



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

## 1. What is the study's background?

This study was funded by the Office of the Minister for Children and Youth Affairs (now the Department of Children and Youth Affairs) under the National Children's Research Programme. The study was undertaken by Dr. Imelda Coyne, Ms. Eilis Hayes, Dr. Pamela Gallagher and Ms. Geraldine Regan, all of Dublin City University (DCU).<sup>\*</sup> The report was independently peer-reviewed and published in 2006.

## 2. What is the study's purpose?

The purpose of this study was to investigate sick children's experiences of participation in consultation and decision-making within the healthcare setting. The specific objectives were:

- » 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.

This briefing note summarises the method of research, key findings, conclusions and recommendations of the study. The full report is available on [www.dcyia.ie](http://www.dcyia.ie)

## 3. How was the study undertaken?

The methods employed were designed to achieve the above objectives. The study was based on:

- » *A literature review* of both international and Irish research studies.
- » *Focus groups and single interviews* with similar numbers of acute and chronically ill children in hospital. The children were aged 7-18 (N = 55) and were sampled from the population of children in three hospitals (two children's hospitals and one children's unit in a District General Hospital).

## 4. What are the key findings?

### 4.1 Children's experiences 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. Being involved in the consultation process made children feel valued, involved, comfortable and less anxious. The significant factors that enhanced the consultation process for the children were:

- » familiarity with hospital and procedures;
- » age level;
- » relationship with health professionals;
- » time.

<sup>\*</sup> The views expressed in this report are those of the authors and not necessarily those of the Department of Children and Youth Affairs.

The age and maturity of the children were important factors in the extent to which health professionals respected their wishes and needs. Health professionals tended to consult with mainly older children, which implies that younger children could be left with unanswered questions and insufficient information. Children with chronic illness reported forming trusting relationships with health professionals and participating more actively in consultations. Knowing the health professionals as people contributed to a trusting relationship, which enabled children to feel that they could ask questions freely and express their concerns. But some children reported difficulty in getting to know their health professionals due to lack of time, lack of frequent contact, many patients, busy workload and lack of continuity due to shift work. The development of a trusting relationship and good communication between health professionals and children should be fundamental aspects of good practice.

#### 4.2 Parents' role in consultation process

The children needed their parents to act as advocates, intermediaries and interpreters in the consultation process. 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 of 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 to limit exposure to potentially worrying information, while others preferred their parents to 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 in participating due to the 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 involved. Parents could inhibit children's attempts to participate by answering questions on their behalf,

telling them to stay quiet, reprimanding them for interrupting discussions and withholding information. Parents' actions may have reflected their need to protect their children's well-being and were thus well-intentioned. Some parents, however, may hold the belief that children should be seen and not heard and thus discourage their active participation. Therefore, parents may need help and encouragement from health professionals before they can support their children's participation efforts.

#### 4.3 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 hospitalisation, particularly fear of the unknown, but also inadequate information and communication led them to feel 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 combined with children's suspicion of health professionals withholding information from them potentially undermined the children's trust in their health professionals' good intentions and added to their 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, with expressions being used 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.

#### 4.4 Influencing factors on children's participation

The children actively sought involvement in consultations with health professionals, but were hindered by factors that included:

- » fear of causing 'trouble' by asking questions;
- » lacking time with health professionals;

- » difficulty contacting health professionals;
- » being ignored;
- » being disbelieved;
- » health professionals not listening;
- » not knowing health professionals;
- » difficulty understanding medical terminology;
- » being sick;
- » parents' actions.

Although there were many factors that appeared to obstruct children's participation, the key factors were health professionals' communication styles, attitudes and behaviours. The children reported that health professionals tended to 'do things' to them with a very brief explanation or no explanation at all. Many children reported difficulty in asking questions because of being rushed during their interactions with the health professionals.

#### 4.5 Children's views on decision-making

Some children wanted to be involved in decision-making, while others were happy for the decisions to be left to their parents and the professionals. Leaving decisions to parents/health professionals does not indicate lack of competence; rather, it demonstrates that children have the ability to choose. 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 ages 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 own beliefs about the age 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.

#### 5. What are the conclusions?

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 involved. It was evident from this study 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, which recognises that children need protection while at the same time allowing flexibility for the child's emerging knowledge and self-determination.

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, and this is in keeping with Goal 1 of the National Children's Strategy. 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.

The study shows that children want to be kept informed about their care; be adequately prepared for specific procedures; and, in particular, be involved in the 'small' decisions about everyday care. Children and young people said they worried when their parents were taken aside by health professionals to talk, and parents themselves were reported as playing a critical role in facilitating and encouraging – but also sometimes obstructing – children's participation. 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.

The study reached the following overall conclusions:

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

- » Children and young people reported that information provided should be tailored so that it is accessible and appropriate according to individual children'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.
- » 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 their 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.
- » 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.

**2. A commitment from senior management to the principle of consultation with children was identified as important and this commitment could take a number of different formats:**

- » It could, for example, include an education and awareness campaign for parents, children and health professionals.
- » Initial and ongoing 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, which would be subject to evaluation, should be advanced.

- » 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, web-based notice-boards).

**3. 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 themselves 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; and overall coping with hospitalisation.

## 6. What are the recommendations?

This section presents the recommendations emerging from the study.

### 1. Health service providers

- » 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 and their lives.
- » Develop and implement initial and ongoing training programmes focusing on children's participation for all healthcare staff working with children.
- » Develop appropriate mechanisms at an organisational level to facilitate children's participation within healthcare settings. These may include formal structures where children are represented, facilitated to participate and have their views taken into account in the decision-making process.
- » Ensure children in hospital are aware of their right to participate and that they develop the necessary skills to do so in a meaningful way.
- » Ensure that written information provided for children is age-appropriate, respects cultural issues and is accessible and relevant.

### 2. Research commissioners

- » Research should be undertaken on how parents and professionals can best facilitate children's efforts to participate.
- » Research should be undertaken that incorporates the perspectives of child–parent–health professional on information-sharing and decision-making.

## 7. What are the benefits of the study?

The benefits of this study arise from the fact that children's views were directly accessed, whereas most of the research on decision-making has taken the adult proxy view (parent or health professional). In the process of researching children's experiences of consultation and involvement in decision-making, what is most important for children is being listened to, being heard and having the opportunity to ask questions. Information is an essential prerequisite for participation in decision-making. Therefore, if children are excluded from the information-sharing process, their efforts to participate are severely curtailed. Children want to be involved in the decision-making process, but for most the process of consultation is of key importance. Some 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.



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Check out [www.dcy.a.ie](http://www.dcy.a.ie) for full report of study