Royal College of Paediatrics and Child Health

# Not just a phase

## A Guide to the Participation of Children and Young People in Health Services

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## Foreword

I am delighted to write this foreword for 'Not Just a Phase – *A guide to the participation of children and young people in health services.*' History reminds us just how far we have come. Gone are the days when parents / carers in the UK were not allowed to visit their child in hospital, gone are the days when parents / carers could only visit their child in hospital from behind a glass window. The way we perceive children and their health care has fundamentally changed over the years. Sir Harry Platt, 50 years ago, had already grasped the importance of creating child health services that took into account children and young people's experiences and perspectives. His Committee's recommendations radically transformed child health services within hospitals.

This new publication "Not just a phase" further emphasises the need to continue on the journey to ensure children and young people access and receive a health service of the highest standard in hospital and in the community.

As President of the Royal College of Paediatrics and Child Health, I strongly believe paediatricians have a duty to respect, protect and promote the health of children and young people. Over the years, I have had the privilege of working with children and young people from many walks of life and I am continually fascinated by their insights, resilience and capacities to deal with traumatic, unfamiliar and at times life threatening situations. We do a great injustice to children and young people when, as a society, we fail to listen to their views, take on board their perspectives and value their contribution in shaping child health services.

This resource provides key information to ensure the safe, meaningful and ethical participation of children and young people within the delivery of health services and practically demonstrates how we, as child health service providers, can contribute towards creating a culture of participation within child health services. The National Health Service should not be a service designed just by older people for older people.

I warmly commend this publication to you and congratulate the authors.

Terence

Professor Terence Stephenson

President, Royal College of Paediatrics and Child Health

# Contents

## Purpose of the guide

*Not Just a Phase* is a guide to the participation of children and young people in health services and has been developed and published by the Young People's Health Special Interest Group of the Royal College of Paediatrics and Child Health. The guide is designed primarily for paediatricians, senior children's nurses and leaders of organisations which provide general and specialised health services for children and young people. Not Just a Phase provides information to ensure the safe, meaningful and ethical participation of children and young people within the delivery of quality child health services and practically demonstrates how we can contribute towards creating a culture of participation.

*Not Just a Phase* is divided into six sections:

- Why paediatricians and service leads need to know about children and young people's participation
- The theory and evidence basis for participation
- Key principles of participation
- Essential elements of a participation strategy and project
- How to create a culture of participation
- Examples of participation in practice.

Not Just a Phase, is not a prescriptive resource detailing the problem, diagnosis, treatment and follow up; it does not seek to cover all aspects of children and young people's participation such as their involvement in their own healthcare management and healthcare pathways.

We intend the guide to be just that, a "guide". A participation initiative is a bit like an overseas holiday or expedition. It needs planning and preparation, you need to think about where you are going and why, how you are going to get there, what will you do when you are there and with whom, and how will you most effectively spend your precious time and resources. When you are there you may have a map or guide book (maybe a bit like ours!) but you'll probably do some things which are not in the guide book. You might take an unexpected turn or try something off the beaten path; you might be creative with your time or just see how things turn out. It's worth remembering you're probably not the only person who has tried something similar before and they may well have documented their journey and some of the wrong turns they took; so a little time researching can pay great dividends. Whatever kind of participation initiative you are planning we hope you will find something in our guide to help you and remember no one ever goes on just one holiday!

We hope you will find our guide insightful and informative.

Dr Damian Wood
Dr Gill Turner
Dr Fiona Straw

> "Not Just a Phase provides an insight into the key information, tools and signposts needed to help you navigate your way as you embark on the journey to ensure children and young people are not only beneficiaries of a health service but key stakeholders influencing the quality and delivery of their health service."
>
> Bharti Mepani, Children and Young People's Participation Manager, RCPCH

The title of this guide "Not just a phase" is a quotation from young people involved in the Northumberland Young People's Health Project, challenging the idea of "adolescence" simply as a transitional period , affirming the experience of being a young person, and reminding all of us of the importance of ongoing participation of children and young people.

## Authors and contributors

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## Executive summary

- Participation is defined as the process by which individuals and/or groups of individuals can influence the decision making process and bring about change.
- Participation involves a continuum from involvement of individual young people in decisions affecting their daily life to the engagement of large groups of young people in making strategic decisions about the use of substantial healthcare resources.
- Children and young people's right to participate in matters affecting their lives is laid out in the United Nations Convention on the Rights of the Child (UNCRC), a legally binding International convention.
- Participation of children, young people and their families in the design and development of services is government health policy.
- There are different degrees of children and young people's participation and it is important to be aware of the pitfalls of non-participation such as tokenism, manipulation and decoration.
- The research evidence base for children and young people's participation is limited. Future research efforts should concentrate on important health outcomes and consider the cost effectiveness of different methods of participation. Consideration should be given to how interventions such as participation impact on health inequality.
- Participation has the potential to reduce health inequalities; however this requires an understanding of existing power imbalances, barriers affecting the involvement of children and young people from diverse backgrounds and a range of experience, and an invested commitment to address the inequalities.
- The ethos, culture and environment in which children and young people participate should be safe, age-appropriate and accessible for children and young people with a range of abilities.
- Safeguarding children and young people, respecting their confidentiality and ensuring their wellbeing at all times is paramount to the success of any participation initiative and strategy.
- There are a number of key steps in planning a participation initiative. Children and young people should be involved in the planning. Youth workers have skills and expertise in facilitating the meaningful participation of children and young people.
- Service leaders should develop a culture of participation within their organisation.
- The participation of children and young people should be evaluated systematically and the outcomes shared with key stakeholders. The contribution that children and young people make should be valued and any successes celebrated.
- Children and young people can participate in many different ways, including commissioning services, designing the built healthcare environment, recruiting and selecting staff, governance of health services and developing healthcare research.
- There are many different methods by which children and young people can participate in health services including questionnaires and surveys, focus and advisory groups, interactive media, youth councils and forums or as mystery shoppers, young inspectors and young researchers.
- The participation of children and young people contributes to the quality of health services for children and young people, it improves the health of children and young people and it's fun!

# Why do Paediatricians and Service Leads need to know about Participation?

What is participation ?
– defining the terms

Children and young people’s right to participate

Participation is government policy

Particpation in our partner agencies

## What is Participation? – Defining the Terms

> “If young people aren’t involved and adults do all the planning then it isn’t as good or effective for us”
>
> 16 year old young person, Northumberland Teenage Health Demonstration Site

Participation is defined as the process by which individuals and/or groups of individuals can influence the decision making process and bring about change (Participation Works 2008). It is not specific to healthcare, nor is it specific to children and young people. Participation is about having the opportunity to express a view, influence decision-making and achieve change. Children and young people’s participation is the informed and willing involvement of all children and young people, including the most marginalised and those of different ages and abilities, in any matter concerning them either directly or indirectly. (Save the Children, 2005).

It is important to understand some of the terminology relating to participation. Participation is not consultation or involvement. Consultation is the process by which children and young people are asked for their views and opinions. Involvement, or engagement, describes the inclusion of children and young people in some form of decision making process. Participation is the process by which individuals and/or groups of individuals can influence the decision making process and bring about change. The meaningful participation of children and young people can directly or indirectly address health inequalities and creates a platform to allow them to influence healthcare services and resource allocation.

### Terminology

**Involvement** - describes the inclusion of children and young people in some form of decision making process

**Consultation** - the process by which children and young people are asked for their views and opinions.

**Participation** - the process by which individuals and/or groups of individuals can influence the decision making process and bring about change

In this guide we will consider the ways in which children and young people can influence the healthcare services which are provided for them. For example, how can children and young people be involved in designing hospitals, developing clinics, recruiting staff, assessing performance, determining healthcare priorities and the distribution of resources. We will also examine the benefits of meaningful participation for children and young people, the services and the potential benefits to others including society as a whole.

### STAYING POSITIVE – EXPERT PATIENT PROGRAMME

The Expert Patients Programme is a self-management course giving people the confidence, skills and knowledge to manage their condition better and be more in control of their lives. Staying Positive is part of the Expert Patients Programme Community Interest Company and is a self-management programme designed for young people with long-term conditions which aims to help them improve their confidence and self-management skills.

Staying Positive is delivered entirely by young people and has a completely different style and approach than the adult Expert Patient Programme. Each of the Staying Positive programmes three one day workshops is run by facilitators aged 14-25 years who have a long term condition. Each will have a "responsible adult" on hand to provide support. Participants are from 12 to 17 years old and have a variety of long term conditions. The workshops address self-management issues through role play and problem solving as well as other important health topics including sex and relationships, emotional well being, alcohol and substance use. Participants learn new skills to help manage their condition as well as meeting new people and getting support from others with similar experiences.

Staying Positive was launched in October 2007 after a successful evaluation of a two-year pilot. So far 150 young people have attended workshops and 22 have become facilitators. The programme is being rolled out nationally, with the aim of training 135 new facilitators and putting 5,000 people through the scheme by 2011. In 2008 the Staying Positive Programme won a Guardian Public Services Award.

www.staying-positive.co.uk www.expertpatients.co.uk

### Decision making in daily life

Participation involves a continuum from involvement of individual young people in decisions affecting their daily life (for example, who will help me with my physiotherapy) to the engagement of large groups of young people in making strategic decisions about the use of substantial healthcare resources (e.g. commissioning services) (Participation Works 2008). There has been much work published on the need for young people to be involved in decisions about their own healthcare management. The development of transition planning is empowering young people with long term conditions to take a greater part in the decision making process (Department of Health 2008). Participation of young people in their own health management is beyond the scope of this guide.

### UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD - ARTICLE 12

Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of the nation.

## Children and Young People's Right to Participation

Children and Young People’s Right to Participation is laid out in the UN Convention on the Rights of the Child (1989). We all have obligations under human rights legislation (both as citizens and as health professionals). As paediatricians we have a duty to respect, protect and fulfil the rights of children. The UN Convention on the Rights the Child, which has been ratified by the entire member states of the UN apart from the USA and Somalia.

The UNCRC is based on the premise that children and young people have the same inherent worth as adults, should be afforded respect and are entitled to preservation of their dignity, whilst recognizing the particular difficulties that children and young people face in influencing decision making. The UNCRC establishes participation as a right for all children and young people and is not limited by age, social status, disability or other characteristic of the child or young person and that participation is voluntary and applies to all matters concerning the child or young person.

### UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD - ARTICLE 23

States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

### UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD - ARTICLE 24

States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

The UK Government agreed to implement the convention in 1991 and thereby pledged to make the rights a reality for all children in the UK. The Department for Children, Schools and Families (DCSF) is currently responsible for making sure

the convention is being implemented in England and coordinates the UK-wide reports on the convention. Other international treaties including The European Convention on Human Rights (ECHR) give children specific rights, including expressing themselves. The ECHR is incorporated into English law through the Human Rights Act 1998.

To learn more we recommend:
www.crin.org

> "Whilst we celebrate the many achievements of the UNCRC in the last 20 years we must also look ahead to the next 20 years. As a College we are committed to advocating for child rights and involving children and young people in influencing policy and practice relating to their health service. We will continue to speak out with and on behalf of children and young people on child rights issues."

Professor Terence Stephenson, President, RCPCH

## Participation is Government Policy

The vision for the participation of children, young people and their families in the design and development of services can be found across a wide range of guidance and policy documents relating to children and young people published in recent years by the UK and devolved governments

For further information visit:
www.childreninwales.org.uk www.sccyp.org.uk
www.allchildrenni.gov.uk www.dcsf.gov.uk
www.doh.gov.uk

Below are some examples from the Department of Health (DH) and the Department of Children, Schools and Families (DCSF) for England

### The Chief Medical Officer's Report

In his Chief Medical Officers Annual report 2007 (Under their skins: Tackling the Health of the Teenage Nation) (Donaldson 2008) Sir Liam Donaldson explains:

"The active participation of young people in making decisions about their health, both at an individual level and at the strategic level of healthcare provision, is key. The free expression of views, given due weight according to the age and maturity of the child, is not only a human right, it is also known to improve health."

### EXTRACT FROM HEALTHY LIVES, BRIGHTER FUTURES

Initiatives to strengthen the voice of children, young people and parents in shaping services include:

- Implementing comprehensive Area Assessments– which from April 2009 will replace the Comprehensive Performance Assessments, Annual Performance Assessments and Joint Area Reviews (all methods of assessing quality of services and provision in a given area) – which will assess the performance of areas in achieving better health outcomes for children and young people, including how the views of children and young people are taken into account in doing so.
- Ensuring that children's voices are given prominence in the new Care Quality Commission's assessments of healthcare organisations.
- Exploring the feasibility of developing child and parent reported outcome measures to sit alongside quality measures and accreditation schemes. This will particularly be the case for children with long-term conditions.

### Healthy Lives, Brighter Futures

The Healthy Lives, Brighter Futures strategy for children and young people's health (Department of Health & Department for Children, Schools and Families 2009) outlines initiatives to strengthen the voice of children, young people and parents in shaping services.

### Every Child Matters

The requirement and entitlement to the participation of children and young people in service design and development is also outlined in Every Child Matters (Department for Children, Schools and Families 2009) and particularly relates to two of the five outcomes:

- Enjoying and achieving – getting the most out of life and developing the skills for adulthood
- Making a positive contribution – being involved with the community and society and not engaging in anti-social or offending behaviour.

## National Service Framework for Children, Young People and Families

The National Service Framework for Children, Young People and Families (Department of Health, Department for Education and Skills 2004) sets out standards for the delivery of health services for children and young people in the UK. Standard three of the national service framework sets out the obligation to all services providing healthcare to children and young people to include them and their parents in planning, evaluating and improving the quality of services.

### National Service Framework for Children, Young People and Families: Core Standards

Standard Three:

Children and young people and families receive high quality services which are co-ordinated around their individual and family needs and take account of their views.

Children, young people and their parents participate in planning, evaluating and improving the quality of services.

User participation follows the principles set out in Learning to Listen: Core Principles for the Involvement of Children and Young People.

Findings from user participation consultation, in all settings, are reviewed at Board level, reflected in improvements in services and are available to children, young people and their families.

## World Class Commissioning for Children and Young people

The Department of Health guidance on world class commissioning for children and young people (Department of Health and Department for Children, Schools and Families 2009) includes eleven commissioning competencies. The third of these competencies: engagement with the public and patients places an obligation on Children's Trusts to engage young people in the commissioning process and that this engagement should move beyond consultation to meaningful roles for young people in priority setting, monitoring and service design and that commissioners actively seek the views of young people and their families, especially vulnerable and hard to reach groups of young people.

### Extract from World Class Commission

Competency 3 - Engage with public and patients

Children's Trust partners engage with children, young people and their families to prioritise outcomes and shape delivery. Children, young people and families are not just listened to, but are fully engaged with the design and delivery of services, in order to secure improved outcomes. Creative and innovative approaches are being used to ensure that children and young people with multiple and complex needs, and vulnerable families are at the heart of this engagement. The engagement is a two-way street, in which the process itself is seeking to raise individual and community aspirations for improved health outcomes and develop a shared vision for achieving them.

### Extract from You're Welcome

Section 7: Monitoring and Evaluation, and Involvement of Young People

7.1 Young people are formally consulted in relation to current services and relevant new developments, and they are included in patient satisfaction surveys. Processes are in place to ensure that information gathered from young people is included in survey results and considered in service development plans.

7.2 The service invites all clients to give their opinions of the service offered and whether it meets their needs – for example by providing a suggestions or comments box with pen and paper in the waiting area, or through online feedback

7.3 Young people are involved in monitoring the service against the You're welcome quality criteria – for example through the mystery shopper studies.

### You're Welcome Quality Criteria

The You're Welcome Quality Criteria Toolkit (Department of Health 2006) includes quality criteria against which services can assess their progress to becoming young people friendly. The You're Welcome Assessment includes four criteria relating to the participation of young people and has been included in the NHS operating framework for 2009/2010.

## Participation in our Partner Agencies

Outside of the health service the development of Children's Trusts (Department for Children, Schools and Families 2008), Children and Young People's Plans for local authority (Department for Children, Schools and Families 2009) and Aiming High for Young People: A ten year strategy for positive activities (HM Treasury, Department of Children, Families and Schools 2007) also outline the obligation on service leaders and managers in our partner agencies to develop a culture of participation within their services.

### Extracts from Children and Young People's Plan Guidance 2009

Section 3: Scope of the CYPP

3.9 The genuine participation of children, young people, parents, carers and families is crucially important. They should all be encouraged to look at their current service provision and be asked about their hopes and aspirations for the future – to help develop a vision of what their services, communities and neighbourhoods should deliver. Local authority good practice shows that children's voices need to be at the heart of service improvements and planning for sustainable futures.

3.10 Some local partners have developed their own participation standards, often based on the National Youth Agency's publication 'Hear by Right' (Badham B & Wade H 2005). Save the Children has produced publications on Minimum Participation Standards, researching and consulting with children and young people (Save the Children 2001 - 2005). The National Children's Bureau (NCB) has produced a series of six leaflets Listening as a Way of Life on listening to young children, with details of research, practice and method (National Children's Bureau 2008).

### Children and Young People's plan DCSF

Each local authorities and its partners is required to produce a Children and Young People's plan (Department for Children, Schools and Families 2009) which sets out how the authority or Trust will improve the well being of children and young people in their area with regard to the five Every Child Matter's outcomes. This includes the commissioning and delivery of services for children and young people. During preparation of the plan the local authority or Children's Trust must involve children and young people in the development of the plan.

### Aiming High for Young People

Aiming high for young people sets out the government's ten year strategy to reform out of school opportunities, activities and support for children and young people (HM Treasury and Department for Schools Children and Families 2007). The strategy is based on the increasing evidence that participation in constructive out of school activities, particularly those that are sustained through adolescence, can have a significant impact on young people's outcomes in later life. Evidence suggests that participation in such activities can: improve engagement with school; improve social and communication

### Extract from Aiming High for Young People: a Ten Year Strategy for Positive Activities 2007

Empowerment – when young people have the opportunity to influence services they are more likely to find them attractive and to access and benefit from them. More marginalised young people can find formal processes unappealing and will need additional support to influence provision. Communities can also play a powerful role in improving and raising the priority of youth support services in their area.

skills and reduce rates of drug misuse, anti-social behaviour and crime. Participation in these activities allows young people to engage with positive role models, develop aspirations for the future and provides a gateway to services when problems develop.

## Working Together Listening to the Voices of Children and Young People

Working Together Listening to the Voices of Children and Young People (Department of Children, Families and Schools 2008) sets out how schools should give young people a say in how decisions that affect them are made in order to improve engagement in learning, develop a more inclusive school environment and improve behaviour and attendance.

The guidance includes information on how children and young people can participate in:

- The strategic planning and governance of the school through associate pupil governors and young people's councils
- Evaluation of school developments and lessons through consultations, lesson observation and working groups
- The recruitment and selection of teaching and other staff
- Peer support on important issues such as bullying

## Summary

- Participation is defined as the process by which individuals and/or groups of individuals can influence the decision making process and bring about change
- Participation involves a continuum from involvement of individual young people in decisions affecting their daily life to the engagement of large groups of young people in making strategic decisions about the use of substantial healthcare resources
- Participation is a right and is enshrined in the United Nations Convention on the Rights of the Child. Paediatricians and other health service providers have a special responsibility to uphold the rights of children and young people.
- Participation is government health policy and is reflected in Every Child Matters, the National Service Framework and Healthy Lives Brighter Futures
- Participation is happening in our partner agencies including education and social care and is part of an overarching strategy to strengthen the voice of children and young people in our society

# The Theoretical and Evidence Basis of Participation

The theoretical basis of participation

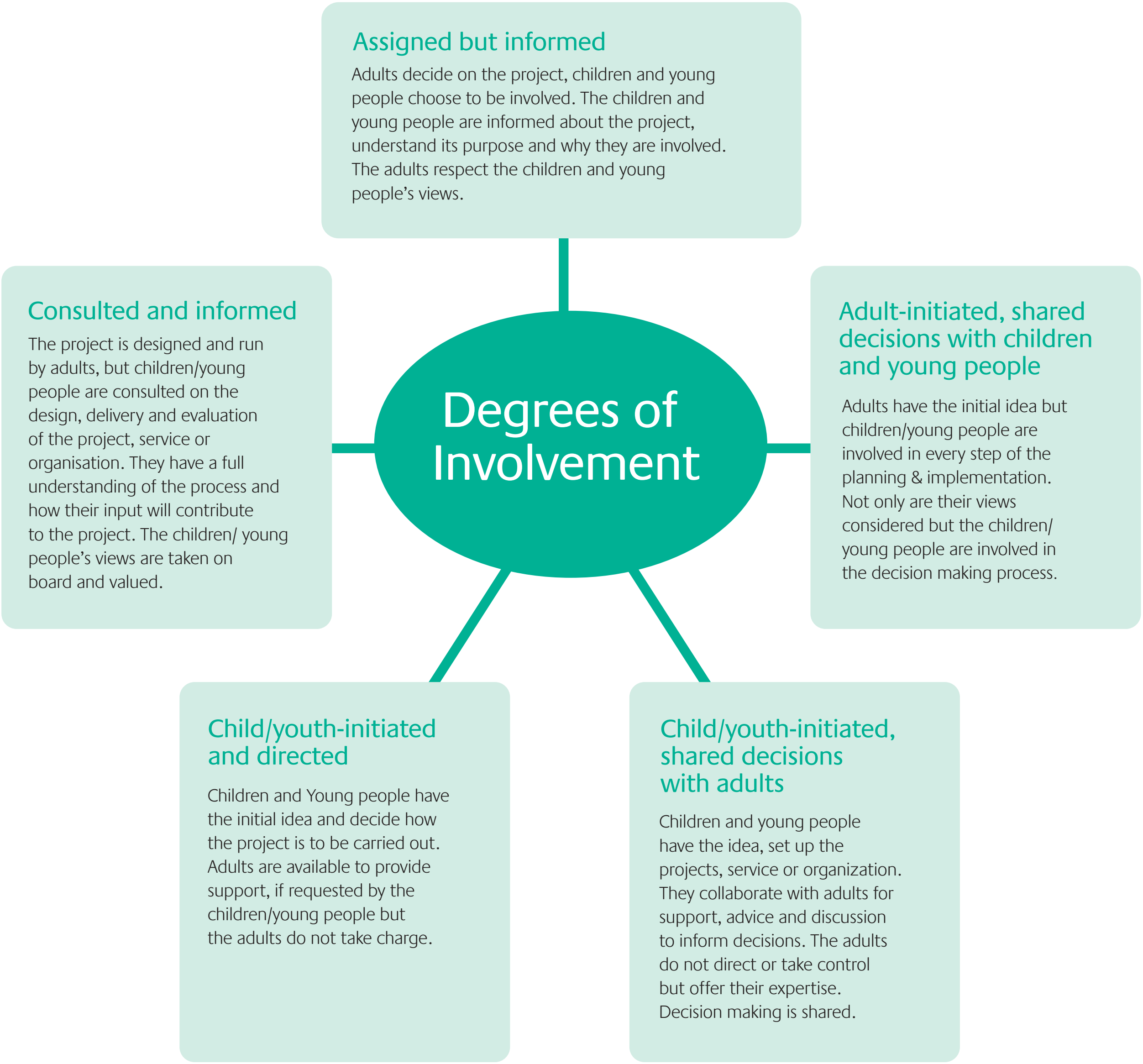
The evidence base for participation in health services

# The Theoretical Basis of Participation

The Five Degrees of Participation model (Treseder 1997) illustrates the different ways children and young people can be involved in decision making, taking into account the different contexts, circumstances and evolving capacities of children and young people. The model also considers constraints of time and resources.

## Defining participation

Boyden and Ennew (1997) provide two interpretations of user involvement. It can mean simply taking part, being present, involved or consulted, alternatively, it can denote a transfer of power so that participants can influence decision making. Thomas and O'Kane (1998) describe participation as "an ongoing process of children's active involvement in decision making in matters that concern them." There are a number of theoretical models to explain the ways that participation can affect social change. The original model of a "ladder of participation" developed by Sherry Arnstien in the late 1960s and the modified by Roger Hart in which a ladder with eight rungs represents the different degrees of participation by young people in decision making (Hart 1992). The lower three rungs of the ladder actually represent non-participation through manipulation, decoration and tokenism.



Degrees of Involvement

**Assigned but informed**

Adults decide on the project, children and young people choose to be involved. The children and young people are informed about the project, understand its purpose and why they are involved. The adults respect the children and young people's views.

**Consulted and informed**

The project is designed and run by adults, but children/young people are consulted on the design, delivery and evaluation of the project, service or organisation. They have a full understanding of the process and how their input will contribute to the project. The children/ young people's views are taken on board and valued.

**Adult-initiated, shared decisions with children and young people**

Adults have the initial idea but children/young people are involved in every step of the planning & implementation. Not only are their views considered but the children/ young people are involved in the decision making process.

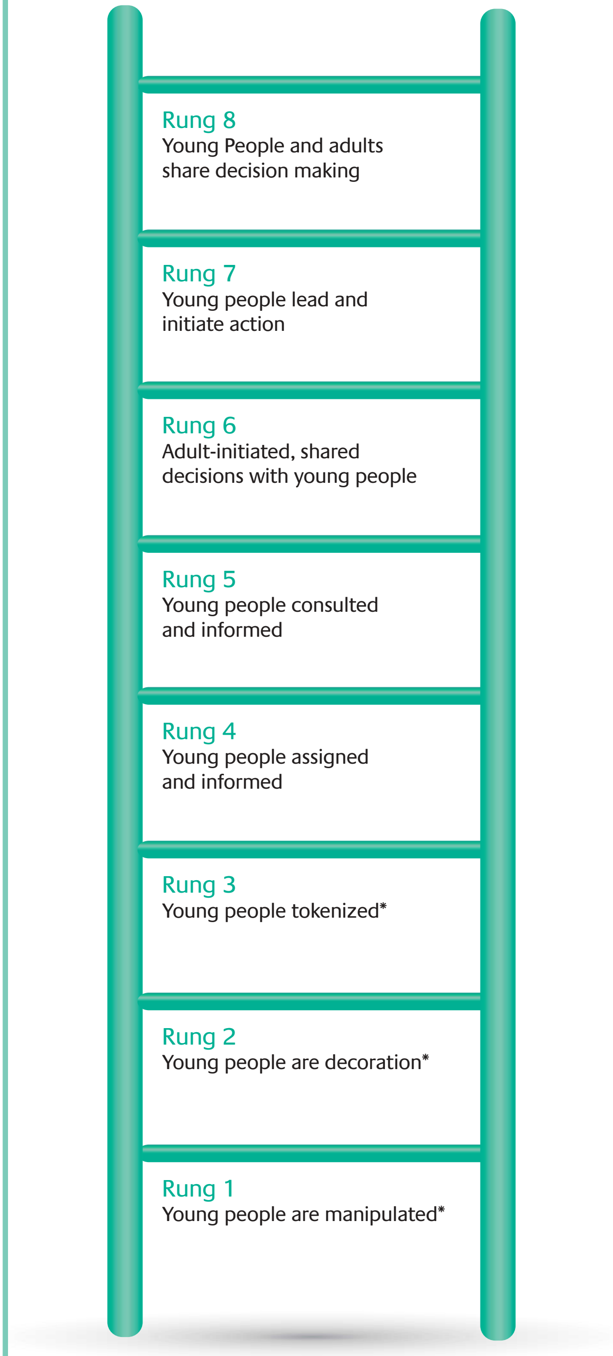
**Child/youth-initiated and directed**

Children and Young people have the initial idea and decide how the project is to be carried out. Adults are available to provide support, if requested by the children/young people but the adults do not take charge.

**Child/youth-initiated, shared decisions with adults**

Children and young people have the idea, set up the projects, service or organization. They collaborate with adults for support, advice and discussion to inform decisions. The adults do not direct or take control but offer their expertise. Decision making is shared.

## Roger Hart's Ladder of Young People's Participation



**Rung 8**
Young People and adults share decision making

**Rung 7**
Young people lead and initiate action

**Rung 6**
Adult-initiated, shared decisions with young people

**Rung 5**
Young people consulted and informed

**Rung 4**
Young people assigned and informed

**Rung 3**
Young people tokenized*

**Rung 2**
Young people are decoration*

**Rung 1**
Young people are manipulated*

*Note: Hart explains that rung 1-3 is non-participation

Adapted from Hart, R. (1992). Children's Participation
from Tokenism to Citizenship.
Florence: UNICEF Innocenti Research Centre.

### The five degrees of participation

ASSIGNED BUT INFORMED – where adults decide on the project and young people choose to be involved.
The young people are informed about the project and if they express a view this is reflected in the decisions made by the adults involved. However young people would not play an active role in the project design, decision making or implementation

CONSULTED AND INFORMED – the project is designed and run by adults, but young people are consulted on the design, delivery and evaluation of the project, service or organization. The young people are able to influence decision making.

ADULT-INITIATED, SHARED DECISIONS WITH YOUNG PEOPLE – adults have the initial idea and choose to undertake the project with young people. Adults open up the decision making process at every step of planning with young people being treated as equal partners. Together they ensure that the project is accessible and suitable for each other's participation. The views of young people are taken seriously and influence decision making. Young people and adults may take on different roles but these roles are defined by mutual consent.

YOUTH-INITIATED, SHARED DECISIONS WITH ADULTS - young people have the idea and set up the project, service or organization. They choose to undertake this in collaboration with adults as equals. Together they ensure that it is accessible and suitable for each other's participation. The young people views are taken seriously by adults and they influence all decision-making. Young people and adults may take on different roles but these roles are defined by mutual consent.

YOUTH-INITIATED AND DIRECTED – Young people have the initial idea and decide how the project is to be carried out. They may choose to seek support from adults, however the adults do not lead the project, but offer their skills and knowledge to the young people, which they may or may not choose to accept. Young people are in control of the process at all stages.

## Non-participation – the pitfalls of manipulation, decoration and tokenism

It is important to be aware of the pitfalls of manipulation, decoration and tokenism in developing a culture of participation.

### Manipulation

Adults can hijack or influence a participation project for their own means (rather than a motivation to ensure children influence decision-making). Manipulation may involve exaggeration of the involvement of young people, coercing young people into projects without their informed consent or briefing young people to such a degree that the views expressed are those of the adult.

### Decoration

Young people may be represented at an event but not actually involved in the event or proceedings, the classic example is the young person who presents a bouquet to a visiting dignitary without knowing who the dignitary is, why they deserve recognition or being involved in the decision to present the flowers.

### Tokenism

Tokenism describes the situation where young people are offered the opportunity to participate but the project has been badly planned and/or implemented. They may have no choice over the style or form of the process and too little time to either formulate an opinion and/or express it. The pretence is that children are being involved and will influence decisions but the reality is that the process is unlikely to be representative of young people's views and that their views will not be taken seriously or influence decision making.

### Case study - tokenism

A large teaching hospital trust is preparing its application for Foundation Trust status. The Foundation status application process requires that the trust show evidence of patient and public participation, including the involvement of young people. In response to this the PPI lead for the trust asks for some young people who are in-patients to receive a patient satisfaction questionnaire. A number of young people complete the questionnaire as requested however the results are not used during the Foundation Trust application as the opinions voiced by the young people were at odds with the views of the trust management team.

## The Evidence Base for Participation in Health Services

The evaluation of effect of participation on the young people involved, on professionals, on services and on the long term health outcomes for service users is complex. Not all activities reported to be participatory are in fact high quality examples of the real participation of children and young people and therefore the effects reported can be confusing.

As there is more and more effective participation of children and young people in health services we will increase our understanding of the effects of participation for individual young people and cohorts of children and young people using services where children and young people are participating effectively and continually. When evaluating participation activities it is helpful to be clear about the outcomes being measured and to ensure that the participation activity is of sufficient quality.

While the positive effects of participation on the responsiveness of the service and the health of service users are important, the broader effects of participation on the holistic wellbeing and longer term outcomes for children and young people are even more exciting. Measuring the effects of specific participation activities on these broader outcomes is challenging due to the number of confounders (e.g. socio economic change, cultural change, change in education methods) particularly when assessed over the longer period necessary for many of these outcomes.

## Systematic reviews

There are two published systematic reviews of involving patients in the design and development of healthcare (Coad 2006, Crawford 2002). One review specifically examines the literature on the participation of children and young people (Coad 2006). Both reviews used systematic search techniques to identify studies from both the published and grey literature using appropriate databases. The studies identified included both hospital and community based studies.

The review by Crawford identified 42 studies that described the effects of user involvement. The vast majority of studies were case reports or series with only a small number of studies describing the use of qualitative research methods. There were no studies using quantitative comparative or experimental research methods. The authors were unable to identify any reports that investigated effects of involving patients on the health, quality of life or satisfaction of those people using services. The review by Crawford found conflicting evidence on the effect on those participating with some studies reporting that staff and patients found the experience rewarding whilst others described dissatisfaction with the process. The most frequently reported effect of involving patients was new or improved patient information resources, but other changes included increasing the accessibility of services, the commissioning of new services, and preventing the closure of services. Some studies reported positive effects on organizational attitudes to involving patients, whilst others found that it slowed the decision making process and in some instances was used to legitimize decisions that had already been made. The authors conclude that whilst patients have contributed to the planning and development of services across a range of settings, and that the methods for engaging patients have been considered in depth, the effects on the quality and effectiveness of services are unknown.

The review of Coad et al attempts to scope the literature on the involvement and children and young people in the decision making process of healthcare services with the aim of highlighting good practice and identifying gaps. The authors state that they did not seek to assess the quality of individual studies. The review identified 20 studies from the published and grey literature which documented the involvement of young people in the health service development in hospital, community and mental health settings. All but one study was cross sectional, thirteen studies employed qualitative methods using a combination of questionnaire, interview and focus group methods. There was no assessment of the quality of the research methodology. The authors conclude that the majority of studies were small and descriptive and that it is difficult to generalize their results. They also state that there was a lack of diversity in the research design and methods employed. Whilst some studies did attempt to include marginalized groups the majority of studies did not include hard-to-reach groups.

The current evidence base for the effects of participation of young people in the design and development of healthcare services is inadequate. This absence of evidence does not mean that participation does not result in positive outcomes. However, the current evidence does not allow us to determine whether participation projects and strategies result in services which deliver improved and cost effective care and ultimately whether this has any impact on important health outcomes. The evidence base available suggests that participation is achievable, may take a number of different forms and may result in positive experiences for both young people and staff.

### Summary of the evidence

There are no high quality systematic reviews of the effects of involving children and young people in the design and development of healthcare.

The majority of studies identified in two published systematic reviews were case reports or series, cross sectional and descriptive rather than comparative or experimental. Some studies used qualitative research techniques but there was no assessment of the quality of these studies.

## Directions for future research

Ensuring that participation itself is meaningful and of high quality is an important part of the evaluation that should be reported on.

Future research of participation should include studies with an experimental/comparative design which employ both quantitative and qualitative methodologies. Studies should seek to include not only current service users but also potential service users and marginalized groups of children and young people. Consideration should be given to whether the views of parents and staff are important in determining the outcome of participation. Researchers need to consider what are the important health outcomes and how are these outcomes affected by complex interventions such as participation. There should also be some assessment of the cost of participation as well as the benefits and advantages both to services and to young people. If we are to develop a better understanding of the role of participation in improving health outcomes for children and young people health researchers need to liaise with researchers and practitioners in the fields of youth work, education, community development and local government among others. The Association of Young People's Health is a multi-agency organisation that is developing a community of professionals working in this important area.

## Summary

- There are different degrees of young people's participation
- It is important to avoid non-participation such as tokenism, manipulation and decoration
- The evidence base for children and young people's participation is limited with no high quality systematic reviews of the effects of involving children and young people in the design and development of health services. The majority of studies identified in two published systematic reviews were case reports or series, cross sectional and descriptive rather than comparative or experimental.
- Future research efforts should concentrate on important health outcomes and consider the cost effectiveness of different methods of participation. Consideration should be given to how interventions such as participation might reduce health inequality.
- The Young People's Health Special Interest Group of the RCPCH and the Association of Young People's Health are developing clinical and research networks of professionals working with young people.

# Section three: Key Principles & Values

Ethical considerations

Honesty & transparency

Health & safety

Confidentiality

Consent to participate

Safeguarding children and young people

Positive environment

Communication

Equality & diversity in participation

## Key Principles & Values

For clinicians and service leaders to engage children and young people effectively and safely in developing health services it is imperative to consider the following key principles and values which underpin the participation of children and young people:

- Ethical issues surrounding children and young people's participation
- Honesty and transparency
- Health and safety
- Confidentiality
- Consent
- Safeguarding children and young people
- A positive environment
- Issues of communication
- Equality and diversity

A participation policy should address how these issues will be dealt with and who has responsibility for ensuring they are given consideration. See section five creating a culture of participation for more information on developing a participation strategy or policy for your organisation.

## Ethical Considerations

As with any health strategy or initiative the basic ethical principles must be adhered to throughout. Consideration should be given to providing training on the ethical considerations for all parties involved. There are inevitable imbalances in power and status between adults and children. An ethical approach is needed in order for children and young people's participation to be meaningful (Practise Standards in Children's Participation, Save the Children, 2005)

Five major principles govern healthcare systems (Smith 1999) and these are as follows:

### Five key principles

Five major principles govern healthcare systems and these are as follows;

1. Health care is a human right

2. The care of individuals is at the centre of healthcare delivery but must be viewed and practiced within the overall context of continuing work to generate the greatest possible health gains for groups and populations

3. The responsibilities of the healthcare delivery system include the prevention of illness and the alleviation of disability

4. Cooperation with each other and those served is imperative for those working within the healthcare

5. All individuals and groups involved in health care, whether providing access or services, have the continuing responsibility to help improve its quality

Reproduced from Smith et al BMJ 1999

By considering the above five key principles clinicians and service leaders will ensure any work undertaken will be worthwhile for the children and young people involved as well as future patients, will change practice and will improve health services for children, young people and their families. If they are not considered then there is danger that despite intensive input from children and young people nothing will change and their time and energy will be wasted. There is the risk of facilitating the tokenistic involvement of children and young people, paying lip service, and reinforcing existing patterns that prevent children and young people from accessing quality health services. The following principles explain further how to ensure the safe, meaningful and ethical participation of children and young people.

## Honesty & Transparency

Clear policies are needed right from the start detailing the objectives, limitations, expected outcomes – (where this is known) and clear information about how the participation of children and young people will add value. This will ensure children, young people and other stakeholders are fully aware of what their participation involves right from the outset. These need to be documented and used as a reference. This enables everyone involved to have ownership of the project. It is also important that the process is closely audited so that lessons can be learned and the process can evolve and improve. Consideration must also be given to the protection of any data collated (Data Protection Act 1998).

## Health & Safety

The health and safety of children, young people and staff must be considered in the planning of a participation initiative. A safe and secure environment is a necessity enabling the process to be accessible by all children and young people whatever their background, experiences, capacities and abilities. There needs to be clear lines of responsibility so that participants know who to approach if there are any difficulties. Alterations and adaptations of the environment may need to be considered as well as resources to aid communication, specific disabilities and requirements. Knowledge of the cultural and ethnic mix of the local population will be useful in planning what resources may be needed. There needs to be a balance between having an environment in which children and young people feel safe and complying with traditional health and safety guidelines in health settings e.g. meeting with young people on the street. Clinicians and Service Leads must take into account their local health and safety guidelines when planning children and young people's participation. It is important that children, young people and their parents/ carers are made aware of the health and safety considerations taken into account.

## Confidentiality

Children and Young people have the same basic human right to confidentiality as adults regardless of their age and competence.

Should a child or young person disclose information suggesting that they are actually being harmed or are at a significant risk of being harmed then this information needs to be passed on to Children's Services. There should be a clear pathway about the process of breaking confidentiality. In most cases the child or young person involved should be informed of your decision unless it is felt that telling them that you are about to break confidentiality and discuss the information with other agencies will result in the child or young person being at a greater risk of being harmed. There should always be clear documentation of the decisions made and consultations with other agencies.

The rules of confidentiality should be discussed at the beginning of the participation process and clearly displayed in a variety of formats (such as leaflets and posters).

## Consent to Participate

Consent is the patient's agreement for them to participate in a clearly defined project. It is voluntary and continuing permission needs to be based on an adequate amount of knowledge of the purpose and nature of the project and their role in it. Permission given under undue pressure is NOT consent (Didcock 2006). The ability to give consent is determined by the 'competency' of the child or young person. Competency is influenced by age, cognitive and social development. Emotional factors and family environment can be very influential. There is no single test of competency in young people, good practice guidelines have jointly drawn up by the BMA and Law Society (BMA & Law Society 2010). They recommend considering the young person's:

Guidance for assessing competency in young people (BMA & Law Society 2010)

- Ability to understand that there is a choice and that choices have consequences
- Willingness and ability to make a choice (including an option that someone else makes that choice)
- Understanding the nature and purpose of the project
- Understanding the alternatives
- Freedom of pressure

There needs to be a clear policy on the involvement of adults with parental responsibility, whether information needs to be shared with them and whether consent is also needed from a responsible adult.

## Safeguarding Children and Young People

Safeguarding describes the broader preventative and precautionary approach to planning procedures that need to be in place to protect children and young people from any potential harm. It is imperative that any project involving children and young people is safe and doesn't put them at risk of being harmed or in a vulnerable situation where they feel pressurised to do things that they feel uncomfortable with. On the contrary, a participation activity should increase children and young people's confidence in expressing their views in ways they choose. Section 11 of the Children Act 2004 places a statutory duty on key people and bodies to make arrangements to safeguard and promote the welfare of children. The statutory guidance on the duty, which was first issued in 2005, has been updated. The revised version was published in April 2007.

Part one of the guidance sets out the arrangements that are likely to be common to all or most of the agencies concerned. Part two deals with implementation in each particular agency to which the section 11 duty applies. These arrangements require all agencies to have:

- senior management commitment to the importance of safeguarding and promoting children's welfare;
- a clear statement of the agency's responsibilities towards children, available for all staff;
- a clear line of accountability within the organisation for work on safeguarding and promoting the welfare of children;
- service development that takes account of the need to safeguard and promote welfare, and is informed, where appropriate, by the views of children and families;
- training on safeguarding and promoting the welfare of children for all staff working with, or in contact with, children and families;
- safe recruitment procedures in place;
- effective inter-agency working to safeguard and promote the welfare of children;
- effective information sharing;
- a local safeguarding policy available to, and accessible by, children and young people.

The guidance on the duty to cooperate is part of an interlocking set of guidance on the Children Act 2004. (Department for Children, Schools and Families 2006). All adults who have contact with children and young people (depending on the level of contact) may need to have a CRB (Criminal Records Bureau) check either a standard or enhanced check

## Positive Environment

The ethos and culture of the environment is crucial in enabling children and young people to participate. The environment should also be safe, age-appropriate and accessible for children and young people with a range of disabilities. The Disability Discrimination Act 1995, 2005 requires service providers to make 'reasonable' adjustments for a disabled person to access a service. The active involvement of young people with disabilities is important and to promote disability equality and involve disabled children and young people in participation activities extra resources may be required.

Safeguarding procedures enable us to develop a safe and positive environment for children and young people where there is no negligence or unnecessary exposure to avoidable risks. Where risks need to be taken policies should ensure that they are calculated, carefully managed and communicated to both children, young people, their parents, carers and staff.

Involving children and young people will help to promote an environment where their welfare is paramount and should help to develop a culture of inclusion, honesty, openness and mutual respect. It will help children and young people recognise that they have a voice and that their views are important and valued. This will make it more likely that they will feel able to raise any worries or concerns appropriately.

It will be important to be aware of the cultural and ethical diversity of the local population to help all young people to feel safe to take part. Faith and culture can be very important to children and young people' identity and often helps to influence their sense of belonging to any society or can make them feel isolated and different. Lack of awareness may lead to inadvertent prejudicial attitudes and exclude them rather than help bring down barriers enabling equality of access to health services.

## Communication

Communication is a two way process between at least two people. Effective communication reassures all parties that they are being heard, their contribution is invaluable, informative and important. Effective communication is central to the meaningful participation of children and young people taking into account their diversity, including age, culture, abilities, disabilities, language, experiences, vulnerabilities, and evolving capacities. Effective communication respects all those involved, it does not esteem one view above another based on status, it assures understanding from a variety of perspectives and takes into account all the expressed views – verbally and non-verbally. Communication can break down for a number of reasons. We must try to anticipate difficulties so that we can fully engage and interact with a diverse range of children and young people. For example, over a million children and young people have communication impairments in the United Kingdom (e.g. hearing, visual impairment, and autistic spectrum disorders), many of these impairments are 'hidden' as they are not always easy to see or recognise. We communicate using speech, gestures, facial expressions and by our behaviour. Sometimes these need to be augmented with the use of alternative communication such as Makaton or sign language.

It is also important to remember the variety of ways children and young people communicate including the use of technology and media. It is good practice to support verbal communication with written or visual information so that children and young people can take information away to process in their own time and perhaps share with a trusted adult.

### Children and young people with communication difficulties

Children and young people with communication difficulties are a marginalized group and present specific challenges when considering their involvement in service design and development. Children and young people with communication difficulties need to access a wide range of both specialist and non-specialist services and they have an equal right to involvement in the design and development of the services, health promotion initiatives and contribution to strategic direction. Lack of suitable equipment or support may inhibit their full participation.

Children with disabilities and communication difficulties may need assistance to participate. There may need to be special provision to enable the participation of children with English as a second language, sensory impairments or with severe/complex communication needs. This might include the use of translators, visual images and symbols on forms, or qualified signers. Telephone or face-face interviews might be appropriate with young people who have visual or reading/writing difficulties.

To learn more we recommend the How to Involve Children and Young People with Communication Impairments in Decision Making Guide from Participation Works www.participationworks.org.uk

## Equality and Diversity in Participation

"Children and young people's participation should not reinforce patterns of discrimination and exclusion but seek to address and challenge existing inequalities. Children and young people's participation should embrace diversity." Bharti Mepani, RCPCH

Meaningful participation does not seek to categorise children and young people as one homogeneous group and seeks to provide equality for all, regardless of their age, race, colour, gender, language, religion, political opinion, national, ethnic or social origin, disability, or status (or that of their parents/ carers). There is a risk that a participation strategy or project further increases health inequalities because of a lack of planning, knowledge or consideration of equality issues. It is important to ensure the participation process is representative of both current and potential service users. Invitations to participate should be inclusive, jargon free, culturally appropriate and accessible. Where necessary, support and opportunities for training and development should be provided to staff, children and young people so that they can contribute effectively.

## Participation of children and young people with a diverse range of experience

The recruitment of children and young people should be an ongoing process and should seek to involve children and young people with a diverse range of experience. Organisations should seek to involve children and young people from marginalised, vulnerable and hard to reach groups including those:

- from minority ethnic backgrounds
- with a disability or special needs
- with communication difficulties
- with English as a second language
- who are looked after
- who are young parents
- living in rural areas or disadvantaged neighbourhoods
- not in education, employment or training
- in the youth justice system
- who are refugees or asylum seekers
- from travelling families
- who are gay, lesbian, bisexual or transgender
- with a diagnosis of HIV

### Tips for success

It may be helpful to work alongside community services or statutory groups who already deliver health and wellbeing services for vulnerable groups (e.g. Children Looked After Team). It may take considerable networking, with frontline staff working with hard to reach communities, or incentives that appeal particularly to underrepresented groups. Consider the potential barriers to such groups participating in health services and develop advertising in conjunction with young people.

To learn more we recommend the **How to work successfully with Children and Young People from Different Faiths and Cultures** and **How to Involve Hard to Reach Children and Young People** guides from Participation Works www.participationworks.org.uk

## Summary

- The following key principles and values underpin the participation of children and young people:
- Ethical issues surrounding children and young people's participation
- Honesty and transparency
- Health and safety
- Confidentiality
- Consent
- Safeguarding children and young people
- A positive environment
- Issues of communication
- Equality and diversity
- Participation has the potential to reduce health inequalities however this requires the involvement of children and young people with a diverse range of experience
- Children and young people's participation should not reinforce patterns of discrimination and exclusion but seek to address and challenge existing inequalities.
- Work alongside community or statutory groups who already deliver health and well being services to children and young people who are vulnerable and marginalised from society.
- The ethos, culture and environment in which children and young people participate should be safe, age-appropriate and accessible for children and young people with a range of abilities

# Section Four: Essential elements of a participation project

Planning a participation project

Facilitating a participation project

Recruiting children and young people to participate

Evaluation of a participation project

## Planning a Participation Project

The meaningful participation of children and young people in healthcare requires organisations to develop a participation culture and strategy. Different organizations will be at different stages in developing a culture or strategy of participation and in reality participation often begins with specific projects designed to address particular service issues such as a consultation or the formation of a youth group. In this section we will provide guidance on planning and implementing a participation project so that you can get the ball rolling or if you are experienced in participation it may help you consider how to improve or streamline your projects. In section five we consider how to build a culture of participation.

### Planning a Participation Project

There are a number of key steps in planning a participation project and young people should be involved in this planning process:

- Be clear about the **aims and objectives** and take into account what resources you have available.
- Be clear about **the degree of participation** (see section on degrees of participation) and how decision-making will (or can) be shared with young people.
- Be **realistic about the extent to which change is possible.**
- Consider **who you will invite to participate**. Is your group representative of current or potential service users? Have you included children from marginalized groups for example, children looked after, black and minority ethnic children, children with disabilities.
- Which **methods of participation** would best suit the aims and objectives, resources and participants? It is preferable to employ a variety of methods and to involve young people in the methods to be used.
- Draw up an **ethical statement,** clarifying issues around consent (by children/parents), confidentiality, anonymity and disclosure.
- Consider developing a **contract of participation?** Will it include rewards for young people who participate?
- Plan **which staff you will be using as facilitators** and ensure they have the necessary skills.
- Consider the practicalities – what **potential obstacles** are there to completing the project?

## Facilitating a Participation Project

It is often useful to have a senior manager or clinician leading the project. The project lead should have close links and clear communication with whoever is facilitating the project. The senior member can take responsibility for organisational commitment and buy-in of health staff.

It is important that whoever is facilitating a participation project has the necessary skills to engage young people in the project and to assist the young people in completing the project. For most projects this will be nursing, medical or allied health professionals with little or no specific training in involving young people but they will of course have a mass of other skills, knowledge and experience to draw on.

Healthcare professionals should be aware that young people will have their own ideas and that the professional's role is to facilitate not to direct. They should respect the views expressed and seek to clarify those views are in a non-judgmental way. The facilitators will have an important role in maintaining the focus of the activity and outlining the boundaries. Staff should consider the words they use and avoid the use of jargon.

### Who might facilitate a participation project?

A YOUNG PERSON – this can be ideal if the young person has experience of participation work and the necessary skills, confidence and time to fulfil this role.

A GROUP OF YOUNG PEOPLE WITH AN ADULT SUPPORTER – in this scenario it is important for the adult supporter to be available, to be able to advocate and "keep track" of the project but not take over.

A PARTICIPATION WORKER – someone with specific training and skills in children and young people's participation. If you use an external participation worker consider how you will ensure the leaders of the organisation and the staff are "bought in to the project" as sometimes recruiting an external agency allows the activity to remain peripheral to the functioning of the service. It may also prevent health staff working with young people to develop their skills in and understanding of participation.

**A YOUTH WORKER** – If there is a youth worker as part of the health team this can be an excellent option. Otherwise the use of external youth workers carries the same risks and benefits as using an external participation worker.

**A HEALTH SERVICE MANAGER** – managers may bring organisational commitment and clarity about how the project fits into the overall priorities of the organisation. This does not necessarily guarantee staff buy in. It is important to ensure they have the correct skills to facilitate a participation project.

**A HEALTHCARE PROFESSIONALS (NURSES, DOCTORS AND ALLIED HEALTH PROFESSIONALS)** – professionals are usually in a really good position to understand what is wanted from the project, the main issues and the details of how the service currently functions. They can often ensure the buy in of other members of health staff. They may need support to develop skills in participation methods to enable young people to be effectively involved.

## What resources will you need?

Often, in practice, the facilitator is a healthcare professional with little or no training in participation. We hope the guidance provided in this pack will be a helpful resource. We recommend you make links with local staff that have experience of young people's participation (often youth workers, local authority staff or community and voluntary sector projects) and ask for their advice.

Whoever is chosen to facilitate the following factors are needed:

- Buy in from the staff of the service and the organisation.
- Clear focus for the project with commitment to listen to and respond to the outcomes.
- Support and training, to learn the basics of participation
- Time:
  - to plan and prepare
  - to work directly with the young people formally and informally
  - to liaise with the project lead (if different to the facilitator)
  - to organise the evaluation and liaise with evaluators if different
- Money – to reimburse the young people where appropriate, room hire, travel, refreshments etc
- Timescale - a clear and realistic timescale that makes it feasible for young people to participate and also gives them feedback on the effects of their involvement in a reasonable timeframe.
- Commitment to feedback to the young people involved, ideally by senior management with the involvement of the facilitator.

## Deciding on the right participation method

In planning your participation project it is important to consider which tools or methods you will employ to engage with children and young people. You should consider which method fits best with the objectives of the project. Other important considerations are whether the method is easily accessible to all potential participants. Web based questionnaires may look good but how accessible are they? Be realistic about the time it will take and the costs involved. Is this a one off project or part of a longer term strategy in which case it may be better to consider a standing advisory or reference group? Once you have decided on the methods you will employ consider who will be excluded and who is unlikely to participate? It is impossible to design a project which is representative of all young people but it is important to understand the limits of the methods you are using.

### What kinds of methods are there?

There are a number of methods of participation which may be incorporated into a project. Some common examples are listed below. There is no perfect method and you may need to employ more than one method.

- Surveys & Questionnaires
- Focus Group Work
- Large scale events
- Advisory & reference groups
- Mystery shoppers
- Young assessors, inspectors or selectors

In section six we consider some of these methods in more detail.

## Recruiting Children and Young People to Participate

### What motivates children and young people to get involved?

There are many reasons why young people choose to participate in developing healthcare services. These can be altruistic "wanting to make things better for other young people" or from a sense of appreciation "wanting to give something back". It may help the young person feel valued "my opinion counted" or allow them to have a voice "I was able to let staff know what needed to change". For others the motivation may be less focussed: it may present a challenge or something interesting to do.

### Asking children and young people to become involved?

Remember first impressions will affect decisions about whether children and young people will agree to participate. Before you start recruiting young people ensure that you have publicised the project and that the publicity materials explain the purpose of the participation, including, who you would like to recruit and some information about the commitment required. Once you start to invite young people you will probably be surprised by the positive response you receive; as long as you are sensitive about the timing of your request (for example, don't ask young people who have just received bad news or are distressed). It is better to approach young people individually and always ensure that they are willing to participate. It is important to explain that they can opt-out at any stage and their responses will remain anonymous and confidential. Consider how factors such as gender, ethnic and religious background, sexuality, disability, age and ability might influence young people's experiences and whether participants have the necessary skills, knowledge, confidence, commitment and time to do what is being asked.

### Valuing the contribution that children and young people make

Valuing the contribution of children and young people involves attention to details such as the timing of any sessions, the venue (is it intimidating for young people), transport and accessibility, and the need for accompanying adult support and childcare or interpreters. It is important to have contact telephone numbers so that young people can be informed if a session is cancelled – remember teenagers have busy lives too!

Young people state that what they want from the participation is reassurance that it will make a difference. If you do offer payment this should be done after their involvement is complete and only if participation has involved a substantial commitment. Young people value trips and meals out as reward for participation.

There should be a clear mechanism for providing feedback on the results and outcome to the participants and a realistic timescale for this to happen.

For more information we please see **How to remunerate and reward children and young people's involvement and How to celebrate children and young people's success** both guides are available from www.participationworks.org.uk

# Evaluation of a Participation Project

Evaluation is an important part of participation as it helps to ensure that you are doing what you set out to do. It also helps to determine whether the project has had the intended impact and if there are any lessons for the future or other projects. It is also important in celebrating and valuing the contribution of young people and providing information to those who fund either services or participation projects. Evaluation should be considered when planning a participation project and you should decide on the methods, resources available and who will undertake and analyse the evaluation at the planning stage.

## What kind of evaluation?

There are a number of different methods of evaluation. Evaluation can be formative or summative. It is important to consider how you will capture both expected and unexpected outcomes in the evaluation and whether the evaluation will look at process, outcomes or both. Evaluations often use more than one method and generate both quantitative and qualitative data.

It is important to consider: what are the key questions for the evaluation? These questions should be closely linked to the planned aims and objectives of the project. You may also need to relate your outcomes to the Every Child Matters or Youth Matters outcomes or to the requirements of funding organisations. In general outcomes of any project should be SMART:

- Specific
- Measurable
- Achievable
- Realistic
- Timely

## Involve young people

To reflect the involvement of young people in the project or your service they should also be involved in the evaluation. Be realistic about the level of participation that is achievable given the time and resources available. Consider how the evaluation will capture the views of hard to reach, marginalized or vulnerable young people.

## Analysis, presentation & dissemination

Having planned the evaluation and collected the data it is important that the data is analysed using appropriate methods. For more information about the analysis of data and how young people can be involved in the analysis please see Evaluating Participation Work – The Guide published by participation works www.participationworks.org.uk

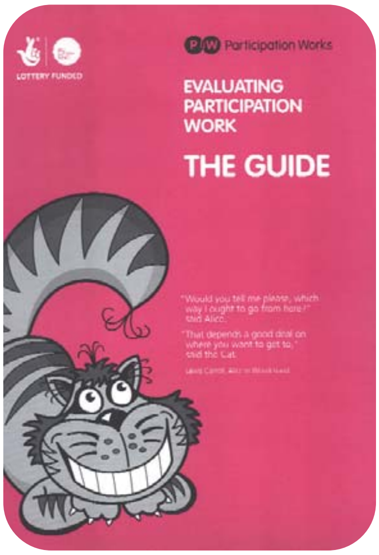
## Measuring change

It is important to assess the impact of the participation work undertaken by children and young people so that we can both improve health services and celebrate the involvement of young people in these positive changes.

Important assessments include:

1. Have young people influenced public decision making?
2. How have decisions been improved by including young people?
3. How has the organization benefited?
4. What have been the benefits for the wider community?
5. What have been the benefits for young people who participated?
6. How have other young people benefitted?

There are a number of tools available to assist you in measuring what changes have taken place including a number of resources published by Participation Works www.participationworks.org.uk. You could use tools such as the **What has changed?** tool from the National Youth Agency http://hbr.nya.org.uk/whatschanged and Measuring the Magic (Kirby 2002).



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Participation Works

EVALUATING
PARTICIPATION
WORK

THE GUIDE

"Would you tell me please, which way I ought to go from here?" said Alice.

"That depends a good deal on where you want to get to," said the Cat.

## Summary

- There are a number of key steps in planning a participation project and young people should be involved in this planning process:
- Be clear about the aims and objectives and take into account what resources you have available.
- Be clear about the degree of participation (see section on degrees of participation) and how decision-making will (or can) be shared with young people.
- Be realistic about the extent to which change is possible.
- Consider who you will invite to participate. Is your group representative of current or potential service users? Have you included children from marginalized groups for example, children looked after, black and minority ethnic children, children with disabilities?
- Which methods of participation would best suit the aims and objectives, resources and participants? It is preferable to employ a variety of methods and to involve young people in the methods to be used.
- Draw up an ethical statement, clarifying issues around consent (by children/parents), confidentiality, anonymity and disclosure.
- Consider developing a contract of participation? Will it include rewards for young people who participate?
- Plan which staff you will be using as facilitators and ensure they have the necessary skills.
- Consider the practicalities – what potential obstacles are there to completing the project?
- Consider who is going to lead the project and who will help to facilitate the project?
- Youth workers have special skills and expertise in facilitating participation projects
- Utilise the capacity that already exist within your organisation and seek support from partner agencies.
- Value the contribution that young people make.
- Evaluate the project, celebrate the success and share the outcomes with young people and other stakeholders.

# Section Five: Creating a Culture of Participation

Developing a participation strategy

Participation in commissioning

Participation in service location and the built environment

Participation in staff recruitment and selection

Participation in governance of health services

Participation to develop research

## Developing a Participation Strategy

Participation is not about one off projects. Rather it represents a philosophy of service user involvement which should pervade every aspect of service design and development. If you are a service lead, clinical director or medical director then developing a strategy of participation is one of your responsibilities. The Hear by Right standards and self assessment toolkit produced by the National Youth Agency (National Youth Agency 2010) and supported by materials produced by Participation Works are a useful guide. The Hear by Right standards are based on the seven “S” model for organizational change. The Hear by Right standards outline what a participation strategy might include and provides an example of a participation policy in the appendix.

The culture of participation within an organisation describes the involvement of children and young people in the service and in particular the organisational values, the extent of children and young people’s involvement, the types of involvement and the extent to which young people’s views are listened to and taken into account. An organisation has developed a culture of participation when the involvement of children and young people is an integral part of the way in which it operates and where the meaningful participation of children and young people is everyone’s responsibility rather than residing in an individual or department. Developing a culture of participation will ensure the meaningful and sustainable involvement of children and young people and the commitment of the whole organisation to this objective.

The development of a culture of participation requires organisations to change by being willing and able to listen to what children and young people say and give it due consideration. There are a number of stages for the organisation to travel through including: unfreezing existing attitudes and practices, using internal and external drivers, identifying leaders for change, establishing senior management support, engaging staff, building capacity and effective partnership working. This involves developing a vision and commitment to participation, understanding what this means in practice, communicating the vision to others and sharing and celebrating success.

### The Hear by Right Standards for Organisational Change

SHARED VALUES
An important starting point is that participation of children and young people is a central commitment of the service and that the service defines its shared values for children and young people’s participation. This includes adopting the convention on the rights of the child (in particular article 12) and involving young people shaping and agreeing the shared values. These shared values can be demonstrated in a number of different ways with vision, mission, policy or charter statements being the most commonly used tools.

STRATEGY
The service should have a written strategy which maps the resources and expertise available to involve children and young people in service development. The strategic plan should identify key staff, roles and resources identified for the implementation of the strategy. Young people should have a role in developing this service strategy.

STRUCTURES

Children and young people should be consulted on and help review the structures in place for their active involvement and a range of approaches to participation should be adopted including both formal and non formal processes that encourage and enable the participation of children and young people on their own terms.

SYSTEMS
Policies should be in place to ensure that the participation of children and young people is safe, sound and effective. These policies should cover consent, safeguarding, safety, access, transport, complaints, incentives and rewards. The service budgeting and financial systems should support the active involvement of children and young people and that recording and evaluation systems are in place to identify and share learning and evidence of change which arises from the participation of young people.

STAFF
The job descriptions for those in key leadership roles should specify the skills and commitment to participation. Children and young people contribute to the recruitment and selection and induction of key staff. The supervision and appraisal of relevant staff should include reviewing their contribution to enabling the effective influence of children and young people on the organization.

SKILLS AND KNOWLEDGE
There should be capacity building for children and young people to develop skills and knowledge to make change happen, including training in negotiation, presentation and finance skills. There is capacity building for staff to gain skills for the safe, sound and effective participation of children and young people. Children and young people should have access to information to allow them to participate fully in issues of importance to them.

STYLE OF LEADERSHIP
Key managers and leaders should act as champions for the active involvement of children and young people, with clearly identified responsibilities. Managers and leaders should support innovation on active involvement, accepting risks of mistakes and are committed to reflection and learning. They should also publicly acknowledge and celebrate the active involvement of children and young people and take an active part in key consultation and participation events.

For more information on developing a participation strategy we recommend the Hear by Right resources from the National Youth Agency www.nya.org.uk/hearbyright

## Participation in Commissioning Services

Commissioning is the process by which statutory organisations (such as health services, local authorities and Children's Trusts) use public money to deliver services to the populations they serve. Commissioning is a structured process which involves identifying the needs of the population, planning the service provision required to meet these needs, procuring services from a variety of organisations to meet these needs and then monitoring the delivery of the services as well as evaluating the outcomes for service users and the population as a whole. This process is encapsulated in the commissioning cycle (opposite). The outcomes from commissioning should match the priorities outlined in Every Child Matters namely being healthy, staying safe, enjoying and achieving, making a positive contribution and achieving economic well-being. There are opportunities for children and young people to be involved in each stage of the commissioning cycle.
The 2006 White Paper, 'Our Health, Our Care' highlights the importance of user involvement in developing services and making them more locally accountable through commissioning. In health services the guide 'Securing Better Health for Children and Young People through World Class Commissioning' (DCSF/DoH 2009) sets out the expectation of the involvement of children, young people and their families.

### Why involve children and young people in commissioning?

The aims of participation in commissioning are to provide services which are designed around the needs of the local population and that development of these services is ongoing and driven by the people who use them.
In addition services will be more accountable to the children and young people of the local population. The benefits to young people include a greater understanding of the diversity and needs of their local community and increasing the skills and confidence of individuals in changing the services provided for them.

### How can children and young people be involved in commissioning?

The meaningful participation of children and young people in commissioning takes time and resources and this should be accounted for in the commissioning strategy.
The commissioning process can be bureaucratic in nature and the effective engagement of young people requires planning in order to break down some of the barriers to involvement. Solutions to these barriers include making it fun and avoiding the use of jargon, long documents and bureaucratic meetings. Commissioners and other stakeholders may need guidance or training on how to work in partnership with children and young people and to ensure that they plan involvement around the availability of young people. Commissioners can build on existing participation work, or effective partnerships that are already in existence,

whilst, taking care that user involvement reflects the diversity of the local population. Children and young people should be provided with information about the commissioning process and the effect of children and young people's involvement at each stage.

Children and young people involved in commissioning may need training to help them understand the financial aspects such as budgets, economies of scale and opportunity costs and allow them to test out different commissioning scenarios to consider the impact of their decision making. Children and young people can also be involved in the governance of the commissioning process.

Service leaders can engage young people in convincing commissioners to invest in their service by identifying and prioritising needs, developing business cases and analysing data and information about the health of the local population and the need for a particular service. It will be more difficult for commissioners to ignore requests for funding based on the needs and priorities laid out by children, young people and their families.

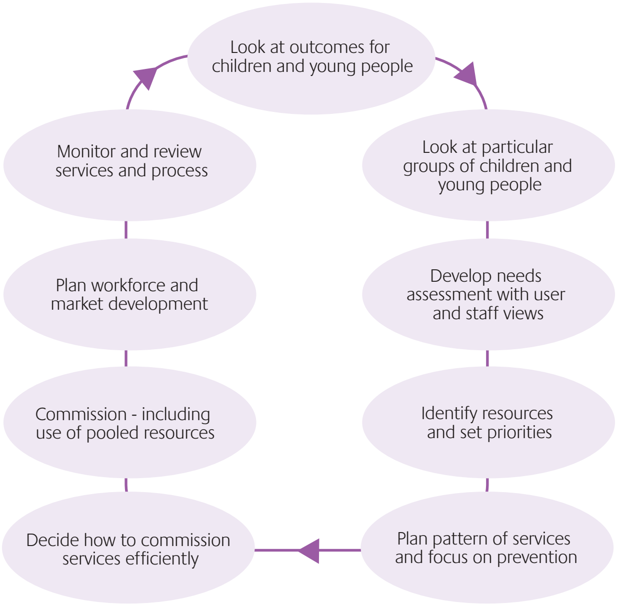
## World Class Commissioning

**Competency Three: Engage with the Public and Patients**

Children's Trust partners engage with children, young people and their families to prioritise outcomes and shape delivery. Children and young people are not just listened to, but are fully engaged with the design, delivery of services, in order to secure improved outcomes. Creative and innovative approaches are being used to ensure that children and young people with multiple and complex needs and vulnerable families are at the heart of this engagement. The engagement is a two-way street, in which the process itself is seeking to raise individual and community aspirations for improved health outcomes and develop a shared vision for achieving them.

Extract from Securing Better Health for Children and Young People through World Class Commissioning. (DCSF & DOH 2009)

## Process for joint planning and commissioning



Case Study

## Bexley NHS Care Trust: Exploring the Commissioning Cycle

Bexley NHS Care Trust has developed a participation model for involving children and young people in the full commissioning cycle. As the main commissioner for health services there are many areas that are directly relevant to children and young people. To embed involvement they are developing a children and young people's council and working with local children and young people's organisations. A diverse group of 20 children and young people attended a workshop with the Trust's commissioning team. They explored the commissioning cycle in depth, producing visual maps of the different stages linked to specific health topics. Groups of children and young people questioned and challenged the commissioners. They prioritised sexual health, stroke, young carers and transitions to adult services. They debated local need, the effectiveness of services, ways to monitor performance and new service models. They felt that services were not as child and young person focused as they could be. And they felt that information and campaigns would benefit from the expertise of children and young people and new ways to communicate with their peer group. A month later the children and young people returned to the Trust to spend another three days working with the commissioners. They researched existing services and developed costed proposals for new service specifications to overcome the gaps and barriers. They formally presented these to the NHS board. The board discussed the proposals and had an opportunity to question the children and young people. An action plan was agreed for each topic. The children and young people committed to continuing their research with their peers in schools and in the community. The proposals were put on the Trust's website. The children and young people will return in three months to receive presentations on the action taken by commissioners.

Extract from How to Involve Children and Young People in Commissioning from Participation Works www.particiaptionworks.org.uk

## Participation in Developing Service Location and the Built Environment

One of the most important determinants of whether children, young people and their families will use a service is its location. Involving service users in planning where services will be located should help to ensure that they are accessible to those who will need to use them. Issues such as proximity to other services, access by public transport, car parking and distance travelled are all important. Involving young people and their families in determining the accessibility and location of new and existing services is essential and is part of the You're Welcome quality assessment. (Department of Health 2006)

Well designed health care facilities can positively affect the experiences of patients and can help the staff do their jobs. When designing new healthcare facilities for children and young people we need to understand the effect the built environment can have on their experiences and recovery. This requires capturing the views of children, young people and their families which requires time, resources and staff with the correct skills. The plans for participation of service users should be included in the initial capital bid with appropriate costings. Analysis of the information provided by this consultation should also involve services users to reduce the risks of misinterpretation and increase the level of participation.

From the outset the Evelina Children's Hospital in London wanted to be a hospital that didn't feel like a hospital, a place designed "by children for children." Bright red rocket lifts, visible from inside and outside the hospital, carry people to a four-storey central conservatory. Floors are identified by their own colour and symbol, all based on the natural world and moving from the ocean and beach on the lower floors right through to the sky at the top. Play is a key activity at the hospital, symbolised by the 17 foot high helter-skelter slide in the outpatients department. It is obvious to the visitor that children were key contributors to the design. A Children's Board, made up of patients and local school children, were partners in the process, contributing their views on everything – from menus and furniture to building design.

The users of any hospital building are the patients it serves, not the staff. Children and young people are entitled to hospital buildings which are:

- Safe
- Secure
- Comfortable allowing them to rest and sleep
- Children and young people friendly in their design and decoration
- Able to provide them with age appropriate food
- Able to maintain the dignity and privacy of young people
- Able to provide them with age appropriate recreational and educational facilities

There are many examples of high quality design projects in which children, young people and their families have participated. We would recommend you visit the websites of Evelina Children's Hospital London, Bristol Children's Hospital and Derbyshire Children's Hospital.

## Case Study – Designing Derbyshire Children’s Hospital

In Derby we have a long history of involving children in planning services, not because we had a Damascene conversion which bade us go out and consult but simply because we could imagine no other way of completing our task. It started in 1990 when we had approval in principle for the replacement of our shabby but loved Derbyshire Children’s Hospital in North Street, Derby, which we had long since outgrown. Led by a remarkable management team we were allowed to explore the potential for not just a new building but a very special building: one designed to do a specific job for a special group of patients.

A fundamental question was “whose hospital is it anyway?” The answer for us, clearly, was that it belonged to the children and their families. This simple decision which may seem obvious—was probably the single most important principle to have adopted when we began. Having unwittingly stumbled upon the most important decision of the whole design process, we were faced with an uncertain way forward. We wanted children and their families to tell us what they wanted from the hospital, but we had no idea how to involve them and get their views. We did have some underpinning principles though: we wanted a hospital which would be for children and young people, not one aimed at the under fives with the odd island of teenage refuge. We knew it had to be acceptable to teenagers and 2 year olds, nursing mothers and grandparents alike.

The answer as to how we should proceed came with the discovery of a group of community artists in Ireland, called l4a (now, sadly, disbanded). They had a mixture of interests and skills and had experience of working with largish groups of children in structured play. Working with them could perhaps enable us to have insight into how children felt about buildings and hospital care. We (and they) realised the only way to get the children’s view was their language—play.

Derbyshire has a mixed demography with areas of inner-city deprivation and rural poverty contrasting with very affluent areas of good housing and excellent schools. To make sure that all our children and families were represented, L4a ran many play sessions in schools, community and shopping centres, play groups etc., some with parents, some without. Staff and planners, technical advisers and managers all joined in. We worked in affluent and deprived areas: with special needs children and those from different ethnic backgrounds; with children who knew a lot about being sick and in hospital and with those who had no experience of hospital at all. We played and played, using music, craft and role play. Artwork was carefully collected, sticky collages and filmed role play stored and then painstakingly documented. When all the play was done the children’s work was analysed and from that analysis came some basic principles which became our central guide for the detailed hospital planning to follow.

When there was sufficiently commonly observed phenomenon—e.g. fear of isolation, getting lost, getting cut off from the outside world—the findings then established challenges for us which begged design responses. For instance the children demonstrated a fear of long empty corridors with goodness knows what through the next door. The design response was to have no long corridors without some feature to break them up. To overcome the fear of what is going through the doorway, we made sure that all the doors have “port-hole” windows in the lower half so children can clearly see what is on the other side. All so very simple, but if we had not asked we could not have done it.

Extract from **Cooke GA. Involving Children in Planning Health Care; The Derby Experience. Current Paediatrics 2004;14:246-251**

## Participation in Staff Recruitment and Selection

Staff recruitment provides a great opportunity for children and young people to participate in the decision making processes of an organisation. Creating opportunities that enable children and young people to influence part or the whole recruitment process can be beneficial as their perspectives and insights bring to light the candidate's knowledge, attributes and key skills necessary to make effective decisions that will ultimately impact children and young peoples' lives. It is important that the children and young people involved are representative of the actual or potential users of the service or organisation which is recruiting and those children and young people from marginalised groups are not excluded.

There are a number of direct and indirect ways children and young people can be involved in recruitment and selection Children and young people can participate in:

- drafting of the job description
- designing the interview process
- generating questions for key aspects of the job description
- being part of the interview panel and influencing the final decision
- taking part in staff induction

Irrespective of the method and level of participation it is important that children and young people are provided with sufficient training and planning to allow them to prepare them for their involvement, have feedback on how their involvement influenced the process and have support from staff throughout the process. It is equally important that staff involved in the recruitment and selection process such as Human Resources and the interview panel members are fully aware of the added value of the children and young people's participation, the process of their participation, the limitations, and their responsibilities to take into account the children and young people's perspectives and insights.

### Key Principles

Children and young people who participate in staff recruitment and selection should:

1. Understand the role the worker will play and have an understanding of the organisation.

2. Expect that the location and timing of the interviews will be convenient for them.

3. Expect that they should be provided with some basic training in interview skills.

4. Be involved in the whole process including discussions and planning for the short-listing and interviews or if involved in part of the process, a clear explanation of the limitations, their role, tasks and added value to the whole process.

5. Be aware of how and who will make the final decision.

6. Know their views will be listened to. There should be a clear understanding of the role that children and young people will play and the influence that they will have on the final decision.

7. Receive and be able to give feedback and know that there contribution has been valued.

### Case Study – Recruiting a CFS/ME Coordinator

Since 2005 the Paediatric Rheumatology Service at Nottingham Children's Hospital has involved young people in staff selection. Our youth worker recruits four young people. They meet on the interview day and start with an icebreaking session followed by a session on the details of the post and their roles and responsibilities within the selection process. The youth worker acts purely in an advisory capacity as the Youth Panel devise their own questions and scoring system. The conventional interview process and ranking occur first.

The Youth Panel also provide comment on their assessment of the ability of each candidate to:

- Work under pressure
- Recognise the young person's perspective
- Be innovative in their practice
- Respect confidentiality.

This is then fed back to the Trust interview panel.

On each occasion the interviewees commented that the youth panel were professional and gave the more challenging interview. Furthermore the Youth Panel's choice has been congruous with the successful appointees.

The young people receive expenses, an honorarium and are given letters of thanks.

Young people are a valuable and resourceful asset providing a further dimension to the interview process. They are able to recognise the value of their investment and acknowledge the importance of their role.

Liz Hutchinson - Lead Nurse Paediatric Rheumatology, Nottingham Children's Hospital, Nottingham University NHS Trust.

## Case Study – Recruiting the CEO for the Royal College of Paediatrics and Child Health (RCPCH)

Members of the Royal College of Paediatrics and Child Health Youth Advisory Panel contributed to the appointment of the Chief Executive Officer in October 2010 and the recruitment of the Children and Young People's Participation Manager in September 2008. To ensure their meaningful participation in the recruitment of the CEO the following steps were taken:

Initial discussions were held between the Head of Human Resources, the RCPCH Registrar, the President of RCPCH and the Children and Young People's Participation Manager to explore the added value of the young people's participation and ways to ensure their meaningful participation, including the extent and limitations of their involvement.

Members of the Youth Advisory Panel were approached with the request for their potential participation in the recruitment of the CEO and information in relation to how their involvement will add value to the whole process, their role, key tasks, timescales and key dates. The information provided helped members to decide whether this was something they would like to participate in and provided them with a basis to raise any further questions to help inform their decision to participate or not.

Three members were involved in the recruitment process and their contribution focussed on key aspects of the CEO's Role and Responsibilities, they generated a range of questions per area of responsibility as well as listing key attributes they would expect the CEO of RCCPCH to have to ensure they valued children and young peoples participation and understood the impact of their role on the lives of children and young people.

The Children and Young People's Participation Manager provided the young members a briefing on recruitment and selection, good practice guidelines, designing interview questions, interviewing skills, analysis and feedback process.

The Youth Advisory Panel members held a pre-meeting to discuss and agree their final questions, the process of the interview and how to ensure effective feedback to the President of RCPCH and the Head of Human Resources.

The Youth Advisory Panel Members held an interview with each candidate. The interviews lasted 45 minutes per candidate. The Young Members also had prompt questions to ensure each candidate had the opportunity to elaborate where relevant. Each young person scored each candidate per question as well as listed a detailed analysis of why they perceived the views/ opinions they did in relation to the answers each candidate provided verbally and non verbally. At the end of each interview the members shared their conclusions, scores and discussed consensus where possible and justified their differing opinions where relevant to help create a feedback presentation per candidate for the RCPCH President and Head of Human Resources following the final interview. One of the candidates was unable to attend the interview with the young people and the questions created by the young people informed the interview process the candidate held with the President of RCPCH and the 'adult' panel interview process.

The RCPCH President wrote to each member to thank them for their participation, letting them know who had been appointed and that how their involvement was both insightful and informative.

Bharti Mepani, RCPCH Children and Young People's Participation Manager, participationzone@rcpch.ac.uk

For more information please see the guide **How to Involve Children and Young People in Recruitment and Selection from Participation Works** www.participationworks.org.uk

## Participation in the Governance of Health Services

Young people are involved in the governance of a range of statutory and voluntary organisations including as school governors and trustees of charities. Children and Young People have a right to be involved in the governance of the organisations which deliver services on their behalf. In this section we will consider how children and young people can and should be involved in the governance of health services, in particular we will focus on the role of children and young people in the governance of NHS Foundation Trusts.

### Young people as governors

Currently young people aged 16-19yrs can become full patient members of the board of Governors on NHS Foundation Trusts. Children under 16 years are not presently allowed to take on the role of governor of an NHS Foundation Trust as being a governor involves statutory responsibilities with legal powers and duties under the NHS Act 2006. The young person sits on the board of governors and along with the other members and has responsibility for the strategic direction of the Foundation Trusts and a legal responsibility to ensure the accounts and finances of the organisation are in order. Young people aged 14 years and older are entitled to full membership of NHS Foundation trusts.

### Advisors to the Board of Governors

Children and Young People can be involved in the governance of health services by acting as advisors to the Governing body. They can be involved in discussions about strategic and financial decisions without being legally responsible. This can be done directly or via a parallel group of Young People (a Youth Council or similar body) working in partnership with the Board of Governors.

### Engaging Young People in Governance

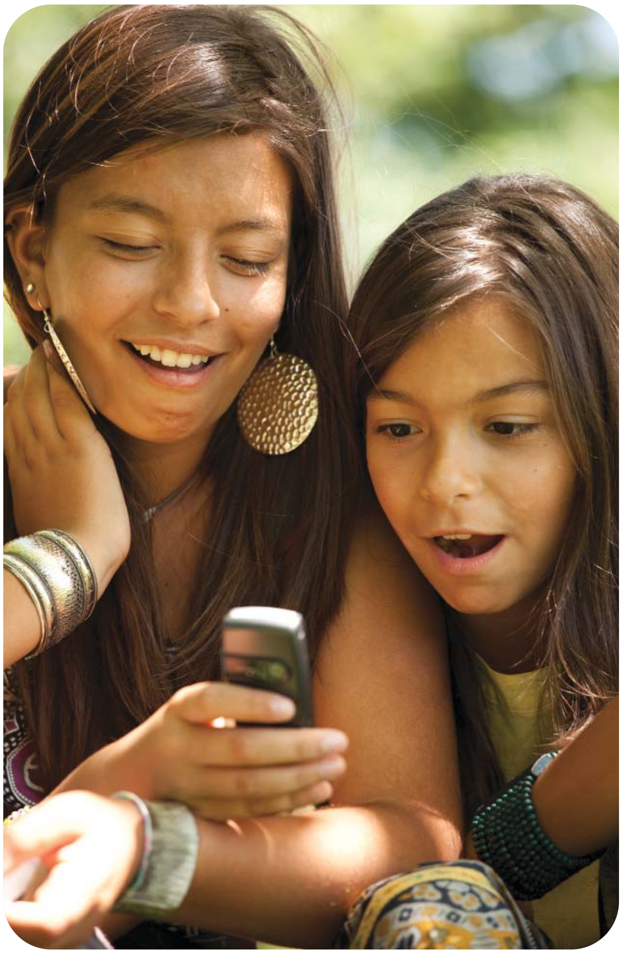
In order to meaningfully and safely engage young people in the governance of health services, service leaders need to explore why the young people are engaged, how their role and remit will meaningfully hold the organisation to account, and what measures need to be in place to ensure their participation is not tokenistic. Service leaders need to plan how they will engage, recruit and retain young people whilst ensuring they are properly inducted, rewarded and their safety ensured. This may require induction and training for board members and young people, the development of a mentor system for young board members and consideration of remuneration for young people.

Participation Works produce a very helpful guide: **How to involve Children and Young People in Governance** which provides more details and case examples www.participationworks.org.uk

### Governors of NHS Foundation Trusts

NHS Foundation Trust governors are the direct representatives of local interests within foundation trusts. Governors do not undertake operational management of NHS foundation trusts; rather they challenge the board of directors and collectively hold them to account for the trust's performance. It is also the governors' responsibility to represent their members' interests, particularly in relation to the strategic direction of the trust.

Legislation provides governors with statutory responsibilities to help deliver these key objectives. The legislation is the National Health Service Act 2006 (the 2006 Act).



### NHS Foundation Trusts - young people as governors

NHS Foundation trusts are not-for-profit, public benefit corporations. They are part of the NHS and provide over half of all NHS hospital and mental health services. NHS foundation trusts are a result of the Government's attempts to devolve decision making from central to local organisations and communities. They provide and develop healthcare according to core NHS principles - free care, based on need and not ability to pay. NHS Foundation Trusts are different from NHS Trusts in that they are not directed by Government so should have greater freedom to decide their own strategy and the way services are run; they can retain their surpluses and borrow to invest in new and improved services for patients and service users; and they are accountable to their local communities through their members and governors, their commissioners through contracts, Parliament and to Monitor as their regulator. It is envisaged that NHS foundation trusts will be more responsive to the needs and wishes of their local communities. In principle anyone who lives in the area, works for a Foundation Trust, or has been a patient or service user there, can become a member of the trust. These members elect the board of governors. However there are a number of obstacles to the participation of young people in this process. According to the rules of Monitor (the regulator of NHS Foundation Trusts) children and young people may be members of a Foundation Trust however only young people, over the age of 16 years may be Governors of a Foundation Trust.

At the time of going to press three UK Specialist Children's Hospitals have achieved Foundation Trust status. These are Alder Hey Children's Hospital, Liverpool, Birmingham Children's Hospital, and Sheffield Children's Hospital. All have young people on their board of governors alongside parents/carers and staff representatives. The number of young people on these boards ranges from 1-4 representing between 3-11% of the constituents of these boards.

The challenge for NHS organisations providing services to children and young people is to ensure the participation of children, young people and their families in the governance of the organisation. This has proved challenging for specialist children's hospitals. Clinicians and service leaders working within NHS organisations which provide services for both adults and children should examine and question the participation of children and young people in the governance of their organisation. Is the board of governors truly representative of its membership? Do the governance structures encourage or limit the participation and involvement of children, young people and their families in the strategic direction and financial accountability of the organisation?

For more information on the Governance of NHS Foundation Trusts visit the website of Monitor - The Independent Regulator of NHS Foundation Trusts

http://www.monitor-nhsft.gov.uk/home

## Participation to Develop Research

Children and Young People are increasingly involved in healthcare research. The oversight of research ethics committees and the development of research networks have enhanced consumer participation and the participation of young people.

### Why should children and young people participate in healthcare research?

Research is concerned with answering hypothesis by collecting and analysing information using appropriate methodology in meaningful settings and then developing arguments based on this analysis. Research involves a number of distinct stages and children, young people and their families can be involved at any or all stages of research.

#### DEFINING THE RESEARCH AGENDA

In order to ensure that researchers are attempting to answer questions which are relevant to children and young people it is important that children and young people are involved in determining the important themes and topics for research. Public and charitable bodies fund the majority of healthcare research in children and young people with the pharmaceutical industry funding a lesser proportion. Funding bodies should take the views of children and young people into consideration when deciding the priority areas for research.

#### DEVELOPING THE RESEARCH QUESTIONS AND PLANNING THE PROJECT

Children and young people are uniquely placed to help researchers develop research questions which tackle the problems that they face as consumers of healthcare. For example they can be involved in reviewing the current literature on a particular topic. This may require researchers to frame the information from a literature search in a way that young people can understand in order to allow them to give their perspective on the current evidence base. They can also assist in determining the most appropriate methodology to be used, the research instruments to be utilized and the population or setting for the research project. It has become routine for children and young people to be consulted on the information and consent materials produced by researchers for study participants. This consultation is important but is only a small part of the research project and the meaningful participation of children requires a wider involvement in the research project or agenda.

## Case Study – The Trent Medicines for Children Research Network

In 2006 the National Institute for Health Research (NIHR) Medicines for Children Research Network (MCRN), with support from the National Children's Bureau (NCB), set up a pilot young person's advisory group to explore how young people could be involved and have their say in the design of clinical research. Based at the MCRN coordinating centre in Liverpool, fifteen members were recruited aged 8 - 19 years. The pilot was such a success that the group has now been re-launched to involve more children and young people. Furthermore, three additional groups have been established to form one large national young person's advisory group. These new groups are based in three MCRN Local Research Networks (LRNs): Trent, West Midlands, and London. Each group comprises of approximately 10 - 17 young members, between 8 -19 years that have experience of living with a childhood condition, illness, disability or taking medicines. The groups meet bi monthly and all views and opinions are fed into the MCRN Consumer Involvement Steering Group and MCRN Board. A training programme for each group is now running covering research methods and clinical research. Already the group has contributed to a range of activities, which includes, helping researchers with their projects, working with organisations such as MHRA, and reviewing patient information leaflets. During 2010 the group will be advising other young people what researchers are finding out (through summaries and a website which the groups will develop), present at MCRN related conferences to highlight the work of the young persons' group and carry out their own mini research project.

If you're interest is in clinical research into medicines for children, it may be possible for you to work with our group of young people. We encourage young people's involvement from the early stages of research design (before funding) right the way through to providing child friendly summaries of preliminary research findings and disseminating research findings to larger audiences.

For further information contact Tina Simpson at the Trent Medicines for Children Research Network.
tina.simpson@nuh.nhs.uk

### RECRUITING PARTICIPANTS AND COLLECTING THE DATA

Children and Young People can be engaged in the collection of data for example recruiting other young people or acting as interviewers. They may need specific training (in consent, confidentiality, safeguarding and data protection) and support of experienced researchers and this should be defined in the project plan and ethics approval application.

### INTERPRETING THE DATA

The interpretation of the results of a research project will depend on a reader or author's perspective. It is evident that research involving children, young people and their families should include their unique perspectives to inform the analysis of the data collected during the course of the research project. These perspectives will help to make sense of the research information for consumers and also inform the requirements for further research.

### CHILDREN AND YOUNG PEOPLE AS RESEARCHERS

Involving children and young people in research can enhance the quality of the research and provide young people with important skills of planning, information gathering and critical analysis. The safe and meaningful participation of children and young people in research will require researchers to plan the involvement of children and young people to ensure their safety and that their involvement is valued and rewarded. Researchers should build on the research skills that children and young people already possess and ensure that the young people involved in the research reflect the diversity of the population and the

## Case Study – Communicating with Children and young people

The RCPCH has developed a Training DVD and resource for Paediatricians and Health Professionals 'How to Talk with Young People by Young People' (2010) based on research conducted with children and young people across the UK (2008-2010). Forty young people attended workshops to share their experiences of communication with doctors and to explain why they perceived some communication strategies preferable to others. The data from these workshops was analysed using a thematic analysis and scenarios illustrating the key themes were written up to produce scripts which were reviewed by some of the young people who attended the workshops, as well as paediatricians and a parents/ carers group. The final script was used to create a Training DVD and resource pack to facilitate discussions about a range of key issues of communication between Paediatricians and Young People covering topics such as: delivering a diagnosis, building rapport, preparing for a procedure, dealing with disclosure and discussing sensitive and confidential issues. A supporting written resource was produced with further input by children, young people and Paediatricians.

The resource will be available summer 2010.

For further information contact Bharti Mepani, RCPCH Children and Young People's Participation Manager, participationzone@rcpch.ac.uk

range of perspectives. Developing children and young people's involvement as part of research networks will allow children and young people and researchers to develop expertise in collaborative and participative research.

For more information see the participation works guide on How to Involve Children and Young People in Research
www.particpationworks.org.uk
www.carnegie-youth.org.uk

## A right to be involved in research

Along with Article 12 of the UNCRC other articles relate to the right of young people to be involved in properly conducted research.

**ARTICLE 13** gives children and young people the right to receive and give information through speaking, writing, printing, art or any other form.

**ARTICLE 17** gives children and young people the right to information, especially information that helps build social, spiritual and moral well-being and physical and mental health.

## Summary

- Participation is not about one off projects. It represents a philosophy of service user involvement which should pervade every aspect of health services.
- Service leaders have a responsibility to ensure that their service or organisation has a strategy to support the participation of children and young people.
- Children and young people can participate in many different ways, including:

- Commissioning services
- Designing the built healthcare environment
- Recruiting and selecting staff
- Governance of health services
- Developing healthcare research

# Section Six: Practical Methods of Participation

Questionnaires and surveys

Focus groups

Interactive multimedia

Youth councils or forums

Service evaluation and mystery shoppers

There are many different opportunities for children and young people to participate in healthcare design and development. In this section we look at some of the common methods and consider the benefits and potential pitfalls of the various methods. The methods include questionnaires and patient satisfaction surveys, focus and advisory groups, interactive websites, and mystery shoppers.

## Questionnaires and Surveys

Questionnaires and surveys are often used to collect the opinions and views of service users and can be used to collect information about knowledge, beliefs and attitudes. They have a number of advantages over other methods however they can provide only limited information and there are some important pitfalls to consider.

Involving young people in designing the questionnaire may be helpful. In particular their views on the design and style of the questionnaire, the length of the questionnaire and the language used can be helpful. Piloting the questionnaire will help to clarify how easy it is to complete. Think about the kind of questions you will use and what kind of data will be collected. Closed questions with yes/no answers or rating scales allow data to be aggregated whereas open questions with free text answers will provide more information. One of the pitfalls of questionnaires and surveys is that they may only be completed by a small and non-representative group of service users. Think about how you will publicise the questionnaire and whether you will include both current and potential service users. Young people will want to know what the survey is for, whether it is anonymous and why it is being conducted; an introductory letter or explanation leaflet is a good idea. Think about how you will target hard to reach groups and how you might ensure that children and young people from hard to reach groups and those with literacy or communication difficulties will be able to participate in the survey.

### A Satisfaction Survey of Young People Attending a Hospital Out-patient Department

A questionnaire survey of the views of young people attending a university hospital children's out-patient department regarding the quality of the services offered revealed that many young people and their parents thought the decoration in the waiting room was too young and aimed at small children whilst they felt the clinic room decoration was age appropriate. The results of the survey allowed staff to target the limited resources available at redecorating the waiting area. Local artists were asked to provide samples of artwork which might be utilised in the redecoration of the waiting area. Young people attending the out-patients as well as hospital youth room and Youth Club were invited to give their opinion on the samples before the artwork for the waiting room was commissioned.

In the same survey the majority of young people believed they had received a confidential service but interestingly many of them had been seen with their parents and had not seen the doctor alone.
This raised questions about what young people understood about confidentiality and publicity materials were developed to explain in more detail about the confidential nature of the service.

*Sands RJ, Sehmi H, Wood DM. Are they welcome? A survey of young people and their families attending the Children and Young People's Out-patients Department at Nottingham University Hospitals NHS Trust 2008.*

| Advantage | Disadvantages |
|---|---|
| Quick | Can't ask for further clarification |
| Cost effective | Poor response rate |
| Can be repeated | Impersonal |
| Large numbers of young people | Requires literacy |
| Cheap | Not good at exploring feelings and what people would like to change |
|  | Results dependent on quality/construction of questions |

## Focus Groups

Focus groups are a specific form of group interview which incorporate group interaction to explore people's experiences and attitudes. Focus groups were originally used in the media industry to assess audience views and opinions on broadcast media such as film and television. They are now widely used to help understand people's experiences of health services. The methodology involves the facilitation of group discussion and interaction to allow participants to explore the issues of importance to them. They can help young people clarify their views and thinking in a way that would not be possible in a one-one or group interview. Young people are able to explore the issues relevant to them, in their own language and develop their own priorities and generating their own questions. This can often take participation work in new and unexpected directions.

Focus groups will not be able to gather as much information from as wide a range of participants as a questionnaire however they can provide a much more detailed understanding of the issues and allows the group to explore solutions and answers to problems. They may be inaccessible to some groups and it is important to consider whether the focus group is representative of current or potential service users and which voices may be excluded. Focus groups require more time and resources and particular attention needs to be paid to the skills and experience of the facilitator in ensuring that young people's participation is safe, confidential and meaningful.

### Case Study – Northumberland Young People's Health Project

Northumberland Young People's Health Project organised focus groups involving young women and young men separately to produce qualitative data relating to their experiences, opinions, perceptions and needs as users of the Health Service. The group discussions provided vocabulary and critical questions for a questionnaire survey.

Contact was made by letter with the Head Teacher of each High School in the seven towns where there was a Young People's Health Session. A meeting with the head teacher and governors was offered to give further information, but this was not requested by any of the schools. Young people were invited in small peer group (tutor or friendship groups), to allow enough comfort for discussion. Information letters for parents and carers for the young people who agreed to take part were distributed by the school. Sheets with an outline of the sessions and an introduction to the facilitators were sent to schools for participants.

A set of discussion guidelines were drafted and discussed with the Centre for Health Service Research, University of Newcastle. The discussions were held in rooms with comfortable seating arrangements and where there would be no interruptions. Each session began with introductions. The facilitators explained that the >

| Advantages | Disadvantages |
|---|---|
| Accessible to those with literacy problems | May compromise confidentiality |
| Can encourage those who are reluctant to participate on their own (intimidated by one-one interviews) | Not as accessible to young people with verbal communication difficulties |
| Can encourage participation from those who feel they have nothing to say but will engage with other group members | Group dynamics may silence individual participants |
| Identify shared and common experiences and attitudes as well as breadth of experience and attitudes | Group composition may not be representative |
| Assist in sharing taboo or stigmatised experiences and attitudes | More costly than a questionnaire |
| Can facilitate the expression of criticism | Requires a facilitator with some experience and expertise |

discussion would be taped, so as not to loose anyone's contribution and that what was recorded would remain anonymous. Participants were asked to respect each other's contributions and confidentiality and to join in at a comfortable level. There was a sheet to write down issues affecting health, and things that might need a one-to-one consultation, so that participants who felt uneasy about saying something in front of the group could still pass on information. Forty nine young people were involved in the focus groups.
Three key themes emerged

1. Safety, including privacy and confidentiality
2. Information, choice and control
3. Respect

Forty eight of the forty nine participants felt that they had had a chance to express their opinions. Three young men expressed anxiety and discomfort about speaking "in front of mates". There was overwhelming appreciation of an opportunity to speak about issues of concern, without feeling pressured, and to be listened to. The focus groups were an opportunity to inform young people of their rights to certain standards of service and detailed information was also given about the local young people's health session.

McNulty A, Turner G. Not just a phase we're going through ..... Final report of the Northumberland Young People's Health Project 1996 – 1998 ISBN 0951961144

## Interactive Multimedia

The internet and multimedia provide an exciting and dynamic way in which young people can participate in health services. There are many methods available including young people creating a video which can be used to stimulate discussion, highlight a problem or start a campaign. Websites developers can adopt the design principles of web 2.0 to create stylish, dynamic and interactive sites which allow children and young people to provide feedback via online surveys, discussion groups, social networking and online blogs (web logs). Online games, virtual worlds and applications for mobile devices such as apps for the iphone and Bluetooth technology are revolutionizing the way in which young people interact with the world around them and the services provided for them.

The use of the internet and multimedia is providing a shared language and platform for service leaders to work in partnership with young people to engage people in services, however we must remember that the use of technology to involve young people in health services may increase health inequalities as those groups of young people who cannot access health services may also have difficulty accessing the internet and multimedia or lack the skills to make effective use of the opportunities available.

Developers and service leaders should work in partnership with young people to devise media which are accessible, age and developmentally appropriate and safe, paying particular attention to the risks of on-line exploitation of young people.

| Advantage | Disadvantages |
|---|---|
| Can reach large numbers of children and young people of different ages and abilities | Requires technical knowledge and resources |
| Media can be tailored to meet the needs of the project | Can be costly to develop |
| Wide range of possible applications and media means young people can be engaged in different ways | May exclude groups who already have difficulty accessing health services. |
| Dynamic and interactive content can engage young people turned off by other methods | Risks of exploitation and bullying |
| Confidential and anonymous | |

For more information we recommend the guide **How to use multimedia tools to engage children and young people in decision making** from Participation Works www.participationworks.org.uk

## Youth Councils or Forums

Youth councils or forums through which young people represent their peers provide a formal and visible mechanism for children and young people's participation in health services. Such groups often run in parallel to other patient and public partnership initiatives such as patient or parent forums. The groups can take many different forms in terms of their constitution and remit. Young people can be supported to arrange their own meetings, set the agenda and determine the format of the meetings. The meetings are often facilitated by health staff or volunteers but this is not always required and young people should be given time and space to have their own discussions and make their own decisions with the facilitator there to ensure safety.

The advantages are that young people can develop their skills a wide range of skills relating to communication, decision making and leadership whilst providing the organisation with a reference group with which it can regularly and readily consult on matters which affect children and young people.

There are some potential disadvantages and pitfalls to Youth Forum or other similar initiatives. The first challenge is developing a recruitment strategy which will engage young people whilst ensuring the group is representative of the views of current and potential service users. In developing a youth forum there is an inherent risk that the group may unwittingly exclude some young people who do not readily engage with health services or provide a voice to a narrow section of the local youth population. Other difficulties can include maintaining membership, balancing the right of young people to set the agenda with the requirements on service leaders to consult on a wide range of issues.

### Case Study - YoH! Youth on Health

YoH! -Youth on Health, is funded by Leeds Primary Care Trust and is a partnership between Leeds PCT, Leeds Healthy Schools, Education Leeds, schools, Youth Services, and the Project West Yorkshire Youth Association, and supports the Citizenship & Investors in Pupils initiatives. Established in 2002 YoH! aims to provide children and young people with the opportunity to share their experiences and concerns, learn about health and health related issues and influence decisions and policies on health, at local, school, city and national level.

There are six YoH groups, five for primary school aged children, based within the city's wedges and a sixth YoH! held centrally for secondary aged young people. Each YoH holds two meetings a term, where the young people meet, play games, discuss issues, share ideas, and think about how they can take what they have learnt back to their schools. YoH members host 'Young Delegate' events, where they meet with representatives from different organisations and agencies that have a responsibility for children and young people's well being.
The children and young people who volunteer to participate in YoH meetings are nominated or elected by their schools or parent organisations and some represent their school councils or healthy school forums. Through the close links with the schools and parent organisations, ideas shared at YoH! meetings can be fed back to improve the health of all, either through formal reports, the newsletter, DVDs or in the creation of information leaflets.

*Extract from Youth Work 4 Health Factsheet published by the National Youth Agency.*

## Service Evaluation and Mystery Shoppers

One of the best ways to determine whether a service is really making a difference to young people is to engage young people in evaluating the service. Young people often have a unique view point on what works and what does not and perhaps more importantly how things could be improved or done differently. An insider's view may highlight unexpected barriers or unexpected outcomes which result from using the service. The use of young people as mystery shoppers has allowed young people's views and experiences to shape the services provided for them and providers become more focused in listening to young people. It is a very powerful way for organisations to include young people and show them that their opinions are valued. Young people are more likely to feel directly involved with the organisation if they feel that they have a specific role and voice. Children and young people who act as mystery shoppers develop skills such as observational skills, expressing their point of view and considering how other people might experience services.

## Nottingham City PCT Contraceptive and Sexual Health Service Mystery Shoppers

Young people aged 14-25 years of age are invited to become Mystery Shoppers and evaluate services within the PCT which provide contraceptive and sexual health services for young people. The young people make phone calls to services, visit the organisations and then complete a report. The young people participate in planning and preparing the phone calls and visits. They are paid for their time and can work towards a qualification. Young people who complete the Mystery Shopping programme have the opportunity to become peer educators to help recruit and train other young people to the scheme.

Base51, Crime Concern and Nacro as a partnership were commissioned in 2006 to support services to reach the Quality Assurance Standards as set out in the You're Welcome document. The partnership saw the mystery shopper exercise as a natural progression of their current work as young people would be putting to the test the quality standards services were being assessed on. It was paramount that the exercise was inclusive while recognising the limitations of the tight timeline set by the commissioners. A flyer was sent out through the youth service and youth organisations.

A series of meetings were held to bring the young people together as a group, introduce them to the project and wait for them to look at how they wanted to "shop" services. Issues of confidentiality were discussed, the scenarios they would use and what the possible consequences could be for the young person. At all times the young persons welfare was paramount wit a protocol in place underpinning the exercise. Parental consent was obtained for all young people aged under 18.

It was important the momentum was maintained with the young people and the third week finished with a weekend residential; to build confidence with the young people look at what they wanted from services and to develop the scenarios they would use. A good combination of fun and work enabled the group to support each other and prepare for the tasks ahead.

Questions and scenarios were developed with the young people over the residential weekend – it was important that young people did not receive any treatment, but could engage with the service enough to be able to report back with their impressions. To do this young people either made phone calls or visited the service – they were supported at all times with a worker who also took feedback from the young person immediately after the call or visit. Some agencies had just a phone call or visit, some received both – some had more than one visit.

A total of nineteen visits were made across the teenage pregnancy hotspot areas of Aspley, Bilborough, Bulwell, Bestwood and St Anns. Thirty six phone calls were made by young people and scenarios ranged from contraception, emergency contraception to STI screening.

A total of 23 services were "shopped" during the two week exercise including GP practices, Health Centres, Children's Centres, Contraception and Sexual Health (CASH) outreach services and Youth Centres. Services were informed before the exercise started about the mystery shopper and that young people would not be using real names to prevent any fictitious issues going on their medical records.

The 2008 Mystery Shopper exercise highlighted the key role of reception staff whether on the phone or meeting the young person. Recommendations from the report included specific training for reception staff, awareness raising of the need to signpost young people to other services, clear information about when services are available and good communication between workers so that young people are not left waiting. Services are supported by the Teenage Pregnancy Quality Assurance Team to implement the recommendations.

*Extracts from Mystery Shopper Report 2008: Our Findings Base 51 Centre for Young People, Nottingham City PCT*

## Summary

- There are many different methods by which children and young people can participate in health services
- When planning a participation project consider which are the most appropriate methods to ensure meaningful and effective participation
- Consider the advantages and disadvantages of different methods and consider new and innovative ways of engaging young people
- Seek out the knowledge and experience of other groups or projects who have utilised similar methods

For less ‘traditional methods’ and creative methods see: Participation—Spice it up! (Dynamix Ltd and Save the Children, 2002), a valuable resource for all professionals who work with children and young people—including local authority staff; teachers; play and care workers and health professionals. www.dynamix.ltd.uk

# Conclusion

## Where to go from here?

There are so many opportunities for children and young people to be involved in health care and so many ways that services for children and young people could be improved that it is easy to feel overwhelmed by the task ahead of us. At this point it is worth remembering

*"The best way to eat the elephant standing in your path is to cut it up into little pieces."* – African Proverb

Start with small, achievable projects and build capacity in your organisation that eventually brings about a culture that values and embeds the safe, meaningful and ethical participation of children and young people throughout its work. Demonstrate the value and benefits of children and young people's participation by showing others what can be done and by celebrating the successes.

Children and young people have a right to participate in matters concerning them and as healthcare professionals we have a special obligation to ensure they have a voice, and that their voice is listened to. It is our responsibility to ensure children and young people are not only seen as beneficiaries but as key stakeholders of their health service.

There are also more pragmatic reasons for participation -
it makes health services better, it improves the health of children and young people and it's fun!

> 'Children and young people have a right to 'the highest attainable standard of health...and (we have a duty to ensure) no child is deprived of his or her right of access to such health care services.'
>
> (UNCRC, Article 24).

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> “Paediatricians should advocate children and young people's participation because one of the fundamental human rights is the right to good health. There is no better way of achieving this than directly and actively involving children and young people in important decisions about the provision and quality of their healthcare - decisions which will undoubtedly have a notable impact on their lives and futures.”
>
> Alex Willsher, RCPCH Youth Advisory Panel Member

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