Contact NHS Trusts to participate in surveys:*

Referred Acute sites have been approached and have agreed to participate in the survey for the project.

These are:
Birmingham Children's Hospital
Birmingham City Hospital
Leicester Royal Infirmary
Luton and Bedford
Middlesex Hospital
North Staffordshire
Wolverhampton New Cross
Wythenshawe
Sandwell Hospital

Further commissioners and sites have contacted the Project Manager to offering themselves as additional sites. Unfortunately budget and time constraints have resulted in these sites being put on a secondary list. This list is being updated and kept as a database to allow for any decline in primary sites on the first list. These secondary sites will be contacted with results of the survey on publication and will be invited to participate in any subsequent research.

4. *Researcher to work in Action for Sick Children local branches and locality:*

The project manager/lead researcher and the project administrator have both maintained regular periodic contact with each of the branch committees. Thus establishing open lines of communication between the project and branch members. Hence the project has gained the support, experience and expertise of key individuals within each branch who have interests in acute adolescent services. Moreover, users interested in participating as Delphi Group or Steering Group members have been identified.

5. *Researcher to distribute surveys and obtain information:*

Unfortunately, due to recent and ongoing changes in the policy on the need for medical ethical approval which emerged since the planning and inception of the project, this stage of Phase 2 will be relocated and accommodated in Phase 3 of the project.

6. *Produce first surveys and disseminate:*

As outlined in objective (e) there has been some delay in fulfilling this key objective with the result that the process of producing and disseminating was postponed until later in Phase 2. Recruitment for the Delphi Group started once ethical approval was given. However, some work had already occurred. Prior to the Delphi Group formation, key themes were identified by consulting with professionals who currently provide advocacy and health services for adolescents and young people. In addition some voluntary advocacy services were approached and agreed to share key themes gained during for their contacts with adolescents and young people. A themes database was developed and presented on 12 October 2002, at the inaugural Delphi Group Meeting and was used to initiate discussion. Topics were identified and draft questionnaires were formulated. The final draft questionnaire is now ready to be utilised in the pilot process.

Additional activities undertaken in Phase 2

Developed terms of reference for the Steering Group.
Developed terms of agreement for the local researchers.
Developed a pilot protocol.
Interim Report provided .
Submitted the pilot through the medical research ethical process and gained approval to commence.)
Commenced recruitment of young people onto the group for the Steering Group.
Continued to monitor newly published and current research
Established links with other groups interested in researching the area of adolescent health – e.g. British Dental Association; Bliss, NHS Trusts.
Dates for the pilot proposed and forwarded to the Acute Health Service Providers.

Conclusion

In conclusion, the action plan and progress of the project has required significant change to accommodate the recent and emerging obligatory inclusion in the medical research ethical review process. The ethical review has now taken place for the pilot phase of the project. Subsequent approval means that the pilot will now commence in the West Birmingham area. The pilot research will survey adolescent service users at Birmingham Children's Hospital and Birmingham City Hospital and Sandwell Hospital. Management and staff at these sites have agreed to contribute to their site's participation.

A further key objective of forming a database of NHS Trusts and other contacts has been achieved. The database will now be audited via systematic review to ensure that all details remain current and that changes are updated.

Recommendations

1. To continue to monitor recently published relevant publications and link with ongoing research.
2. Due to financial and time constraints, it was agreed not to progress developing ways of accessing adolescent views via 'adolescent friendly' mediums such as Internet and Mobile Phone Text Services, but to recommend these as future activities and to suggest that Action for Sick Children seeks further funding, for this purpose.
3. To review the questionnaire tool in order to develop accessing adolescents' issues.
4. To review the processes used in order to draw up guidance for accessing young people's views
5. To progress research at further sites, once the current information has been disseminated to Health Trusts, Department of Health and other identified parties.
6. To set up Phase 3 as outlined in Study Design (see page 6) when appropriate.

Action for Sick Children

Joining parents and professionals in promoting quality health care for sick children at home and in hospital.

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