



**Principles for
Involving Children and Young People in the
Service **Planning and** Delivery Processes
for Hospital Services**



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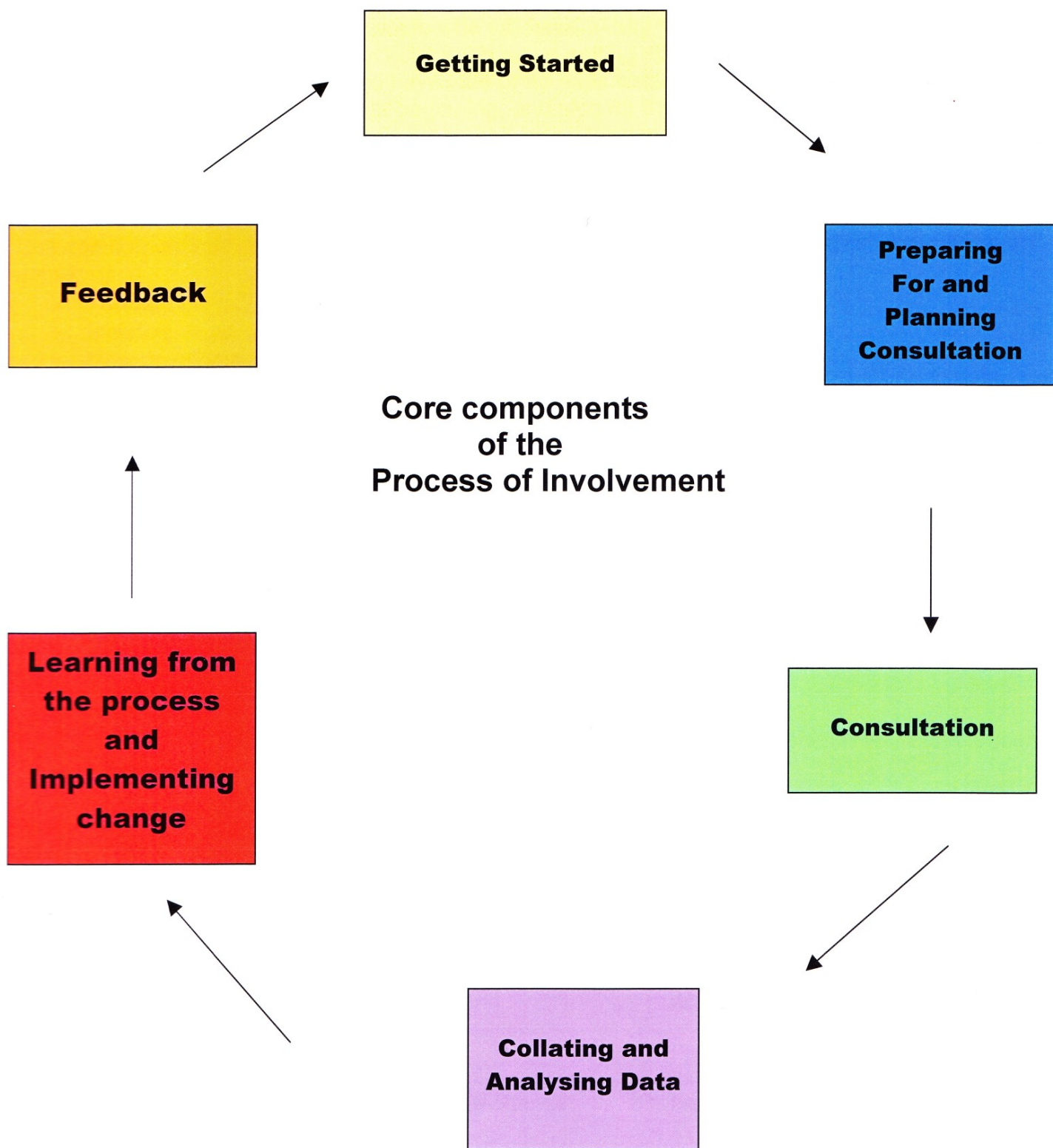
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Diagram 1. Core components of the process for Child and Young Person Involvement.



How to Use This Guide

This is a simple practical guide on how to consult and involve children and young people for staff working within an acute hospital setting. The guide highlights some of the key issues to consider and gives practical examples of different approaches.

In recognition of the spectrum of people who will have a duty to involve children and young people in the planning and provision of services in an acute setting, the guide is written for a broad audience. This includes those who have little or no experience in consulting with children and young people and are therefore just beginning, and also for those who want to build upon previous consultation activities. The aim of this resource is to act as an aid and easy to use guideline, however if greater detail is required on involving children and young people in consultation further reading is recommended and a section on this has been included.

Consultation with children and young people could be about gathering information and opinion on a specific

- Theme
- Initiative
- New development
- Service provision or
- Policy

Consultation is more than asking the child or young person for their views. It is also about listening to them and turning their ideas into reality.

When undertaking the consultation process it is necessary to consider the aims and objectives of the project and the need to identify which children and young people will be affected. In addition there may be many different approaches that can be taken depending on the type of project to be undertaken and the age and development of the groups of children and young people to be consulted. This guide gives guidance in these areas however it is not exclusive and many other ways may exist which are equally successful. It also gives a checklist at the end of each chapter for 'things to do'.

Each section of the guidance is colour coded and deals with a specific theme. These can be used as a whole or as individual units.

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Introduction

Chairman's Introduction

If we are serious about involving children and young people and giving them the opportunity to take an active part in the shaping of the services they will use, we need appropriate guidelines when understanding this work. Those of us who enter into involving children and young people must have real commitment not only to organisational change but to listening to and taking seriously the views of children and young people. The involvement of children must be safe, sound and effective, otherwise the exercise could be ineffective, frustrating and even damaging for those taking part.

Action for Sick Children has over 40 years experience of working with families, children and young people, and alongside professionals. We have attempted to draw together the Principles of involving Children and Young People in Service Planning and Delivery Processes for Hospital Services in this publication.

We recognise that many of us need guidance on the process and we offer some guidelines alongside examples of good practice.

I recommend this publication to all of those wishing to involve children and young people in the decision making for new and reconfigured services.

Pamela A Barnes

Chairman

Background to patient and public consultation and involvement

There has been a marked difference in the approach taken in today society by involving the public in decisions that affect them. Additionally public and patients are now consulted on services and developments in healthcare and participate at all levels in the process.

National Health Service

The NHS Plan (Department of Health 2000) puts patients at the centre of health care. National Health Service organisations and staff are strongly urged to ensure that they provide and develop health services and care that are truly responsive to the needs of users. A key element to this is the introduction of systems to ensure the public and patients are included in service development and their opinions are taken into account. In support of this a number of services have been developed, which include the Patient Advice and Liaison Services, Independent Complaint Advocacy Services and Patient Forums.

Why involve children and young people?

A number of initiatives, at national and international level, have influenced the way we view children and young people. No longer does the old Victorian saying 'children should be seen and not heard' apply but they are now actively encouraged to share their opinions and be involved in decisions that affect them, this includes their views on developing services.

With the exception of some initiatives, like Sure Start and Quality Protects, children and adolescents have not been seen as a defined client group and have been less involved in influencing changes in healthcare delivery. Policy and legislation however is changing and this requires children and young people to be involved in decisions not only about their own lives but the impact they have in society.

United Nations Convention on the Rights of the Child 1989

As far back as 1989, the United Nations Convention on the Rights of the Child was adopted and opened for signature, ratification and accession by General Assembly resolution 44/25. This powerful document, which has international status, stated that children and young people have the right to have their voices heard.

The Children Act 1989

One of the principles of this Act was that children should not only be kept informed about decisions made that affect them but that they should also actively participate in those decisions that are made about their future. The involvement of children and young people, in the decision making process, is enshrined here in legislation.

Getting the right start: National Service Framework for Children. Standard for Hospital Services 2003

This policy document was the first major piece of national policy that set standards for children's health and social care, stating, "Children and young people should receive care that is integrated and coordinated around their particular needs, and the needs of their family". It further promoted the ethos that children and young people should be involved in the decision making process and that they should be "encouraged to be active partners in decisions about their health and care and, where possible, exercise choice"

It went on to say that child centred hospital services are about working "in partnership with children, young people and parents to plan and shape services and to develop the workforce". Children, young people and families should be routinely involved in the planning and improvement of services. Methods of seeking children's and young people's views should be consistent with the government principles of participation; this was previously stated in a document published by the Department of Health 2003 Involving Children and Young people – an Introduction.

As part of the Patient Advisory and Liaison Service and Patients Forum agenda children and young people may have access to an advocate, and make a complaint if they wish and that children, young people and parents should be included in Trust patient surveys.

Although it has been demonstrated that children and young people are to be involved in decision making and development of services through examples of policy and legislation there are additional benefits to seeking their views. Children and young people can give a very different perspective to a proposal or theme and therefore for that reason alone their views are a valuable commodity.

Involvement; who, when and where

Involvement of families in healthcare decision-making and the promotion of family centred care.

In the United Kingdom and the United States the concept of shared decision- making is relatively new, as is the concept of family-centred care ((Baucher 2001), which has really only come to the fore front in the last ten to fifteen years (Hutchfield 1999). It has however led to a major shift in the way care is delivered from primarily a nurse led model, where the nurse controlled the amount of involvement the parent had in the care of their child, to one which is based on a partnership model, whereby a more collaborative relationship exists (Nethercott1993).

This model has further developed as the child and young person is also now seen as someone in their own right who has a view and can contribute both to their plan of care but also to the development of the service which delivers that care.

“Listening directly to children and young people often prevents the power of the messages being lost in translation. In the past children’s comments may have become quite distorted when passed on from child to parent to nurse to manager- like a game of Chinese whispers” (Cunliffe and English 1998 p. 19)

All children and young people may participate or be involved in many different healthcare settings, these include:

- The healthy child
- Children on a ward
- Children attending a clinic
- Children in adult focused areas
- District general hospitals or specialist children’s hospitals
- Children having surgery
- Children that are day case patients
- Children with chronic illness & children with disabilities

This list is not exhaustive.

However, the type of involvement and the approach that is used will depend on the age and development of the child or young person, as the method of involvement chosen for one group may not be applicable for use with another.

Additionally the purpose of the consultation will also influence what group is required; for instance the project may be to

- Improve services that already exist
- Design new services
- Work in new ways
- Share information.

All these issues must be considered.

Childhood Development

The developmental differences across the age range of children and young people are vast. Indeed this is true not just from a physical perspective but also on the development and abilities of the specific group being considered. With this in mind a number of areas need to be recognised and provided for, when establishing the correct method to be utilised in which to engage with the child or young person. Below are some of the areas, which have relevance.

- Attention span
- Language development
- Communication skills (Reading and writing ability)
- Play skills
- Physical abilities/development
- Sensory and intellectual development
- Social and emotional development
- Motivation

It is recommended that any additional information regarding these and other areas of childhood development can be obtained through further reading as suggested in the further reading section

1. Getting Started

Before embarking on any patient consultation there are a number of issues to be considered, most of which will be considered in the next chapter. The following however will contribute to the potential success of an involvement process if organised prior to the start of the project

Assigning Responsibility

In some hospitals there is a lack of representation for children and in particular a lack of paediatric leadership. It is crucial, when proposing to undertake a project that includes the involvement of children and young people, to identify a lead person or team leader to coordinate the activities and who have the level of authority to take action based on responses.

They need to: -

- Have experience in working with children and preferably in public involvement.
- Give advice on how to involve users and ideas on how specifically to engage children and young people.
- Highlight any training needs. This may include not just for the children themselves but the professionals who are already working with children and young people and will be involved in the project. It does not always follow those professionals who are clinical experts have user consultation skills.
- Have autonomy and authority to make decisions

The leader however of the project may not actually facilitate the group, their role will be discussed further later in the document.

Reviewing Current Activities

There are many levels of public and patient involvement and some patient and public involvement may have already taken place within the hospital setting. These may or may not have included the involvement of children and young people however some of the experiences from this may be shared and learning from previous work could help in the proposed project. Gathering information on previous projects and methods may contribute to the future work proposed.

How this integrates with the organisation

There are a number of issues to consider when planning consultation activities and events with children and young people. It is important to weigh up the risks and benefits of the consultation activities, thus good planning and preparation are essential. It is also paramount that you consider how the work that you are about to undertake relates to the rest of your organisation and therefore whom you may need to notify before you undertake a user consultation activity with children and young people.

Policies and Procedures within your Organisation

Additionally you will need to consider how the following policies and procedures will affect the consultation process and what arrangements need to be put in place in relation to the child, young person and family: -

- Data protection
- Confidentiality
- Consent issues
- Ethics and research committee approval
- Equal opportunities
- Support for children and families
- Practical issues such as contact details, transport, access
- Payment and acknowledgement

Some of these policies may already incorporate application to children and young people but where they do not mechanisms will need to be put in place to ensure the child and young person is protected.

CHECK

Do you have a lead for the project and do they have the right skills?

Are their responsibilities and remit clear?

How does the project impact on the organisation?

Do others in the organisation need to be aware of the project, if so have they been contacted?

Are there policies or procedures, which need to be taken into account when running the project?

Are they relevant to children?

2. Preparing for and Planning Involvement

Principles for involving children and young people

As with many processes some time spent at this stage can save both time and resources later and will have a direct impact on the quality of the information gathered. It is also important to assess any potential risks associated with the project and consider the ways to eliminate or minimise them at this stage.

The challenges in involving children and young people in the process.

There can be difficulties in user and public involvement generally, for instance;

- the reliability of particular techniques
- the lack of accurate representation of the diversity of views of service users, and user issues.
- the organisational culture,
- the professional culture
- the commitment of front line staff and the wider organisation.

Involving children and young people may bring additional problems specifically for that group.

These may include

- some people not valuing children's views
- thinking that it is not appropriate to involve children and young people in service development
- difficulty in knowing how to contact the children and young people
- thinking that the processes are too complex and time consuming for children and young people to be involved.

Consideration should be given as to how each of these issues is to be approached and managed.

The Children's Task Force states *"participation work requires capacity building and investment both in developing skills in children and young people themselves and in developing interpersonal skills with staff to create change within the culture of the organisation"* (DOH website).

Investment at the outset in explaining the value of involving children and young people and the potential benefits will reap benefits later.

Type and level of involvement

What is important however is to establish at the beginning what is the aim of the consultation, what is it that is to be achieved, how the views are going to be obtained and how will they influence the delivery of service. The type and level of involvement will depend on the specific project or piece of work and the children or young persons it will affect.

It is important to establish at the beginning what type of involvement is required from the child or young person. The following cover a spectrum of potential ways:

- One-off
- Indirect
- Ongoing
- Direct
- Adult initiated
- Child/young person initiated
- Children lead the project
- Adults lead the project
- Children/young people share the decision making with the adult.

In addition the approaches used can be acknowledged formally or they may be based in practices that are informal.

Example:

- *Can you fill out this questionnaire please?*

Formal, individual basis. The information from this is gathered and collated into a larger group, which then can be used to make changes for the greater environment.

Example

- *Did you enjoy your lunch? Are you comfortable?*

Informal, individual basis. Responses may not be recorded, but they may be acted upon to create change for the individual but are unlikely to be recorded to create wider change/action.

Consulting with Children and Young People.

A number of principles should be applied when consulting with children and young people and consideration must be taken into account of their specific needs. Apart from ensuring the right method is used for the right group it is important that children and young persons

- Understand their role in the process, including the time and commitment required
- Views are respected
- Are only asked about issues that are meaningful to them
- Are given realistic expectations of what will happen with the information
- Consent to participating and are able to 'opt out' if they wish
- Understand that their individual contribution will be confidential
- Enjoy the process and have fun.

Mediums Available for Use with Children and Young People

Consulting children presents some challenges as some methods traditionally employed may not be appropriate or feasible for children and may fail to reach this particular group or not encourage them to feedback their views. Difficulties can include: -

- Age,
- Ability to communicate,
- Comprehension,
- Attention span
- Motivation

Therefore it is important to choose a method that is suitable for the individual or group involved in the consultation

There are a number of potential mediums that are available for use with children and young people. The following are examples.

- Pictures and Words drawn by children and young people —E.g. Pictures of Healthcare Package - Action for Sick Children
- Play - e.g. See example page 29 from Leicester Royal Infirmary
- Video e.g. see example page 28 Middlesex Adolescent Unit
- Activities e.g. see example page 26 example from Wolverhampton

- Workshops and suggestion forms e.g. see page 32 example from Doncaster and Bassetlaw Hospitals NHS Foundation Trust
- Interactive websites
- Child representation on advisory boards
- Written questionnaires

Time and Resources available

Once agreeing the aims of objectives of the project, assessing the type of involvement required and the potential medium to be used it will be necessary to assess what will be the resources required to successfully complete the project and fulfil the objectives.

It is important to be realistic at this point and include not only the financial considerations of the project such as staff and patient costs but also the amount of time that is to be allocated to the project.

CHECK

What are the risks to the project and how will they be managed?

What is the aim of the project?

What group of children or young people will you be consulting?

How will you prepare the child or young person?

What will be the medium of consultation?

Have the allocation of resources, including time been agreed?

3. Consultation

In order to undertake the consultation you will have identified your group of children and young people and agreed how and where the process of the consultation will take place.

As this guidance relates to the acute setting it is likely that the children or young persons will be contacted via that source.

Consent

Consent for the children or young persons involvement must be obtained before the consultation actually goes ahead. It is preferable to get consent from the child or young person and their parent or guardian. At this stage the child or young person will be explained:

- What the consultation is about.
- How they will be participating
- That they can change their minds and opt out at any time
- How the information will be used
- How they will be given feedback.

At this stage it is also important to remember that if a child's name, quotes, drawings or photos are to be used in any report consent will also need to be obtained.

Roles and Responsibilities of Staff

The project maybe undertaken by one individual or there may be a team of people undertaking the work, however whatever method is chosen safeguards must be put into place to protect the child or young person. For instance procedures should be in place if problems arise. This may include:

- Ensuring facilitators know what to do if they hear or see anything that concerns them about the child or young person's safety.
- Making sure that consultation is voluntary and without force or pressure
- Ensuring that the child or young person knows that they can stop the process at any time.
- Ensuring that the child or young person has another identified adult they can go to for help or advice.
- Making sure that that contact is supervised.

Role of facilitator

The role of the facilitator is vital to the success of the project and they must therefore be experienced with working with children and young people.

The following are 'good practice' principles of a facilitator;

- Good listener with an open mind, allowing the child to express itself and take the lead.
- Flexible in dealing with different age groups and the specific needs of children and young people
- Fair
- Aware of differing developmental requirements of children and young people and able to adapt to these.
- Creative and able to make consultation rewarding and fun.

Recording the involvement responses.

Like the medium used there may be a number of different methods for recording the information gained from the consultation. These may be;

- Written, such as questionnaires or drawings
- Videos
- Recordings

The facilitators may have to make their own record of the event or discussion with the child or young person in the event of a drawing being a medium or where a discussion has taken place where there is no recording.

It is important to explain to the child or young person what will happen with their responses and how they will receive feedback on how the information was used and what have been the outcomes from this information. (Do not make a promise to the child or young person if you cannot keep it)

This material is confidential and so mechanisms must be in place to ensure its security.

Finally ensure that the child or young person is thanked in some way for their involvement, this may take the form of a certificate, thank you letter or small gift.

CHECK

Have you obtained consent for all aspects of the consultation?

Do the staff involved in the project understand their roles and responsibilities?

Have you employed a facilitator with the right skills?

Have you recorded the responses?

Have you thanked the child or young person for their participation?