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.

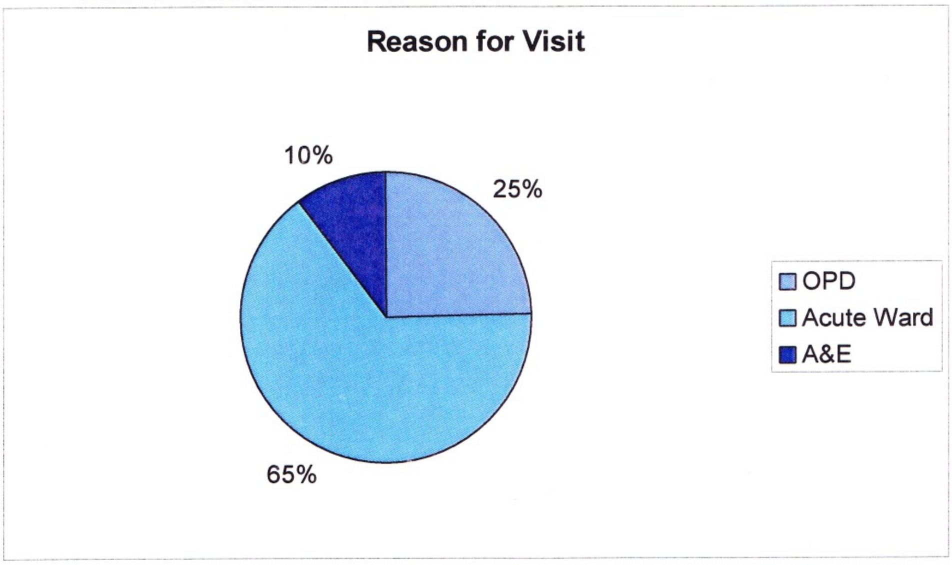
The cohort consisted of 91 adolescents who were either visiting or were inpatients in the seven Acute Trusts over the data collection period of three months. Each of the seven Trusts was only visited on one occasion.

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.

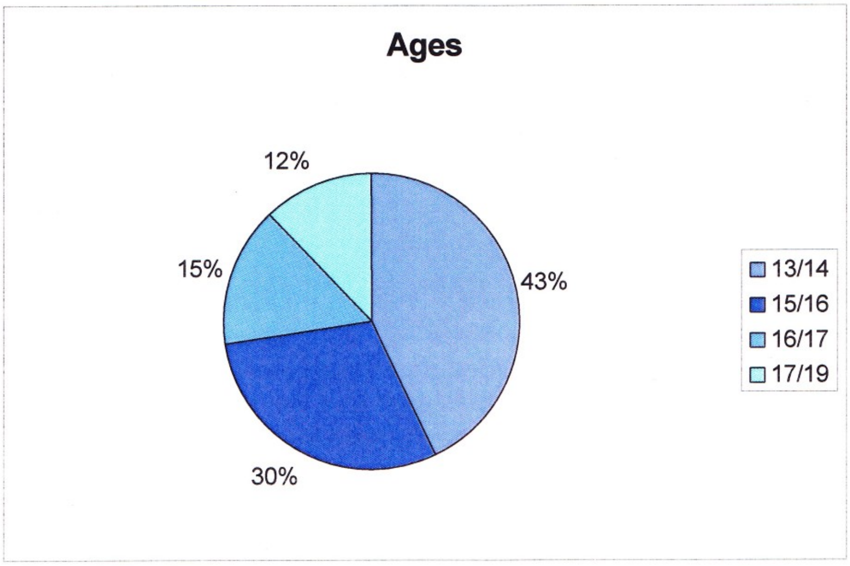
Demographic details are presented in Table 1.

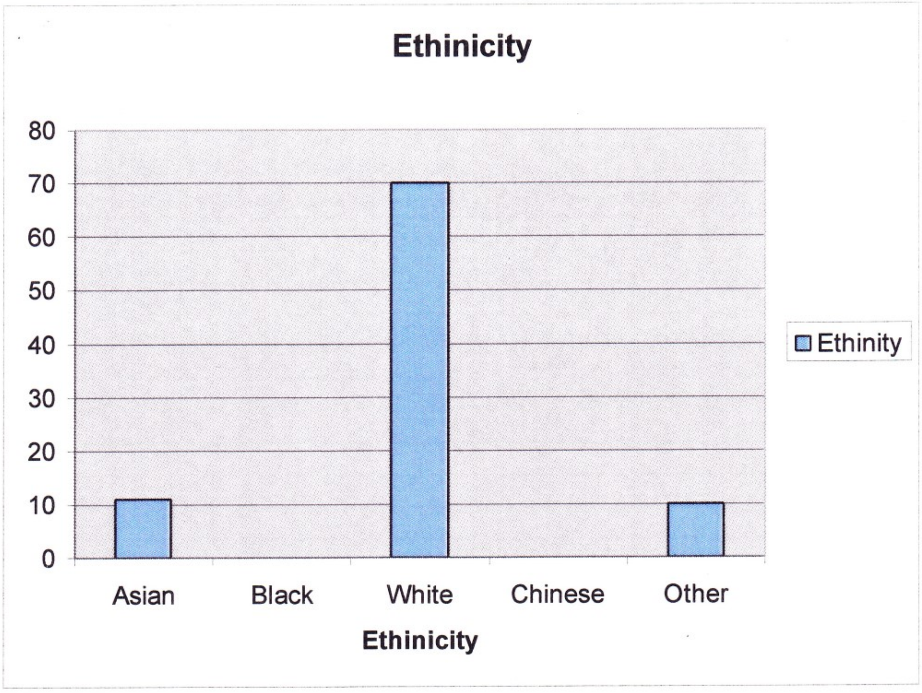
Table 1

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

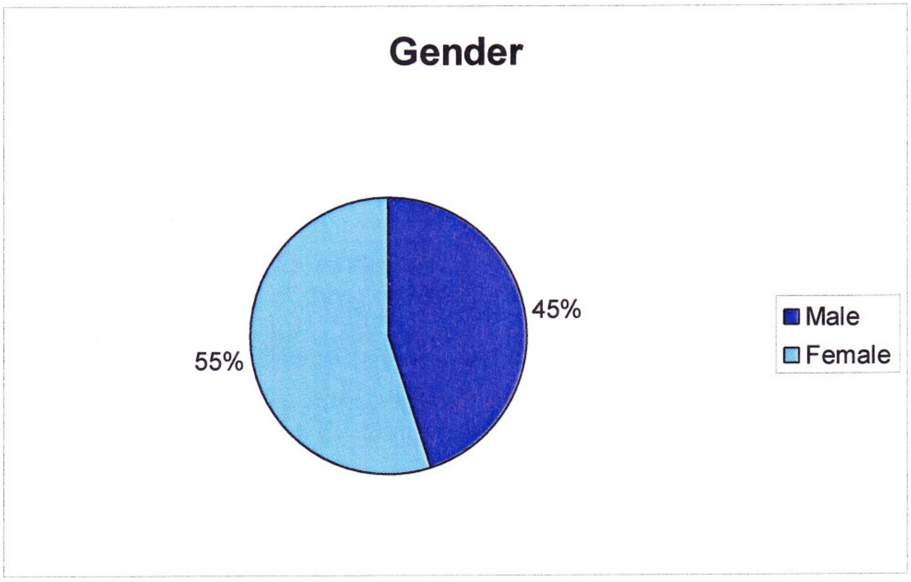


Only one young person indicated that this was their first visit to the hospital. No young person was cared for in an adult setting.





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.

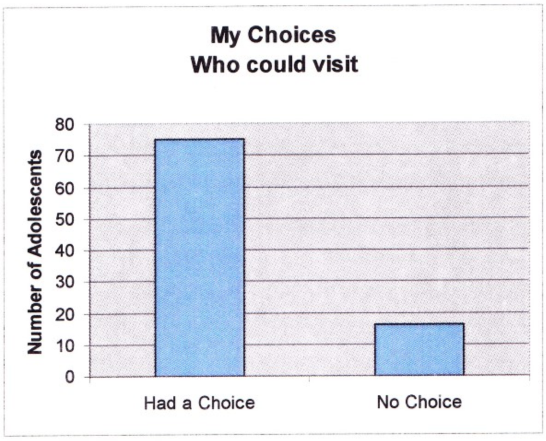
Nearly 30% (n19) of the sample did not have food due to just visiting or not eating due to treatments, but from those who received food only 44% (n29) indicated that the portions were good, and only 30% (n20) felt that it was hot, with 42% (n25) relying on snacks and sweets as 40% (n26) felt that the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

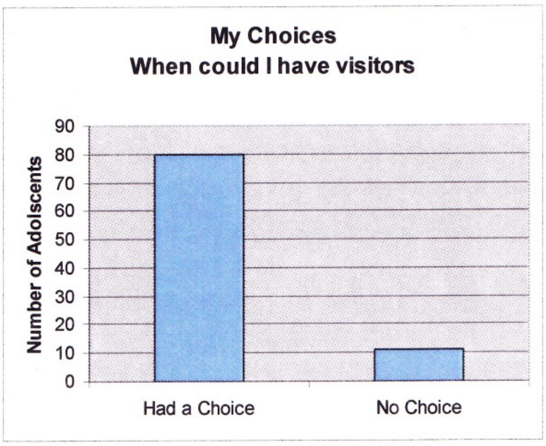
The main criticisms in the comments supported the quantitative data emphasising that the portions were too small and they got hungry between meals. A few relied on food being brought in from home, particularly as most commented that there was little choice, it was not very healthy, it lacked taste and 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)

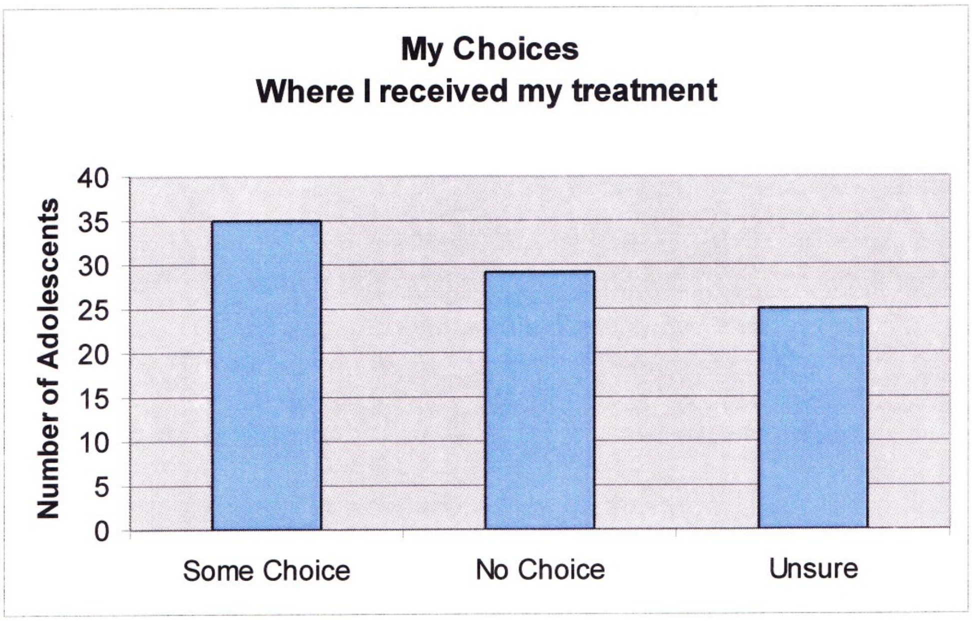
My Choices

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.

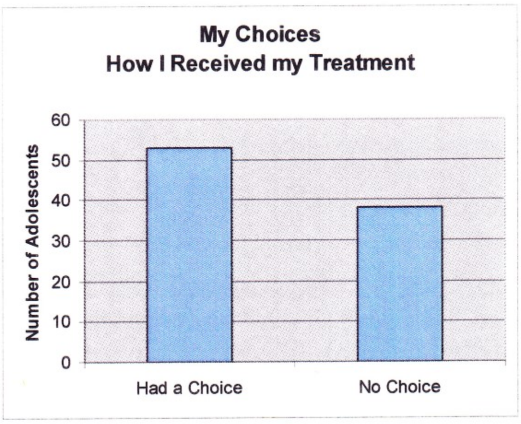


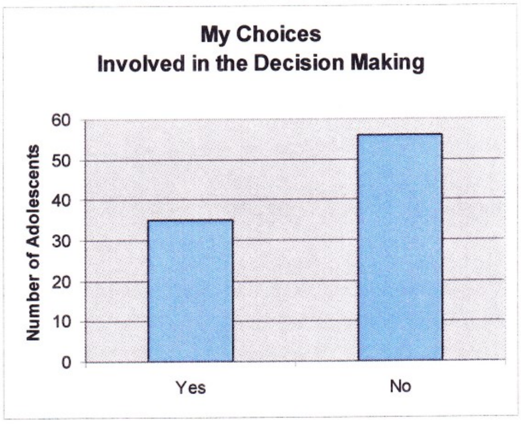


38.7% (n35) felt they had some choice about where they received treatment. 32.5% (n29) felt they had no choice and 27.5% (n25) were not sure. With regard to when they received treatment, the proportions of those who were unsure were roughly consistent with the "where they received treatment" results,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

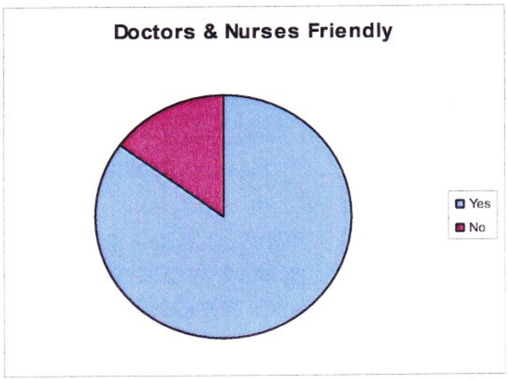
The young people felt that, at times, there was very little choice offered; although they indicated that they were listened to if they asked for something.

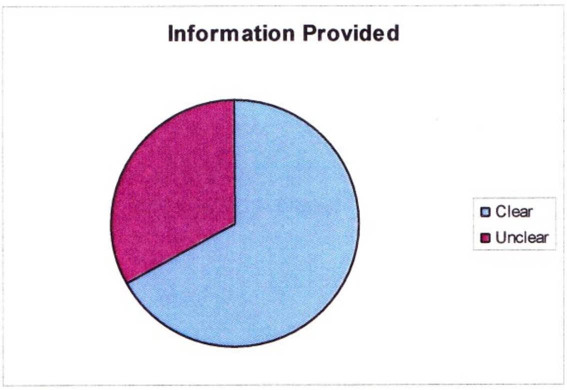
How people treated me

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)

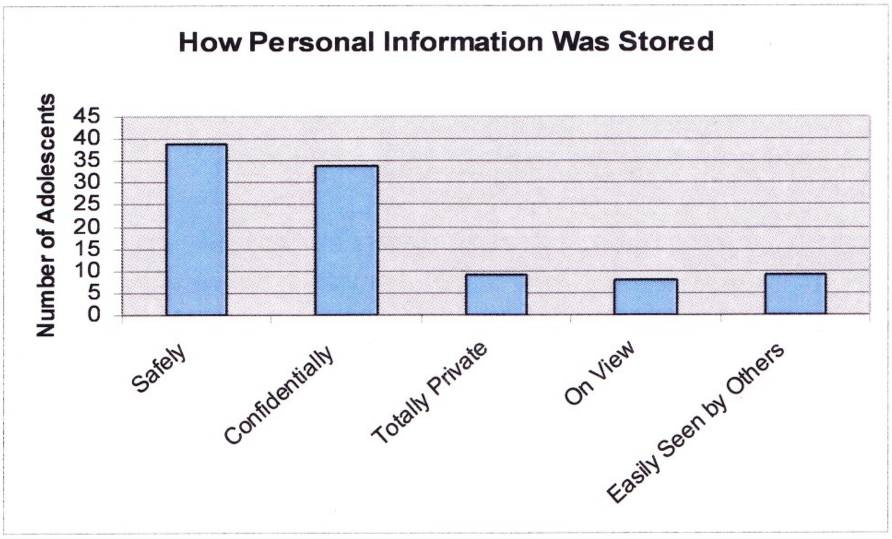




The picture with regard to how information was given and stored raised a number of issues for the young people:

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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