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Giving Children a Voice: Investigation of children's participation in consultation and decision making in Irish hospitals

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Office of the Minister  
for Children

Oifig an Aire do Leanaí



# Giving Children A Voice

Investigation of children's  
experiences of participation  
in consultation and decision-  
making in Irish hospitals

The National Children's Strategy  
Research Series



# Giving Children A Voice

**Investigation of children's  
experiences of participation in  
consultation and decision-making  
in Irish hospitals**

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September 2006

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*'Well, I think there is, there always is another way that they can explain things better. See, most people would just sit there and they'd be there talking, you don't understand, you don't want to be like annoying to ask them. I think that they can explain things, explain words like operation, if you're having an operation, to explain things bit by bit. If they are treating children, they should know how to talk to children.'*

Girl, aged 13

# CONTENTS

<b>Acknowledgements</b>	<b>v</b>
<b>Executive Summary</b>	<b>1</b>
Findings	2
Conclusions	4
Recommendations	6
<b>Definition of Key Terms</b>	<b>6</b>
<b>Chapter 1: Introduction</b>	<b>7</b>
Background to the study	8
<b>Chapter 2: Literature Review</b>	<b>9</b>
Children's voices, children's rights	11
Children as healthcare consumers	11
Children and decision-making	13
Children, empowerment and the healthcare system	16
Conclusions	17
<b>Chapter 3: Research Design</b>	<b>19</b>
Aims and objectives	20
Methodology	20
Profile of children who participated	23
Implementation and ethical issues	23
Data analysis	26
<b>Chapter 4: Findings</b>	<b>27</b>
Children's experiences of hospitalisation	28
Children's experiences of consultation	29
Factors that enhanced the consultation process	30
Parents' role in the consultation process	32
Children's experiences of non-consultation	34
Factors that inhibited the consultation process	40
Views on decision-making process	40
Factors influencing decision-making process for children	42

<b>Chapter 5: Discussion and Conclusions</b>	<b>45</b>
Children's experiences of being in hospital	46
Children's experiences of consultation	46
Factors that enhanced the consultation process	47
Parents' role as advocates in the consultation process	48
Children's experiences of non-consultation	49
Factors that inhibited the consultation process	52
Children's views on decision-making process	53
Frameworks of consultation	55
Conclusions	56
<b>Bibliography</b>	<b>59</b>
<b>Appendices</b>	
<b>Appendix 1a:</b> Hart's Ladder of Participation	70
<b>Appendix 1b:</b> Hart's Degrees of Participation	71
<b>Appendix 2:</b> Parent information letter	72
<b>Appendix 3:</b> Information sheet for older child	73
<b>Appendix 4:</b> Parental consent – Permission to approach child	74
<b>Appendix 5:</b> Parental consent – Permission for child participation	75
<b>Appendix 6:</b> Older child consent	76
<b>Appendix 7:</b> Younger child consent	77
<b>Appendix 8:</b> Protocol 1 — Child displaying anxiety during interview	78
<b>Appendix 9:</b> Protocol 2 — Signs of illness during interview	79
<b>Appendix 10:</b> Protocol 3 — Disclosure of sensitive information	80
<b>Appendix 11:</b> Treseder's Degrees of Participation	81
<b>Appendix 12:</b> Children's Levels of Participation	82

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I hope that the results of this study will contribute towards our understanding of children's views on consultation in the healthcare setting. I hope that the findings will advance the realisation of Goal 1 of the National Children's Strategy and the process of recognising children's views in matters that affect their health and their lives. All errors and omissions are the author's, whose views do not necessarily reflect those of the Office of the Minister for Children.

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# EXECUTIVE SUMMARY

The focus of this research was to investigate sick children's experiences of participation in consultation and decision-making within the healthcare setting. This aim led to the following objectives:

- To describe children's experiences of consultation in the healthcare setting.
- To identify the factors that enhance children's involvement in consultation and the decision-making process.
- To identify the factors that hinder children from involvement in consultation and the decision-making process.
- To explore strategies that will empower children to participate in their own healthcare decisions.

The research was comprised of the following elements:

- A literature review and information gathering.
- Focus groups and single interviews with acute and chronically sick children in hospital. The sample was comprised of children aged 7-18 (n = 55), drawn from the population of children in three hospitals.

## Findings

### Experience of consultation

The children had varying experiences of being involved in consultations and decision-making, which was consistent with previous research. Some children had positive experiences of being involved, consulted and heard in relation to their information needs. The children liked receiving information because it helped prepare them for what to expect and thus ameliorated their worries and provided reassurance. Receiving information and having their views respected enhanced children's understanding and adaptation to the hospitalisation. The overall effect of being involved in the consultation process was that the children reported feeling valued, involved, comfortable and less anxious.

The significant factors that enhanced the consultation process for the children were (1) familiarity with hospital and procedures; (2) age level; (3) relationship with health professionals; and (4) time. The age and maturity of the children were important factors in the extent to which health professionals respected their wishes and needs. It appears that health professionals tended to consult with mainly older children, which implies that younger children could be left with unanswered questions and insufficient information. It was also evident that knowing health professionals contributed to a trusting relationship, which enabled children to feel that they could ask questions freely and express their concerns.

Children need time to absorb information. Thus, having sufficient time with health professionals clearly enhanced the children's ability to participate because they had time for discussion and time for clarification of information. However, some children reported difficulty in getting to know health professionals due to lack of time, lack of frequent contact, many patients, busy workload and lack of continuity due to shift work. It is not surprising then that only children with chronic illness reported forming trusting relationships with health professionals. The development of a trusting relationship and good communication between health professionals and children should be fundamental aspects of good practice.

### Parents' role in consultation process

The children described needing their parents to act as advocates, intermediaries and interpreters in the consultation process. It is evident from the data that many children preferred their parents to be their advocates and/or interpreters in the communication process because of fear of bad news, but mainly due to difficulty in understanding the style of communication adopted by the health professionals.

The children identified elements of their parents' role that both facilitated and constrained their participation in consultations. Some children were content to be represented by their parents in consultations in order to limit exposure to potentially worrying information. Most children were

content to share the consultation with their parents so that they could then help explain and clarify information received from health professionals. These children were of different ages, which indicates that the relationship between children's ages and preferences for communication is not as straightforward as assumed. Most of the children reported difficulty participating due to health professionals' style of communication and therefore were very reliant on their parents to be their advocate/interpreter in the consultation process.

Although most children appeared to value their parents' role in the consultation process, some expressed unease with the constraining aspects of the role. The parents inhibited some children's attempts to participate in the consultation process by answering questions on their behalf, by telling them to stay quiet, by reprimanding them for interrupting the discussion and by withholding information. It may be argued that the lack of support from some parents in relation to children's active participation sends a clear message to children that they should be seen and not heard. The parents' actions may have reflected their need to protect their children's well-being and thus were well intentioned. Alternatively, parents may hold the belief that children should be seen and not heard, and thus discourage children's active participation. Parents may experience difficulty balancing their need to protect their children with encouraging children's participation. Therefore, parents may need help to consider how children's interests might best be served and encouragement from health professionals to facilitate children's participation in the communication process.

### **Lack of consultation**

Consultations were largely carried out between parents and health professionals, which seemed to leave children without a voice. Most of the children in this study appeared to occupy a marginal position in consultations, without direct access to information about their healthcare. The children expressed a range of fears about the hospitalisation, particularly fear of the unknown, but also inadequate information and communication led to them feeling unprepared and anxious. Some children had to undergo procedures without adequate information or preparation, which created stress and unnecessary anxiety.

Avoidance of children's questions and children's suspicion of health professionals withholding information from them potentially undermined their trust in health professionals' good intentions and added to anxiety levels. Some children felt that their contributions were not given due weight and consideration, and the feeling of being disbelieved caused them stress and potentially undermined their confidence. The children expressed strong feelings about being excluded from the consultation process, such as feeling disappointed, sad, confused, angry, 'rotten', worried, misled, shocked, betrayed, lonely and ignored. The range and depth of these feelings clearly illustrate the impact of non-consultation on many children.

The children actively sought involvement in consultations with health professionals, but were hindered by factors that included (1) fear of causing 'trouble' by asking questions; (2) lacking time with health professionals; (3) difficulty contacting health professionals; (4) being ignored; (5) being disbelieved; (6) health professionals not listening; (7) not knowing health professionals; (8) difficulty understanding medical terminology; (9) being sick; and (10) parents' actions.

Although there were many factors that appeared to obstruct children's participation, the key factors were the communication styles, attitudes and behaviours of the health professionals. The children generally reported that health professionals tended to 'do things' to them with very brief or no explanations. Many children reported being unable to ask questions because of being rushed during their interactions with health professionals. It was obvious that children's ability to participate in discussions about their treatment was hindered by health professionals allowing insufficient time for discussions.

### **Views on decision-making**

Some children wanted to be involved in the decision-making process, while others were happy for the decisions to be left to parents and health professionals. Leaving decisions to parents/health professionals does not indicate a lack of competence; rather, it demonstrates that children have the ability to choose. Children who may be competent to make their own decisions may,

nevertheless, choose to allow parents to make decisions on their behalf. Participation rights do not necessarily confer the right to be the main decider, nor do children want to exclude their parents from the process. It appears that the issue of decision-making should be seen as existing on a continuum rather than an 'all or nothing' approach. The view of 'all or nothing' obscures the fact that there are multiple levels and ways to involve children in decision-making. There are also different types of decisions ranging from minor to major and the decision-making process can change depending on the situational context.

Children of all age groups (from 7-18) indicated a willingness to participate in decision-making and therefore their age was not the deciding factor. There was also variability in the children's beliefs about the ages at which children could be expected to be competent. This indicates that health professionals should assess each child's ability and willingness to participate, rather than making assumptions about involvement based on a child's age. Children's ability to participate may be frequently underestimated since health professionals tended to communicate with mainly older children, although there were exceptions.

The findings indicate that decision-making for children is a complex process that evolves over time and that may be shared or contested with parents and health professionals depending on the type of decision. It was evident that parents play an influential role in children's ability to participate, which indicates that an awareness of the family's usual pattern of decision-making can be helpful. It suggests a pragmatic approach, recognising that children need protection while at the same time allowing flexibility for the child's emerging knowledge and self-determination.

## Conclusions

The children in this study expressed strong desires to have their voices heard in relation to everyday decisions about their care and treatment. Many children felt that they had a right to be involved because it was about matters that affected them and their bodies. This is in keeping with Goal 1 of the National Children's Strategy, which states that '*children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity*'.

It is clear, however, from the children's accounts that many of them were not included in everyday decisions about matters that affected them. The fact that the experiences of children recruited from different locations were essentially similar suggests that difficulties of communication between children and health professionals are widespread. The findings from this study suggest, therefore, that there is a need for a greater awareness by all stakeholders that a failure to include children and young people in the decision-making process can have adverse effects on their physical and emotional welfare. Children are important users of the health service, yet their views appear to be given insufficient priority or respect by health professionals.

The findings from this study show that children wanted to be kept informed about their care, wanted to be adequately prepared for specific procedures and, in particular, wanted to be involved in the 'small' decisions about everyday care. Children and young people said they worried when their parents were taken aside to talk with health professionals. Parents themselves were reported as playing a critical role in facilitating and encouraging children's participation, but sometimes in obstructing it. Parents need to be supported in enabling their children to participate and their advice should be sought by health professionals on how best to involve individual children.

Three areas of critical importance were identified by children and young people in respect of the decision-making process.

- First, they reported that *information provided should be tailored* so that it is accessible and appropriate according to the individual's level of understanding. Where children cannot be provided with their first choice, they strongly suggested they should be given an explanation of why their preference cannot be met and offered alternatives where possible.
- Second, children and young people reported that *sufficient time* needs to be given to them to consider the information provided and also to be able to talk to health professionals and others so that clarifications can be sought. This can be greatly assisted by the allocation of a primary carer (nurse) so that a relationship can develop.

- Third, assumptions about the ability or willingness of individual children to participate should be based on *the needs of the child*. Health professionals should be aware that some children could be reluctant to challenge aspects of their care, while others use an information-limiting strategy as a mechanism for coping. For that reason, health professionals, while actively encouraging participation, should also be sensitive to the needs of individual children so that they can be best supported to make decisions that they themselves feel able to make.

A commitment from hospital senior management to the principle of consultation with children was identified as important in this study and it was suggested that this commitment could take a number of different forms. It could, for example, include:

- an education and awareness campaign for parents, children and health professionals;
- initial and on-going training commitment for staff in communicating with children and ensuring their right to participate is asserted;
- the development of codes of conduct in this regard that would be subject to evaluation;
- the provision of a forum that includes children and young people to address specific needs identified by them (such as those relating to space, recreation, play facilities, play therapists, equipment, the need for separate units for adolescents and appropriately designed information materials — all of which emerged throughout this study);
- the development of materials to promote children's right to participate in healthcare decisions that affect them (e.g. art activities, stories, poems, role-playing, graffiti boards and web-based notice boards).

The findings from this study suggest that it is important that all stakeholders, including senior managers, health professionals and parents, develop a greater awareness of the need to communicate with children in a way that facilitates their participation in issues that affect them. Health professionals' attitudes and assumptions about children need to be challenged and addressed, and health professionals need to re-evaluate their practices to ensure that they embrace a more flexible approach to children's participation in consultations and decisions. Health professionals have a duty and responsibility to ensure that children of all ages and abilities have a voice in decisions about their health and to exercise control as much as possible about what is done to their bodies.

The facilitation of children's participation may be seen by some as time-consuming and labour-intensive, but it should be recognised that all professionals have an ethical and clinical obligation to support children's involvement in consultations and decision-making. The benefits for children include:

- better provision of information;
- having an opportunity to express feelings;
- developing confidence;
- increasing skills in decision-making;
- enhancing self-esteem;
- overall coping with hospitalisation.

It is imperative that efforts are directed towards facilitating and supporting children's involvement because it will improve the quality of care provided for children and their families. Furthermore, it is an important investment, with immense future potential benefits for children, staff and the health service.

## Recommendations

There are a number of specific recommendations arising from the conclusions drawn above:

**Recommendation 1:** Steps should be taken to increase awareness of all stakeholders — including children and young people, parents, healthcare professionals and managers — of children's right to be consulted in matters that affect them.

**Recommendation 2:** Initial and on-going training programmes focusing on children's participation should be developed and implemented for all healthcare staff working with children.

**Recommendation 3:** Appropriate mechanisms at an organisational level to ensure children's participation within healthcare settings should be developed. These may include formal structures where children are represented, facilitated to participate and have their views taken into account in the decision-making process.

**Recommendation 4:** Special attention should be paid to ensuring children in hospital are aware of their right to participate and that they develop the necessary skills to do so in a meaningful way.

**Recommendation 5:** Written information provided for children should be designed and presented in a way that ensures it is accessible and relevant to children.

**Recommendation 6:** Research in the area of children's participation in Ireland is at a relatively early stage and additional research should be undertaken, particularly in the area of how parents and health professionals can best facilitate children to participate.

## Definition of Key Terms

**Consultation** has been defined as asking the advice of, or seeking the views of, children and young people and using the information that is forthcoming to inform decisions about matters and services that affect their lives (Cohen and Emmanuel, 1998, p. 6).

**Involvement/Participation** is the overall term for children and young people being included in the decision-making process at any level (Treseder, 1997, p. 4).

**A child** is defined as any human being under the age of 18 years. Many children over the age of 16 would resent being called 'children' and are now more usually referred to as 'young people'.

**Children:** For the purpose of this report, the term 'children' is used to refer to children *and* young people.

# 1 INTRODUCTION



## Background to the study

The past decade has seen a growing recognition of the importance of children's rights and listening to and consulting with children, both at a national (Department of Health and Children, 2000a and 2000b) and international level (United Nations Convention on the Rights of the Child, 1989; Mayall, 1995; Lowes, 1996; Roche, 1999; Shevlin and Rose, 2003).

The United Nations Convention on the Rights of the Child (1989) states that the best interests of the child must be the primary consideration and that the child's views must be given due weight in accordance with the child's age and maturity. Although children's rights have increasingly been acknowledged in the last decade, there are still certain characteristics attributed to children that can reduce the relevance of attempts to listen to their views (Flatman, 2002). In recent years, changes in Irish society have attempted to dispel this by the creation of a National Children's Office, a Children's Ombudsman and a National Children's Strategy, whose vision aims to create an Ireland where 'children are respected as young citizens with a valued contribution to make and a voice of their own' (Department of Health and Children, 2000b). Although the National Children's Strategy is not a rights-based document, Goal 1 of the Strategy clearly establishes the right of children to be heard as a matter of national public policy: *'Children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity.'* The National Children's Strategy emphasises the importance of all organisations developing children's consultation mechanisms so that children are involved in decisions that affect their lives.

In consideration of these influential changes, it is clear that views on childhood are changing, with an increased awareness of the child as an active citizen in Ireland. However, children's views represent a rich source of data that has been largely unexplored until recently. This is because most of the research in the past has obtained data from parents or professionals on children's lives and has thus been *on* or *about* children, rather than *with* children. This is now changing. Increasingly, researchers are recognising the importance of directly recording children's own perspectives, as evidenced by recent Irish studies (McAuley and Brattman, 2002; Crisis Pregnancy Agency, 2003; Devine, 2003; Lodge and Lynch, 2003; Shevlin and Rose, 2003) and by British studies (Alderson, 1993; Brannen *et al*, 1994; Oakley *et al*, 1995; Alderson and Goodey, 1996; Hill *et al*, 1996; Hood *et al*, 1996; Ireland and Holloway, 1996; Mahon *et al*, 1996; Coyne, 1998; Balen *et al*, 2001). The National Children's Office (NCO) — now the Office of the Minister for Children — has a strong commitment to hearing children's voices and has established a comprehensive programme of research into matters that affect children's lives (NCO, 2004 and 2005).

Despite these studies, the research into children's participation in Ireland has been scarce and particularly so in the area of healthcare. Shevlin and Rose (2003) carried out research into the marginalisation of disabled children in Ireland, but there has been no research that has focused on children's participation in consultation and in relation to healthcare. There is limited empirical data from the children's perspective here in Ireland. Generally, interventions have been developed for adult populations and these have then been extrapolated for work with children.

Increasingly, it is being recognised that children are present and future healthcare consumers, which has resulted in calls for empowering children to be active in their healthcare (Pittman, 1992; Hart and Chesson, 1998). This does not mean, however, that all children want to be responsible for all decisions about their care, particularly when they are feeling sick and vulnerable. Children may want to participate in discussions about their care so that their voices are heard in relation to their needs rather than have full responsibility for decision-making. Alternatively, children's needs may vary along a dependence/independence continuum due to the effects of the illness and disruption of the hospitalisation. This indicates the need for research of children's experiences of participation in consultation and within the Irish healthcare setting.

# 2 LITERATURE REVIEW

**'The only thing I would change [in Ireland] would be that we would listen to our nation's children and young people much more, as we are the next generation that will have to run the country. The voice of innocence can sometimes be wiser than a hundred years of experience.'**

***Report of the Public Consultation for the National Children's Strategy***  
(Department of Health and Children, 2000a)

These are wise words, yet they come from the mouth of one who is often seen as having limited wisdom — they come from the mouth of a child. Lowden (2002) argues that childhood 'belongs to children least of all' and that the study of children remains 'largely a study of adults' attitudes to and practices with children'.

Pinning down an exact definition of childhood is difficult since children's experiences of it differ not only throughout history (Aries, 1962; Hart, 1991), but also geographically in modern-day society. Childhood for a street child in Calcutta is a very different experience from that of an affluent child growing up in the USA. Similarly, experiential differences in childhood can vary within the same location: growing up as a homeless child in Ireland is in stark contrast to an Irish child growing up with a roof over his or her head. Notions of weakness and need for protection are important issues in childhood. One common theme of childhood is that it should be a happy time. Yet this is not always the case as the assumed innocence and helplessness that accompanies the notion of childhood can often be abused by those in power, namely adults (Thomas, 2000).

Aries (1962) highlights that prior to the 16th century, children were seen as 'small adults' and that once they were over the age of 6, they were not viewed separately from adults. They were viewed as valuable property for their contribution to family work and supporting their parents in their old age. They remained as such up until the 18th century, when a sudden vulnerability status was attached to children (Lowden, 2002). Hart (1991) notes that this status of the vulnerable child went hand-in-hand with rapid changes in the conditions of immigration, industrialisation and urbanisation at the time. Children were seen as needing protection from these changes, which were viewed as having the potential to create undesirable behaviour and to threaten the very core of society. Hart describes it as very much an era of 'child-saving'. The 19th century onwards saw an increased separation of the child from adults, to the stage where children became a special class of people in need of protection from those who were much older and wiser.

Historically, children did not have any rights. They were either seen as property or in need of protection (Aries, 1962; Hart, 1991; Lowden, 2002). However, the introduction of the UN Convention on the Rights of the Child (UNCRC) in 1989 challenged the way in which children were treated and sought to secure improvement in their lives. The UNCRC gave substance to the rights of children and affirmed that children need special consideration and that they have a voice. This led many nations to draw upon its principles in relation to children and to draft and amend legislation.

In Ireland, it led to the development of the National Children's Office and the production of the National Children's Strategy in 2000 on how to implement children's rights in Irish society and how to make society more child-centred. People are beginning to take note that children have a voice, but more importantly that it needs to be heard. Children's views are now being sought in relation to education, social care, disability, family law, health, play and becoming an active citizen (Thomas and O'Kane, 1999; Murray and Hallett, 2000; Department of Health and Children, 2000b; O'Quigley, 2000; Oldfield and Fowler, 2004). One of the most challenging of these areas is that of health where not only children can be found in a passive role, but adults (parents) also who can often find themselves subordinate to the expert knowledge of healthcare professionals (Ross, 1997).

In Scandinavia and Hungary, health professionals are beginning to involve children in consultations and decision-making related to healthcare (Schultz, 1993). Much of the research into children's right to participate and make decisions regarding their healthcare has been conducted in Scandinavia and the USA. There exists a small body of research in the United Kingdom, while in Ireland the research is lacking.

This review will look at the changing face of children's rights, the child as an active healthcare consumer, and children and empowerment in the healthcare system, before concluding with an examination of 'who knows best' with regard to children's healthcare.

## Children's voices, children's rights

Rodham (1973) has described children's rights as 'a slogan in need of a definition'. What are rights? Are they just words on a piece of paper, a given thing we have in society or are they acquired through practice? Is it only when our rights are exercised or denied that we realise we have them? Thomas (2000) argues that the debates surrounding rights are whether children should have rights and whose obligation it is to meet those rights.

Children's rights can be classified into two different categories — nurturance rights and self-determination rights (Archard, 1993; Thomas, 2000; Kennedy and Mohr, 2001). Nurturance rights (sometimes termed 'welfare rights') are the child's right to the provision of beneficial objects, such as education, housing and healthcare. Self-determination rights fall under the category of the child's right to participation and control over his or her life through active participation in choice.

The UN Convention on the Rights of the Child gave increased societal emphasis to the need for a balance between the child's nurturance rights and their self-determination rights (Lowden, 2002). Kennedy and Mohr (2001), however, note that although a balance is what is strived for, quite often societies can tip the balance in either favour. They argue that in the USA there is strong political support for nurturance rights, but far less support for self-determination rights despite the large numbers of children's movements present in that country. Very often, exercising nurturance rights can leave you without self-determination rights, and vice versa. Take the example of a child worker in Guatemala: he or she may live alone and exercise their right to self-determination, yet the absence of a home, a family, education, healthcare is an abuse of their nurturance rights through no fault of their own. Archard (1993), drawing on Piaget's theory of cognitive development, sees both nurturance and self-determination rights as being determined by age — that the needs of young children up to the age of 7 are chiefly to do with nurturance, while self-determination rights are of limited relevance to them and only apply to middle childhood and adolescence.

Lowden (2002) states that most research on children's rights falls into three main categories of approaches — protectionist, liberationist and pragmatist. Lowden asserts that unfortunately children are still defined from a protectionist adult perspective, which hinders the development of competence. Only future research will deem if change is possible. Protectionists argue that children need protection while they learn to exercise sound judgement and gain the knowledge they need to manage successfully in the world. However, Archard (1993) notes that it is quite often those who are supposed to protect children who may end up abusing them.

Liberationists argue that the rights, privileges, duties and responsibilities of adult citizens should be made available to children and young people, and that they should have an active role in society (Holt, 1974; Cohen, 1980; Franklin, 1986; Van Eys, 1986).

Pragmatists argue that there should be a balance between the liberationist and protectionist ideas, one that recognises the protection needed for children while at the same time allowing some flexibility for the child's emerging knowledge (Hart, 1991; Harrison *et al.*, 1997; Ross, 1997). The study by Alderson (1993) on children's consent to surgery found that several young patients wanted to 'consent' to surgery but were unwilling to sign the consent form, thus signalling a desire to be involved but also a desire for informed adult support. With the problems surrounding informed consent, competency and what exactly the child's 'best interests' are, the pragmatic approach seems to be a safe one. It encompasses the best of two extreme positions and allows a balance between protection and self-determination, which may help to overcome conflicts, confusion and problems between the diverse approaches.

## Children as healthcare consumers

Every day we switch on the television to witness advertisements aimed at children and young people. Yet in the arena of healthcare, it is the parents rather than the children that are seen as the consumers (Fulton, 1996). Market research and advertising companies often conduct focus groups with children, yet children rarely participate in the planning of health services. In the UK, the National Youth Agency and the British Youth Council surveyed statutory and voluntary sector

organisations in England (n = 849) in order to establish the extent to which children are involved in public decision-making (Oldfield and Fowler, 2004). They found that the level of participation was greatest in organisations that had a specific remit to work with children, but more limited in health and criminal organisations. Similarly, in Ireland the Children's Rights Alliance and the National Youth Council found that voluntary organisations were more likely to consult with children as compared to statutory organisations (McAuley and Brattman, 2002). Sloper and Lightfoot (2003) note how little information is available on children's involvement in healthcare treatment services, although more information is available about children's involvement in local government. Children account for up to one quarter of all UK GP consultations and represent 30% of the workload in Accident & Emergency departments (Hart and Chesson, 1998). Children are without question important users of the health service, yet their views are given insufficient priority by policy-makers and health service professionals.

The research studies that have been conducted with children in hospital indicate that children have varying experiences of being consulted and involved in their care (Alderson, 1990 and 1993; Runeson *et al*, 2000; Carter, 2002; Coyne, 2003) and that children are largely excluded from the process (Angst and Deatrck, 1996). Children also experience less than optimal communication and have unanswered informational needs (Alderson, 1990 and 1993; Epstein and Wayman, 1998; Beresford and Sloper, 2003). Similarly, studies on children's medical encounters in clinics reported that all children, even the older ones, were routinely excluded from discussions and granted limited autonomy (Strong, 1979; Silverman, 1987; Inman, 1991; Shiminski-Maher, 1993; Van Dulmen, 1998; Carter, 2002). Pearlman and Abromovitch (1987) note how quite often no explanation of treatment or reasons for it are given to children. In their study of child-parent-physician interaction in healthcare consultations, they found that 92% of the children studied had questions regarding the consultation. Epstein and Wayman (1998) argue that communication with the child patient is imperative, finding medical procedures to be lacking in 'appropriate verbal structuring' for infants, while conversations regarding treatment were unresponsive to children's interaction. It appears, therefore, that the practice of speaking with children, listening to them and involving them is not widespread among health professionals.

It may be argued that cults of paternalism and protectionism have led to the child being seen as passive, with decisions being made by parents or health professionals. Research has indicated that age, communication and experience of all have a role to play in how children are perceived as inactive, incompetent consumers of their own healthcare (Brewster, 1982; Igoe, 1991; Pittman, 1992; Oppong and Heycock, 1997; Epstein and Wayman, 1998). Some research found that children were more likely to be involved if they were older (Alderson, 1990 and 1993; Deatrck, 1984). Brewster (1982) argues that children under 7 years of age see illness as occurring as if by 'magic' or else as the result of bad behaviour; they have no real concept of their illness. From the ages of 7 to 11, children have a better understanding of their illness, but inaccurately infer the reasons for treatment. Children from 11 years up to adolescence have a more detailed understanding and become aware that illness can be aggravated by psychological factors (Bibace and Walshe, 1981). It has been argued that the present level of knowledge on children's cognitive development has not been sufficient to provide clear guidance on children's ability for self-determination (Hart, 1991) and developmental theories are an inadequate base for assessing children's abilities for self-determination (Alderson, 1993; Mayall, 1994, 1996a and 1996b).

The effect of hospitalisation can be a factor in constraining children's active healthcare participation. Hospitalised communication with children takes place within a typically chaotic and unstructured environment, which can be unsettling for a child. Bonn (1993) argues that a lack of communication leads the child to be unfamiliar with routines, procedures and people, which can lead to psychological distress. Peterson (1989) argues that children may not always want to be involved and adopt an information-avoidance coping style. Thompson (1994) also found information-limiting to be an effective form of coping behaviour. LaMontagne (2000) sees coping as being an individualised experience: children will choose to seek information actively or else purposely avoid it, depending on their individual needs and various situations. Research has shown how the presence of healthcare professionals and parents and a positive experience of

hospitalisation can increase children's autonomy (Jago, 1987; McClowery, 1988). Jago (1987) suggests that a positive experience of hospitalisation can help the child to be a more active health consumer and the child 'interested in its own health, will listen in on the doctor's conversation and make their own interpretation of it'. While other research has found that children are happy to remain in a protected role (Lumley *et al*, 1990; Tong and Sparacino, 1994), McClowry (1988) argues that research into the effects of hospitalisation on self-determination in children is inconclusive and that predisposing family factors need to be considered.

What is the future for children's active participation in their healthcare consumption? Pittman (1992) argues that 'empowering children and adolescents to recognise their roles in their own healthcare should be an expectation'. Epstein and Wayman (1998) assert that to transform patients into active healthcare consumers in a healthcare system that is traditionally paternalistic is a 'monumental undertaking'. Similarly, Dixon-Woods *et al* (1999) argue that children's right to participation has little chance of being realised until there is more research-based evidence about the 'outcomes of, how the competence of children can be assessed, how information can be shared with children, and how shared should be managed in practice'. This is an important point since there is a deficit of good quality research on these issues. Dixon-Woods *et al* (1999) also make the point that health professionals and parents require reassurance that children's participation will not produce adverse effects in the long term, hence the need for good quality evidence to reassure and guide them in how to manage children's participation.

This is the era of consumerism and consumer participation in healthcare is viewed as a requisite for effective bargaining for quality care in the healthcare industry. But the evidence suggests that there are many obstacles to the realisation of children's participation in the healthcare arena.

## Children and decision-making

One of the central issues in the children's rights debate is whether children have the right to make their own decisions and this is extremely apparent in the domain of healthcare. Lowes (1996) states that during a child's hospitalisation, minor decisions are repeatedly made by the parents and are enforced without consulting the child for his or her view. Research has also shown that where there is conflict between the child and healthcare staff members, parents have tended to take the side of the staff as opposed to that of their own child (Angst and Deatrck, 1996; Runeson *et al*, 2002a and 2002b). The positive value of being able to exercise choice has been documented in many psychological research studies (Kennedy and Mohr, 2001). Lansdown (1995) notes that although participation is a fundamental right of citizenship, children's potential for participation in healthcare is grossly undervalued in society.

There is a tendency among adults and health professionals to view children's participation in terms of legal consent to major healthcare issues (Dyer, 1999). Decision-making is frequently seen in relation to life-threatening issues, yet few decisions about treatment are of the 'life and death variety' and the really complex ethical problems that can occur are usually the exception rather than the norm (British Medical Association, 2001). This view of decisions, as consisting of only life-changing major decisions, can result in the 'all or none' view of participation, which health professionals may use to inhibit children's participation. Most of the research on children's decision-making has tended to focus on children's involvement in decisions about surgical treatment rather than everyday on-going care (Alderson, 1993). In fact, there are multiple levels and ways to involve children in decision-making. Decisions should be seen as existing on a continuum, ranging from everyday decisions to major decisions, with the majority consisting of simple, everyday decisions about on-going care — ones that children could easily participate in (Dixon-Woods *et al*, 1999; Rylance, 1996). Equally, acknowledging children's rights to be heard is not the same as giving them the sole responsibility of making decisions. Research has found that even when children are deemed capable of making healthcare choices, they need the support for their decisions from family members and the healthcare team (Deatrck, 1984; Harrison *et al*, 1997).

The literature on children's capacity to engage in decision-making appears to focus on the ability to give 'informed consent'. Atherton (1994) states that informed consent is where a person is 'both



willing and able to agree to a course of action based on full knowledge of what the action entails'. According to Pursell (1995), the lack of research and experience in this area compounds the prejudices of many healthcare staff who believe that children are incapable of giving consent. A child may be willing and able to agree to surgery, but what if they do not possess the full knowledge of what surgery entails? Information may be kept from children by both parents and healthcare professionals because of the traditional view of the child as incompetent and being in need of protection. It is difficult to see how children can grow as autonomous decision-makers if withheld information hinders their ability to give informed consent. Thus, having the relevant information is as important as having the ability to make a decision.

Other research has found that supplying children with information regarding procedures, including the associated risks and benefits, helped enhance children's understanding of the process and consequences of participation (Lewis and Lewis, 1990) and increased their internal locus of control and decision-making ability (Taggart *et al*, 1991; Tieffenberg *et al*, 2000). Children's capacity to participate is determined to a degree by the effort of preparing them to participate and the quality of the preparation. Similarly, children learn how to make decisions by practice and therefore need the opportunity to exercise decision-making skills. Pursell (1995) argues that if children had competency based on their ability to make decisions rather than age, as adults do, then the onus would be on adults to justify children's non-involvement.

Lee (1991) argues that participation does not rest solely on consent, but on three levels: consent, assent and permission. *Consent* can only be given by an autonomous person who is able to control their own lives by being in a position of self-determination. *Assent* is where a child over the age of 7 may give agreement based on evidence of knowledge and understanding, and a willingness to cooperate. *Permission* is where a parent gives consent on behalf of the child. Lee (*ibid.*) sees adolescents as capable of giving consent; middle children as being capable of assent; and babies and infants as requiring permission. While much of the focus is on the child's ability to give 'informed consent', the child's capacity for 'informed refusal' must not be diminished (Harrison *et al*, 1997; Alderson, 2000; Hallstrom and Elander, 2004). The British Medical Association (2001) reviewed the law on children's consent and found that in most cases their wishes have been overruled by the Court and concluded that the rights of children to refuse treatment is limited. Thus, children may be seen as competent on some occasions and incompetent on others if they refuse treatment. It appears that the law on children's consent is the subject of much academic debate and its inconsistencies can be confusing for all concerned.

Children's capability to engage in decision-making also seems to centre on whether the child is deemed 'competent' or not, and commonly held perceptions often see children as 'incompetent'. Health professionals, particularly doctors, have traditionally seen child patients as incompetent and thus of subordinate status in the communication process (Aronsson and Rundstrom, 1998; Gabe *et al*, 2004). Beauchamp and Childress (2001) define competence as the 'ability to perform a task' and a child is competent to make decisions if 'he or she has capacity to understand the material information, to make a judgement about the information in light of his or her values, to intend a certain outcome, and to freely communicate his or her wishes'. The evolving capacities and maturity of the child have been set as primary criteria by the UN Convention for determining the degree of self-determination allowed to children. Yet there are few empirical studies of children's competence in decision-making and formal tools to assess this do not exist. Most authors appear to rely on the seminal study by Weithorn and Campbell (1982), which found that children of 14 years of age had a similar level of competence to adults, while younger children were less competent than adults. Thomas (2000), in a UK study of social care reviews with 120 children, found that age was a determining factor in children's ability to make decisions. He noted that from the age of 8, participation begins and increases at a steady rate through adolescence, while below the age of 8, children's participation was insignificant. In separate studies, Alderson (1993) found the mean age at which to allow children to make decisions was 10.6 years, while Rushforth (1996) found it to be 10.3 years.

However, the sole reliance upon age as a determinant of competency has been challenged by other research. Deatrick *et al* (2003) revealed shortcomings with the competency scale used by Weithorn

and Campbell (1982) to assess children's competency in decision-making and advised against reliance on these findings. Alderson and Montgomery (1996) argue that children's experience, not necessarily their age, can determine their understanding. The influence of experience on children's capacity to make decisions has been confirmed in research with very young children who have chronic illnesses (Nitschke *et al*, 1982; Christensen, 1998; Alderson, 1993). In Alderson's 1993 study with 120 children aged 8-15 years old, she found that children who experience long-term serious illness or major surgery develop a capacity for understanding that far exceeds common perceptions of child incompetence. She concluded that competence develops in response to experience and reasonably high expectations rather than gradually over time through ages or stages. This indicates that children who experience many hospitalisations may be more capable of participation in consultations and decisions.

Deatrick *et al* (2003) suggest that further research is necessary to determine the influence of other variables in addition to age on children's capacity to participate, such as cognitive ability, past illness, gender, parental influence and consequences of the decision. There is a general lack of information on how various factors may influence children's ability for self-determination. There is also a deficit of guidance on how children's ability for self-determination may be assessed (Hart, 1991; Dixon-Woods *et al*, 1999).

It is clear from the above discussion that it is a major assumption that capacity can be defined or measured solely by a child's age. Furthermore, age may not equate with a child's psychosocial or cognitive development. Therefore, judging or justifying children's participation in consultations and decisions by reference to their chronological age is a crude measure. It is evident that there are many other variables that may influence children's capacity to participate, such as cognitive ability, insight, judgement, experience, nature of illness, family background and education, to name a few. Although developmental milestones may give us a general idea of children's capacities, two children of the same age may differ quite markedly in their ability to make choices. Hence it may be argued that apart from babies, children and young people are generally competent to have a coherent view on a wide range of matters (British Medical Association, 2001; Thomas, 2000). Therefore, it should follow that the onus should be on health professionals to justify non-consultation with children about matters and decisions that affect them.

In a period spanning over 30 years, several models, frameworks and schemata have been developed to structure the involvement of children in decision-making (Hart, 1992; John, 1996; Alderson and Montgomery, 1996; Treseder, 1997; Lansdown, 2001). Alderson and Montgomery (1996) see participation as operating on four levels of consultation with the child — being informed, expressing a view, influencing, and being the main decider. Participation by consultation with the child allows the child varying degrees of autonomy and responsibility depending on the individual needs of the child.

Hart (1992) adapted Arnstein's (1969) model of citizen participation, which was developed for adults, by altering some wording to make it more appropriate for children and young people. This was the model chosen for presentation in the National Children's Strategy (2000). In Hart's 'Ladder of Participation', participation is commensurate with the child's age and capacity (*see Appendix 1a*). The 'rungs on the ladder', numbering 8 in total, represent degrees of participation or opportunities that range from tokenism to child-initiated, shared decisions with adults (*see Appendix 1b*). This model has been criticised for several reasons: (1) for structuring various levels of consultation in a hierarchy, which does not recognise that participation usually exists on a continuum, with movement across the levels depending on the context of the consultation (McAuley and Brattman, 2002); (2) that it was developed for children's participation in projects rather than general situations (Murray and Hallett, 2000); and (3) that children may have different views on their levels of participation.

Despite these limitations, the existing frameworks are useful because they promote understanding of the different degrees of involvement and they highlight the complexities involved in structuring children's involvement in consultation and decision-making.



## Children, empowerment and the healthcare system

According to Toce (2004), children 'belong to themselves' and are autonomous human beings. However, in the healthcare setting, they are traditionally seen as belonging to their parents, in need of protection and having decisions made for them instead of by them. Alderson (1993) notes that the tension between children's empowerment through participation and their need for protection can be at its most extreme in relation to healthcare. Adults have traditionally exercised control over children making decisions about their welfare based on the belief that 'adults know best'. Beals (2003) and Ross (2002) both note how often the decision about what is best for the child can come into conflict with what is best for the family. Beals (2003) states that the views of all parties involved need to be carefully considered and respected when making healthcare decisions relating to children and that the child's assent should be sought in all cases. Similarly, the British Medical Association (2001) emphasises that all children who are capable of expressing a preference should be involved in decision-making, whether or not they are the main decision-makers.

Ross (2002), however, argues that decisions regarding children's healthcare should be made using a model of 'constrained parental autonomy', whereby respect is given to the child's views but their autonomy is constrained yet accommodated to respect the child's developing personhood. Ross's central argument is that children need a protected period in which to develop self-determination, and therefore children's present-day autonomy should be limited because children have limited world experience and so their decisions are not part of a well-conceived life plan. This view is supported by Harrison *et al* (1997) who assert that it is more 'helpful and respectful of the child to affirm the parents' responsibility for the care of their child while allowing the child to exercise choice in a measure appropriate to his or her level of development and experience of illness and treatment'.

Knafl *et al* (1988), in a large-scale study of paediatric nurses, families and children, found children to be seen as 'objects' that had things done to them rather than being involved or having a voice. Aronsson and Rundstrom (1998) argue that there is a cult of paternalism within hospitals, whereby children are subordinate to both medical and parental authority. They argue that the child's subordinate position only serves to conserve parental authority and to increase child dependence. Coercion and subordination bring minimal choice, respect and freedom for the child — the total antithesis of what the UN Convention on the Rights of the Child stands for. Bricher (2000) asserts that a failure to recognise the power imbalance between adults and children can be quite useful to adults, but denies children their rights.

Prilleltensky *et al* (2001) argue that a sense of personal control, empowerment and self-determination are associated with positive mental health. Gaut and Kieckhefer (1988) state that to become empowered in a health setting, you need first to have the power to understand what you need to do to become well and, secondly, to have the power to accomplish this action. Quite often, children may understand their illness but lack the power to access treatment on their own. Alderson and Montgomery (1996) assert that parents can actively nurture empowerment in children by encouraging them to exercise it, trusting them, having high expectations and by supporting them regardless of the outcome.

Empowerment brings choice, but it also brings responsibility. It is worth noting that not all children may wish to be empowered to make decisions regarding their healthcare. Alderson (1993), in a study of children's consent to surgery, noted that while many children were willing to consent to surgery, they were unwilling to take full responsibility by signing the consent form. So should children be empowered to make decisions regarding their healthcare? Alderson and Montgomery (1996) note how over 10,000 children in the UK are the main carer for a sick or disabled relative, some as young as 3 years of age. This is empowerment, but is it empowerment by choice? Moss-Morris and Patterson (1995) argue that children are more likely to comply with treatment regimes and be less distressed if they are allowed to be empowered and take some control of their health through active participation. Some children, however, do not want to be empowered and wish to leave the responsibility of choice to their parents and healthcare professionals, while others wish to actively engage in some form of empowerment but do not wish to be responsible for it. Initiatives need to be put in place to encourage autonomy in children in a healthcare setting, but in the end it is up to the child to determine the level of empowerment they wish to engage in and it is up to parents and healthcare professionals to encourage and respect that chosen level.

## Conclusions

Throughout this chapter, we have looked at childhood and children's rights from an historical perspective, the child as an active health consumer, and children and children's empowerment in the healthcare system. So who really does know best when it comes to the health of children? Liberationists believe that the autonomous child should have all the say in regard to their healthcare (Holt, 1974; Cohen, 1980; Franklin, 1986). Protectionists argue that the child is incompetent to make their own decisions and it is up to the parents to decide (Feinberg, 1980). Pragmatists hold the view that a balance between protection and self-determination is essential in children's healthcare (Alderson, 1993; Archard, 1993; Harrison *et al*, 1997; Ross, 1997).

Who knows best is not really the issue. It is more about giving children a voice and paying attention to the individual needs of each child. Furthermore, the legal and ethical concept of the best interests of the child has become contentious because some feel it is vague, unknowable, individualistic and open to abuse (Kopelman, 1997). Lowes (1996) argues that we should 'ensure every child is treated as an individual and, while encouraging a child's right to autonomy, it must be remembered that what is considered beneficial to one child may be detrimental to another'. It must also be considered that involvement in consultations or decision-making may allow for the possibility of empowerment, but is not intrinsically empowering in itself. Furthermore, if children are involved in a tokenistic way (i.e. consultation done inappropriately), then this may 'disempower' children and result in them feeling undervalued.

Providing children with opportunities to participate in consultations and decision-making is of the utmost importance. The benefits for children include better provision of information; having an opportunity to express feelings; developing confidence; developing competence and maturity; increased compliance and take-up of service; developing civic skills and encouraging participation in wider society (Cohen and Emmanuel, 1998; Sloper and Lightfoot, 2003). Young people of all ages are capable of formulating and expressing very clear ideas about the way in which local services are planned and delivered (Elliott and Watson, 1997) and allowing children to make decisions about simple matters facilitates the development of skills that they will need later in relation to making complex decisions. Excluding children from participating in decision-making can increase their fear, especially in difficult situations (Runeson *et al*, 2002b).

Communication has a huge role to play in giving children a voice within the healthcare setting. Lack of information exchanged between parents and children, children and healthcare professionals, and parents and healthcare professionals can only lead to confusion and fear. Perrin and Perrin (1983), in their study of physicians' perceptions of child understanding, found that the majority of physicians did not know what to expect children to understand and treated all children as if they understood at a cognitive level of middle childhood. Effective communication with parents and the child could have helped alleviate this. The extent to which a child wanted to exercise their right to autonomy would benefit greatly from honest, open and effective communication from all parties involved. Chambers (1992) argues that children's voices could be empowered if nurses were to engage in advocacy on behalf of the child, whereby if they saw the child was in distress or needed clarification, they would intervene on the child's behalf with parents and physicians. Nurses are in a prime position to act as advocates since they are in close contact with the child, parents and physicians.

In conclusion, what is needed is a change in the public perception of the child as incompetent when it comes to having a role in consultation, especially in the area of healthcare. Children are not belongings or property that we can treat how we like, but human beings with a voice and developing autonomy. It is up to us as older, wiser and powerful adults to respect children's views and to help give them their voice. Attention needs to be paid to what each individual child's voice is saying. Participation through consultation allows children's voices to be heard without handing them the responsibility to make decisions, which some of them may not be ready to make. Children, parents, nurses and doctors need to come together to determine the individual child's competence, but above all to listen to their views and decide how to respect those views.



# 3 RESEARCH DESIGN

## Aims and objectives

As shown by the literature review in Chapter 2, there is a dearth of Irish research that has sought hospitalised children's views on their involvement in consultation and decisions about their care. Beresford (1997) suggests that methodological and ethical arguments, together with simple failure to accept the value of the child's viewpoint, have precluded children in general from being accepted as *bona fide* participants in research. Children may be viewed as potentially vulnerable and therefore more at risk of having their views ignored or discredited. Having an impairment or illness marginalises some children even further. Therefore sick children are potentially 'doubly disadvantaged' when it comes to being involved in research. However, the focus on children and their lives has eventually filtered into the research arena and researchers are increasingly recognising the importance of directly recording children's own perspectives (Coyne 1998; Cree *et al*, 2002).

Eliciting children's views and documenting their experiences are essential in providing services that are responsive to their needs since they are the main focus of care while hospitalised. It is imperative that children's voices are heard and valued in decisions that affect their health and welfare, and in identifying strategies that will enhance the hospital experience for them. Specific data about children's lives are critical for needs and resource assessment, planning, monitoring and outcomes evaluation. Health-related research is immeasurably important when it comes to improving the health and well-being of children, both individually and collectively (Miller and Kenny, 2002). Therefore efforts directed towards those endeavours will ultimately enhance the quality of care provided for the child and consequently for the family.

The overall aim of the present research is to examine children's experiences of participation in consultations and decisions about their healthcare within the hospital setting. The specific objectives include:

- to describe children's experiences of consultation in the healthcare setting;
- to identify the factors that enhance children's participation in consultation and decision-making;
- to identify the factors that hinder children from participation in consultation and decision-making;
- to explore strategies that will empower children to participate in consultation and healthcare decisions.

## Methodology

This study adopted a qualitative approach since many researchers have noted that qualitative methods are appropriate for collecting valid and meaningful accounts from children (e.g. Hill *et al*, 1996; Ireland and Holloway, 1996; Mahon *et al*, 1996; Morrow, 1996; Coyne, 1998; Thomas and O'Kane, 1999; Murray and Hallett, 2000; Balen *et al*, 2001; Noyes, 2000; Carter, 2002).

To be effective in research with children, researchers need to be flexible in the methodology they use in order to ensure that children's rights and needs are respected in the research process. The research methods should be flexible enough to take account of differences in age, individual personalities, context and preferred form of communication. It was also considered important to adopt an approach that would allow children to have a voice. Mayall (1996a) argues that children may be unnecessarily silenced through a neglect of research and adults to listen to their views and see the world through their eyes. Lansdown (1995) also argues that we have a culture of not listening to children and thus have made few attempts to understand children's lives in their own terms. It is frequently noted in research studies how the child is seen more as a research 'object' than a research 'subject' (Mayall, 1996b; Alderson, 1995; Ward, 1997; Hill *et al*, 1996). Many studies on children have relied on adults' perspectives of what children think, leading some researchers to lament that research has been 'on' children, only rarely 'with' them or 'for' them (Hood *et al*, 1996; Faux *et al*, 1988). Hood *et al* (1996) argue that research 'assumes adult knowledge and values as the standard against which children's performance is to be measured'. But children are not adults — they do not hold adult knowledge or see their social world through adult eyes.

As a means of gaining an insight into children's understanding and perceptions of their role in consultation and decision-making in a healthcare setting, qualitative methods were most appropriate for this study. To hear children's voices, a method is required that values subjectivity, enhances empowerment and allows us to enter the respondents' world of meaning and belief. Greene and Hogan (2005) argue that qualitative research allows us access to children and the world around them through their own self-expression. Qualitative research also corresponds well with young children since it allows them freedom of expression to tell what is meaningful to them. Bricher (1999) notes that children's voices are different to parents' voices and are based on a different kind of knowledge. The strength of qualitative methods, such as focus groups or interviews, is that they usually leave the children's perspective intact, as well as generating rich, detailed and valid data (Bender and Eubank, 1994).

Sensitivity is another feature of qualitative methods. Where young children and adolescents are concerned, sensitivity and a non-threatening atmosphere are of extreme importance. In this study, we were not only dealing with young children, but also sick children. Amato and Ochiltree (1987) note that when interviewing children, researchers need to be aware of any anxieties the child may have or distress he or she may be in. Quantitative methods allow no such room to monitor the child's stress or anxiety levels. Hern *et al* (1998) argue that disclosure of sensitive information is also a feature of researching children and when disclosed, such information should be handled in a respectful manner that enhances trust. It is easier to create a relaxed and trusting atmosphere when a researcher is present to calm any anxieties the respondent may have. This is best done through qualitative methodology.

Looking at our research questions, the age of our respondents, the effort to hear previously silenced voices and the sensitive nature of researching sick children, qualitative methods offer the best means of ensuring rich, valid and, most importantly, meaningful data on the part children play in decision-making. To be effective in research with children, researchers need to be flexible in their research tools in order to ensure that children's rights and needs are respected in the process.

### Methods of data collection

The data collection tools in this study consisted of focus groups and individual interviews. Hill *et al* (1996) found individual and group interviews were the most economical and effective way of ascertaining children's views. Focus groups are small discussion groups in natural settings. The commonality of group participation may provide support and encourage children to be vocal about their experiences. The group context can be a useful way of encouraging more reticent children to offer information they might not provide in an individual interview (Mates and Allison, 1992; Hoppe *et al*, 1995; Beresford, 1997). Research has also shown that most children feel safe and comfortable in groups with children of a similar age (Mauthner, 1997; Heary and Hennessy, 2002). Indeed, several researchers have found focus group interviews to be a valuable means of collecting data from children (Amato and Ochiltree, 1987; Deatrick and Faux, 1991; Alderson, 1993; McCormick *et al*, 1999; Mayall, 2002; Wilkinson, 2003). Mayall (2002) has over 20 years' experience of researching children's views on various issues and noted that focus groups with young people enhanced discussion through swapping of experiences and development of themes.

It is important to note that some children may want to be involved in the research study, but may be reluctant to participate in group sessions and consequently express a preference for individual interviews. There was also the possibility that focus groups with a particular age group may not be possible because of the number of children available at any one time on the ward or because the children were too ill to participate. These potential problems have been reported elsewhere in research studies with sick children in hospital (Alderson, 1993; Wilkinson, 2003). The intention was to accommodate the children who consented to be involved in the research; hence in such instances these children were interviewed on their own. Although some recent studies have highlighted difficulties when using interviews as a research tool with children (e.g. children being intimidated by the experience; being less attentive and having more difficulty understanding questions than adults), they have also demonstrate that useful information can be acquired from children through the use of interviews (Amato and Ochiltree, 1987; Faux *et al*, 1988; Deatrick and

Faux, 1991). Alderson (1993) interviewed 120 hospitalised children aged 8-15 years about their views and experiences of children's consent to treatment and she found that in every age group the children were very keen to talk to her in detail. Individual interviews can be useful for discussing personal experiences with children since they allow more detailed and confidential discussions to take place than in group situations. Therefore, individual interviews were conducted with children who preferred to be interviewed privately and who were able to handle the close nature of a one-to-one interview.

### Topic guide

An interview schedule was used to facilitate in-depth exploration of the perspectives of children and to create discussion on children's experiences of involvement and consultation during the focus groups. The key topics were:

- experience of attending hospital;
- experiences of consultation;
- involvement in decision-making;
- relationship with health professionals;
- factors that enhance and hinder children from participation.

It is important to note that this topic guide only acted as a prompt as children were sharing their individual experiences of hospital. It was intended that the interviews should remain relatively unstructured so that the children would have the opportunity to identify issues that emerged, in particular to their experience of hospital consultation. The approach taken was to enter the interview with a list of broad topic areas and a set of sub-topics to be used as a guide to the discussion. We did not seek to cover the list of topics on our interview agenda in the same order with each participant. Instead, we adopted the approach of allowing the interview with each participant to follow a course, which was, within the broad confines of the interview agenda, largely determined by age and hospital experience of the participant. It is important that children's views are elicited in an open forum and not strictly controlled by a structured interview schedule. Children need to be allowed to talk about their daily lives so that rapport and trust can be established. Hence, Faux *et al* (1988) suggest that when children are ready to tell their story, the researcher will get credible data, i.e. what is meaningful to the children.

### Setting

In a qualitative study of this nature, there is a need to use methods, sites and respondents that allow for the full range and variation of behaviour of the phenomena under study to emerge (Chenitz and Swanson, 1986). Therefore, the samples in this study were drawn from three different care settings — two children's hospitals and one large district hospital.

### Sample

The first selection criterion was that children were hospitalised with an acute or chronic illness. The reason for including both was to gain experiences of a broad range of children who require consultation in the healthcare setting.

The second selection criterion was that children should be aged between 7 and 18 years at the time of interview and that there should be a balance between males and females. The reason for selecting this age range was that children within the age range of 7-18 would have increased cognitive, linguistic, social and emotional maturity and be able to handle an interview situation. Also, there is a broader range of data collection techniques available to the researcher to tease out the experiences of children within healthcare in this age group.

The third selection criterion was that the children should be divided equally between three different hospital settings. The reason for selecting different settings is that the experiences of the children in a specialised setting may be different from those in a generalist setting because of different philosophies of care and different organisational constraints. Selection of three different sites would increase the promise of quality, depth and richness in the research findings.

The fourth selection criterion was that children/adolescents would be interviewed without parents or health providers present within the hospital setting in order to create the conditions of privacy and confidentiality necessary for participation.

Since children might feel more secure being interviewed with others from their own peer group, children were grouped within different age bands for the focus groups — 7-9, 10-13 and 14-18 years. This ensured that younger, less confident children would not feel intimidated by older children and that more vocal adolescents did not overwhelm shy or anxious children. Those children who were reluctant or unable to participate in a group session and who expressed a preference for single interviews were accommodated.

In spite of careful planning, at the time of the research study there were four main reasons why all 3 sites were not suitable for data gathering in focus groups:

- Firstly, successful infection control measures were being implemented to prevent the spread of the winter vomiting bug in all 3 sites. Consequently, bringing children together on wards for focus groups or moving children between wards had to be done with caution to ensure effective outcome.
- Secondly, there was an increase in the numbers of children being admitted under 7 years of age and many infants requiring hospital admission with bronchiolitis. This led to fewer children being hospitalised within our proposed age groups on all 3 sites.
- Thirdly, some children within the relevant age group were unable to participate due to feeling unwell.
- Fourthly, the children endured different routines on units (e.g. attending school, playroom, physiotherapy, X-rays, scans, meals, medication, doctors' rounds and family visits), thus making gathering of children for focus groups extremely difficult. Different times during the day were determined as opportunities to approach children and parents about the study, when activities on the units appeared less hectic (e.g. morning time between 11am-12pm, 2-4pm and 6-7pm). The researcher also approached children on a Saturday, when units were less 'busy' and more conducive to child participation.

## Profile of children who participated

The sample of children participating in the study across 3 healthcare facilities consisted of 52 Irish nationals and 3 foreign nationals. Of these, 38 participated in individual interviews and 17 in focus groups (*see Table 1 for details*).

**Table 1: Summary of sample**

Age range	Gender	Conditions
7 – 9 years	8 boys and 9 girls = 17	6 chronic and 11 acute
10 – 13 years	19 boys and 10 girls = 29	15 chronic and 14 acute
14 –18 years	3 boys and 6 girls = 9	7 chronic and 2 acute
<b>Total</b>	<b>30 boys and 25 girls = 55</b>	<b>28 chronic and 27 acute = 55</b>

## Implementation and ethical issues

To ensure that all ethical guidelines and standards of research rigour were adhered to, the following procedures were implemented. Gaining access to children required negotiating and communicating with multiple 'gatekeepers' within the 3 healthcare settings. Permission to enlist the children as research participants was sought and obtained from the Ethics Committees in the 3 hospitals, from the parents and from the children themselves. The professionals involved directly with the sites, such as senior nurse managers, ward sisters and doctors, were informed of the study and their cooperation sought. Meetings were held with senior personnel from the



3 hospitals and follow-up discussions took place on an informal basis with healthcare providers. An information package was compiled and distributed to all units where access to children was permitted. The researcher also spent time trying to identify key gatekeepers on the units in order to facilitate the data collection process.

Through liaison with the ward staff and parents, the research team ensured that children suffering from critical illness were not approached since an interview situation could cause them further distress. Children who were very distressed by the hospitalisation were approached at a later date, when they were less distressed, to ascertain if they would like to be interviewed. Omitting children who are distressed at being hospitalised may introduce bias because such children may indeed have valid accounts to tell. However, the aim was to ensure that children would not be placed under additional pressure when they were already experiencing difficulty coping with hospitalisation.

The researcher approached the children's parents in order to seek permission for the child to participate in the study. Written consent on permission to approach the child to discuss the research study and to undertake the interview programme with their child was compiled for parents. Parents who were not present to consent to the study (11 out of 55) were contacted by phone and the study was discussed in considerable detail so they could make an informed decision on their child's participation. No parent refused. Once parental consent was received, the child was approached by the researcher and asked to participate in the study.

The parents and children were provided with an age-appropriate letter of introduction and an information leaflet (*see Appendices 2 and 3*), explaining the study and the general content of the interview questions. It was anticipated that through the use of age-appropriate language in the information sheets, the child would fully understand the interviewing process, thus making it less difficult for the child. Furthermore, to enhance sensitivity to children's concerns, the researcher chatted informally with the children before seeking their consent to participate in the study. The children were approached with due care and consideration, and were given the time to decide whether or not they wanted to participate in the study. Therefore, interviews may have been conducted on another day. Once verbal consent was obtained, the children were asked to provide written consent to be tape-recorded.

The issue of informed consent is of utmost importance in any research, but particularly with children who are vulnerable and sick (Mastroianni and Kahn, 2002). Considerable time was spent creating specific information for the child to ensure each one understood the research programme. Consent forms were compiled for parents to approach the child to participate and to assent to their child's participation in the study (*see Appendices 4 and 5*). Consent forms were also developed for younger children, as well as for older children (*see Appendices 6 and 7*). Pictures of Shrek, Spongeball, Spiderman and Rudolph were used to attract the child's attention and elicited lots of discussion around the character, which eased the researcher into the interview schedule. Each participant was talked through the voluntary nature of participation and that the interview was not a test; there were no right or wrong answers. The children were informed that they could withdraw from the study at any time in the research process and that they would not be required to provide a reason. The confidentiality of the data was also repeatedly emphasised.

Confidentiality of all data is a fundamental part of respecting and protecting the participant in any study. Identification numbers were substituted for children's names and their individual identities were not linked to the information they provided and publicly divulged. The data collected through the focus groups and interviews were only viewed by members of the research team. The tapes were stored in a locked cupboard and destroyed on completion of the study. Children have the same rights and needs as adults for privacy and confidentiality to be maintained. Adolescents are especially concerned with confidentiality since they are often experimenting with new ideas and ways of presenting themselves (Faux *et al*, 1988; Hern *et al*, 1998). Therefore, the children were assured that responses would not be shared with parents or with healthcare professionals unless they desired it. However, in the case of revelation of child protection issues, the researcher would proceed in line with the *Children First: National Guidelines for the Protection and Welfare of Children* (Department of Health and Children, 1999).

To ensure the welfare of children at all times during the study, the research team drew up three protocols that were based on best practice identified in the 2002 policy document by Our Lady's Hospital for Sick Children, Crumlin, entitled *Guidelines for good practice*, and on the 1999 national guidelines, *Children First* (Department of Health and Children, 1999). The first protocol was concerned with steps to be followed should a child show signs of anxiety during the interview process (see Appendix 8). The second protocol related to steps to be followed should a child show signs of illness during the interview process (see Appendix 9). The third protocol related to steps to be followed should a child disclose sensitive information during the interview process (see Appendix 10). If any child displayed signs of discomfort or distress during an interview, then the option of withdrawing from the interview would be immediately offered to them. The nurse manager on the ward would also be informed of the child's anxiety. Where there might be signs of fatigue, the remaining part of the data collection would be modified to conclude as rapidly as possible.

All the focus groups and individual interviews were conducted by a Registered Sick Children's Nurse (RSCN) who has over 15 years' experience nursing children and their families. Every effort was taken to ensure that the research did not interfere with the children's medical and nursing care. Interviews were scheduled in collaboration with the children to take place at a time and venue that suited them. The interviews were not held following an invasive procedure or when it might be perceived as inconvenient for the child (e.g. during visiting times, experiencing pain or wanting a rest).

The researcher approached all available children within the age category so that there was no bias to the selection criteria. In order to ensure that all children were offered access to the study, each unit was contacted by telephone on a daily basis to identify the number of children that met the age criteria. The researcher visited the units and prepared the child and family. Prior to the interview, the researcher spent time with the children to develop rapport and build trust. For example, time was given by the researcher to get to know things about the child unrelated to the hospital setting — things like the music they liked, what football team they supported, what pets if any they had at home, what was their favourite TV programme, what they liked about where they were growing up, their favourite foods. When the interview was complete, some children requested the researcher to play 'Connect 4' and card games, listen to music or chat.

On completion of each interview, the children were asked if they wanted to write down anything that was important. Many of the children's writings confirmed issues raised during the interview and was a method of validating the data gathered from the interviews. The researcher encouraged the children to explain their writings as a way of developing rapport and concluding the interview in a way that left the child comfortable about the interview process. The children's writings validated what they wished to say and placed emphasis on the issues pertinent to them. The writings also validated that the interpretations of what children were saying in their writings were not just interpreted by the 'adult' researcher, but have been interpreted in the children's final statements that concluded the interview.

All focus groups and individual interviews were tape-recorded and field notes were used to keep a systematic record of observations made during each interview. Research has found that children generally do not find tape-recording to be distracting (Amato and Ochiltree, 1987; Heary and Hennessy, 2002; Balen *et al*, 2001). All children were encouraged to participate in testing the equipment before each interview or focus group. There was little evidence to suggest that any of the children were unduly affected by the use of a tape-recorder and many contacted friends or parents afterwards, talking excitedly about having being interviewed and appeared to enjoy the special attention given to them during the process. The average length of an interview was 40-60 minutes. (One interview exceeded that time because the participant's hospitalisation was over an 8-week period and he wanted to spend the time discussing issues that were pertinent to his care.) In general, interviews varied in time depending on the experiences, age and cognitive ability of the child.

An initial pilot study helped to determine the reliability and validity of the tools and provided an opportunity for feedback from the children themselves. It also enhanced familiarity with the

interview guide, knowing how and to what extent issues needed to be clarified, and understanding what questions might be eliminated if it became necessary to shorten the discussion. The children's transcripts in the pilot phase were incorporated into the main study.

## Data analysis

The individual interviews and focus groups were transcribed verbatim as soon as possible on completion and the data analysed using the data analysis package QSR Nvivo 2 software. The tapes were listened to and the transcripts read on a number of occasions to gain a sense of the overall findings. The focus was on the collation of the concepts and categories into core categories. The data analysis package enabled the coding of the transcripts. It also facilitated the merging of the codes, which resulted from their constant comparison and the reading and re-reading of the transcripts throughout the analysis. It also used the respondents' own words where possible in the coding process, which is important for the participatory approach.

The next step was to confirm and examine the main categories identified. These were renamed on several occasions as they gathered more coding, which was a vital step in discovering the central categories that emerged from the data gathered. The literature was used to further the process of comparative analysis through seeking similarities and differences to the categories identified from the data gathered. A thorough read through the transcripts ensured that the analysis and the coding of themes and sub-themes accurately reflected what participants stated.

With focus groups, the group rather than the individual is the unit of analysis. The data are analysed for content, whereby the researcher is looking for particular patterns, themes, concerns or responses that are posed repeatedly by respondents in the focus groups (Bender and Ewbank, 1994). The individual interviews were similarly analysed for content. Then both sets of data were collated to provide a composite view. The size of the sample ( $n = 55$ ) was sufficient to permit valid conclusions to be drawn (Carey, 1994).

The children's quotations are reproduced throughout this report, with minimal editing to them in order to retain the flavour of the spoken word.

# 4 FINDINGS

## Children's experiences of hospitalisation

The experiences of children in hospital provide background for the discussion on children's participation in consultations and decision-making in relation to their healthcare. Most of the children seemed aware of the need for hospitalisation in order to receive treatment for their condition or illness. They appeared willing to endure the discomfort of the investigations and treatments in order to get better and return home to their everyday lives. However, they expressed a range of fears and anxieties about the hospitalisation and frequently used the term 'getting used to', which indicated significant adaptation on their part. The children used a variety of terms to describe their fears about the hospitalisation (see Table 2).

Table 2: Children's fears

Fear of being alone	Fear of dying
Fear of the unknown	Feeling sad
Fear of nurses' mistakes	Feeling worried
Fear of operations	Feeling scared
Fear of needles	Feeling terrified
Fear of incurable infection	Feeling embarrassed
Fear of procedures	

Similar fears and concerns were identified by Barnes *et al* (1990), who conducted a content analysis of 186 descriptive case studies of hospitalised children that spanned a 20-year period. 'Fear of the unknown' was the most frequently mentioned concern of the children, which indicates the importance of information and preparation. Some children spoke about the importance of 'feeling safe' in hospital, which indicates anxieties about the environment. As one boy aged 9 said: *'I don't actually mind staying in hospital as long as I know that I'm safe.'*

The children also spoke about the importance of their parent or parents, which was usually the mother staying with them throughout the day and sometimes at night because they disliked being alone. The children also relied on parents being there to help meet their needs. Research has found that parents are a familiar presence that provides reassurance and security for children and helps to normalise the hospital environment (Coyne, 2003). From the children's perspectives, the advantages of the hospitalisation included getting better, getting presents, making friends, playing with toys and attending school. Some children reported bringing in familiar objects from home to help them cope with the hospitalisation, like their own blanket or pillow, games, books and photographs of family. As one girl aged 9 said: *'Well, I'd say just bring stuff with you that you like, that would calm you down. Like if you have something that you can't sleep without, bring that with you. Just have stuff to calm you down and stuff to stop you crying.'*

The most common disadvantages of the hospitalisation cited by the children were losing contact with friends and siblings, missing home comforts and schooling, and losing freedom and privacy. The hospitalisation also generated many dislikes for the children (see Table 3).

Table 3: Children's dislikes

Being in pain	Lack of play equipment
Operations	Restricted play
Needles and blood tests	Being bored
Food in hospital	Restricted space
Crying babies	Lack of privacy
Being alone	Lack of showers
Noisy wards	Lack of parent accommodation
Doctors' examinations ('being poked')	Change/disruption
Long hospital stay	Older nurses
Waiting	Missing school
Taste of medicines	Theatre outfits
Uncomfortable beds	
People being sick	

The predominant dislikes for all the children were being in pain, operations and needles, being bored, and lack of play facilities. Nearly all the children stated that they disliked the pain associated with blood tests and needles. They disliked the food because it was fast food, greasy, lack of choice and was often cold. Many children found the ward environment too noisy (e.g. phones ringing, nurses talking, babies and children crying), which caused some to experience difficulty sleeping. Some children resented the lack of space, tiny rooms and consequently spoke about needing their own room, own space and more privacy. Most of the children spoke about the lack of play facilities for their age group and being bored. Thus family, friends and peer groups were important because they helped to keep the children occupied. As one boy aged 12 said: *'It's kinda got worse as you've got older like, because the rooms are quite tiny and there is not much you can do, and like there's not much in the place to do anyway, like years ago there used to be a pool room and we used all go down and sit in that, but now there's nothing.'*

Many of the older children reported that the play facilities were aimed at younger age groups and as such were 'babyish'. They had many suggestions as to how the facilities could be improved. The inadequate play facilities would have hindered children's attempts to keep occupied and therefore distract themselves from painful treatments. The range of fears expressed by the children, particularly fear of the unknown, indicates the importance of providing children with enough information so that their fears can be allayed. However, as discussed later, most of the children experienced difficulty gaining information and being heard in relation to their need for consultation.

## Children's experiences of consultation

### Receiving information

Most of the children spoke about the importance of having enough information so that they would know what to expect. The children reported receiving information from a variety of health professionals (nurses, student nurses, doctors, medical students, dietician, ambulance staff, ultrasound technician). It was predominantly the nurses and latterly the doctors who provided information, which was generally related to the children's condition and procedures. Receiving information appeared to be reassuring for many children rather than provoking anxiety. As one girl aged 13 said: *'They were very nice and they just explained it all and I felt kind of comfortable coming up here so I wasn't freaked out or anything.'*

The children with chronic conditions spoke about knowing what to expect through learning from experience due to frequent admissions. Other children appeared to gain information on hospitals by reading books, watching hospital soap operas and having pre-admission visits. Knowing what to expect and feeling prepared were frequently identified as needs, which indicates the importance of information and pre-admission visits. The children who had experienced pre-admission visits reported being less anxious because they knew what to expect. It was usually the nurses who explained the information and some used 'props' to help prepare the children for procedures. As one girl aged 10 said: *'Because you come in for a visit the day before you come in, they show you all the stuff and there's two dolls called Tara and Ben. And my Ma's name is Tara and my little sister's Da is Ben. They show you everything that they do, like they put cream on you and all. The girl from the playroom showed me the cream that they put on you and the thing that squeezes your arm to check your blood pressure and the thing that's put on your finger. It's better to come in before, to see what you are going to look forward to and what are the good points.'*

As can be seen from the above, the children valued the information they received from the nurses because it helped prepare them for procedures in hospital. Some children reported that doctors tried to impart information in simple words, which enhanced the children's understanding. It appeared that some doctors were better skilled than others at communicating with children, in that they tailored their information for the children's level of understanding. As one boy aged 14 said: *'He broke it down into English words, like he explained to my Mam in medical words, but then he explained it to me, like he explained what the words meant and all that to me.'*

The health professionals tended to involve both the parent (which was usually the mother) and the child when they imparted information. Some children did not expect to be included in the information-giving process and were quite pleased to be included. As one boy aged 14 said: *'Yeah, they did involve me because they talked to me a lot. I just thought I would have been in here and they would have just explained it to Mam, but like it was a regular thing that they were explaining to me and bringing me into all the conversations as well.'*

Only a few children reported that doctors involved them actively in consultations and these were generally children aged 13 and upwards. Similarly, research studies have found that children were more likely to be involved in consultations and decision-making if they were older (Alderson, 1990 and 1993; Deatrick, 1984).

### Asking questions and being listened to

Some of the children spoke about being asked questions by health professionals that were usually related to their symptoms. However, only a few children reported asking questions of the health professionals, who tended to be nurses. This did not indicate that the remaining children did not want to receive information; they provided several reasons that explained why they did not ask questions, which will be discussed later in this report. The children's questions were mainly in relation to meeting basic needs, whether procedures would be painful, length of stay and discharge date. By posing questions to the staff and parents, the children obtained information about their illness and what was planned for them during the hospitalisation. As one girl aged 9 said: *'Yeah, I'd be able to ask someone because well the nurses and the doctors are there for helping you, so don't be afraid to ask questions because they'll answer you and tell you what you want to know.'*

The children felt it was important to be listened to and, again, it was mainly nurses who appeared to listen to them. As one boy aged 14 said: *'They just are like really nice about it and they'd take your thing [temperature and blood pressure] and they'd be asking you are you alright and all, and saying like they were asking me are you nervous about tomorrow and they were giving me like reassurance that it wouldn't hurt at all.'*

It was evident from the children's accounts that those who were involved in the consultation process felt valued and pleased to be involved. When health professionals took the time to provide information in understandable terms, the children felt reassured and less anxious.

## Factors that enhanced the consultation process

There were four main factors that enhanced the consultation process for the children — age level; familiarity with the hospital and procedures; knowing the health professionals; and time.

### Familiarity with the hospital and procedures

The children with chronic illnesses spoke about becoming more involved in the consultation process over time. This is not a surprising finding since it is more likely that children will learn how to participate in the consultation process by repeated experiences and familiarity with the environment and health professionals. Similarly, repeated hospitalisations would enable children to develop relationships with health professionals over a long period of time as compared to children with short-term illnesses. It was only the oldest, chronically ill children who spoke positively about the consultation process and that they felt very involved. As one boy aged 18 said: *'Yeah, they've been involving me all the way, they've been coming and telling me what's going on, and they've been listening to me as well, like the medication, that I don't like it, I don't like the taste, I don't like the smell, and I tell them I don't want this and they would understand, so OK we'll change it to something different.'*

### Age level

Although some older children described being involved, only two of them reported situations where they felt able to query care and procedures. As one boy aged 18 said: *'I asked her, "What do you mean, probably be an injection?" and she said, "Oh yeah, you get an injection". So I said, "I don't like injections, I prefer a cannula", so she said "OK, we will look into that". So I went in and they*



*scanned my head. After a few minutes he came back and he was about to just inject, so I said, "Hey, hey, what are you doing ... I said no, I prefer a cannula" and he said, "Are you sure?" and I said, "Yeah, I don't like injections".*

Although this older child (aged 18) felt able to be assertive with his health professionals, he had to keep repeating his requests before he was taken seriously. Such experiences suggest that much younger children would require considerable courage to assert their right for inclusion and therefore may experience difficulties in having their voices heard. It indicates that age and maturity influence some health professionals' style of communication with children, which has been reported elsewhere (Runeson *et al*, 2001).

### Knowing the health professionals

Many of the children spoke positively about the health professionals as being kind people who helped care for them. The children appeared to know the names of some of the health professionals either because they had introduced themselves or they had discovered their names by looking at their name badges. They frequently distinguished health professionals by their dress code. They used positive terms to describe the nurses, such as nice, funny, kind and helpful, which indicated that they found them approachable. The children reported asking nurses more questions because they were more consistently present than the doctors and were also more approachable than doctors. As one boy aged 7 said: *'I'd probably ask the nurses because they'd be around more times than the doctor.'*

The children liked nurses who were friendly and attentive, and these characteristics appeared to lead to a more open relationship and better communication between children and nurses. Children also appreciated nurses who were friendly and willing to chat with them as they carried out their nursing care. Being asked personal questions about home and school indicated to some children that nurses wanted to get to know them as individuals. They appeared keen to know the nurses as people rather than health professionals since they listed approachability, kindness and warmth as the qualities they liked about nurses. Children found it easier to ask questions when the person they were in contact with was more familiar to them and afforded them time to seek information.

The relationship is illustrated in the following comment from a girl, aged 9: *'The nurse keeps coming in and out, but you see I wouldn't know which doctor to go to because it could be a doctor that doesn't know anything about the patient or it could be a doctor that knows everything about you, but I wouldn't know which was which. It's a lot easier to ask a nurse because a nurse keeps coming in to me and asks am I OK and how is your stomach and stuff, so I know that she knows about my thing, so I just ask her the questions.'*

Only the children with chronic illnesses reported knowing their doctors, which is understandable because of repeated hospitalisations and frequent contact with health professionals. Knowing the doctors made children feel more confident in their good intentions, thus providing reassurance. Knowing the doctors as people encouraged children to ask questions and be involved in the consultation. Children found it easier to ask them questions, as illustrated by the following comments: a girl of 13 said, *'He started telling me about himself, which got me more kind of like trusting to him that he's going to make the right decision'*, while another girl of 18 said, *'I kind of look forward to coming to my consultations because I know him very well and I know he's going to tell me the truth.'*

Knowing the doctors could also have the effect of making children feel confident that they were being informed of all the relevant information and thus being respected as people rather than patients. As one boy aged 18 said: *'It's nice having the same person again and again because you kind of build a relationship and you get to know them. I think it's good to build a relationship with the doctors and be open to each other, and when they come to you and just be friendly, because if you're friendly with them and be open to them and make jokes and stuff like that, that's when you get to really know what's going on with you.'*

Being able to have a 'normal' chat with a doctor implies consultation on an equal level rather than a formal doctor/client relationship, where the child occupies a subordinate position. Conversely,



children who were unable to establish relationships with health professionals for whatever reasons (e.g. lack of time and health professionals' attitudes) could be inhibited from active participation. The following comment from a girl aged 9 illustrates this: *'I'd probably be a little shy. I don't know him very well. If he was a friend and if I was to see him every day, I wouldn't be shy ... I sort of leave it to my parents.'*

As can be seen from the above, a trusting relationship strongly influenced the children's ability to participate actively in the consultation process. This implies that children with short-term acute illnesses may be more disadvantaged in the communication process because of lack of familiarity with doctors.

### Time

Having sufficient time with health professionals clearly enhanced the children's ability to participate because they had time to develop a relationship in which they felt comfortable asking questions. It also allowed time for discussion and time for clarification of information. Children need time to absorb information. But several children reported difficulty getting to know the health professionals (doctors and nurses) due to a lack of time, lack of frequent contact, many patients, busy workload and lack of continuity due to shift work. Consequently, some spoke about the importance of having the same nurses, so that they could get to know them over time. As one girl aged 13 said: *'I think it would be nice if you had the same nurse, like when that nurse is on because then you'd get to know one nurse really well. I've had a few different nurses, but I have got the same nurses as well and they're on a few times. I think it would be nice if you had the same nurse all the time.'*

## Parents' role in the consultation process

### Relying on parents as advocates

The children described using their parents as advocates, intermediaries and interpreters in the consultation process. A few children explained that they did not like asking questions because they might hear information that could cause them worry. One child made the point that health professionals should give you enough information so that you can prepare yourself, but not cause undue anxieties. Another child wanted his mother to be informed so that she could then 'filter' the information, so that he only heard the positive information. Thus he wanted his parent to shield him from any negative information that could potentially increase his anxieties.

There is evidence that some children cope with the stress of hospitalisation by using an 'information-limiting strategy', which can be quite effective in managing the stress of anticipated hospitalisation (Thompson, 1994). As one boy aged 10 said: *'No, I don't want to know bad things. I don't want to be told bad things because it might make me really sad and scared, so it's better that my mum only tells me the good things.'*

Many children described using their parents as advocates in the consultation process, in that they briefed their parents to seek information on their behalf or allowed parents to respond to health professionals on their behalf. They needed their parents or relatives to ask the questions because they were unable to obtain the necessary information. As one girl aged 13 said: *'I'd tell my aunt to tell her [the doctor] again today when she comes up. The thing about it is, I'm really anxious to know what it is and it's really hard for me to like get some sleep and deal with the pain as well, wondering like what's inside me, what's wrong with me. I just wish somebody would tell me that.'*

### Relying on parents as interpreters

Some children noted that health professionals tended to discuss issues with their parents and then the parents would explain to the child what was planned for them. It is not surprising, therefore, that many of the children reported receiving explanations and reassurance from their parents, mainly their mother who tended to be with them for large periods of the hospitalisation. As one boy aged 12 said: *'The doctor and my Mam would, well the doctor would explain it to my Mam first and then my Mam would explain it to me.'*

Most children were content to share the consultation with their parents so that parents could then help explain and clarify information received from the health professionals. Some children preferred to hear the information first-hand from their parents because they were better at explaining the information than the health professionals. Some children also wanted to share the consultation so that their parents could ask their questions, which were different from the children's questions. The children had observed that their parents tended to ask more future-orientated questions of the health professionals, in contrast to their own questions which would be more focused on the immediate situation.

These points are illustrated by the following comments. One boy aged 11 said, *'I'd rather me Mam and Dad because you'd understand them more than the doctors, because the doctors leave you without an answer.'* Another boy aged 12 said: *'Yeah, I think like if the doctors and nurses were to speak to us all together and then if you didn't understand something, your parents could like break the words down in an easier explanation when they've left.'*

Many children needed their parents to explain and interpret for them because they had difficulty understanding the medical terminology used by health professionals. Over half the children spoke about being reluctant to ask questions of health professionals because of difficulty understanding the terminology. The use of unusual or 'big' words precluded the children from contributing to the dialogue taking place during the consultation process, which has been reported before (Beresford and Sloper, 2003). As one boy aged 10 said: *'I let my mummy ask the questions and she tells me. I prefer them to talk to my mummy and my mummy can tell me. Sometimes I don't understand what they are talking about; they use big words so I don't ask because I don't remember the words sometimes.'*

There is a danger that some children may become accustomed to parents acting as their advocates in the communication process and thus fail to develop confidence in their own abilities to communicate. Continued dependence on parents as communication brokers may mean that these children lack an opportunity to develop participation skills. This is clearly illustrated by the following comment from a girl aged 18, who would be seen as capable of independent thought: *'I just feel stupid sometimes asking all these questions, but like now I realise that it's not, I'm asking the doctor more questions myself than having my Dad do it. I just always had my Dad do it. I was always shy.'*

It is evident from the above discussion that many children preferred their parents to be their advocates and/or interpreters in the communication process mainly due to difficulty in understanding the style of communication used by health professionals. This indicates that children may be forced to rely on their parents performing such roles out of necessity rather than out of choice.

### Parents constraining children's participation

While some children welcomed their parents' role in the communication process, others expressed unease with the constraining aspects of their parents' role. Some children reported that their parents hindered their involvement in consultations by certain actions, such as answering questions on their behalf, telling them to stay quiet and not supporting their attempts to gain information. Some parents answered questions that were meant for the child, thus not allowing the child to respond. As one boy aged 11 said: *'Yeah, like the doctors asking your mum "Does he feel sick or anything?" and your Mam is there saying, "Ah no" and you're like there saying, "Yeah, I do". But you're afraid to say it because your Mam is just "No, you aren't, you don't feel sick at all" and you're like, "Yeah I do".'*

Similarly, children in the study by Beresford and Sloper (2003) described how their parents dominated consultations, making it difficult for them to contribute to the interaction. Some children also described trying to ask questions of health professionals and being told to stay quiet by the parent. As one boy aged 13 said: *'Like, when my mam was talking to the doctor, I said what's this all about and she just kept on talking and nobody listened to me and I kept saying it loads of times and she said "Shhhh, I'm talking".'*

Other children recounted occasions when they asked parents for information and it was withheld from them for whatever reason, which caused them to worry. The children spoke about being worried when parents and health professionals were talking for a long time and yet they only received minimal information afterwards. They expressed unease at the perceived disparity between how much information they had been given by parents and what their parents had been told. This is clearly illustrated in the following comment from a boy aged 11: *'They just tell you. They'd use big words and I wouldn't be able to understand them and then I'd ask my father what did they mean and he wouldn't really tell me. My father wouldn't tell me really half of it. I think it might be bad news then or something like that because if the doctor is talking for nearly 15 minutes or so and your father only tells you a couple of seconds, then there has to be more in the story. It makes you kinda worried.'*

The children's description of the communication process revealed that they subjected the parents-professional interactions to considerable scrutiny and were highly conscious of any disparities in the amount of information they received from parents. Clearly, parents frequently played a key role in the communication process, which facilitated children's need for information and allowed them to participate in some consultations. At the same time, the role of parents could be problematic in that they could obstruct children's attempts to participate in the consultation process and limit their access to information. Similarly, in the study by Young *et al* (2003), the children (n = 13) identified elements of their parents' role that both facilitated and constrained their communication with health professionals.

## Children's experiences of non-consultation

It seemed that the children experienced considerable difficulties in having their voices heard through no fault of their own. The lack of involvement in the communication process had a profoundly negative effect on children. The children used a wide variety of terms to describe their feelings about non-involvement, including disappointed, sad, confused, angry, rotten, worried, misled, shocked, betrayed, lonely and ignored. The children obviously wanted to be involved in the consultation process and the range and depth of feelings clearly illustrate the impact of non-involvement on many children. Instead of being valued as an active participant with an important contribution to make to the communication process, children felt ignored and rejected. As one boy aged 13 said: *'Yeah, I feel real disappointed like, yeah, just disappointed because I feel I'm kind of rejected in a way.'*

The children described situations where they felt excluded from the communication process, such as when health professionals communicated with parents only or where the children were involved only in a tokenistic way. They experienced difficulty obtaining information and difficulty being heard. The resultant lack of information meant that many had to endure procedures without adequate preparation. All of these issues will now be discussed in turn.

### Communicating with parents rather than the child

As seen earlier, children were generally happy to share consultations with parents because their parents acted as advocates and interpreters in the communication process. They relied on parents to explain the information, mainly due to difficulty in understanding what the health professionals were saying. Although a few children appeared happy for health professionals to direct the communication to their parents because of fear of hearing bad news, most other children disliked being excluded and wanted to be included in the consultation process. It seemed that consultations were largely carried out between parents and health professionals, which tended to leave children without a voice.

As one boy aged 13 said: *'When the nurses are talking to your mum or dad or the doctor, you're like why am I stuck in the middle of this. I'm the one sick, why aren't they listening to me. Why are they talking to my mum and dad, why aren't they talking to me? I'm the one that's sick, they should be asking me the questions.'*

Other children described situations where they were involved in a 'tokenistic' consultation with health professionals. This occurred when health professionals, mainly doctors, would ask one or

two specific questions to the child and thereafter conduct most of the consultation with the parents. The following comments illustrate this. One girl aged 9 said: *'Yeah, they talk to Mummy a lot. They like ask me my age, but they never really talk to me, they never tell me like, as I said, most of them **don't** tell me what they are going to do and how long it's going to take and when I'm going to see them again.'* Similarly, a boy aged 11 said: *'Well, they talked more to my parents because they'd just come into the room and say "Hello, David [pseudonym], how are you?" and then they just start talking to my father and then just say goodbye.'*

When health professionals directed conversations to parents only, children felt unimportant and uncertain, therefore marginalised. It made some children feel that their parents were having the treatment rather than them. Being excluded caused upset and worry because they lacked information on what was happening to them. As one girl aged 9 said: *'It felt like it was her [child's mother] having the operation and not me. It's not her that's having the operation and I'd like to know a little bit more about it.'*

Some children resorted to trying to overhear what the health professionals were saying to their parents. Other children described situations where doctors took their parents elsewhere to talk or they actually asked the child to leave, thus totally excluding the child from the communication process. Many children spoke about asking parents to relay the information that they wanted to hear first-hand. As one boy aged 11 said: *'I'd like him [the doctor] to come in and talk to me and tell me everything that's going to happen because sometimes he tells me to go out of the room or something when he's talking.'* Again, a girl aged 17 said: *'They just tell you, they don't explain everything. The first time I was getting PFT, I didn't know what it was. I hadn't got a clue what it was. He didn't say it when I was there. He said it to Mam behind the curtains. I was upset because I don't know what it's for or anything like that.'*

When health professionals chose to talk to parents alone, this caused the children to assume that the information must be very serious and that something 'bad' was going to happen to them. This had the effect of making them feel scared and apprehensive. As one girl aged 13 said: *'He kept having to talk to Mam on her own and I was getting really worried like because if they want to speak to Mam about something, either it's because they need to do something really bad or something's bad happening. I need to know because otherwise I'm going to be sitting there panicking, going all paranoid thinking about the worst scenario and everything.'*

### **Having a right to be involved**

Conducting discussions with parents or involving children in a tokenistic fashion were unsatisfactory options for many children. The children wanted the health professionals to explain the planned treatment to them directly because it would help them feel involved and more courageous. Most of the children spoke about having a right to be involved in consultations because it concerned them directly. They had a right to hear the information because they were the people who were experiencing the illness. As one girl aged 9 said: *'I'd like them to explain it more because it makes the children feel braver and more involved.'* A boy aged 12 put it more simply: *'Because if it's about me, then I should be part of it.'*

Some children made the point that sometimes parents do not always provide the correct information on the child's behalf; therefore children should be allowed the opportunity to volunteer their own information. As one boy aged 13 said: *'I think the children should get the opportunity to tell what they think it is and not just what their parents or the doctors think it is.'*

These statements from the children clearly illustrate that they wanted to be involved in discussing issues concerning their care and treatment. They felt that they had a right to participate because it concerned them directly. It was important that they were allowed to participate for two reasons: firstly, parents could provide incorrect information and, secondly, being allowed to participate would help prepare them for what to expect. They wanted to be respected as having opinions about themselves and their bodies, and consequently wanted health professionals to consult with them directly and give them opportunities to hear information and also provide information.

### Difficulty obtaining information

All the children spoke about needing information so that they would know what to expect while in hospital. They spoke about needing information on such issues as their illness, procedures, possible risks associated with procedures, outcome of procedures, medications, basic needs and length of stay. The children, however, reported a general lack of information on many aspects of their treatment and hospitalisation. One boy aged 9 said, *'They didn't really explain much'*, while another boy aged 12 said, *'This morning they were talking to my parents and then he [the doctor] was talking to the nurse, and the nurse was writing it down and I was kinda getting lost like, but nobody would explain it to me. I had to ask myself. He wouldn't explain unless you asked.'*

One child aged 17 recalled a situation where he asked the doctor to repeat his explanation and the doctor subsequently apologised. This child may have been capable of assertiveness, but such action would have posed considerable challenges for shy and reserved children. Some children spoke about feeling forced to ask questions and demanding explanations because of being excluded from the communication process. Even then, certain doctors could ignore their queries. As one girl aged 9 said: *'One time I was going to the doctor and I wanted to ask him something about my ear. He was talking to my mammy and then when he was finished I asked a question again when we were leaving and he never answered me. It made me feel that you don't want me to be asking that question, you don't want me to know what that is.'*

Although the children had unmet informational needs, many of them (35 out of 55) spoke about being afraid to ask questions of health professionals (mainly doctors) for fear of inconveniencing or annoying them because they were busy, important, intimidating people. Asking questions could be seen as wasting their time, therefore children were constrained from seeking information. As one boy aged 13 said, *'I didn't know as much because I was afraid to ask questions. I'd say he'd just probably be too busy and I might distract him'*, while another boy aged 9 put it more succinctly — *'I'd get into big trouble.'*

Causing annoyance to health professionals could get children 'into trouble', the implication being that they could be punished for improper behaviour. Children, especially those in the younger age group, ascribed very high status to their doctors and this was reflected in a sense of their own inferiority. This was an issue particularly for those children who were shy or lacking in confidence, as the following comments illustrate. One girl aged 7 said, *'I was a bit scared to tell them. I think they'd start to laugh at me'*. Another girl aged 15 said, *'Yeah, and sometimes I don't understand what it means and I just leave it. I'd be afraid to ask what it meant. I'd just feel stupid'*.

Even older children were afraid to ask questions because they found the doctor could be intimidating or react angrily to repeated questioning. One girl aged 17 said, *'I wouldn't have the guts to say. I don't know, he comes across as a very intimidating man'*. One boy aged 13 said, *'If you were asking loads of questions, they'd get annoyed. "You weren't listening, you should have listened". They'd keep getting annoyed if you keep asking them questions, so then you just stop and stop asking them questions'*.

The attitude of health professionals towards questions from children was observed by the researcher during data collection. On one occasion, a doctor replied in an angry voice in response to a child's question, *'I don't have time for this now'*. Similarly, parents reported finding health professionals difficult to approach because they appeared busy and parents feared a negative response to questions (Skipper and Leonard, 1986). Some children noted that doctors were busy people and therefore children should wait for an opportunity to talk with them. Yet children described several situations where they lacked opportunities to ask questions because of a lack of time with the health professionals. As one boy aged 11 said, *'Nearly all the time the doctors are in a rush'*. Another boy aged 17 said, *'The last time Dr. Kerry [pseudonym] came in to me, he stuck his head in the door. "How are you doing? OK, bye." That's it and he walked off and I haven't seen him since. That was on Thursday'*.

Popping one's head around a door is non-verbal behaviour that conveys the distinct impression of being too busy to spend time and represents tokenistic consultation. The following conversation



between three boys, aged 11-13, in one focus group illustrates the problems that children faced with obtaining information and being involved:

*'It's like don't interfere when adults are talking.'*

*'Yeah, this is adult conversation, don't get in, don't get all hurt, and don't interrupt.'*

*'Yeah, I will tell you later.'*

*'But then they don't and then you are afraid to ask again because you think they're going to say, they're going to give out, "You asked that question earlier on".'*

*'It's like don't be rude and interrupt us and all that.'*

*'When you don't realise that you are actually rude, you just want to know what's going on.'*

Some children described waiting for the health professional to provide information and learning that waiting was easier than asking questions because it did not cause annoyance. As one boy aged 11 said: *'If you keep being on them and asking all these questions, they are going to get annoyed and they'll tell you anything, so you shouldn't really ask them that much, ask them a few times, that's it. Yeah, because they have to do their job and you just have to wait until they come to you and if you wait they're much nicer to you.'*

This comment demonstrates that children have to assess the appropriate time when to ask questions of adults in order to achieve a favourable response. This sounds quite a demanding task for any child, but even more difficult for sick children. In light of the difficulties children experienced with asking questions, it is not surprising that many children did not bother to ask questions and consequently described just accepting and going along with whatever was planned for them. As one boy aged 11 said: *'I'd just be a bit nervous. You can't exactly tell a doctor that I want this or will you do this. I just go along with what they're doing or whatever.'*

In summary, the comments recorded indicate that, across a broad range of age groups, the children were reluctant to ask questions, even though they wanted to be involved in the consultation process. Children needed sufficient time with health professionals so that they could ask their questions, get clarification and have time to digest the information. Difficulty in obtaining information left many children feeling anxious and unprepared for procedures and treatments. The fact that children perceived health professionals as busy, important, intimidating people indicates that they would need considerable courage in order to ask questions of health professionals. Therefore, shy or reserved children would be very reluctant to demand involvement in the communication process. Even when children had the courage to ask questions, health professionals could ignore their queries. The comments about fear of wasting health professionals' time conveys the impression that some children may view their needs as unimportant in relation to the needs of the health professionals. All of these issues clearly illustrate the difficulties children experienced in obtaining information and clarifying it with the health professionals.

### **Difficulty being heard**

Together with difficulty obtaining information, children also experienced difficulty being heard by health professionals. Many children (32 out of 55) described situations where they provided information on themselves and their symptoms, but were not listened to and their views were not being taken seriously. For example, some spoke about providing health professionals with specific information about their allergies, the medicines that worked for them and their preferences with regard to blood tests and cannulation techniques. Some children seemed aware of communication breakdowns because they spoke about doctors lacking knowledge of their medical history, giving different opinions or being uncertain, and a lack of correspondence or exchange between medical teams. The children found it frustrating when health professionals did not take account of their views or respect their knowledge.

One boy aged 12 reported: *'The doctors should listen more. I'm not saying that they don't listen, I'm saying that children should have a say. Like the other day, the doctor put me on big tablets that I couldn't take. It would be good if he asked and then they had to change the tablets into medicine, but it would be good if he asked me was I able to take the tablets, instead of him telling me to take the tablets which I couldn't take. He could have told me, he could have asked me a question, it would have saved time, "Can you take them?", except he didn't.'*

Another child reported feeling frustrated because he had informed health professionals of an allergy to a particular medicine on a number of occasions, but still doctors continued to prescribe the medication, which implied that they were not listening and respecting his knowledge. One child made the insightful comment that sick children have difficulty making their voices heard and health professionals need to be good listeners. Some children spoke about their contributions not being taken seriously or being paid 'lip service', because health professionals viewed them as cognitively impaired due to age.

As one boy aged 13 said: *'I'd say I don't know what you are really talking about there and as soon as I said the first bit of it, he'd [the doctor] just start talking over me and we were like "Will you listen to me or something!" They don't listen to you because you're too young, because they think you don't know what you're talking about.'*

One child described a situation where she had to reply to the same questions posed by a variety of personnel over a short period of time. This could have the effect of making the child feel that her account was being questioned or disbelieved. Another child reported feeling very angry and upset when a doctor made a comment about her complaining unnecessarily, which implied that she was pretending or 'wasting' his time when her symptoms were genuine. Being labelled as 'difficult' understandably caused distress. As one girl aged 14 said: *'One time when I was sick and I was in one of the rooms and the doctor told my Mam that every morning I'd wake up saying what will I complain of next. That wasn't the case.'*

Other children recounted situations where their accounts of symptoms were disbelieved, therefore not taken seriously. Many of the children's comments about being disbelieved were in relation to experiencing pain. As one girl aged 13 said: *'Yeah, you feel like you are ignored sometimes, laughed at by everyone, like you're asking the nurse a question and she was there, she was like, "I'm with someone else", and you feel like you're being ignored with your pain and you feel no-one is listening to you.'*

The children's accounts of being ignored or disbelieved imply a lack of recognition and respect for their views. The feeling of being judged and disbelieved appeared to cause stress and potentially undermined the children's confidence. Many of the children talked about suffering pain at some point in their hospitalisation, which caused upset, distress, suffering and restricted movement. Some children's pain experience was not helped because of the difficulty they experienced in receiving attention from nurses and doctors for their pain. Byrne *et al* (2001) found that nurses tried to prevent children from displaying pain behaviour and when it did occur, they construed pain as unreal, unwarranted or not deserving of help. Children complained about having to wait for medication for pain relief and having to 'shout' for painkillers.

One boy aged 18 recalled: *'Yes, like tonight I was worried. I can't move and can't get up and open the door, like what if I was so much in pain I can't handle it, what is going to happen next. I go stiff, I can't move, I can't get off the bed, and if there is no-one in there, then I won't get any help for a while. I think those buzzers are really important.'*

There was a request by many children to have buzzers installed so that they could easily obtain attention from nurses and consequently feel more 'safe'. Several children spoke about the difficulty in contacting nurses during the night and of feeling scared that they might deteriorate and nobody would notice. Some children spoke about asking for help and their requests going unheard, which caused frustration and annoyance. Other children reported that nurses spent too much time chatting to other nurses and ignoring the children. Other children, however, excused the nurses' behaviour because they felt they were very busy people with many patients and were therefore unable to respond to individual children's requests for help. As one boy aged 7 said: *'Because sometimes they have work to do and sometimes they have business with someone else and you don't want to disturb them. Probably I'd just wait or do it yourself.'*

Other children reported instances where nurses agreed to help, but then appeared to forget their requests. This indicates that children who are shy and reserved would need considerable confidence to call a nurse for help.

## Enduring procedures without adequate preparation

The children had a clear need for information, but unfortunately many reported that health professionals tended to 'do things' to them with very brief, or no, explanations. One boy aged 11 described the following: *'I was a bit nervous because I didn't know what was going to happen to me or anything. Well, I just thought they were talking about what they were going to do, but I didn't really know what they were talking about exactly. Sometimes when you go down, they have this tray of knives and everything and you think, "Oh my god, what are they going to do, are they going to cut me up or what?" So if the doctor doesn't describe it to you, you don't really know what's going to happen.'*

Some children spoke about trying to gain information themselves, but then being rushed by health professionals to undergo a particular procedure. They needed adequate time to digest the information and prepare themselves. As one girl aged 9 said: *'Let the children know what they [health professionals] are doing and what they [the children] are going in for, and not to know at the last minute, so they can think it over what they are having done to themselves. You can't even think in an operation, you're having anaesthetic to put you to sleep, you're sleeping, you're not thinking, you don't know, you don't think it over.'* Again, a boy aged 9 said: *'I got this book about what it feels like, but when I started to read it they came in and they started to put it down [nasogastric tube] so I didn't get any time to read what it would be like.'*

At the same time, many children spoke about the lack of choice with regard to procedures or medications. Only a few children (6 out of 55) described being given choices with regard to medications, blood pressure monitoring and method of anaesthesia. The children were aware that there was a ward routine (e.g. sleeping, waking, eating schedule) and they had to adhere to it. As one girl aged 11 said: *'Well, they should tell you do you think it would be better if we do this or that or something like that, instead of just saying that we're going to do this the next time and they don't tell you that they could do another thing.'*

Some children described having to endure blood tests and cannulations without the necessary preparatory cream (called EMLA and containing a local anaesthetic) because the health professional chose not to use it. The following conversation between a boy and girl, both aged 17, describes such a situation:

Girl: *'Some of them would come around and wouldn't put cream on and ...'*

Boy: *'Stab you in the hand with the needle.'*

Girl: *'Stab you and you'd be sore and be bruised. I'll never get used to blood tests, I hate them, yeah, I hate them.'*

Boy: *'Actually getting bloods done hurts more than getting a cannula in.'*

Girl: *'It's just because you're poking around for the blood.'*

The children described their physiological feelings of pain during blood tests and cannulation as poking, stabbing and stinging, and their psychological feelings as worry, fear, anxiousness, nervousness and feeling rotten. Although many children were aware of the benefits of EMLA cream, some actually also stated that they would not be able to ask for the spray or cream, even though it makes the procedure less painful. One boy aged 13 said: *'Well, I was shocked because I thought they would have told me, and like I'm real bad for getting cannulas in, so I always ask them for the cream, you know the cream. Yeah, but they never gave it to me, they never gave it to me then. I didn't want to bother the nurse.'*

As demonstrated earlier, many children lacked information and were unprepared for procedures because of a lack of time with health professionals (to ask questions, clarify things, etc). The time factor is often used as an excuse for not preparing children adequately for procedures. Taking the time to provide children with sufficient information to feel prepared will take time initially, but will save time in the long term because children will be more cooperative. Previous studies show that children need preparation (Visintainer and Wolfer, 1975; Alderson, 1990). The findings from this study show that the children appreciated staff who were kind and who took the time to explain procedures to them. Enduring procedures without adequate information and preparation is a violation of children's right to be prepared appropriately and adequately. It could also be seen as abusive practice because health professionals are aware of the distress that blood tests cause to



children without adequate preparation. Rushing children to undergo procedures indicates a lack of consideration of children's needs. The need of health professionals to 'get the job done' appears to have priority over children's need for adequate preparation. Although children were aware of what they needed, they found it difficult to be heard by health professionals, with the result that they just did not 'bother'. This implies that, with repeated experiences such as these, children may become socialised into passive obedience, which is antithetical to exerting their autonomy.

## Factors that inhibited the consultation process

As can be seen from the preceding discussion, there were numerous factors that inhibited the consultation process for the children. These can be summarised into 3 areas, with most of the factors relating to the behaviour and attitudes of health professionals (*see Table 4*).

**Table 4: Factors that inhibit children's involvement in the consultation process**

Not knowing health professionals Fear of causing 'trouble' by asking questions Doctors viewed as busy, important people Lack of time with health professionals Duration of consultation Being ignored Being disbelieved Difficulty contacting health professionals Health professionals not listening Difficulty understanding medical terminology Forgetting questions because of delay	<b>Health professionals</b>
Parents hindering child's participation	<b>Parents</b>
Unable to participate because of illness Not wanting to hear bad news Shy personality	<b>Children</b>

The data indicated that parents appeared to play a key role in the consultation process and could either facilitate or constrain children's participation. The other key factor that hampered children's participation in consultations and decisions were health professionals' attitudes and behaviour. Children's views and opinions were not given the due respect they deserved. Some health professionals appeared to lack communication skills and did not adapt explanations for children's understanding. Most of the discussions/consultations appear to have occurred between parents and health professionals, which excluded the children from participation. The children did not report instances where parents demanded of health professionals that the child be included in the discussions, but that is not to say that this did not occur. The children did recount instances where parents constrained them from participation, which indicates that parents may have an influence on health professionals' behaviour.

Notwithstanding this point, what was clear was that health professionals' behaviour did not facilitate or encourage children's participation in consultations. Furthermore, there were many examples where health professionals actively obstructed children's participation and appeared to hold negative views on their competence to participate. Children appeared to occupy a marginal subordinate position relative to health professionals' powerful status in the interaction process.

## Views on decision-making process

### Difference between 'small' and 'serious' decisions

When the issue of decision-making was explored with the children, they tended to categorise decisions into 'small' and 'serious' decisions. Some children made the point that they could be

involved in making 'small' decisions, such as decisions related to everyday events, diet and medications, but that they would leave the 'serious' decisions (e.g. operations) to their parents and health professionals. As one girl aged 13 said: *'Like, small, if they were to ask you "Do you want tablets or medicine?", yeah, of course, you can make those decisions. It's your body, you should decide what you want to do.'* Similarly, another girl aged 10 said: *'Small and big [decisions]. If you wanted medicine, like if you're only having a little operation and a cut gets infected, that would only be little ... and big would be like an operation that was life-threatening.'*

In relation to the decision about hospitalisation, the children generally described reporting being unwell to their mother, their mother then phoned the relevant doctor and consequently the child was admitted to hospital. Most of the children said that the doctors made the decision of hospitalisation and that they went along with that decision because they wanted to get better. Only one child, aged 13, reported that her parent tried to involve her in the decision to be admitted to hospital. She said: *'Well, my Mum said is it really painful and I was just like, I was in loads of pain so I was like yeah, it's really painful. She goes do you want to, we can go to the hospital now and it might be something so simple that they won't have to even look at you without knowing, so we can just go in and just make sure you're OK and I was like yeah, because I didn't want the pain to go on because it was actually so painful. I couldn't explain it, I thought I was dying, so she did consult me and I did agree with it because I didn't want to go on with the pain.'*

### Leaving decisions to doctors and/or parents

Nearly half the children (n = 23) provided several reasons why they would prefer to leave the 'serious' decisions to health professionals and/or their parents. These reasons included 'doctor knows best', doctor is the expert, doctor is more skilled and trained, would refuse treatment if worried, and would say no if decision involved painful treatment.

As one girl aged 13 said: *'Probably yeah, because knowing me I'd be afraid of the pain, so I would tell them not to do it, but it would be of benefit to do it so it would be best for someone else to make the decision for me because I would probably end up in an awful lot of pain.'*

One child felt that doctors should make the decision because they know best, but also because children may not want the treatment because it could be painful. At the same time, he acknowledged that one might have to endure painful treatment for long-term gain, which is quite sophisticated reasoning. This challenges the notion that young children are not mature enough to choose present pain in order to achieve future benefit. This young boy, aged 13, described his feelings: *'I wouldn't really like them to do it [insert nasogastric tube], but they kinda have to do it because it's helping and they have to help you really. It [the decision] should be their's [the doctors], but sometimes you might not want it, but sometimes they have to do what's kinda bad, sometimes they have to do what's bad ... it should be their decision really. Sometimes you have to do something cruel just to actually do something nice.'*

Similarly, children spoke about leaving decisions to their parents because they know best, children are used to their parents making the decisions and children may not know what to do due to cognitive immaturity. Other children spoke about needing parents and health professionals to make the decisions because of a lack of confidence in their own abilities. One boy aged 9 said simply, *'Always leave them up to my mum'*, while a girl aged 12 said, *'I think I would leave it to my mum and dad ... like kids are just too young to understand what's right and what's wrong, like about medical situations they should just leave it up to your parents and doctors until you get old enough where you can make those decisions.'*

### Sharing decisions with parents and health professionals

Some children felt that decision-making should be a shared process in which the key people — the child, parent and health professional — should all be involved. One boy aged 13 said, *'Well, I'm really fine with the operation and I think it should really be everybody's decision. Everybody should agree on it really.'* A girl aged 12 agreed with this comment: *'Everyone should be included.'*

This position is supported by the British Medical Association (2001), which states that shared decision-making is the preferred option in most instances. Its view is that it is never acceptable to

exclude children from participating in decisions on matters of healthcare that concern them, but that parents and health professionals should be involved in the decision-making process also. Children need support and guidance, and should not be left to take decisions alone since this could be an onerous responsibility.

### Wanting to take 'serious' decisions

Although some children appeared content to leave the serious decisions to health professionals and parents, other children wanted that responsibility. Some children spoke about having the right to make some decisions and wanting to be the person who had the final say in decisions because they involved their bodies. These children were aged from 7 to 18 years.

The following comments illustrate the point. One boy aged 7 said: *'I think it should be my decision [about hospitalisation].'* A girl aged 9 said: *'I think it's my decision. I never heard anyone saying do you want me to do this or not, and it's not their decision, it's not their bodies they are doing it on, it's mine and other children's, that maybe we don't want it changed.'* Again, a boy aged 18 said: *'Yeah, I think I can make my own decisions and probably sign my own consent form when going for the biopsies. I think that I do have rights to make some decisions.'*

One boy, aged 12, spoke about making the decision to stay longer in hospital and of the doctor being surprised at his decision, but nonetheless respecting it: *'No, I came back a few days after and I said I'm not feeling well, I'm not going home again early and I stayed in for three weeks the last time. I'm not going home until I feel I want to go home and then he said OK. He got kind of surprised and looked and I said, "I'm going home when I feel like going home, alright!"'*

### Factors influencing decision-making process for children

As seen from the above, some children spoke about leaving decisions to parents and health professionals, while others wanted to take decisions for themselves. There were also other children who spoke about their participation in decisions being influenced by factors such as age, personality and competence, as well as by parents/health professionals' attitudes, preparedness and support. For example, some children felt that they should be involved in the decision-making process when they were older. When asked what would be an appropriate age, they provided a range of responses, ranging from 9 to 18 years of age. At the same time, some children noted that it depended on the individual, which implied that age was not the deciding factor.

The range of ages supplied indicates that the children did not see decision-making as occurring at a set age or set point in their lives; rather, it was an evolving process dependent on individual factors. The fact that decision-making could be a gradual process is illustrated by this comment from a girl, aged 18: *'Well, I don't know, I don't like saying once you're 16 and once you're 18 you automatically get all this stuff. I mean, I think it should always be not just once it happens, it's just when you're 13 or when you're 16. It is a gradual thing, it's not like it's a fixed, cut-off point.'*

One child, a girl aged 13, felt that it was the child's responsibility to inform others when he or she has decided to take on the responsibility for decision-making: *'Probably around 18, maybe not, it depends on their own self. But I would say around 18 they're like old enough to be going through life to be part of that. It's up to you if you feel you're ready, then you're ready and just tell other people.'*

It could also be the child's responsibility to prove to parents and health professionals that they were capable of taking on responsibility for decisions and their care. Children may need to ascertain parents' readiness to accept their child's need for participation in decisions. As one girl aged 14 said: *'I'd have to take time to see, well, is my Mam and Dad ready to hear that I'm old enough to listen to my own decisions and to know the responsibility of my diet and take more responsibility, than having my Mam to do it all.'*

These statements indicate that participation is not a simple matter that occurs overnight; rather, it can involve a delicate negotiation process between parents and children. Another child made the point that health professionals need to assess the child's maturity and ability to understand before they can be included in taking serious decisions. Similarly, nurses in a study conducted by Miller (2001) listed knowing the patient and the context as influencing factors in their facilitation of children's decision-making.

A boy aged 18 commented: *'Yeah, if you see the reaction in the way the person is, if they're mature enough to understand what's going on and they're accepting, and they know what's going on and then their reaction to what's going on is good and you think this is a person you can talk to and listen to.'* This indicates that doctors need to have a relationship with children in order to judge their competence over time. Thus, involvement in decision-making is not a single event, but rather a process that is dependent on the patient-provider relationship, as noted in a study by the British Medical Association (2001).

Another child, a girl aged 13, made the point that children need practice and help at being independent and taking decisions. She was encouraged to make choices and be involved in decisions by her parents and as a result feels more confident in taking decisions: *'Well, I definitely think there's an age that people [can make decisions] like teenagers ... well, it depends on what type of person they are, if they're kind of shy and childish, I'm not slanging anybody, a childish kind of person, they will need help with deciding things because then it's kind of like independent, and probably they haven't had as much time making decisions for themselves. But I'm not one of those people. I've been given decisions all my life and my parents told me that it's my choice to make them, but if I needed any help they'd be like there for me, which was kind of nice because I thought like I was in control of my life, but yet my parents were still beside me, making sure I was OK all the time. So I definitely think that there definitely should be questions asked to children if like they're the type of people who answer their own questions and make their own decisions in life.'*

Similarly, Gabe *et al* (2004) noted that the extent to which children are encouraged by their parents to take responsibility for decision-making (in the home) would influence the children's willingness to take an active part in the consultation and their subsequent compliance with whatever is decided.

The above discussion indicates that as well as encouragement to participate, children also need support and guidance from their parents and health professionals. Indeed, some children reported that with their parents' help, they could be involved in the consultation process and in the making of decisions. As one girl aged 9 said: *'Yeah, but with their parents to help them maybe. Some of them might not be that intelligent to know what they really should do with their lives, to make that happen in their lives or not.'*

It could be argued that when children are not given the opportunity to participate and not allowed to practice making decisions, they are prevented from developing competence in their own abilities. Some of the data supports this notion because one older child, a girl aged 18, who ordinarily would be seen as capable of independent decision-making, spoke about being reluctant to make decisions because her father usually made all the decisions and she lacked confidence in her abilities: *'I always like the decision to be made by my doctor or my dad. I don't know, I guess it's just I don't feel confident enough to make my own decisions. I just don't.'*

In Deatrick's (1984) research with chronically disabled adolescents ( $n = 24$ ) on decisions about orthopaedic surgery, the children experienced difficulties with their involvement in the decision-making process. They reported fears and concerns about the responsibility for decision-making due to difficulty interpreting the varying opinions of doctors and to difficulty handling parents' spoken or unspoken desires. Consequently, Deatrick strongly recommended that children's participation in the decision-making process should be supported by information and guidance from parents and health professionals. Deatrick's findings correlate with those of the present study, in that children spoke about the need for support and guidance from parents primarily and then from health professionals.

### **Excluding the child from decision-making**

Some children felt that the health professionals had made the decisions beforehand and that they, the children, were usually presented with a *fait accompli*. The following accounts indicate that children were not involved in decisions and most of them knew that the health professionals had already made the decisions and that they just had to accept this.

One girl aged 17 put it simply: *'They just make the decisions and you have to go by them.'* A boy aged 18 expanded on this: *'I think decisions are made most of the time before they come to me, like*

*the medicine and everything, like all the scanning and everything, they have already decided what to do before they come to me and ask me. But like the way, I might be starting another medicine on Monday, they have already probably decided that I'm going to start another medicine.'*

One child, a girl aged 13, felt that doctors generally do not see children as capable of making decisions and as such do not involve them: *'Well, I know that a lot of doctors don't actually listen to the children because they actually don't think they're responsible to make their own decisions.'*

Some children felt annoyed that they were excluded from the decision-making process and felt that they had a valuable contribution to make. As one boy aged 12 said: *'I think I know my own asthma. I could say like, I might know if I'm going to get better or anything, so if they [the doctors] say to you "Oh, you have to go to hospital", you might think, I mightn't need to go to hospital, like this has happened loads of times and I felt fine a few hours later. They're the ones making the decisions and they don't give you a say.'*

Others spoke about being asked about hospital services and then no action being taken. As one girl aged 17 said: *'They've been asked before. One actually came in and said "What would ye like in your playroom?" about two years ago, and that stuff never showed up. Like we were sat down and asked what we actually wanted and we said a few jigsaws, puzzles, even a little shelf for drawing books or whatever, books that are actually readable not like kids books.'*

The involvement of children in a decision-making process without follow-up or feedback has been described as tokenism (Treseder, 1997). The lack of follow-up could discourage children from participating and offering suggestions for improvement.

# 5 DISCUSSION AND CONCLUSIONS

## Children's experiences of being in hospital

The advantages and disadvantages of hospitalisation cited by the children in this study were quite consistent with those reported in previous research (Gusella *et al*, 1998; Sartain *et al*, 2000; Carney *et al*, 2003; Coyne, 2003; Battrick and Glasper, 2004).

The most common advantages cited by the children included getting better, getting presents, making friends, playing with toys and attending school. The children reported keeping occupied through various means, such as playing board games, using computer games, watching television and videos, reading magazines and listening to music. The issue that appeared to be of key significance for all the children, irrespective of age, was friendships and relationships with peer groups, which has been reported elsewhere (La Greca *et al*, 1995; Gusella *et al*, 1998). Friendships were viewed as a positive aspect of hospitalisation, which helped pass the time and relieved boredom. The maintenance of usual activities, such as playing, talking with friends and attending school, could be viewed as helping to restore a sense of normality to the children's lives within the hospital setting.

The most common disadvantages of hospitalisation cited by the children were losing contact with friends and siblings, missing home comforts and schooling, and losing freedom and privacy. The predominant dislikes for all the children were being in pain, operations and needles, being bored and lack of play facilities.

Some of the older children and those with chronic illnesses spoke at length about the inadequate play facilities and had many suggestions on how the facilities could be improved. Inadequate play facilities have been reported in other studies with children in hospital (Gusella *et al*, 1998; Kari *et al*, 1999; Cross and Gregory, 2002), while inadequate numbers of play specialists have been identified by the National Children's Office in its *National Play Policy* (NCO, 2004). Play serves an important function for hospitalised children in that it restores a sense of normality, reduces anxieties, serves as an outlet for tensions and conflicts, facilitates communication and speeds recovery (Lansdown, 1996; Children in Hospital Ireland, 2000). Therefore, keeping occupied through play is an important strategy that children use to cope with hospitalisation. Inadequate play facilities potentially hampers their abilities to deal with the situation.

It was evident from the study that provision for adolescents' social and play needs was inadequate across the three hospitals concerned, which indicates the need for better provision of play facilities and consideration of separate units for adolescents. The *National Play Policy* specifically states that all the recommendations in relation to play that are outlined in the report by the Children in Hospital Ireland (2000) be actively implemented and that the therapeutic value of play should be recognised and actively promoted by health boards and hospitals (Association for the Welfare of Children in Hospital, 1993).

Although the children accepted the need for hospitalisation in order to get better, they nevertheless expressed a range of fears and anxieties and frequently used the term 'getting used to', which indicated significant adaptation on their part. Their fears were mainly in relation to being separated from family, unfamiliar environment and people, and fear of the unknown, all of which have been reported elsewhere (Barnes *et al*, 1990; Glazebrook and Sheard, 1994). It is generally accepted that psychological distress in children is partly due to the unfamiliarity of routines, procedures and health professionals in a hospital ward, as evidenced by the increased use of preparatory procedures and pre-hospital admission programmes (Lansdown, 1996). This indicates the importance of providing children with enough information so their fears may be allayed. Yet, the findings revealed that many children experienced a lack of information and thus a lack of preparedness before investigations and treatments took place. Thus children's fears may have been exacerbated through a lack of information.

## Children's experiences of consultation

It was found that the children had varying experiences of being consulted, which is consistent with findings from other studies (Alderson, 1990 and 1993; Carter, 2002). Although children reported receiving information from a variety of health professionals, it was mainly doctors and



nurses who provided information that was generally related to the children's condition and procedures. Only a few children ( $n = 5$ ) reported feeling able to ask questions and that health professionals were willing to offer explanations and information. Their questions were mainly in relation to meeting basic needs, e.g. whether procedures would be painful, length of stay and discharge date. These particular children often used the expression 'they tell me enough', but did not elaborate on the point. This could imply that they wanted minimal information and when it was provided they were relieved. Alternatively, it could mean that they did not know what information they should know and therefore were satisfied with a brief explanation.

It appeared that some nurses and doctors made a good attempt to explain procedures and events to the children by using props or simple words. The children also spoke about receiving information from their parents. Some children appeared to gain information from other sources, such as reading books, watching hospital soap operas, pre-admission visits and through repeated hospitalisations. The explanations, pre-admission visits and prior experience helped to prepare children for what to expect during the hospitalisation. Some children spoke about being asked questions, which were mainly in relation to symptoms. They felt it was important to be listened to and their experiences were that nurses generally listened to them. They appreciated staff who were calm, kind and who took their time with them, which has been reported in other studies (Hockenberry-Eaton and Minick, 1994).

The children liked receiving information because it helped prepare them for what to expect and thus ameliorated their worries and provided reassurance. Receiving information and being informed of the risks involved were reassuring for some children rather than upsetting. These findings are consistent with other studies, which have shown that when children acquire knowledge about their condition, treatment, likely pain and prognosis, they are more willing to cooperate and endure painful treatments more patiently, show less emotional upset and recover better (Visintainer and Wolfer, 1975; Reissland, 1983; Peterson and Toler, 1986; Alderson, 1990). The overall effect of being involved in the consultation process was that the children reported feeling valued, involved and less anxious.

## Factors that enhanced the consultation process

The significant factors that enhanced the consultation process for the children were age, familiarity with hospital and procedures, knowing health professionals, and time. Similarly, Beresford and Sloper (2003) found familiarity with health professionals to be an influencing factor on adolescents' experiences of communicating with their doctor. The children with chronic illnesses spoke about being more involved in the consultation process over time. This is understandable since it is likely that children will learn how to participate in the consultation process by repeated experiences and familiarity with the environment and health professionals. Furthermore, children with chronic illness may become quite familiar with the medical terminology and therefore will be more effective in the consultation process because they speak the 'same language' as the staff. Similarly, Alderson (1993) noted that children of the same age might differ significantly in their ability and willingness to participate because of the nature of their illness.

The age and maturity of the children were important factors in the extent to which their wishes and needs were respected by health professionals, which has been reported in other studies (Deatrick, 1984; Alderson, 1993; Runeson *et al*, 2001). Only the oldest, chronically ill children (18 years) appeared actively involved in the consultation process: they reported being heard by health professionals on most occasions when they questioned procedures or asked for alternative methods of cannulation and medications. None of the younger children reported situations where they challenged care or treatments. Instead, they often used the expression that they 'did not want to bother' the health professionals. The fact that health professionals may only communicate with older children may be a strong deterrent for young children to feel able to participate. It is also likely that health professionals will hear protests from older children because they possess the verbal skills and confidence to challenge adults. Equally, some health professionals may find it quite threatening when children question their care or refuse aspects of treatment, but may find it easier to accept such assertive behaviour from older children because they see them as more



'adult-like'. There is evidence in the literature that younger children who protest by crying are often ignored and not given credibility by health professionals (Bricher, 2000; Runeson *et al*, 2001).

Children found it easier to ask questions when the person they were in contact with was more familiar to them. Knowing the doctors and nurses helped children to feel confident in their good intentions and thereby provided reassurance. Children who had formed relationships with the health professionals spoke about feeling able to ask questions and participate in discussions about their care. This suggests that children need to feel comfortable with health professionals in order to ask questions, which is not unusual when one considers the powerful position that adults hold in relation to children's subordinate status. Health professionals who were approachable and willing to chat encouraged children's participation since they felt confident to ask questions and seek information. However, some children reported difficulty getting to know the doctors due to a lack of time, lack of frequent contact, many patients and busy workload. Other children spoke about difficulty knowing nurses because of a lack of time and lack of continuity due to shift work. It is not surprising then that only older, chronically ill children reported forming trusting relationships with health professionals.

Adequate contact time with professionals seemed to be a significant factor that influenced the development of the child-professional relationship. Several studies of nurse-family relationships have found that the development of trust is a process that takes time to develop, so the concept of time is a fundamental element in the process of getting to know someone (Thorne, 1993; Robinson, 1996; Bricher, 1999). Similarly, Wilson *et al* (1998) found that a consistent care-giver was the most significant factor that influenced the development of a trusting relationship between children and health professionals. This suggests that the absence of a primary carer on a daily basis may discourage the children from trying to build relationships, particularly with nurses. In like manner, infrequent contact and lack of time with doctors could hinder the development of child-doctor relationships. Furthermore, children may require more time to become open to a relationship with health professionals because of their age, personality or fears of professionals generally.

## Parents' role as advocates in the consultation process

The children described relying on their parents to act as advocates, intermediaries and interpreters in the consultation process, which has been reported elsewhere (Beresford and Sloper, 2003; Young *et al*, 2003). The advocacy role was demonstrated by children asking their parents to ask the questions that they felt unable or afraid to ask. Some children did not want to receive information because it would only increase their worries and consequently preferred their parents to be informed by the doctors. Using parents as 'buffers' to limit exposure to potentially worrying information has been reported by other sick children (Young *et al*, 2003). There is evidence that some children cope with the stress of hospitalisation by using an 'information-limiting strategy', which can be quite effective in managing the stress of anticipated hospitalisation (Thompson, 1994). This suggests that sensitivity is required to ensure that children are not overwhelmed with information, particularly if they use an information-limiting strategy to cope. Parents' advice should be sought on how best to involve children. Some children also spoke about wanting to share the consultation with their parents so that their parents could ask their questions, which were different from the children's questions. The children also observed that their parents tended to ask more future-orientated questions of health professionals, while their own questions tended to be more focused on the immediate situation. This finding has not been reported before.

Most of the children experienced difficulty understanding information due to the style of communication adopted by health professionals. Some children felt that the doctors did not explain things properly because they used technical terms and medical terminology that was confusing. Hence the children were reliant on their parents to act as interpreters and many children reported receiving explanations and reassurance from their parents, mainly their mother who tended to be with them for most of their stay in hospital. The fact that health professionals' communication was difficult to understand illustrates the difficulties that children face in being

involved in the consultation process, which has been revealed in other studies (Alderson, 1990 and 1993; Epstein and Wayman, 1998).

Most children were reluctant to ask questions of health professionals because of their attitude and style of communication. The children listed factors such as not knowing the health professionals; fear of causing 'trouble' by asking questions; lack of time and difficulty contacting health professionals; being ignored; being disbelieved; and health professionals not listening. These factors presented serious obstacles to the children's involvement and consequently may explain their reliance on their parents for information and to act as their intermediaries. This indicates that children may be forced to rely on their parents as advocates or intermediaries out of necessity rather than out of choice. There is a danger that some children with repeated hospitalisations may become so accustomed and reliant on their parents asking questions that they never get the opportunity to develop their own skills and confidence to enable them to participate actively. There was evidence that this had occurred with an older child with a chronic illness, who was aware that she was now, at the age of 18, only beginning to be involved in discussions and decisions about her care and treatment.

Although parents appeared to play an important role as advocates, they could also obstruct children from participating actively in the consultation process, which has been reported before (Angst and Deatrick, 1996; Horner, 1999; Runeson *et al*, 2001; Tates *et al*, 2002; Beresford and Sloper, 2003; Young *et al*, 2003). Some children described situations where their parents inhibited their attempts to participate in the consultation process by answering questions on their behalf, by telling them to stay quiet, by reprimanding them for interrupting the discussion and by not supporting their attempts to gain information. There were also occasions where children asked parents for information and the parents withheld it for whatever reason. Lack of support from parents in relation to children's active participation sends a clear message to children that they should be seen and not heard. Thus, some children's silence may have reflected their motivation to conform to socially desired behavioural norms for children, rather than a reluctance to participate. What this evidence indicates is that, firstly, many parents played a key role in enhancing children's opportunities to participate and, secondly, if parents do not support their children's participation, then this further limits the children's opportunities for participation in decision-making.

However, it could be argued that parents may withhold information out of a desire to protect their child rather than being difficult, which has been reported elsewhere (Young *et al*, 2003). Parents' actions may have reflected their need to protect their child's well-being and thus were well intentioned. But this does not fully explain why some parents overruled their children or silenced them in front of the health professionals.

There may be several different reasons why parents do not support their children's participation. Parents may themselves feel unequal to the authority of the health professionals, particularly doctors, and therefore may feel more comfortable adopting a subordinate position. Equally, parents, because of their culture or social class, may be socialised to a role that values obedience to professionals. Parents' beliefs may be heavily influenced by their own upbringing, in that they may have been discouraged from participation and thus may apply the same parenting style to their own children. Parents may hold the belief that children should be seen rather than heard, and therefore will discourage children's active participation. Alternatively, parents' emotional involvement may decrease their ability to support their children in stressful situations. The potentially inhibitory role played by parents in the child-professional interaction process indicates that this is an important area for further research and an area in which to explore a change in practice.

## Children's experiences of non-consultation

Most children wanted to share consultations with parents because their parents acted as advocates and interpreters in the communication process. They relied on parents to explain the information, mainly due to difficulty in understanding the medical terminology and style of communication used by the health professionals. Due to fear of hearing bad news, some children seemed content for health professionals to communicate directly with parents. However, the majority of the children

wanted to be included in the consultation process, but were generally excluded. The data indicated that consultations were largely carried out between parents and health professionals, which tended to leave children without a voice in matters that affected them. Many of the children used the phrase 'they didn't tell me anything' to illustrate their experiences and they strongly resented being excluded from the communication process.

Children also described situations in which health professionals, usually doctors, would direct one or two specific questions to them and then conduct most of the consultation with the parents. This could be seen as a tokenistic consultation, whereby the children are involved minimally at the start of the consultation. Similarly, seminal work on children's medical encounters in clinics (Strong, 1979; Silverman, 1987) and studies on wards reported that all children, even the older ones, were involved in a tokenistic way and routinely excluded from discussions (Shiminski-Maher, 1993; Van Dulmen, 1998; Bates and Meeuwesen, 2001; Carter, 2002; Beresford and Sloper, 2003). Some children noted that the doctor's consultation ranged from ignoring them completely to discussing decisions with other doctors or their parents in front of them. Similarly, observational studies of patient-professional interactions have revealed that children are often relegated to a non-participant status in consultations (Epstein and Wayman, 1998; Pearlman and Abromovitch, 1987; Stewart *et al*, 1981; Bates and Meeuwesen, 2001). Discussing children's treatment in their presence, often with only minimal efforts to involve them, clearly demonstrates who is in control and whose decisions matter. Talking over child patients is a means by which language may be used to exert power.

Children felt they had a right to be involved because they were the people with the illness and therefore should be the focus of the information exchange. It made some children feel that their parents were having the treatment rather than them. This marginalisation has been reported in observational studies of doctor-parent-patient interaction (Bates and Meeuwesen, 2001). Some children resorted to trying to overhear what the health professionals were saying to their parents and also asking parents to explain. This was not always possible; some children reported being completely excluded from the consultation because doctors took their parents elsewhere to talk or they actually asked the child to leave. When health professionals excluded them, this resulted in the children feeling worried because they lacked information on what was happening to them. Furthermore, they assumed that the information must be very serious and consequently felt very scared and apprehensive.

Nearly all the children ( $n = 52$ ) spoke about wanting information so that they would know what to expect while in hospital and also to make them feel more involved. Information-seeking was a predominant coping strategy used by the children during hospitalisation, which is consistent with other research (Cady *et al*, 1984; Peterson, 1989). However, many children reported a deficit of information on many aspects of their treatment and hospitalisation. Children described situations where they received conflicting information from health professionals regarding admission, length of stay, discharge plan and playing sports and general activities. Although some children tried to obtain information by asking questions of health professionals, they reported that their questions were frequently ignored and not answered. This indicated to some children that health professionals did not want them to ask questions and or were unwilling to provide information. Such experiences undoubtedly acted as a strong deterrent to these children contributing to future consultations.

Children felt that they should be allowed the opportunity to hear information directly, ask questions and volunteer their own information, therefore being actively involved. However, the findings revealed that a broad range of children (from 7-17 years) were reluctant to ask questions, even though they wanted to be involved in the consultation process. Consequently, they reported accepting and going along with whatever was planned for them. Many children ( $n = 35$ ) spoke about being afraid to ask questions of health professionals due to fear of inconveniencing or annoying them because they were viewed as such busy and important adults. Children needed sufficient time with health professionals in order to ask their questions and have time to digest the information. However, many children felt unable to ask questions because of 'being rushed'

during their interactions with health professionals. Even older children experienced difficulty asking questions. Some reported being afraid to ask questions because they found the doctor could be intimidating or react angrily to repeated questioning. Consequently, they described learning through experience — that waiting for the health professional to provide information was easier than asking questions because it did not cause annoyance and the health professional was then much 'nicer' to them. The children also described having to assess the appropriate time when to ask questions of adults in order to achieve a favourable response. Gauging the right time to ask questions of adults seems quite a demanding burden on sick children and should not be expected of them, but unfortunately it seemed to be the reality for some.

Thus, the attitudes and behaviour of health professionals were significant factors that influenced children's ability and willingness to participate in the consultation process. Similarly, Lewis and Lewis (1990) found that the principal obstacle to children's participation came from doctors because their power status was threatened, they lacked the skills to deal with empowered children and, moreover, they lacked conviction that it was beneficial for children. The present findings indicate that many health professionals, particularly doctors, do not actively support or facilitate children's participation in consultations.

Children had difficulty being heard. Many children ( $n = 32$ ) reported expressing their needs to nurses and doctors, but then of not being listened to and their views not being taken seriously. Several children spoke about doctors lacking knowledge of their medical history, doctors giving different opinions or being uncertain, and a lack of correspondence or exchange between medical teams. They spoke about providing health professionals with information on various issues (such as allergies, the medicines that worked for them and their preferences with regard to blood tests and cannulation techniques) and then of their views being disregarded. Some children felt that they were judged, disbelieved and labelled as 'difficult', and this compounded the stresses they were already dealing with, which has been reported elsewhere (Carter, 2002). Many of the children's comments about being disbelieved were in relation to expressions of pain. This finding is supported by other research studies, which found that nurses often misinterpret children's expressions of pain, underestimate their pain and provide inadequate pain relief (Gonzalez *et al*, 1993; Byrne *et al*, 2001; Carter, 2002). Some children felt that health professionals did not 'care about them' because their expressions of pain went unheard. Similarly, other studies have found that children perceive inadequate pain relief as a form of punishment or evidence of an uncaring attitude from health professionals (Ross and Ross, 1984; Gaffney and Dunne, 1986 and 1987).

The children wanted health professionals to listen and therefore it was frustrating for them when health professionals did not take account of their views and respect their knowledge. Some children felt that their contributions were not given due weight and consideration because health professionals viewed them as cognitively impaired and therefore lacking understanding. The children's accounts of being ignored or disbelieved imply a lack of recognition and respect for children's views. It could be argued that such experiences would serve as a strong deterrent to children's active participation in the communication process.

Some children experienced difficulties contacting nurses for assistance with basic needs, particularly in relation to pain relief. The children were concerned because they had no means of contacting the nurses, such as the use of a call system, and consequently if parents were not around, they would have to rely on someone passing by or shouting in the hope that a nurse might hear them. The same concerns about contacting nurses was reported over 30 years ago, when Hawthorn (1974) found that children had no means of attracting a nurse's attention other than calling, setting out to look for one or finding someone else to act for them. Some children spoke about asking for help and their requests going unheard, while other children reported instances when nurses agreed to help but then appeared to forget their requests. Some children noted that nurses were very busy with other patients and so were reluctant to 'bother' the nurses because this could cause them to get annoyed. Other children viewed nurses' actions as being uncaring because nurses chose to spend time chatting to other nurses and ignore the children. This indicates that many children experienced difficulties being heard, which is of concern with regard to the quality of care provided for children in hospital.

The lack of information meant that children often had to endure procedures without adequate preparation. Children generally reported that health professionals tended to 'do things' to them with very brief, or no, explanations. Similarly, Epstein and Wayman (1998) found that the conversations surrounding hospital procedures tended to be sparse, unresponsive and non-contingent, which suggested that health professionals treated the children as passive objects rather than active participants. Again, Knafl *et al* (1988), in their study of families and children (n = 62), found that the child was like an object that had things done to it, rather than being involved or having a voice.

Many children spoke about the lack of choice with regard to procedures and treatments. They noted that there was a ward routine and that children had to adhere to it. They also described situations where they were not given time to think about the information and digest its implications. Some children described being pressurised to undergo procedures with minimal explanations and no preparation. For example, some children described having to endure blood tests and cannulations without the necessary preparatory cream (called EMLA and containing a local anaesthetic) because the health professional chose not to use it. Although many children mentioned the benefits of the cream, some actually stated that they would not be able to request for it to be used because they did not want to cause 'bother'. It appears that children were generally reluctant to challenge health professionals about inadequate care. Similarly, the study by Runeson *et al* (2002a) explored children's participation in decision-making during hospitalisation (n = 24) and found that children were forced to undergo procedures with minimal preparation and information.

### Consequences of non-consultation

The children used a wide variety of terms to describe their feelings about being excluded from the consultation process. These included feeling disappointed, sad, confused, angry, 'rotten', worried, misled, shocked, betrayed, lonely and ignored. The children clearly wanted to be involved in the consultation process and the range and depth of feelings listed here clearly illustrate the impact of non-involvement on many children. It may be argued that such feelings, allied with an imposed subordinate role, may adversely affect the physical and emotional welfare of the child. Children's perceptions of their personal value are important because research suggests that there is a relationship between self-esteem, self-worth and medical outcomes (Schmale and Iker, 1971; Herzlich, 1973; Norbeck and Tilden, 1983; Prilleltensky *et al*, 2001).

The consequence of non-consultation was that some children felt forgotten and depersonalised, as if they were inanimate objects with no feelings. The depersonalisation effect of being treated as a non-person has been described by Goffman (1961) as 'the wonderful brand of non-person treatment whereby the patient is greeted with what passes as civility, and said farewell to in the same fashion, with everything in between going on as if the patient weren't there as a social person at all, but only as a possession someone left behind'. Similarly, adult patients who experienced such situations reported feeling insignificant and objectified, which resulted in feelings of fear, anger and shame (Drew, 1986). If adults feel objectified, then these feelings could be compounded for children who are in a more vulnerable position because of their illness, their limitation of understanding and their lack of control over what is happening to them.

### Factors that inhibited the consultation process

As can be seen from the preceding discussion, there were numerous factors that inhibited children from actively participating in consultations. These included not knowing health professionals; not wanting to hear bad news; fear of causing 'trouble' by asking questions; lack of time with health professionals; being ignored; being disbelieved; difficulty contacting health professionals; health professionals not listening; difficulty understanding medical terminology; and parents' actions. Being sick was another factor that inhibited children's participation since some children spoke about wanting to participate but being unable to due to their symptoms or being restricted to their beds.

Parents appeared to play a key role in the consultation process and could either facilitate or constrain children's participation. Although the role of parents was significant, the key factor that



hampered children's participation in consultations and decisions appeared to be the attitudes and behaviour of the health professionals. These findings are consistent with previous research in this area. Many other research studies have reported that health professionals' attitudes play a key role in whether children are allowed or encouraged to participate (Strong, 1979; Silverman, 1987; Lewis and Lewis, 1990; Runeson *et al*, 2001).

The research in this area indicates that doctors do not support children's participation in consultations for a variety of reasons. These include lack of time, chaotic environment, loss of power and control, having their views and approaches questioned, not agreeing with the child's wishes, uncertainty about a child's competence, lack of conviction of the benefit to children and lack of communication skills with children (Strong, 1979; Van Eys, 1986; Lewis and Lewis, 1990; Rylance, 1996). According to some paediatricians, there has been a tendency to overlook the rights of children to express their views because of paediatricians' protective attitudes and overcautious assessment of children's ability to understand and reason in an environment of traditional adult superiority (Strong, 1979; Van Eys, 1986; Rylance, 1996). Alternatively, doctors could be threatened by the notion of empowered children who could possibly challenge them and/or the status quo. American paediatricians Lewis and Lewis (1990) concluded from their research over an 18-year period that the principal resistance to children's participation in consultations and decision-making came from the doctors themselves because their power status was threatened, they lacked the skills to deal with empowered children and they lacked conviction that it was beneficial for children. Thus, the evidence indicates that negative beliefs on the part of health professionals about children's participation may be a central issue.

However, others would argue that the organisational and legal setting needs to be taken into account, as well as the beliefs and agenda of health professionals (Gabe *et al*, 2004). Doctors often experience difficulty reconciling opposing objectives: on the one hand, children are seen as immature and in need of protection, while on the other hand, they have a right to be heard (British Medical Association, 2001). Gabe *et al* (2004) suggest that the poor standard of accommodation in the public health system (e.g. restricted space on wards), time pressures and tight time-slots result in hurried consultations. There is a risk that when children's need for information and consultation are weighed against saving time or money, the short-term solution (lack of information) is given preference. Tates *et al* (2002) suggest that doctors may actually be orientated towards facilitating children's participation, but may be constrained by the parents' presence and demands for inclusion. They argue that previous research on doctor-patient interactions has failed to consider how parents may influence the behaviour of health professionals. The communicative needs of children and parents may be quite different and health professionals may experience difficulties meeting both parties' requirements in a time-pressured consultation. This brief discussion indicates that further research is required to address these important issues more thoroughly.

## Children's views on decision-making process

The children held varying views on involvement in decision-making and appeared to see decisions as falling into two categories — 'serious' and 'small' decisions. The children were willing and keen to participate in taking 'small' decisions, such as those related to everyday events, diet and medications. When it came to 'serious' decisions, nearly half of the children said that they would prefer to leave these to parents and health professionals. Most of the children explained that the doctors made the decision of hospitalisation and that they went along with that decision because the doctor is the expert and they just wanted to get better. They also said that they would leave the 'serious decisions' about treatment to the doctors because of their expertise and training. Similarly, some children reported leaving decisions to their parents because parents 'know best' and they were accustomed to their parents making the serious decisions. Others spoke about needing parents and health professionals to make the decision because of a lack of confidence in their own abilities and because of their cognitive immaturity. Other children felt that with their parents' support they could be involved in the consultation process and in the making of decisions; they stated that making decisions should be a shared process between the child, parent and professionals, with all parties being involved.

Although some children appeared content to leave the 'serious' decisions to health professionals and parents, other children wanted that responsibility. They spoke about having the right to take 'serious' decisions, such as admission to hospital and operations. These children ranged in age from 7 to 18, which indicates that age or cognitive levels may not be the sole influence on decision-making. Some children felt that they should be involved in the decision-making process when they were older. When asked what would be an appropriate age, they provided a range of ages, from 9 to 18, with many choosing 16 as the cut-off point. Similarly, in Alderson's (1993) research with children (n = 120), the children had views about whether they wished to give consent to treatment or delegate that responsibility to their parents, and many children could propose an age when they thought it was appropriate to decide for themselves. Weithorn and Campbell (1982) noted that children as young as 9 appeared able to participate meaningfully in personal healthcare decision-making. The range of ages supplied indicates that children do not see decision-making as occurring at a set age or set point in their lives; rather, it was an evolving process dependent on individual factors. This suggests that health professionals need to assess each child's ability and willingness to participate, rather than making assumptions about involvement based solely on the child's age.

At the same time, some children noted that it depended on the individual rather than their age. One child made the point that health professionals need to assess the child's maturity and ability to understand before including them in taking serious decisions. Other children felt that it was the child's responsibility to inform parents and health professionals when they were ready to take on the responsibility for decision-making. Angst and Deatrick (1996) found that many parents (n = 48) were waiting for the health professionals to tell them when it was appropriate to involve their children in decisions and planning their care. If this is the case, then parents may never encourage children's participation unless they receive permission from health professionals. Some children were aware that they required practice, help and support from parents in order to become confident in making decisions. It appeared that some children were encouraged by parents to play a part in decision-making and thus were accustomed to participation. This indicates that children's capacity to participate is determined to a degree by the effort of preparing them to participate and the quality of the preparation. Thus parents play an influential role in children's ability to participate, which indicates that an awareness of the family's usual pattern of decision-making can be helpful. Parents may need guidance and encouragement from health professionals before they can enable and support their children's participation in decision-making.

Some children described situations where they were excluded from the decision-making process, which is not surprising in light of their experiences of non-consultation discussed above. Some children felt that health professionals make the decisions and then present the children with a *fait accompli*, thereby allowing no opportunity for discussion. Similarly, Hallstrom and Elander (2004) found that children and parents made few decisions themselves and even if they disagreed with the decision made, few decisions were reconsidered. One child felt that doctors generally do not see children as having the competence to make decisions and as such do not elicit their views or involve them. According to Rylance (1996), a consultant paediatrician, there has been a tendency to overlook the rights of children to express their views because of paediatricians' protective attitudes and overcautious assessment of children's ability to understand and reason in an environment of traditional adult superiority. The children were aware that they were excluded from the decision-making process, which resulted in feelings of annoyance; they felt that they had a valuable contribution to make and resented being excluded. Preventing children from involvement restricts their ability to gain competence in decision-making over time. Other children spoke about being asked about hospital services and then no action being taken. The involvement of children in a decision-making process without follow-up or feedback has been described as tokenism (Treseder, 1997). The lack of follow-up could discourage children from future participation and offering suggestions for improvement.

As can be seen from the discussion above, some children wanted to be involved in 'small' decisions, while others were willing to be involved in 'serious' decisions. It was evident that many children desired involvement in the decision-making process, particularly in everyday decisions about their care and treatment. The literature on decision-making is replete with lengthy debates

about children's informed consent, which does not address the issue of participation in simple everyday decisions. When the issue of decision-making is mentioned, most people tend to think of court cases that involve decisions about life threatening treatment (rather than simple everyday decisions). These examples tend to be extreme and unusual, yet they have led to uncertainty and anxiety about routinely involving children in decision-making.

The findings indicate that the issue of decision-making should be seen as being on a continuum rather than on an 'all or nothing' basis. It should also be viewed as a process that is dependent on the type of decision, child, parents and health professionals' opinions, and the situational context. The findings support the position that the assessment of competence should be based on children's functional ability, not on age or outcome of decision (Alderson and Montgomery, 1996; Rylance, 1996). However, this may be problematic since it is easy to assume that children are competent only if they make the decisions that doctors want them to make (Dixon-Woods *et al*, 1999). The children in the present study held clear views on the issue of decision-making and could recount the factors that would influence their participation in the decision-making process. As seen earlier, some children wanted to leave decisions to adults or share decisions with them. Unwillingness to participate should not be interpreted as incompetence since choosing to leave decisions to adults demonstrates the ability to choose. The children showed quite sophisticated reasoning in their awareness that due to their cognitive immaturity they often need help with decision-making. Hence, it may be argued that children of all ages, apart from babies, are capable of making decisions and as such they have a right to be informed and included in decisions that affect their welfare. Health professionals, therefore, have a responsibility to justify non-involvement of children in matters and decisions that affect them.

## Frameworks of consultation

Several models, frameworks and schemata have been developed over the years to structure the involvement of children in consultation and decision-making (Hart, 1992; John, 1996; Alderson and Montgomery, 1996; Hermerén, 1996; Treseder, 1997; Cohen and Emmanuel, 1998; Lansdown, 2001). Most of these writers have based their frameworks on the model developed by Hart (1992) called the 'Ladder of Participation', which was originally created by Arnstein (1969) as a model of citizen participation (*see Appendix 1a*). The 'rungs' on Hart's Ladder number 8 in total and represent degrees of participation or opportunities that range from tokenism to child-initiated, shared decisions with adults (*see Appendix 1b*). Some of the findings from the present study can be linked to 3 rungs on this ladder — 'Assigned but informed', which is participation, 'Tokenism' and 'Manipulation', both of which are seen as 'non-participation'.

Hart's model was developed for children's participation in projects rather than general situations. Therefore, it is not surprising that it does not contribute towards a full understanding of the findings on consultation in this study. Hart's model has also been criticised for structuring various levels of consultation in a hierarchy, which does not recognise that participation usually exists on a continuum, with movement across the levels depending on the context of the consultation (McAuley and Brattman, 2002) and also that children may have different views on their levels of participation. The model has also been criticised for assuming that child-initiated and directed participation is the eventual aim for all those who wish to empower children and that other 'levels' of participation are merely steps on the way to that eventual goal (Treseder, 1997).

Treseder (1997) provides an alternative model that displays all levels of participation as equal forms of good practice in a circular layout (*see Appendix 11*). Although this model is an improvement on previous ones, the description of the levels does not easily fit with the context of the healthcare setting. The level of 'Child-initiated and directed' participation will be inappropriate in most healthcare decisions because adults need to be available and responsible for the children, especially during illness. The findings from this study are structured in a new framework (adapted from Treseder's model) that illustrates children's experiences rather than the ideal (*see Appendix 12*).

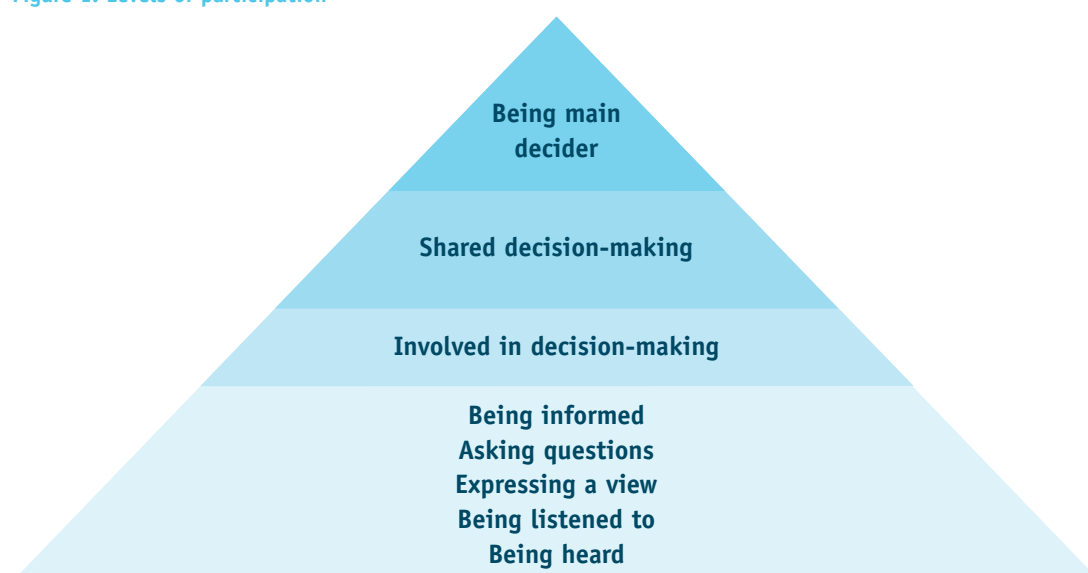
From the children's data, it is possible to devise a framework that encompasses the levels of participation from their perspectives, thus a framework for best practice (*see Figure 1*). The children



described 7 levels of participation in consultations, which were being informed; asking questions; expressing a view; being listened to; being heard; involved in decision-making; shared decision-making; and being the main decider.

From the children's perspectives, all of these levels were important at different stages of their hospitalisation. Being involved in the communication process was more important for many children than necessarily being involved in serious decision-making. This was understandable in light of the difficulties the children experienced in having their views heard and being involved in discussions about their care in hospital. The levels could also be arranged in a circular diagram to illustrate that they were not ranked in order of importance.

**Figure 1: Levels of participation**



## Conclusions

It was clearly evident that children want to be involved in the consultation process. Most of the children wanted to be consulted about their care and to be respected as having opinions about their care and treatment. Many children felt that they had a right to be involved because it was about matters that affected them and their bodies. They spoke about needing information so that they could understand their illness, be involved in their care, prepare themselves for procedures and direct their actions towards 'getting well' again. It was clear that some children were consulted and received information and explanations. When children were provided with information and consulted about their care, they felt less anxious about undergoing operations and treatment.

It was also evident that some children used an information-limiting strategy to cope, in that they did not want to hear any 'bad news'. Many children preferred their parents to be their advocate or intermediary in the consultation process because of the difficulty understanding medical terminology and not wanting to know 'bad things'. Thus for some children, parents play a key role in protecting them in the consultation process. At the same time, some children reported that parents constrained their participation in consultations and that they felt excluded by doctor-parent interactions. Thus parents' role appeared to both facilitate and constrain communication interactions for the children.

It may be argued that the children's dependence on their parents as brokers in the consultation process arose out of necessity because they encountered considerable obstacles that hindered their active participation. Most children experienced considerable difficulties in expressing their views, getting their views taken seriously and obtaining sufficient information to enable them to participate in discussions concerning their welfare in hospital. Their voices were not heard and they appeared to occupy a marginal position in consultations. They described feeling upset, angry

and depressed when health professionals ignored or excluded them. They expressed a need to be included in the consultation process, but were hampered mainly by the actions of the health professionals. By restricting the amount of information given to children, health professionals limit children's opportunities to participate and leave them with limited choice in the decision-making process. The findings suggest that the practice of speaking with children, listening to them and involving them in the decision-making process is not common practice for many health professionals. This is a situation that needs to be improved since a lack of involvement may contribute negatively to children's self-worth, their recovery from illness and overall adaptation. By health professionals communicating with and involving children, this emphasises that children are important, enhances children's coping skills and contributes to effective adaptation.

Some children wanted to be involved in the decision-making process, while others were happy for the decisions to be left to parents and health professionals. Participation rights do not necessarily confer the right to be the main decider, nor do children want to exclude their parents from the process. The findings indicate that the issue of decision-making should be seen as existing on a continuum rather than an 'all or nothing' approach. The view of 'all or nothing' obscures the fact that there are multiple levels and ways to involve children in decision-making. There are also different types of decisions ranging from minor to major and the decision-making process can change depending on the situational context. The findings indicate that decision-making for children is a complex process that evolves over time and that may be shared or contested with parents and health professionals depending on the type of decision. It suggests a pragmatic approach, which recognises that children need protection while at the same time allowing flexibility for the child's emerging knowledge and self-determination.

The focus of this study was on children's experiences of consultation and involvement in decision-making. Most of the data was in relation to the process of consultation, which indicates that being listened to, being heard and being given the opportunity to ask questions is what is of most importance for children. They also want to be involved in the decision-making process, but for most children the process of consultation is of key importance. Some authors see participation in consultation as being synonymous with decision-making, but this is not always the case. Giving children a voice in matters that affect them directly is not the same as giving them the sole responsibility for decisions and their consequences.

Health professionals, like all adults, may be open to the possibility of consulting children, but they may also have reservations. They might find certain aspects of consulting children difficult for reasons that include a lack of time, chaotic environment, loss of power and control, having their views and approaches questioned, not agreeing with the child's wishes, not being able to do what they want to do, and feeling worried about lack of necessary skills and competence. There is a need for further research to determine the attitudes and feelings of health professionals about consultation with children; clearly, the findings demonstrate that some must have reservations about involving children. This information could then be used to identify interventions that will encourage professionals to re-evaluate their practices and embrace a more flexible approach to children's participation in consultations and decisions.

There is also a need for further research into parents' perceptions of children's involvement in consultations and decisions. This is because parents have a significant influence on their children's competence to participate. The research on child and parent participation in healthcare decisions is limited, in that the process of involvement has not been examined. There is a lack of information on how parents, children and health professionals interact in relation to the decision-making process. Few studies of doctor-child-parent communication have taken the triadic nature of this communication into account. There is a lack of method and assessment tools devised for healthcare settings to assess the competence of children of different intellectual abilities, including those with intellectual disabilities. Children have the right to participate effectively, but recognition of the wider benefits of this participation is essential to sustaining this wider process of cultural and organisational change. There is a need for a programme of research that more clearly identifies and quantifies the range of personal, social and economic benefits of children gaining greater influence over decision-making and participation in healthcare.



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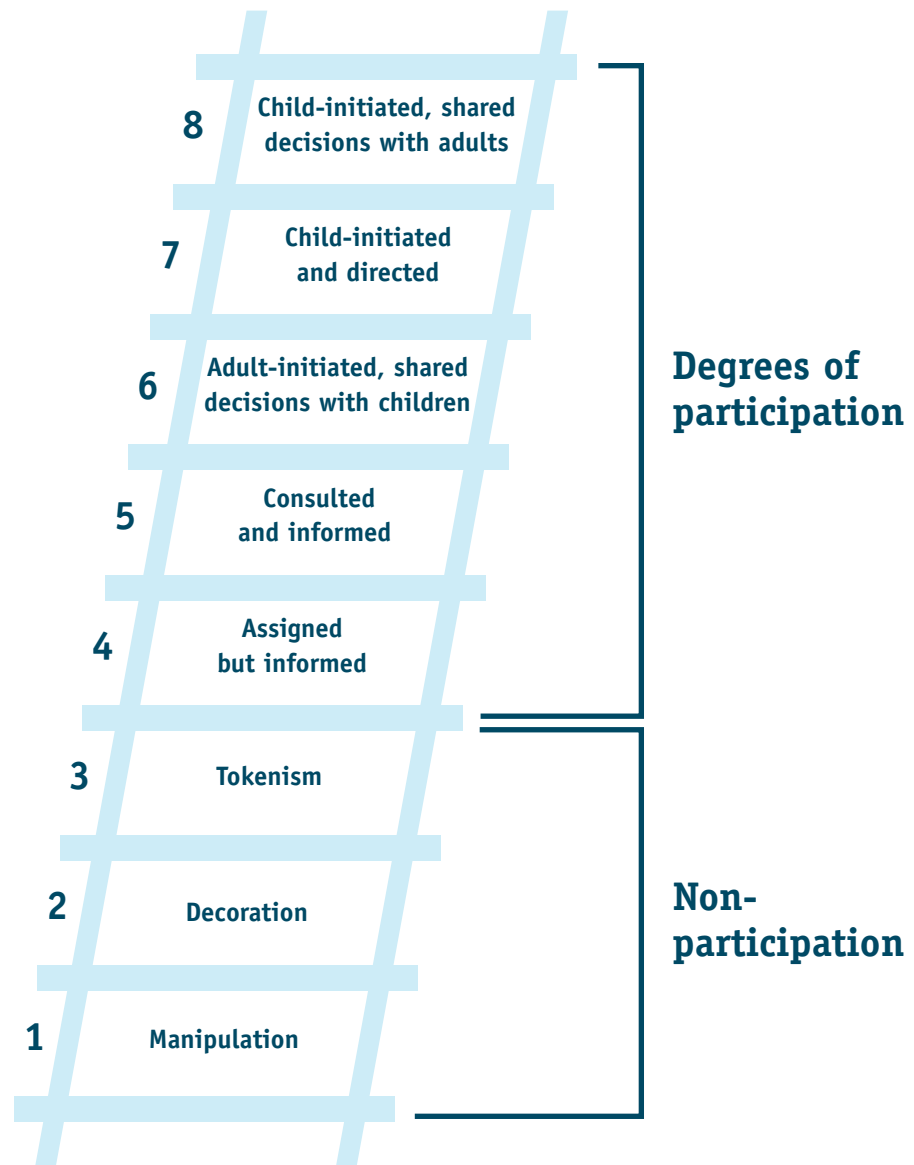
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# APPENDICES

## Appendix 1a: Hart's Ladder of Participation



Source: Adapted by Hart (1992) from Arnstein (1969)



## Appendix 1b:

### Hart's Degrees of Participation

8. **Youth-initiated, shared decisions with adults** is when projects or programmes are initiated by youth and decision-making is shared among youth and adults. These projects empower youth, while at the same time enable them to access and learn from the life experience and expertise of adults.
7. **Youth-initiated and directed** is when young people initiate and direct a project or programme. Adults are involved only in a supportive role.
6. **Adult-initiated, shared decisions with youth** is when projects or programmes are initiated by adults, but the decision-making is shared with the young people.
5. **Consulted and informed** is when youth give advice on projects or programmes designed and run by adults. The youth are informed about how their input will be used and the outcomes of the decisions made by adults.
4. **Assigned but informed** is where youth are assigned a specific role and informed about how and why they are being involved.
3. **Tokenism** is where young people appear to be given a voice, but in fact have little or no choice about what they do or how they participate.
2. **Decoration** is where young people are used to help or 'bolster' a cause in a relatively indirect way, although adults do not pretend that the cause is inspired by youth.
1. **Manipulation** is where adults use youth to support causes and pretend that the causes are inspired by youth.

Source: Adapted from Hart (1992)

## Appendix 2: Parent Information Letter

### Giving Children a Voice

#### Children's voices within the healthcare setting

Dear Parent,

We are carrying out research into children and their role in consultation and decision-making in a hospital setting and would like your assistance. Our project is funded by the National Children's Office and our aim is to give children a voice and for their opinions to be heard. We are looking to interview children aged 7 to 18 years to participate in focus groups on decision-making. These focus groups will last for approximately 45 minutes and will be conducted by trained researchers who are also qualified paediatric nurses. We may approach you for your consent to allow your child to participate in these focus groups and if consent is given, we will also seek consent from your child prior to participation. Confidentiality is assured and your child may withdraw from the focus group at any stage. We would greatly appreciate you and your child's co-operation to help make this research enhance the lives of children, but ultimately to allow their voices to be heard.

If you have any queries, please do not hesitate to contact us, either by approaching us directly or at the telephone number below.

Yours sincerely,

Eilis Hayes  
*Research Assistant*

## Appendix 3:

### Information Sheet for Older Child

#### Giving Children a Voice

##### Children's voices within the healthcare setting

Dear Participant,

My name is Eilis and I am writing not only to inform you about this research study, but also to invite you to become involved in the study.

The aim of the study is to explore how children feel about being involved in consultations and decisions about their care and whether children want to be involved in these decisions. I would like to talk to you about your experiences of involvement in care and decisions whilst in hospital. The questions I will ask will be easy to answer and if you do not want to answer some of them that is okay. Some examples of the questions I might ask you are: 'What it is like being in hospital?' and 'What care you like to do for yourself?' and 'Are you involved in decisions about your care?' It is hoped that the results from this study will be used to help to improve the care provided for other parents and their children who come into hospital.

The information will be collected through the use of interviews. Therefore should you agree to participate in the study I (the researcher) will arrange to conduct an interview with you on the ward at a time that is convenient for you. The interview will take approximately one hour and will be tape-recorded. You are under no obligation to participate in the study and the information that you provide will be viewed only by the researcher and will not be shared with your parents or nurses.

If you have any questions that you would like to ask me, you can call me on my phone XXXXX or ask your parents to call me and I will call into you to answer your questions.

Thank you for taking the time to read this information sheet.

Eilis

## Appendix 4: Parental Consent — Permission to approach child

### Permission to approach their child to participate in the study

I \_\_\_\_\_ hereby declare that  
I have also received clear explanations and reasons for the need  
to involve children in the study. Having received detailed information  
about the study from the researcher, I am now making a fully  
informed decision to allow my child \_\_\_\_\_  
to participate in this study, if he/she is willing to participate.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

Witnessed: \_\_\_\_\_

Dated: \_\_\_\_\_

## Appendix 5:

### Parental Consent — Permission for child participation

#### Giving Children a Voice

##### Children's voices within the healthcare setting

#### Consent Form for Parents

I \_\_\_\_\_ have read the information sheet provided by the researcher about this study.

I hereby declare that I have also received clear explanations about the above named research study and I am now making a fully informed decision to participate in this study.

In agreeing to take part in the research study, I understand that all of the information I provide will remain strictly confidential and my anonymity will be preserved at all times.

Should I no longer wish to participate in the study, it is entirely my right to withdraw from the study at any stage and I have been assured that my decision will not influence any present or future treatment.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

Witnessed: \_\_\_\_\_

Dated: \_\_\_\_\_

## Appendix 6: Older Child Consent

### Giving Children a Voice

#### Children's voices within the healthcare setting

This research study has been explained to me. The researcher has answered all of my questions and I understand what will happen during the study. All of my questions have been answered and I do want to take part in the study.

I \_\_\_\_\_ have read the information sheet that the researcher has given to me, which explained what the study was about.

If I agree to take part in the research study, I know that anything I tell the researcher will not be told to anybody else and my name will not be written down anywhere. This way nobody will be able to know what I tell the researcher.

If I decide to stop participating in the study, that is okay and nobody will be annoyed with me.

Child's Name: \_\_\_\_\_

Child's Signature: \_\_\_\_\_

Witnessed: \_\_\_\_\_

Dated: \_\_\_\_\_

## Appendix 7: Younger Child Consent

### My name is EILIS and I need your Help !!

I am doing a project for my school on how children feel about being involved in their care and decisions about their care. If you have time, I would like to talk to you about:

- **What it is like being in hospital**
- **Things you like to do for yourself in hospital**
- **How much you are involved in your care**
- **How much you are involved in decisions about your care**

If you would like to help in my project, all you have to do is write your name below. If your answer is yes, then I will come to talk with you.

Name: \_\_\_\_\_

**Thank you**



## Appendix 8:

### Protocol 1: Child displaying anxiety during interview

#### Steps to be followed should a child show signs of anxiety during the interview process:

1. The interview and recording will cease immediately.
2. Reassurance and comfort will be given to the child by the researcher.
3. The child will be reunited with their significant others and with ward staff.
4. The child's family and ward staff will be updated on the child's emotional state and events leading up to the child's feelings of anxiety.
5. Reassurance will be given to the child and the family that the termination of the interview will in no way negate against any future medical and nursing interventions that the child may require during their hospital admission.

Signed: \_\_\_\_\_

Dr Imelda Coyne, *Principal Investigator*  
Ms Eilis Hayes, *Research Assistant*

## Appendix 9:

### Protocol 2: Signs of illness during interview

#### Steps to be followed should a child show signs of illness during the interview process:

1. The interview and recording will cease immediately.
2. Reassurance and comfort will be given to the child by the researcher.
3. The child will be reunited with their significant others and ward staff informed.
4. The researcher will update the child's family and ward staff on the child's present condition, alterations observed (if any) during the interview process and events leading up to the deterioration in the child's condition.
5. Reassurance will also be given to the child and the family that the termination of the interview will in no way negate against any future medical and nursing interventions that the child may require during their hospital admission.

Signed: \_\_\_\_\_

Dr Imelda Coyne, *Principal Investigator*  
Ms Eilis Hayes, *Research Assistant*

## Appendix 10:

### Protocol 3: Disclosure of sensitive information during interview

#### Steps to be followed should a child disclose sensitive information during the interview process:

1. In the event of a child disclosing information of a sensitive nature to the researcher, the researcher will cease recording immediately and allow the child to complete their dialogue.
2. Reassurance will be given to the child that they will not be punished in any way for the information that they have disclosed and comfort measures will be implemented to allay any anxiety that the child may have regarding same.
3. The researcher will inform the child that the information that they have disclosed must be communicated to senior ward staff.
4. Although all the participants will be told that the information they provide will be treated confidentially, if a child discloses information that raises concern for the interviewer, at all times the safety and welfare of the child must take priority and appropriate action must be taken.

#### **Giving information to others for the protection of a child is not a breach of confidentiality.**

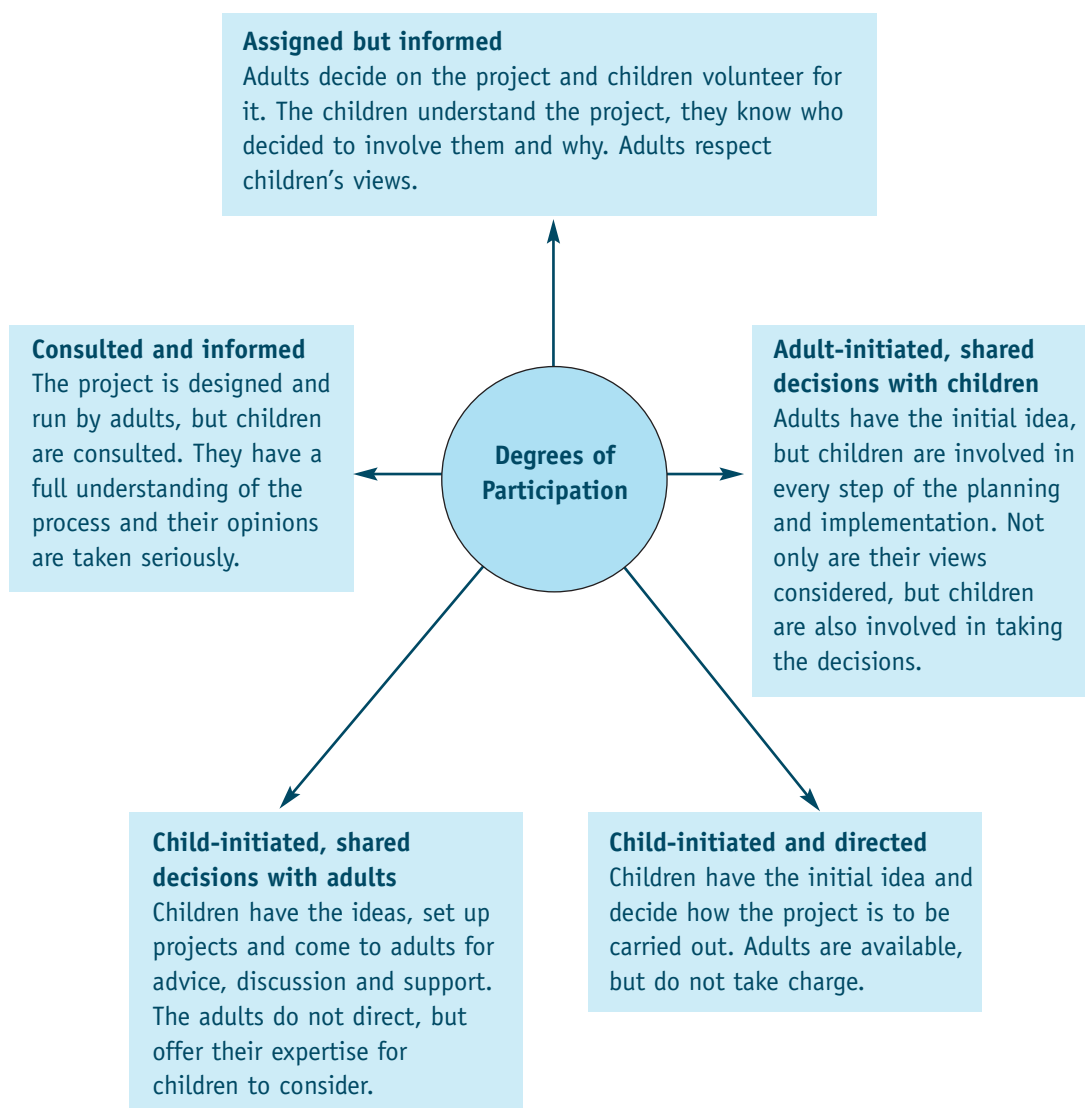
*(Children First: National Guidelines for the Protection and Welfare of Children, Department of Health and Children, 1999)*

5. Any reasonable suspicion of abuse (physical, emotional, neglect) must elicit a response from the care-giver/those responsible for the child, i.e. the interviewer (*Children First*, 1999).
6. The child will be reunited with their significant others and with ward staff.
7. The researcher will inform senior ward staff about the information that the child has disclosed during the interview process and all events leading up to disclosure.
8. Based on the information disclosed by the child, senior ward staff will in turn act appropriately in accordance with local guidelines for dealing with issues such as this (*Children First*, 1999).
9. Reassurance will also be given to the child and the family that the termination of the interview will in no way negate against any future medical and nursing interventions that the child may require during their hospital admission.

Signed: \_\_\_\_\_

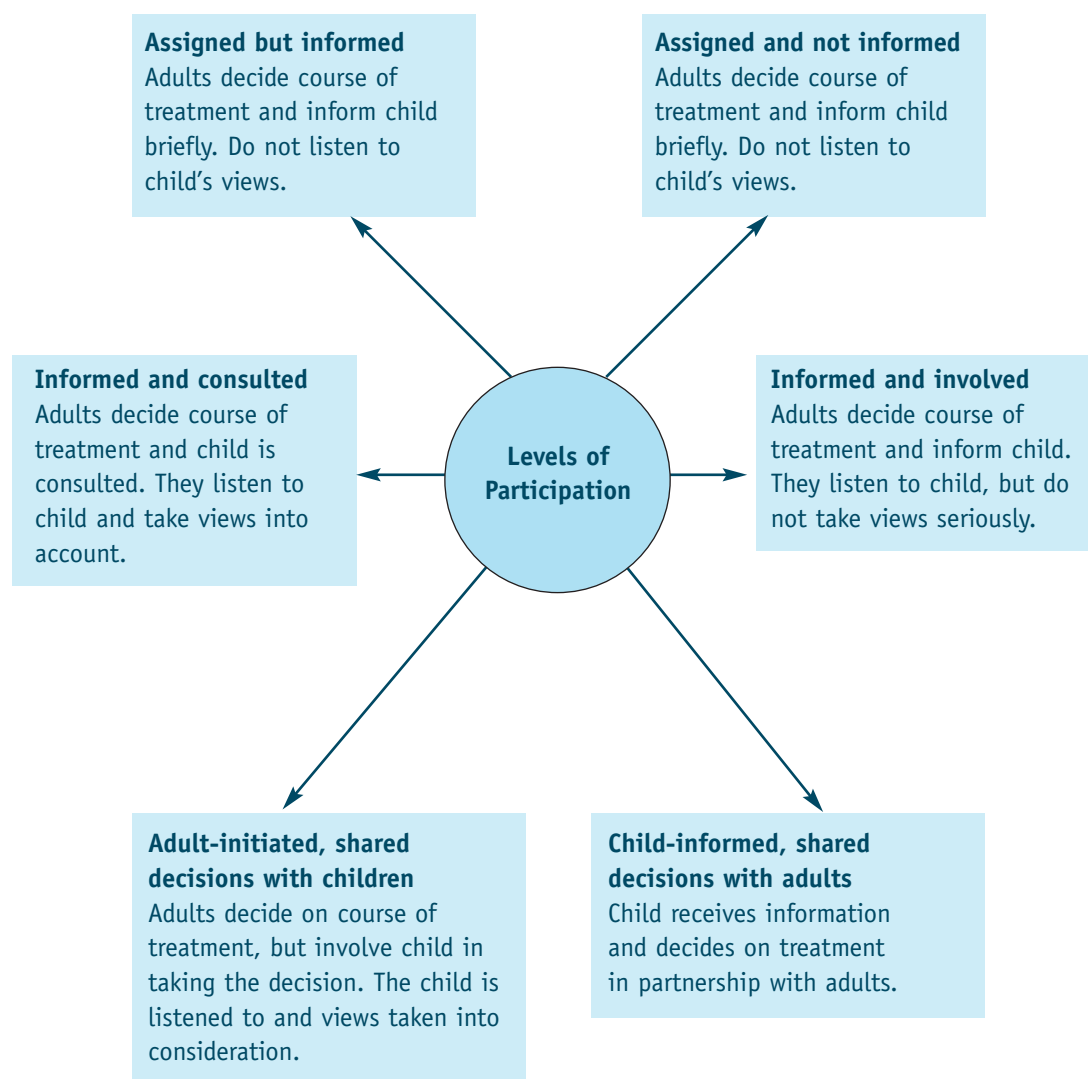
Dr Imelda Coyne, *Principal Investigator*  
Ms Eilis Hayes, *Research Assistant*

## Appendix 11: Treseder's Degrees of Participation



Source: Treseder (1997)

## Appendix 12: Children's Levels of Participation



Source: Adapted from Treseder (1997)





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